ANNEX 1: Key terms and definitions

Adherence: A term used in the context of treatment. Adherence is a measure of how well a patient complies with a treatment programme. Adherence and retention are linked in that patients need to be retained in care in order to adhere to treatment.

Adolescents: People between the ages of 10–19 years old are generally considered adolescents. However, adolescents are not a homogenous group; physical and emotional maturation vary among them, and different social and cultural factors can affect their health, their ability to make important personal decisions and their ability to access services.

Attrition: Refers to patients who discontinue care and treatment. It includes patients known to have died, stopped treatment for medical reasons and registered as so in the clinic, in addition to patients LTFU whose outcome is unknown.

Community level: Outside of healthcare facilities (e.g. in outreach sites, health posts, home-based services, or utilising community groups).

Consent: Consent is the agreement, expressed either verbally or in writing, to a proposed action or situation. For purposes of medical intervention or research, consent given by a person for a procedure or course of treatment, or any other particular health intervention to be performed, must be informed, i.e. the person has received information about the intervention, and they must indicate that they have understood what is entailed about the possible risks and/or benefits to themselves, and that consent, if it is given, has been given voluntarily without any feeling of coercion.

Disclosure: When one partner shares his or her HIV status with another partner (or any other person), this is referred to as disclosure. When individuals learn their HIV test results alone, they often bear the burden of disclosing their HIV status to their partners without assistance from a trained counsellor or health care provider.

Epidemiological scenarios: Key to planning an effective HIV prevention response is knowing who is at higher risk of HIV; the extent to which HIV is prevalent amongst different populations; and the risk behaviours, laws and policies that may facilitate the transmission of HIV. The three main scenarios are:

- Low-level – HIV has not spread to significant levels in any sub-population
- Concentrated – HIV prevalence is high enough in one or more sub-populations to maintain the epidemic in that sub-population
- Generalized – HIV prevalence of 1–5% in pregnant women attending antenatal clinics, indicating that the presence of HIV among the general population is sufficient for sexual networking to drive
the epidemic; in a generalized epidemic with more than 5% adult prevalence, no sexually active person is ‘low-risk’

**Key populations:** The term ‘key populations’ or ‘key populations at higher risk of HIV exposure’ refers to those most likely to be exposed to HIV or to transmit it – their engagement is critical to a successful HIV response. In all countries, key populations include people living with HIV.

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

This work will specifically address adolescent key populations, aged 10 to 19 years. Other adolescents who are vulnerable to HIV may be considered including adolescents in prisons and closed settings.

**Sex work by definition includes adults only. The involvement of children under 18 in sex work is classified as sexual exploitation.**

**Loss to follow-up (LTFU):** A term used to classify patients who fail to present to a clinic (or medication pick-up) within a certain period of time. The definition is period sensitive: some clinics may use a few days after the date of missed appointment to code patients as LTFU, while others may use a longer missing period. WHO recommends using a coding period of missing for 90 days since the last missed appointment to classify patients as LTFU. Patients that are LTFU are re-grouped into a range of different outcomes, including those that may have died, those that are alive (and have either transferred to another clinic referred to as ‘silent’ transfer, or true defaulters) and those that are untraceable. Active tracing in the community is needed in order to determine outcomes of patients LTFU.

**Retention:** This term implies the opposite of attrition and includes all patients who are NOT registered as deceased, stopped or LTFU for any reason. Patients are known to be alive and continuing to visit the clinic. Measuring retention (all patients ever started minus [death + stop + LTFU]) is the critical information to be reported by sites and programmes.

**Slow progressors:** Children infected perinatally, but not diagnosed; only become symptomatic/recognized by the health services during their early adolescent years.
**HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV**

**ANNEX 2: PICO questions and references**

**PICO 1**

**Should HTC be offered to adolescents?**
- a) living in countries with generalized epidemics
- b) living in countries with a concentrated epidemic
- c) among key affected populations of adolescents at high risk of HIV

**Bibliography of included studies: Adolescent HTC**

**Generalised epidemic**


**Concentrated epidemic**


**Key populations in low-level epidemic**

Disclosure
a) Should adolescents disclose their HIV status to parents, family members, sexual partners and others?
b) What is the best way to support adolescents to disclose their HIV status safely and effectively?

Bibliography of included Studies: Adolescent Disclosure

PICO 3a: Should adolescents disclose their HIV status to parents, family members, sexual partners, others?


**PICO 3b: What is the best way to support adolescents to disclose their HIV status safely and effectively?**

**GRADE-d:**
3. Otis J et al. Effects of an empowerment program on the ability of women living with HIV (WLHIV) in Mali to manage decisions regarding whether or not to disclose HIV status. 19th International AIDS Conference: [Abstract no. MOPES02].


**To be addressed separately:**


2. Dewo Z et al. Strengthening treatment, care and support to people living with HIV through community-based treatment services. : 19th International AIDS Conference: [Abstract no. TUAD0202].


**PICO 3**

*Can training of health workers in adolescent health improve retention and adherence among adolescents living with HIV?*

**Bibliography of included studies**


**PICO 4**

*Can community-based approaches improve adherence to treatment in care among adolescents?*

**Bibliography of included Studies: Adolescent community-based approaches**

**GRADE:**


RCTs in high-income countries:

To be addressed in narrative form:
HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV

ANNEX 3: Systematic review – HTC for adolescents

HIV testing and counselling (HTC) for preventing HIV transmission and improving uptake of HIV care and treatment in adolescents

Background
More than 34 million people are presently living with HIV. In 2009, there were more than 7000 new HIV infections each day worldwide (UNAIDS 2010a). Around 2500 of these new cases were in adolescents and young adults aged 15-24. Additionally, while most of the approximately 1000 new cases of HIV each day in children under 15 were caused by perinatal transmission, a small percentage were the result of early sexual debut (UNAIDS 2010b). Adolescents and young people remain extremely vulnerable to acquiring HIV infection, especially those who live in settings with a generalised HIV epidemic, or who are members of populations at high risk for HIV acquisition or transmission.

HIV testing and counselling (HTC) is an essential component of efforts to achieve universal access to HIV prevention, treatment, care and support. Young people 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. HIV testing and counselling can serve as a means for adolescents and young people to be diagnosed and to receive care and treatment as early as possible.

Objectives
The objectives of this systematic review are to provide a summary of the key evidence, along with practice and implementation recommendations, on effective or promising HTC interventions for improving uptake of HIV treatment, care and other services in adolescents. It will also identify gaps and prioritise areas where further research is required.

Methods
Criteria for considering studies for this review

Types of studies
- Randomised controlled trials (RCTs)
- Non-randomised controlled trials
- Pre- / post-intervention evaluations
- Observational studies (e.g. cohort studies)

Types of participants
- Adolescents living in countries with a generalised HIV epidemic (HIV prevalence >1% among women attending antenatal clinics)
- Adolescents living in countries with a concentrated HIV epidemic (HIV prevalence >5% among subpopulations but <1% in the general population)
- Key populations of adolescents (e.g. drug users, sex workers, transgender persons, youth with male sex partners of any age, and other populations at higher risk of acquiring or transmitting HIV infection than the general population)

We define adolescents as individuals 10-19 years of age. For the purposes of the systematic review, we excluded studies that included both adolescents and adults, unless the data were stratified by age and could be disaggregated. As evidence was sparse, however, we included non-stratified studies (and even studies of only adults) in the GRADE evidence profiles. The quality of evidence from the literature of mixed or adult-only studies was downgraded, as appropriate, for indirectness.

**Types of interventions**
- HIV testing and counselling (HTC)
- HIV testing (without counselling)
- HIV counseling (without testing)

**Types of outcome measures**

**Primary outcomes**
1. Change in HIV incidence
2. Change in HIV mortality
3. Change in HIV morbidity
4. Change in STI incidence

**Secondary outcomes**
1. Access to and uptake of health care services
   1. HIV care and treatment
   2. Uptake of and adherence to antiretroviral therapy
   3. Sexually transmitted infections screening and treatment
   4. Tuberculosis screening, treatment and completion
   5. Hepatitis screening and treatment
2. Access to and uptake of prevention services
   1. Provision of condoms
   2. Male circumcision
   3. Prevention of mother-to-child HIV transmission
   4. Drug services
   5. Other relevant measures
3. Behaviour change
   1. Increased condom use
   2. Reduced sexual risk behaviour
   3. Delayed sexual debut
4. Psychosocial impact
   1. Reduction in mental health symptoms
   2. Reduction in stigma and discrimination
   3. Increased psychosocial support
   4. Improved quality of life
**Search methods for identification of studies**

See search methods used in reviews by the Cochrane Collaborative Review Group on HIV Infection and AIDS.

**Electronic searches**

We formulated a comprehensive and exhaustive search strategy in an attempt to identify all relevant studies regardless of language or publication status (published, unpublished, in press and in progress). Full details of the Cochrane HIV/AIDS Review Group methods and the journals hand-searched are published in the section on Collaborative Review Groups in The Cochrane Library.

**Journal and trial databases**

We searched the following electronic databases, in the period from 01 January 1985 (the year in which the first HIV antibody test was licensed in the United States) to the search date (1 October 2011):

- CENTRAL (Cochrane Central Register of Controlled Trials)
- EMBASE
- PsycINFO
- PubMed
- Web of Science / Web of Social Science
- World Health Organization (WHO) Global Health Library (www.globalhealthlibrary.net), which includes references from AIM (AFRO), LILACS (AMRO/PAHO), IMEMR (EMRO), IMSEAR (SEARO), and WPRIM (WPRO)

Along with appropriate MeSH terms and relevant keywords, we used the Cochrane Highly Sensitive Search Strategy for identifying reports of randomised controlled trials in MEDLINE (Higgins 2008), and the Cochrane HIV/AIDS Group's validated strategies for identifying references relevant to HIV infection and AIDS. The search strategy was iterative, in that references of included studies were searched for additional references. All languages were included.

See Appendix 1 for our PubMed search strategy, which was modified and adapted as needed for use in the other databases.

**Searching other resources**

**Conference databases**

We searched the Aegis archive of HIV/AIDS conference abstracts, which includes abstracts for the following conferences:

- British HIV/AIDS Association, 2001-2010
- Conference on Retroviruses and Opportunistic Infections (CROI), 1994-2008
- European AIDS Society Conference, 2001 and 2003
- International AIDS Society, Conference on HIV Pathogenesis, Treatment and Prevention (IAS), 2001-2005

We also searched the CROI and International AIDS Society web sites for abstracts presented at conferences subsequent to those listed above (CROI, 2009-2011; IAC, 2008-1010; IAS, 2007-2011).
Other resources
In addition to searching electronic databases, we contacted individual researchers, experts working in
the field and authors of major trials to address whether any relevant manuscripts were in preparation or
in press. The references of published articles found in the above databases were searched for additional
pertinent materials.
We searched WHO’s International Clinical Trials Registry Platform (ICTRP) to identify ongoing trials.

Data collection and analysis
Two authors (GWR and MLL) independently extracted data into a standardised, pre-piloted data
extraction form. To the extent possible, the following characteristics were extracted from each included
study:
- Administrative details: trial identification number; author(s); published or unpublished; year of
  publication; number of studies included in paper; year(s) in which study was conducted; details
  of other relevant papers cited;
- Details of the study: study design; type, duration and completeness of follow up; location/orientation of study (e.g. higher-income vs. low or middle-income country; stage of HIV epidemic)
- Details of participants: age range; gender, sexual or gender orientation if appropriate; clinical
  characteristics if appropriate
- Details of intervention: venue; qualifications of counselling personnel; characteristics of HIV
  diagnostic tests (e.g. rapid vs. standard)
- Details of outcomes
- Details necessary for risk of bias assessment

Risk of bias in included studies
Two review authors independently assessed risk of bias for each study using the bias assessment tool
described in the Cochrane Handbook (Higgins 2008). The Cochrane approach assesses risk of bias in
individual studies across six domains: sequence generation, allocation concealment, blinding,
incomplete outcome data, selective outcome reporting and other potential biases.

Sequence generation (checking for selection bias)
- Low risk: investigators described a random component in the sequence generation process, such
  as the use of random number table, coin tossing, card or envelope shuffling.
- High risk: investigators described a non-random component in the sequence generation process,
  such as the use of odd or even date of birth, algorithm based on the day or date of birth,
  hospital or clinic record number.
- Unclear risk: insufficient information to permit judgment of the sequence generation process.

Allocation concealment (checking for selection bias)
- Low risk: participants and the investigators enrolling participants cannot foresee assignment
  (e.g., central allocation; or sequentially numbered, opaque, sealed envelopes).
• High risk: participants and investigators enrolling participants can foresee upcoming assignment (e.g., an open random allocation schedule, a list of random numbers), or envelopes were unsealed, non-opaque or not sequentially numbered.

• Unclear risk: insufficient information to permit judgment of the allocation concealment or the method not described.

**Blinding (checking for performance bias and detection bias)**

• Low risk: blinding of the participants, key study personnel and outcome assessor and unlikely that the blinding could have been broken. Not blinding in the situation where non-blinding is unlikely to introduce bias.

• High risk: no blinding or incomplete blinding when the outcome is likely to be influenced by lack of blinding.

• Unclear risk: insufficient information to permit judgment of adequacy or otherwise of the blinding.

**Incomplete outcome data (checking for possible attrition bias through withdrawals, dropouts, protocol deviations)**

• Low risk: no missing outcome data, reasons for missing outcome data unlikely to be related to true outcome or missing outcome data balanced in number across groups.

• High risk: reason for missing outcome data likely to be related to true outcome, with either imbalance in number across groups or reasons for missing data.

• Unclear risk: insufficient reporting of attrition or exclusions.

**Selective reporting**

• Low risk: a protocol is available which clearly states the primary outcome is the same as in the final trial report.

• High risk: the primary outcome differs between the protocol and final trial report.

• Unclear risk: no trial protocol is available or there is insufficient reporting to determine if selective reporting is present.

**Other forms of bias**

• Low risk: there is no evidence of bias from other sources.

• High risk: there is potential bias present from other sources (e.g., early stopping of trial, fraudulent activity, extreme baseline imbalance or bias related to specific study design).

• Unclear risk: insufficient information to permit judgment of adequacy or otherwise of other forms of bias.

The quality of evidence across the body of evidence was assessed with the GRADE approach (Guyatt 2008), which defines the quality of evidence for each outcome as “the extent to which one can be confident that an estimate of effect or association is close to the quantity of specific interest” (Higgins 2008). The quality rating across studies has four levels: high, moderate, low or very low. Randomised trials are considered to be of high quality, but can be downgraded for any of five reasons; similarly, observational studies are considered to be of low quality, but can be upgraded for any of 3 reasons. The 5 factors that decrease the quality of evidence are 1) limitations in study design; 2) indirectness of
evidence; 3) unexplained heterogeneity or inconsistency of results; 4) imprecision of results; or 5). high probability of publication bias. The three factors that can increase the quality level of a body of evidence are 1) large magnitude of effect; 2) if all plausible confounding would reduce a demonstrated effect; and 3) if there is a dose-response gradient.

Observational studies were assessed for risk of bias using the above criteria, as well as other measures including the Newcastle-Ottawa Quality Assessment Scale (Wells 2011). Specifically, the scale uses a star system to judge three general areas: selection of study groups, comparability of groups, and ascertainment of outcomes (in the case of cohort studies). As a result, this instrument can assess the quality of non-randomised studies so that they can be used in a meta-analysis or systematic review.

**Assessment of Quality of Evidence across Studies**
We assessed the quality of evidence across a body of evidence (i.e., multiple studies with similar interventions and outcomes) with the GRADE approach (Guyatt 2008), defining the quality of evidence for each outcome as “the extent to which one can be confident that an estimate of effect or association is close to the quantity of specific interest” (Higgins 2008). The quality rating across studies has four levels: high, moderate, low or very low. Randomised controlled trials are categorised as high quality but can be downgraded; similarly, other types of controlled trials and observational studies are categorised as low quality but can be upgraded. Factors that decrease the quality of evidence include limitations in design, indirectness of evidence, unexplained heterogeneity or inconsistency of results, imprecision of results or high probability of publication bias. Factors that can increase the quality level of a body of evidence include a large magnitude of effect, if all plausible confounding would lead to an underestimation of effect and if there is a dose-response gradient.

**Measures of effect**
We used Review Manager 5 provided by the Cochrane Collaboration for statistical analysis and GRADEpro software (GRADEpro 2008) to produce GRADE evidence profiles. We summarized dichotomous outcomes for effect in terms of risk ratio (RR), Odds ratio (OR), and Hazards ratio (HR) with their 95% confidence intervals. We present finding in GRADE evidence profiles for all outcomes of interest.

**Results**
**Description of studies**
**Results of the search**
Searches were conducted on 1 October, 2011, and produced 282 titles after 6 duplicates were removed. After initial screening of titles by TH, 99 titles and abstracts were selected for further review by two authors (GWR and MLL). GWR and MLL independently conducted the selection of potentially relevant studies by scanning the titles, abstracts, and descriptor terms of all downloaded material from the electronic searches. Irrelevant reports were discarded, and the full article was obtained for all potentially relevant or uncertain reports. GWR and MLL independently applied the inclusion criteria. TH acted as arbiter where there was disagreement. Studies were reviewed for relevance, based on study design, types of participants, types of interventions and outcome measures. Fifteen full-text articles were closely examined by two authors (GWR and MLL). We thus identified 5 randomised controlled trials and 5 observational studies that met our inclusion criteria for data extraction, coding and analysis.
Included Studies:
We identified five randomized controlled trials (Apoola 2011, Bolu 2004, Muhamadi 2011, Coates 2000, Wanyenze 2011) and four observational studies (Gwadz 2010, Kabiru 2010, Muller 1995, Naughton 2011) that met our inclusion criteria. The five RCTs were conducted in six countries. Three studies were conducted in countries with generalized HIV epidemics, including Uganda (Muhamadi 2011, Wanyenze 2011), Kenya, Tanzania, and Trinidad (Coates 2000). Two RCTs were conducted in concentrated or low level HIV epidemic settings among key populations of youth in STD clinics in the United States (Bolu 2004), and youth in substance misuse services in the United Kingdom (Apoola 2010). Five observational studies were conducted in four countries. Two observational studies were conducted in countries with generalized HIV epidemics including Kenya (Kabiru 2010) and South Africa (Naughton 2011). Two observational studies were conducted in concentrated or low level HIV epidemics, one in Thailand (Muller 1995) and one in the United States among key populations of homeless youth (Gwadz 2010).

Randomized controlled studies in generalized epidemic settings

Muhamadi 2011: This randomized, controlled trial was conducted in three health facilities in Eastern Uganda. Eligible participants were newly screened and identified HIV-positive clients from voluntary testing and counseling (VCT) at the three health facilities who were 18 years and older and not part of the PMTCT program. From July 2009 to June 2010, 400 participants were randomized to either standard of care where posttest counseling was delivered by staff not trained in basic counseling or the intervention arm consisting of specialized counseling delivered by staff with training in basic counseling skills and combined with home visits by community support agents for extended counseling and support. The primary outcome was the proportion of newly detected and counseled persons living with HIV (PLHIV) who had received pre-ARV care in the subsequent three months (+2 months). Uptake of pre-ARV care was significantly higher among HIV-positive patients who received the intervention compared to standard of care post-test counseling (RR 1.75, 95% CI 1.44 to 2.14). Additionally, among those who came for pre-ARV care, the majority of patients in the intervention arm (64.5%) compared to the control arm (34.5%) had disclosed their HIV status to their family.

Coates for the Voluntary HIV-1 Counseling and Testing Efficacy Group 2000: This randomized controlled trial was conducted in three sites in Nairobi, Kenya, Dar es Salaam, Tanzania, and Port of Spain, Trinidad. Eligible participants were 18 years and older and were not known to be infected with HIV. From 1995-1998, 3120 individuals were randomized to either voluntary counseling and testing, based on the US CDC client-centered HIV-1 counseling model or provision of standard health information. The VCT model includes personalized risk assessment and development of a personalized risk reduction plan for each client. At first follow-up, all health-information participants were offered VCT and all VCT participants were offered retesting. Primary outcomes were unprotected intercourse with primary and non-primary partners and STI incidence at six month follow-up. Unprotected sexual intercourse with a non-primary partner was significantly reduced among both men (RR 0.74, 95% CI 0.6 to 0.91) and women (RR 0.72, 95% CI 0.56 to 0.93) who received VCT compared to those who received basic health information only. STI incidence decreased (non-statistically significant) among those individuals who received VCT compared to standard health information (OR 0.80, 95% CI 0.53 to 1.20).

Wanyenze 2011: This randomized controlled trial was conducted at one site in Kampala, Uganda. Eligible participants were hospitalized in-patients who were over 18 years of age with unknown HIV
status. Exclusion criteria included those with altered mental status and those too ill to provide informed consent or to be interviewed. From March 2004 to March 2005, 3120 individuals were randomized to either free immediate inpatient HIV voluntary counseling and testing, based on the US CDC client-centered HIV-1 counseling model or referral for free outpatient HIV counseling and testing post-discharge. The VCT model includes personalized risk assessment and development of a personalized risk reduction plan for each client. Those randomized to the control group were given a referral card and an appointment to return for counseling and testing one week after discharge to the same hospital. Primary outcomes were linkage to medical care, including ARVs, and mortality at six months follow-up. Fewer HIV-positive patients in the intervention arm attended a HIV clinic compared to the control arm (RR 0.76, 95% CI 0.59 to 0.98). Fewer hospitalized HIV-positive adults who received VCT as inpatients were still alive compared to HIV-positive patients referred for VCT post-discharge (RR 0.83, 95% CI 0.68 to 1.0). Of note, 69% (171/249) in the control group (VCT referral post discharge) and 3/251(1%) in the inpatient intervention group were not tested for HIV.

Observational Studies in Generalized Epidemic Settings
Kabiru 2010: Kabiru and colleagues analyzed cross sectional, population-based data collected on a sample of youth aged 18-24 years from June to July 2007 in Kisumu Kenya. Information was collected from a 10-year retrospective life history calendar, including HIV testing since age 14 until the survey, capturing most of the HIV counseling and testing history. Outcomes included evaluating the impact of having an HIV test in the previous 6 months on subsequent sexual behavior, specifically concurrent sexual partnerships, unprotected sex in any partnership, or risky sexual partnerships (defined as partnership with a casual partner, commercial sex worker or client, one night stand or stranger) in a given month. Results were analyzed separately by sex and for females based on pregnancy status at first test.

Males who reported having an HIV test in past 6 months were significantly more likely to report concurrent sexual partnerships in a given month (HR 3.18, 95% CI 1.51 to 6.72) and having had a “risky” sexual partner in the past 6 months (non-statistically significant) (HR 1.11, 95% CI 0.61 to 2.01) compared to men who did not report HIV testing. Fewer men who had an HIV test in the past six months (non-statistically significant) reported having had unprotected sex (HR 0.98, 95% CI 0.75 to 1.28). However, males with greater number of cumulative HIV tests were significantly less likely to report concurrent sexual partnerships (0.57, 95% CI 0.40, 0.82). Among “ever pregnant” women, those having had an HIV test in the past 6 months were significantly less likely to have had unprotected sex in any given month, (HR 0.59, 95% CI 0.47 to 0.75) than those women who did not test. Though not-statistically significant, more “ever pregnant” women who had an HIV test in past 6 months reported having had a “risky” sexual partner (HR 1.18, 95% CI 0.33 to 4.16) and concurrent sexual partnerships (HR 1.67, 95% CI 0.51 to 5.48) compared to women who did not test. Among “never pregnant” women, having an HIV test in the past 6 month was significantly more likely to have had a “risky” sexual partner (HR 3.54, 95% CI 1.48 to 8.45) and (non-statistically significant) of unprotected sex in any given month (HR 1.64, 95% CI 0.94 to 2.83) compared to women who did not test. However, fewer “never pregnant” women (non-statistically significant) who had an HIV test in the past 6 months reported concurrent sexual partnerships (HR 0.69, 95% CI 0.07 to 7.12).
**Naughton:** 2011 Naughton and colleagues reported data in an abstract from a retrospective case series among children >12 years old attending schools in Mbhasha district, Eastern Cape, South Africa. Voluntary counseling and testing teams visited 12 schools between June 2008 and August 2009 to establish HIV education and counselling programs which included group education on HIV, individual counselling for HIV testing, and Point of Care (POC) HIV testing. Follow-up attempts were made by trained lay counselors to enroll those that tested HIV positive into local HIV wellness program. Retrospective analysis of the program was conducted with follow-up period of 2-14 months. Of 758 adolescents tested for HIV, 7(0.9%) tested positive. However, none (0%) of the 7 HIV-positive adolescents identified subsequently attended the clinic for care. There was no control group, and the relative effect was not calculable.

**Randomized controlled studies in low-level epidemic settings or among key populations**

**Bolu 2004:** Bolu and colleagues conducted a subgroup analysis of a randomized, controlled trial of HIV counseling efficacy (Project RESPECT) conducted in 5 public STD clinics in the United States. Eligible participants were 14 years old and older, English-speaking, who reported vaginal intercourse within preceding 3 months. Male-male sex within past 12 months was exclusion criterion. From July 1993 to September 1996, 4328 participants were randomized to four intervention arms with varying intensity of safer-sex counseling with trained HIV counselor or clinician, arm 1: enhanced counselling (1 20-minute counselling session + 3 1-hour sessions with counselor); arm 2: brief prevention counselling (1 20-minute counselling session + 1 20-minute session 7-10 days later-based on CDC’s client-centered HIV counseling) or Arm 3: HIV prevention education (one 5-minute session with clinician + one 5-minute results reporting session). The subgroup analysis included 14-20 year old participants (N=764) in the trial in first three arms that followed participants up to 12 months. Primary outcome was STI incidence, based on laboratory diagnosis during the 12 months after the intervention. Neisseria gonorrhoeae was diagnosed by culture or urethral swab Gram stain, Chlamydia trachomatis by endocervical PCR or urine, and syphilis by treponemal and non-treponemal tests, and HIV. STI incidence was decreased in adolescents in the HIV counseling interventions (brief or enhanced) (17.3%) compared to those in the educational messages group (26.6%) (RR 0.65, 95% CI 0.49 to 0.86). The efficacy of brief counseling was similar to enhanced counseling.

**Apolla 2011:** This randomized controlled trial was conducted in the UK. Eligible participants were 13 to 19 years of age attending young person’s substance misuse service who were deemed competent to participate. From 2007 to 2008, 54 participants were randomized to either pre-test discussion with immediate oral swab for HIV, HBV and HCV, with results available in two days, and appointment at STI clinic for genital infection screening (N=27) or pre-test discussion counseling with referral to the STI clinic for same day blood testing for HIV (also offered testing for syphilis, hepatitis B and C and genital infection screening) (N=27). Primary outcome was attending STI screening at STI clinic and secondary outcomes included number receiving results within a week of testing, and number receiving at least one dose or all three doses of HBV and Hepatitis A vaccination. With 1 week follow-up, attendance at STI clinic for STI screening increased in adolescents undergoing oral swab HIV testing (33%) vs. those offered referral for blood HIV testing (11%), though not statistically significant (RR 3, 95% CI 0.91 to 9.88). Uptake of HIV, HBV, and HCV testing increased in the immediate oral swab compared to referral group (RR 8.77, 95% CI 4.73 to 16.26) but there was no difference in receipt of all 3 doses of HAV and HBV vaccines (RR 0.90, 95% CI 0.43 to 1.85).
Observational studies in low-level epidemic settings or among key populations

Gwadz 2010: Gwadz et al conducted a cross sectional study of 217 homeless youth, ages 15-24 years, who were recruited through respondent driven sampling in New York City in 2007-1008. The objective was to compare practices and the context of rapid and conventional HIV testing among this population and to examine the extent of referrals and linkages to services post HIV testing. Outcomes were referral or linkage to care including medical care, mental health, HIV prevention services, homeless shelter or other community services after the last rapid or conventional HIV test. Most of the youth had been tested for HIV in the past year (82%), and had received pre- and posttest counseling (77%) for both rapid and conventional tests. Overall, only 44% received referral to or linkage to health and/or community services after testing. More patients received referrals and linkages following a conventional test (35%) than following a rapid test (26%) (p=.092)

Muller 1995: Muller and colleagues conducted a cross sectional study among 300 HIV-positive consecutive patients attending the immune clinic in Bangkok, Thailand about their HIV testing history, sexual behavior, including number of sexual partners and condom use, after receipt of their positive HIV test result. These self-report data were compared to similar data collected among 300 consecutive age- and gender-matched controls attending the anonymous VCT clinic before voluntary counseling and testing. With a median of 23 months follow-up, adolescents and adults in the intervention group (after VCT) were significantly more likely to report condom use during the last 3 episodes of sexual intercourse, compared to controls (RR 3.78, 95% CI 2.65 to 5.39) and to report having had fewer sexual partners (N=0-1) in the past six months compared to controls (RR 1.82, 95% CI 1.53 to 2.15). This was largely due to the difference in those reporting no sexual partner (42% vs 14%).

Excluded studies
We excluded four studies after reviewing the full text articles (and in one case the conference abstract). Mollen 2008, and Sattin 2011 were excluded because they did not include a comparison. Tolou-Shams 2007 was excluded because the intervention was designed to improve testing rates. Woods 2002 was excluded because there was no comparison between tested and not tested (the study combined HIV-negative and untested).

Risk of Bias in included studies

Effects of Interventions
Using Cochrane Collaboration methods, we performed a systematic review.

Should HIV testing and counselling be used for HIV prevention and linkage to care among adolescents in generalised epidemic settings?

In generalized epidemic settings, three randomized controlled trials examined the efficacy of HIV counseling and testing among participants who were 18 years of age and older (Coates 2000, Muhamadi 2011, Wanyenze 2011). There were no trials that examined HIV testing and counselling specifically among adolescents less than 18 years of age. Each of these trials examined different study populations,
interventions, and outcomes and, therefore, could not be combined into a meta-analysis. One RCT examined the efficacy of CDC’s client-centered HIV counseling compared to standard health information among participants who were not known to be HIV-infected on the incidence of laboratory confirmed STIs and self-reported unprotected sexual intercourse (Coates 2000). Another trial compared an enhanced post-test counseling intervention with community support to standard post-test counseling among newly screened HIV-positive patients on uptake of pre-ARV care (Muhamadi 2011) in Uganda. The third trial compared immediate inpatient HIV client-centered HIV-1 counseling and testing to referral for outpatient HCT post-discharge among hospitalized patients in Uganda on attendance at HIV clinic and survival six month post-discharge for those who tested HIV-positive (Wanyenze 2011). There were two observational studies that included adolescents in the study population (Naughton 2011, Kabiru 2010), one presented as an abstract only (Naughton 2011). Results for these observational studies are presented separately.

Randomized controlled trials
One randomized, controlled, multi-site trial examined the efficacy of voluntary HIV counseling and testing, based on the US CDC client-centered HIV-1 counseling model, compared to provision of standard health information among adolescent and adult populations 18 years of age and older who were not known to be HIV-infected (Coates 2000). The study included participants from three countries (Kenya, Tanzania, and Trinidad). Unprotected sexual intercourse with a non-primary partner was significantly reduced among both men (RR 0.74, 95% CI 0.6 to 0.91) and women (RR 0.72, 95% CI 0.56 to 0.93) who received VCT compared to those who received basic health information at six months follow-up. STI incidence decreased (non-statistically significant) among those individuals who received VCT compared to standard health information (OR 0.80, 95% CI 0.53 to 1.20).

In an RCT addressing an enhanced post-test counseling intervention compared to standard of care among newly identified HIV-positive patients, uptake of pre-ARV care was significantly higher among HIV-positive patients who received the intervention, consisting of enhanced post-test counseling by trained staff combined with home visits by community support agents for extended counseling compared to standard of care post-test counseling (RR 1.75, 95%CI 1.44 to 2.14) (Muhamadi 2011).

In an RCT that examined the effectiveness of an inpatient HIV testing intervention compared to referral for HIV after discharge (control), fewer HIV-positive patients in the intervention arm attended an HIV clinic at six months follow-up compared to those who received referral for VCT post-discharge (RR 0.76, 95% CI 0.59 to 0.98) (Wanyenze 2011). Fewer hospitalized HIV-positive patients who received VCT as inpatients were still alive at six months compared to those referred (RR 0.83, 95% CI 0.68 to 1.0). However, 69% of those in the control group (VCT referral post discharge) were not tested for HIV compared to only 1% in the intervention arm.

There were no trials that examined the efficacy of HIV counseling and testing on the health outcomes of HIV incidence or morbidity, quality of life, stigma, or TB or hepatitis screening and treatment.

Observational Studies
Two observational studies of very low quality were identified that included adolescents <18 years in the study population. Evidence from these two studies found mixed results compared to the indirect evidence from RCTs among adults. HIV testing among adolescents did not result in safer sexual behaviors for all subpopulations nor increased enrollment in HIV care for those identified as positive. In
one observational study (Kabiru 2010) with 6 months follow-up, males who reported having an HIV test in past 6 months were significantly more likely to report concurrent sexual partnerships in a given month (HR 3.18, 95% CI 1.51 to 6.72), and significantly more “never pregnant” women who had an HIV test in past 6 months reported having a “risky” sexual partner in the past 6 months, compared to women in the control group (HR 3.54, 95% CI 1.48 to 8.45). Though among “ever pregnant” women, those having had an HIV test in the past 6 months were significantly less likely to have had unprotected sex in any given month, (HR 0.59, 95% CI 0.47 to 0.75) than those women who did not test. The other observational study of very low quality (Naughton 2011) was a retrospective analysis, with no control group, of the impact of an HIV education, counselling and point of care HIV testing program conducted in schools. Despite follow-up attempts made by trained lay counselors, none (0%) of the seven adolescents identified as HIV positive enrolled in the HIV wellness program.

Should HIV testing and counselling be used for HIV prevention and linkage to care among key populations of adolescents in concentrated/low-level epidemic setting?

Among key populations of adolescents in concentrated/low level epidemic settings, two randomized controlled trials examined the efficacy of HIV counseling and testing among adolescent populations (Bolu 2004, Apoola 2011). One conducted a subgroup analysis of 14-20 year old participants (N=764) from a larger HIV prevention counseling trial in the United States (Bolu 2004), and another was conducted among 13 to 19 years of age attending young person’s substance misuse service in the UK (Apoola 2011). Each of these trials examined different study populations, interventions, and outcomes and, therefore, could not be combined into a meta-analysis. One RCT examined the efficacy of HIV counseling (Project RESPECT) interventions of varying intensities of one-on-one safer sex counseling with a trained HIV counselor conducted in STD clinics. Both enhanced counseling and brief prevention counseling were compared to HIV prevention education on the incidence of STDs at 12 months follow-up (Bolu 2004). The other trial evaluated the efficacy of pre-test discussion with immediate oral swab for HIV, HBV and HCV testing and appointment at STI clinic for genital infection screening or pre-test discussion counseling with referral to the STI clinic for same day blood testing for HIV on uptake of HIV, HCV, and HBV testing, HAV and HBV vaccination, and attendance at the STI clinic. (Apoola 2011). There were no trials that examined the outcomes of change in HIV incidence, HIV morbidity and mortality, linkage to HIV care, access to and uptake of prevention services, behavior change or psychosocial impact.

There were two observational studies (Gwadz 2010, Muller 1995). One included homeless youth 15 to 24 years of age (Gwadz 2010) in the United States, and one included a non-stratified mixed adult/adolescent population in HIV and VCT clinics in Thailand (Muller 1995). Results for these studies are presented separately.

Randomized controlled trials

Data from a subgroup analysis of adolescents in an RCT of HIV counseling efficacy (Project RESPECT) (Bolu 2004) demonstrated that HIV prevention counseling (brief or enhanced) resulted in fewer STDs for adolescents compared to those who received HIV educational messages (RR 0.65, 95% CI 0.49 to 0.86), with brief interactive counseling (CDC client-centered HIV prevention counseling model) having similar efficacy to enhanced counseling in reducing new STDs.
In the other RCT (Apoola 2011) with 1 week follow-up, uptake of HIV, HBV, and HCV testing increased significantly in adolescents engaging in substance misuse services who had immediate oral swab HIV testing compared to those offered referral for blood testing (RR 8.77, 95% CI 4.73 to 16.26) but there was no difference in receipt of all 3 doses of HAV and HBV vaccines (RR 0.90, 95% CI 0.43 to 1.85). Attendance at STI clinic increased (non statistically significant) in those with oral swab HIV testing vs. those referred for blood testing (RR 3, 95% CI 0.91 to 9.88).

**Observational Studies**

In one observational study providing very low quality evidence (Gwadz 2010) 26% of HIV-positive adolescents subsequently attended clinic for care, while 35% in the control group attended clinic. In the second observational study of very low quality (Müller 1995), adolescents in the intervention group (after VCT) were significantly more likely to report having had fewer sexual partners (N=0-1) in the past six months (RR 1.82, 95% CI 1.53 to 2.15) and significantly more likely to report condom use during the last 3 episodes of sexual intercourse (RR 3.78, 95% CI 2.65 to 5.39) compared to controls.

**Discussion**

**Summary of main results**

We found few randomized controlled trials examining the impact of HIV testing among adolescents and young adults in either generalized epidemic settings or high-risk populations in low level epidemics on patient important outcomes. In generalized epidemic settings, there are no randomized trials conducted specifically among adolescent populations. However, indirect evidence from RCTs conducted among adults found that HIV counseling and testing is effective at reducing unprotected sexual intercourse with non-primary partners and STI incidence among those at risk for HIV infection. Additionally, enhanced post-test counseling that includes community support agents is effective at improving uptake of pre-ARV care among HIV positive patients. Observational studies, despite including the target population of adolescents were of very low quality and evidence was mixed concerning the impact of HIV testing on sexual risk taking behaviors or uptake of HIV care.

Data from RCTs and high quality observational data are needed about the efficacy of HIV testing in adolescent populations on HIV incidence, morbidity and mortality as well as uptake of services and risk behaviors in generalized epidemic settings. Applicability of the current evidence among adults to adolescent populations is not known. With new evidence to support treatment as prevention and impact of potent antiretroviral regimens on reductions in HIV related morbidity and mortality, more data are needed on impact of different HIV counseling and testing strategies for reducing HIV incidence and improve linkage to HIV care for adolescents that are HIV-infected. Most data on effectiveness are based on the CDC VCT model, which includes personalized risk assessment and development of a personalized risk reduction plan for each client. The impact of more brief discussions with HIV testing needs further evaluation among adolescent populations. Furthermore, data are needed on most cost-effective strategies for testing adolescent populations, whether in facilities, prevention services, or in the community and effective strategies to link those that test positive to HIV care and treatment.
In low level epidemic settings among high risk youth where general population HIV prevalence rates are much lower than in Sub-Saharan Africa, data from sub analysis of one RCT demonstrate the effectiveness of HIV counseling and testing in reducing the incidence of STDs among heterosexual adolescents attending STD clinics. This interactive, risk-reduction counseling that includes personalized risk assessment and risk-reduction plans has not been studied in all high-risk populations, including young men who have sex with men or homeless and substance-abusing youth where more data are needed. Though this model has also demonstrated effectiveness in generalized epidemic settings among adults, the applicability of these data to adolescents in low level epidemic settings is unclear where there may be a need for specialized counseling due to higher risk behaviors, lack of HIV knowledge, and community outreach approaches. Data from another RCT among youth in substance abuse services support the use of community testing using rapid, oral, point-of-care technologies in improving uptake of HIV, HBV, and HCV testing and may provide a unique model for high risk populations. No studies evaluated the impact of HIV testing among adolescent populations in low level epidemics on HIV incidence, morbidity and mortality. More data are needed among young men who have sex with men and other high risk groups on efficacy of HIV counseling and testing interventions on patient important outcomes and linkage to care.

**Quality of evidence**

**GRADE**

In the GRADE system, well-conducted randomized controlled trials, without additional imitations, provide high quality evidence, and observational studies, without any additional strengths or limitations, provide low-quality evidence. The quality of evidence provided by a body of literature comprised of observational studies would be graded as low.

In this analysis, we found that the quality of evidence among RCTs varied from very low to moderate in generalized epidemic settings and low to very low in low level epidemics. Quality of evidence was moderate for the outcome of STI incidence based on one RCT (Coates 2000), which was downgraded only for indirectness due to a largely adult population. However, for all other outcomes in both generalized and low-level epidemics, evidence from RCTs was either of low or very-low quality, downgraded for imprecision (few participant and events) and indirectness (evidence from largely adult populations, or self-reported behavioral outcomes). Additionally, one study was also downgraded for indirectness as the population was sick, hospitalized inpatients (Wanyenze 2011).

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

**REFERENCES**

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

ANNEX 4: Systematic review – ALHIV: Disclosure, adherence and retention in care

Disclosure

Adolescent disclosure of HIV status

Narrative of results and findings, with evidence quality

PICO 3a. Should adolescents with HIV infection disclose their HIV status to parents, family members, sexual partners, others?

3a. Results, Quality of the evidence, Findings

Inclusion criteria included controlled trials (randomized or not), pre-post-intervention evaluations and observational (retrospective or prospective) studies in which there is a comparator. No controlled trials were identified to address PICO 3a. Because of the expected paucity of adolescent studies, study design criteria were broadened to include adult studies. Of the 29 publications (27 distinct studies) included after removal of studies not eligible for inclusion and duplicates, nine were from high-income countries and 18 from low or middle-income countries. Adolescents were defined as ten through 19 years of age. Only three studies were of adolescents (Dempsey 2012, Lam 2007, Sherman 2000). The remaining studies described adults.

None of the evidence for PICO 3a could be subjected to GRADE analysis, for the following reasons. Two of the three adolescent studies were cross-sectional (Dempsey 2012, Lam 2007). The third was a prospective observational study that compared the difference in mean immunologic and behavioural test results between children (age 8 to 18 years old) who had and had not disclosed their HIV status (Sherman 2000). All but three adult studies used a cross-sectional, descriptive, or case control design, and thus were not amenable to GRADE analysis. The remaining three were cohort studies but presented insufficient information needed for GRADE analysis because they reported only hazard ratios (Chepkurui 2012), regression parameters (Strachan 2007), or outcomes (prevention of maternal-to-child transmission [PMTCT] outcomes) not pre-specified for this PICO question (Jasserson 2011). Therefore, associations are described below, without measures of effect or confidence intervals.

Overall, the adolescent studies showed that disclosure was associated with increased percent of CD4 cells (Sherman 2000), decreased number of partners (but not with decreases in unprotected sex) (Dempsey 2012), and increased distress when disclosure was to acquaintances, but no statistically significant association with mental health symptoms with disclosure to family or close friends (Lam 2007).

Seven studies of adults showed disclosure was associated with linkage to care and ART adherence (Sayles 2006, Beyene 2009, Ochieng-Ooko 2010, Rotheram-Borus 2010, Abaynew 2011, Ding 2011, Hatcher 2012), but one showed no association (Skogar 2006). Other studies showed disclosure was
associated with higher CD4 counts (Strachan 2007), and nondisclosure was associated with virologic failure at 48 weeks (Chepkurui 2012). Disclosure was associated with better HIV testing and nevirapine adherence in infants (Peltzer 2010, Peltzer 2011), and nondisclosure was associated with suboptimal PMTCT outcomes (Jasserson 2011).

Other studies of adults reported on the following additional outcomes. Disclosure to sexual partners was associated with increased frequency of condom use and reduced number of sexual partners; those who disclosed to HIV-negative partners were significantly less likely to engage in unprotected anal sex compared to those who did not disclose their HIV status (Sixgashe 2001, Crepaz 2003, Kebede 2005, Parsons 2005, Wong 2009, Bird 2011, Seid 2012). One study of adult women of three ethnic groups in the US found no association between disclosure and depressed mood or health-related psychological distress, except among Latinas in whom a modest association was found (Comer 2000). In four studies of adults, disclosure was associated with higher levels of HIV stigma; women who disclosed to sexual partners reported negative experiences such as anger and blame, including one study where women reported that partners reacted with violence and ending the relationship (Kilewo 2001, Kebede 2005, Gari 2010, Holzemer 2012).

PICO 3b: What is the best way to support adolescents to disclose their HIV status safely and effectively?

3b.1 Results of seven studies amenable to GRADE analysis

Seven studies were amenable to GRADE analysis, of which five of which were controlled trials (Rotheram-Borus 2001a, Rotheram-Borus 2001b, Wolitski 2005, Murphy 2011, Serovich 2011) and two were cohort studies (Mundell 2011, Otis 2012). Only one was conducted of HIV-infected adolescents (Rotheram-Borus 2001a). These seven studies are described below, based on type of intervention utilized to support disclosure of positive HIV status.

**Small group discussions or group counselling (USA).** A randomized controlled trial including HIV-infected adolescents was conducted in a high-income country (USA) in the pre-antiretroviral therapy era, and utilized small group discussions to support disclosure (Rotheram-Borus 2001a). In comparing adolescents exposed to the intervention and those in standard care, no statistically significant differences were observed in disclosure to sex partners at 15 months (RR 1.2, 95% CI 0.79 to 1.6), mean T-cell count (MD 8.4 higher, 95% CI 12.58 lower to 29.38 higher), emotional distress scores at 9 or 15 months (MD 0 higher 95% CI 0.42 lower to 0.42 higher; the same at each interval), or mean physical disease score at 15 months (MD 0.1 lower, 95% CI 0.52 lower to 0.32 higher). Participating adolescents had significantly more missed appointments at 9 months, compared to those receiving standard care (MD 0.6 higher, 95% CI 0.18 to 1.02 higher). However, adolescents participating in small group discussions were less likely to report unprotected sex compared to those receiving standard care (RR 0.15, 95% CI 0.03 to 0.73).

In an RCT conducted in the USA in the pre-antiretroviral therapy era (Rotheram-Borus 2001b), HIV-infected parents participating in small group discussions with their adolescent children had higher mean depression scores at 3 months (MD 0.28 higher, 95% CI 0.06 to 0.5 higher), but lower mean depression scores at 15 months (MD 0.22 lower, 95% CI 0.44 lower to 0 higher) and 24 months (statistically non-significant) (MD 0.12 lower, 95% CI 0.34 lower to 0.1 higher) (Rotheram-Borus 2001b). No statistically significant differences were observed when comparing intervention to control groups with respect to
Disclosure of HIV status to at least one adolescent at 24 months (RR 1.04, 95% CI 0.96 to 1.14) or to disclosure of HIV status to all children at 24 months (RR 1, 95% CI 0.91 to 1.1). Note: Lower scores indicate less depression.

In an RCT of group counselling by trained facilitators in the USA (Serovich 2011), HIV-infected adult men who have sex with men (MSM) were not significantly more likely to disclose to a higher number of family members than were the wait-list controls (RR 1.1, 95% CI 0.91 to 1.34).

Structured support groups or workshops (Africa). Two observational studies evaluated structured groups or workshops to support disclosure by adult HIV-infected women. In a South Africa study (Mundell 2011), more HIV-infected pregnant women who participated in structured support groups had disclosed their HIV status at two months of follow up (RR 1.2, 95% CI 1.09 to 1.32) and at eight months of follow up (RR 1.18, 95% CI 1.09 to 1.28) compared to before attending the support groups. However, there was no difference in participants’ report of feelings of depression at eight months compared to reports obtained before attending the support groups (RR 1, 95% CI 0.92 to 1.08). In an observational study evaluating the effect of empowerment workshops for HIV-infected women in Mali (Otis 2012), no difference was observed between pre- and post-intervention mean scores for the weight of keeping their HIV status a secret (MD -1.07 lower, 95% CI -1.3 lower to 0.81 higher).

One-on-one counselling. In an RCT conducted in the USA (Murphy 2011), adult HIV-infected mothers participating in four-session, one-on-one counselling were more likely to disclose their HIV status to their children (ages 6 to 12 years old), compared to those receiving standard care (RR 4.56, 95% CI 1.4 to 14.77).

Peer-led behavioural interventions. An RCT to evaluate the effectiveness of peer-led behavioural sessions on disclosure and related behavioural outcomes was conducted in the USA (Wolitski 2005) with HIV-infected adult MSM. No statistically significant difference was observed between intervention and control groups with regard to disclosure – neither to some sex partners (RR 1.06, 95% CI 0.85 to 1.32) or to all sex partners (RR 1.04, 95% CI 0.87 to 1.25). No statistically significant difference was observed between groups in sexual behaviour, including unprotected anal intercourse (RR 0.87, 95% CI 0.69 to 1.1), or consistent condom use during insertive anal intercourse (RR 1.03, 95% CI 0.8 to 1.34). MSM participating in peer-led behavioural sessions 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 (MD 0.57 higher, 95% CI 0.41 to 0.73 higher).

3b.2. Findings of the seven studies amenable to GRADE analysis

Small group discussions or group counselling (USA) for supporting disclosure was shown in a trial of HIV-infected adolescents to significantly decrease the adolescents’ report of unprotected sex, but there was no statistically significant difference in disclosure of HIV status to sexual partners (Rotheram-Borus 2001a). When small group discussions were used to support disclosure by HIV-infected parents (Rotheram-Borus 2001b), there was no significant increase in disclosure to their adolescent children, and the parents had significantly higher mean depression scores at 3 months (but no significant difference at 15 or 24 months). HIV-infected adult MSM were no more likely to disclose to a higher number of family members (statistically non-significant) than was the wait-list control group (Serovich 2011).
Structured support groups or workshops (Africa) were shown to significantly increase disclosure by HIV-infected pregnant women at two and eight months of follow up, but there was no statistically significant difference in reported depression (Mundell 2011). Another study (Otis 2012) found no significant difference one week after HIV-infected women participated in empowerment workshops for the weight of keeping their HIV status a secret.

One-on-one counselling was shown to significantly increase disclosure by HIV-infected mothers to their young children (Murphy 2011).

Peer-led behavioural interventions were shown to significantly increase adult MSM’s self-reported motivation to inform sexual partners (Wolitski 2005).

3b.3. Quality of the evidence for the seven studies amenable to GRADE analysis

In the GRADE system, well-conducted RCTs (without additional limitations) provide high quality evidence, and observational studies without any special strength (and without additional limitations) provide low-quality evidence. In this analysis, we found five controlled trials and two cohort studies which provided very low quality evidence for the benefits of several methods for supporting disclosure of HIV status. The evidence for all outcomes was very low quality evidence due to serious indirectness (studies conducted in adults, and/or in the USA), and serious or very serious imprecision (small number of events reported).

Small group discussions or group counselling sessions were found to significantly reduce unprotected sex in adolescents with HIV (Rotheram-Borus 2001a), and to significantly decrease depression in the short term in HIV-infected parents (Rotheram-Borus 2001b). However, these interventions resulted in no statistically significant increase in disclosure by HIV-infected adolescents to their sexual partners, HIV-infected parents to their children, or HIV-infected MSM to family members. The estimates of effect are very uncertain from these controlled trials. The quality of evidence is very low due to serious or very serious imprecision (few or very few events) and serious indirectness (studies were conducted in a high-income country, and two were conducted in HIV-infected adults rather than adolescents).

Structured support groups or workshops in Africa significantly increased disclosure by HIV-infected pregnant women (Mundell 2011), but there was no statistically significant difference in reported depression (Mundell 2011) or perceived weight of keeping their HIV status a secret (Otis 2012). The quality of evidence is very low from these two observational studies. Evidence quality was graded down for indirectness (adult population), and serious imprecision (few events).

One-on-one counselling was found to significantly increase disclosure by HIV-infected mothers to their young children (Murphy 2011), but this is very low quality evidence. This randomized controlled trial provides a very uncertain estimate of effect because of very serious imprecision (very few events) and serious indirectness (study conducted in a high-income country, and in HIV-infected adults rather than adolescents).

A peer-led behavioural intervention was shown to significantly increase adult MSM’s self-reported motivation to inform sexual partners (Wolitski 2005). The quality of evidence is very low, so this measure of effect is very uncertain. Evidence quality from this randomized controlled trial was graded down for very serious indirectness (adult population, study was conducted in the United States, and self-reported data), and serious imprecision (few events).
3b.4. Summary of nine studies not amenable to GRADE analysis

Nine additional studies were included but were not amenable to GRADE analysis because of inadequate data. Four were conducted in the USA, one in Ethiopia, one in Haiti, one in Nigeria, and two in South Africa. Only one addressed HIV-infected adolescents; the remaining studies were of HIV-infected women or MSM. One study was a disclosure-only intervention (Serovich 2009); the remaining were more comprehensive interventions designed to address multiple issues relating to HIV infection.

Studies in adolescents

Small group discussions. There was limited evidence from the one adolescent study (Smith Fawzi 2012) that professional-led small group sessions had a positive effect on the adolescents’ mental health.

Studies in adults

Small group discussions. A cluster randomized controlled trial of HIV-infected pregnant women found small group teaching by peer mentors resulted in increased preventive behaviours, decreased maternal depression, and better infant outcomes (Rotheram-Borus 2012). A randomized controlled trial found professional and peer-led support groups increased condom use in low-income HIV-infected women (Teti 2010).

Community-based interventions with disclosure component. Dewo (2012) found that HIV-infected adults had reduced loss to follow up and improved retention after receiving support from case managers, adherence counsellors, and community volunteers. Wouters (2009) found that HIV-infected adults with community health worker support were significantly more likely to disclose their serostatus to family members.

Individual counselling-based interventions. Olley (2006) found that adults with new HIV infection had a significant decrease in depression scores four weeks after assessment, and a significant increase in their intention to disclose their status. Patterson (2003) found that HIV-infected adults who reported unprotected sex with an unknown partner all showed a reduction in unprotected sex, regardless of their randomized assignment to intervention or control groups.

Online, computer-based interventions. Chiasson (2009) found that HIV-infected and uninfected MSM had no difference in HIV disclosure but were less likely to report a new or casual sexual partner or unprotected anal intercourse compared to before the intervention. Serovich (2009) found that HIV-infected MSM had improved disclosure behaviours after facilitated administration of an intervention tailored for disclosure to casual sexual partners.

Training for health workers

Can training of health care providers in adolescent health improve retention and adherence among adolescents living with HIV?

Training of health care providers in adolescent health for improving retention and adherence among adolescents living with HIV infection

1.1 Results
No studies were found evaluating the training of health workers who provide care and treatment to adolescents living with HIV, and the effect of this training on pre-specified adolescent health outcomes and quality of care outcomes for adolescents living with HIV infection.

However we did identify three studies that did not meet inclusion criteria but which inform this research question. Two randomized control trials (RCT) and one serial cross-sectional study were identified that evaluated the training of health workers providing care to adolescents with other chronic care needs (asthma, diabetes, and reproductive health services, respectively), and report the effect of this training on adolescent health outcomes and quality of care outcomes.

**Asthma.** The first intervention was published in one manuscript (Lozano 2004). The peer leader RCT intervention consisted of training one physician per practice in asthma guidelines and peer teaching methods. The planned care arm combined the peer leader intervention with nurse-mediated organizational change through planned visits with assessments, care planning and self-management support in collaboration with physicians. The trial randomized children ages 3-17 years of age living with asthma in the United States to a planned care intervention arm (n=213), a peer leader intervention arm (n=226) or a control arm of standard care (n=199).

**Diabetes.** The second intervention, “Talking Diabetes,” was published in two manuscripts (Robling 2012; Gregory 2011). The RCT involved training providers in agenda-setting, guiding communication style and a flexible menu of consultation strategies to support patient-lead behavior change. The trial randomized youth ages 4-15 living with diabetes in the United Kingdom to the intervention arm (n=399) or to a standard care control arm (n=334).

**Reproductive health services.** The third intervention was published in a grey literature report (ICRW 2012). This study looked at the effect of using the World Health Organization (WHO) Orientation Programme on Adolescent Health for Health Care Providers (OP) and the Adolescent Job Aid (AJA) program to build the capacity of health workers globally to respond to adolescent and young clients effectively. To evaluate the use of these tools, an intervention was conducted in early 2009 in two districts in the state of Gujarat, India among young women aged 15-25 years receiving reproductive health services at primary healthcare centers. Medical officers (MO) received a five-day training on the use of the OP and the AJA and an evaluation was then conducted to assess the effectiveness of this training. One district served as the control district and the other as the intervention district. A total of 40 MO were trained in the intervention district with 28 participating in the follow-up measure. Client exit interviews were conducted in the intervention arm (n=230 at baseline, n=140 at follow-up) and the control arm (n=155 at baseline, n=195 at follow-up). Observations of MO practices were conducted in the intervention arm (n=123 at baseline, n=85 at follow-up) and the control arm (n=108 at baseline and n=119 at follow-up). Follow-up was conducted at 4-5 months.

1.2 Findings

**Asthma.** The intervention training health workers in asthma care for youth found that the planned care intervention did have a significant effect on asthma symptom days compared to the control arm and a
trend favoring the peer leader intervention compared to the control arm. Both intervention arms had lower oral steroid burst rates compared to the control arm. The authors concluded that planned care is an effective model for improving asthma care in the primary care setting, and while peer leader education on its own may also work it is much less comprehensive than planned care.

**Diabetes.** The intervention training health workers in diabetes care for youth found that training diabetes care teams had no effect on HbA1c levels (a marker for diabetes control) or on self-reported adherence to diabetic medications. The authors reported that improving glycemic control in children attending specialist diabetes clinics might not be possible through brief, team-wide training in consultation skills.

**Reproductive health services.** The reproductive health services intervention found that MOs in the intervention district increased in their belief that health problems of young female clients not only stemmed from their sexual activity, but were also due to their lack of awareness about their sexual health (21 MOs at baseline versus 27 MOs at follow-up) (p<0.05). Some of this knowledge increase was also seen in the control district. They also found that compared to the control district, MOs in the intervention had a better understanding of the need to ensure client privacy. MOs in the intervention condition showed improvement in all areas recommended for care of young female clients, including improvements in pre-examination explanations, physical examinations, complaint assessment and case management. More MOs in the intervention arm were found to be sensitive to the need to spend time building rapport with their clients and gaining their confidence. However, no difference was found between baseline and follow-up for trained MOs in regards to their case management practices. Significantly, more clients showed confidence in their provider at follow-up and reported having greater privacy during the interactions, including an examination in a separate room. Clients from the intervention arm were more likely to report that they understood information given to them by the MO and fewer clients reported this in the control arm (81% in the intervention arm vs. 69% in the control arm at follow-up). Overall, client satisfaction with the services and information received and ease of following advice increased from 62% at baseline to 81% at follow-up (z=3.69, p<0.05).

1.3 Quality of the evidence
The overall quality of this evidence is very low due to the very serious indirectness of the populations studied to the present review question, the heterogeneity of the outcomes reported, and the relatively small sample sizes. GRADE evidence profiles were not created for this review.

**Community-based approaches**

*Can community-based approaches improve adherence to treatment and retention to care among adolescents?*

*Community-based approaches to improve adherence amongst adolescents*

*Narrative of results and findings with evidence quality*
Our search yielded a total of 656 records. After removing 116 duplicates, we screened 540 records, and reviewed 79 full-text articles. Twenty-seven were determined to be eligible for inclusion in this review. Of the 27 publications included, 17 were amenable to inclusion in GRADE analysis. The remaining 10 could not be analyzed with GRADE because they presented insufficient information needed for GRADE analysis (Igumbor 2011; Stubbs 2009), had no comparator or because the comparator was not the comparator of interest (Achieng 2012; Bekker 2006; Chang 2009; Kipp 2010; Kipp 2011; Nglazi 2011; Nglazi 2012; Rich 2012).

Interventions described included: home visits by community/lay health workers who conducted health assessments, provided education and/or support, and made referrals (Fatti 2012; Grimwood 2012; Kabore 2010; Kipp 2012; Munoz 2011; Williams 2006); use of mobile health (mHealth) technologies (e.g., cellular phones, pagers) for home visitors to communicate about the index patients’ health and adherence to a centralized database, or for peers to communicate with each other (Chang 2010; Chang 2011; Selke 2010; Simoni 2009); socioeconomic support (Talisuna-Alamo 2012); peer support (e.g., “mentor mothers”, treatment partners) (Futterman 2010; Simoni 2007; Simoni 2009; Taiwo 2010); and community-based, directly administered antiretroviral therapy (DAART) (e.g., directly observed therapy via mobile outreach units, home-based directly observed therapy by lay health worker) (Altice 2007; Macalino 2007; Pearson 2007). Reported effects of these interventions are described by outcome below.

Results of 17 studies included in GRADE analysis

Of the 17 records eligible for inclusion in GRADE analysis, five reported on studies conducted in the USA (Altice 2007; Macalino 2007; Simoni 2009; Simoni 2007; Williams 2006), and 12 reported on studies conducted in low- and middle-income countries including Botswana, Lesotho, Kenya, Mozambique, Namibia, Nigeria, Peru, South Africa and Uganda. None of the studies focused on adolescent populations. One of the studies was focused on children under age 16 years (Grimwood 2012). The remainder included adult populations only, including general adult populations on ART (Chang 2010; Chang 2011; Fatti 2012; Kabore 2010; Kipp 2012; Munoz 2011; Pearson 2007; Selke 2010; Taiwo 2010; Talisuna-Alamo 2012; Simoni 2007; Simoni 2009; Williams 2006); pregnant women (Futterman 2010), and injection drug users (Altice 2007; Macalino 2007). Ten of the studies were randomized controlled trials (Altice 2007; Chang 2010; Chang 2011; Macalino 2007; Pearson 2007; Selke 2010; Simoni 2007; Simoni 2009; Taiwo 2010; Williams 2006). The remaining seven were observational studies (Futterman 2010; Fatti 2012; Grimwood 2012; Kabore 2010; Kipp 2012; Munoz 2011; Talisuna-Alamo 2012). The results are described below by outcome and intervention type.

1. Adherence
Eleven of the 17 studies (nine RCTs, two observational) provided data regarding the efficacy or effectiveness of a community-based intervention on antiretroviral therapy (ART) adherence.

1. Home-based health assessment, education and support by community health workers
One RCT conducted in the USA (Williams 2006); and two prospective cohort studies – one conducted in Peru (Munoz 2011) and one multi-site study including participants in Botswana, Lesotho, Namibia, and South Africa (Kabore 2010) – provided data examining the effectiveness of interventions in which lay,
paraprofessional and/or professional health workers provided home-based health assessments, education, and/or support to HIV-infected individuals on improving ART adherence. All of the studies included adult populations only. Adherence level was associated with exposure to home-based support services in one study (Kabore 2010), but not in the others (Munoz 2011; Williams 2006).

In Kabore 2010, a greater proportion of participants who received home-based care and food support demonstrated better ART adherence, compared to participants who received no community services (RR 1.15, 95% CI 1.03 - 1.27). However, Williams (2006) did not show a statistically significant intervention effect on >90% adherence (RR 1.53, 95% CI 0.79 - 2.95). Similarly, one prospective cohort study evaluating the efficacy of tailored home-based ART support, microfinance and/or psychosocial support (Munoz 2011) found no statistically significant difference in adherence between participants exposed to the intervention and their matched controls at 2 years of follow-up (RR 1.05, 95% CI 0.88 to 1.27).

II. mHealth support intervention used by peers or community health workers at home visits
One RCT conducted in the USA (Simoni 2009), two cluster-RCTs conducted in Uganda (Chang 2010; Chang 2011), and one cluster-RCT conducted in Kenya (Selke 2010) provided data examining the effectiveness of community-based interventions in which mobile health (mHealth) technology was used on improving ART drug adherence. None showed significant differences in adherence between intervention and control groups, regardless of the percentage used for measure optimal adherence.

Simoni 2009 compared participants assigned to one of four study arms: group 1: peer support involving 6 twice monthly 1-hour peer meetings and weekly phone calls from peers to participants; group 2- pager messaging including customized messages to remind the participant to take their medication, provide educational information about medications, and assess adherence; group 3- both strategies; or group 4- usual care (control group). There was no statistically significant difference in mean 1-week adherence at 6 months (MD 5.6% lower [21.39% lower to 10.19% higher]) or at 9 months (MD 3% higher [11.83% lower to 17.83% higher]) in the peer+pager group compared to the control group.

Selke 2010 examined the effectiveness of home visits in which peer health workers (“Community Care Coordinators “ [CCC]) used a Personal Digital Assistant (PDA) which provided prompted guidance to the CCC concerning patient symptoms and adherence assessment and delivered alerts as indicated by the entries made. There was no statistically significant difference in adherence level at 12 months follow-up between participants in the intervention compared to the control group (RR 0.93, 95% CI 0.82 to 1.06).

Chang 2010 and Chang 2011 examined the effectiveness of home visits in which peer health workers used a mobile phone and tasked to use text messaging or send home visit data back to a central clinic. Using “less than 95% adherence” (<95%) as the measure, no significant difference in adherence was observed at 26 months (RR 0.57, 95% CI 0.23 to 1.37, Chang 2010; RR 0.24, 95% CI 0.05 to 1.07, Chang 2011). Using 100% adherence as the cut-off for optimal adherence, no significant difference in adherence was observed at 26 months (RR 1.09, 95% CI 0.87 to 1.37, Chang 2010; RR 0.98, 95% CI 0.78 to 1.23, Chang 2011).

III. Socioeconomic support
IV. Peer support
Two RCTs conducted in the USA (Simoni 2007; Simoni 2009) and one RCT from Nigeria (Taiwo 2010) provided data on the efficacy of peer support interventions on improving ART drug adherence. Taiwo 2010 showed that HIV-infected adults randomized to receive support from a patient-selected treatment partner had significantly higher rates of adherence at 48 weeks follow up compared to patients randomized to standard care (RR 1.19, 95% CI 1.07 to 1.33). Simoni 2007 and Simoni 2009 compared ART adherence between HIV-infected adults randomized to participate in six twice-monthly one-hour group meetings at the clinic with peers and other study participants as well as weekly phone calls from peers to participants to HIV-infected adults who received standard care. No statistically significant difference in mean 3-day adherence level was observed at three months (MD 0 higher [13.49 lower to 13.49 higher]) or six months (MD 8.1 lower [23.2 lower to 7 higher]). No significant difference in mean 1-week adherence was observed at three months (MD 8.3 higher [7.78 lower to 24.38 higher]) (Simoni 2007), or six months (MD 3.8 lower [20.05 lower to 12.45 higher]) (Simoni 2009). No significant difference in mean 4-week adherence was observed at three months (MD 2.9 lower [18.47 lower to 12.67 higher]), or 6 months (MD 3.3 lower [18.96 lower to 12.36 higher]) (Simoni 2007).

V. Community-based DAART
One RCT conducted in Mozambique (Pearson 2007) and one RCT conducted in the US (Altice 2007) provided data examining the effectiveness of community based DAART on improving ART adherence. Neither showed significant differences in adherence between intervention and control groups, regardless of the cut-off used for determining optimal adherence or length of follow up. Pearson 2007 compared HIV-infected adults randomized to receive six weeks of daily peer-delivered, modified directly observed therapy to those who received standard care showed no statistically significant difference in >90% adherence level at the 12-month follow up between intervention and control groups (RR 1.09, 95% CI 0.99-1.18). Altice 2007 compared HIV-infected drug users randomized to receive directly administered ART (DAART) to those who received standard care showed no statistically significant difference in >80% adherence level at 6-month follow up between intervention and control groups (RR 1.18, 95% CI 0.9 to 1.56).

2. Mortality
Ten of the 17 studies (five RCTs, five observational) provided data regarding the efficacy or effectiveness of a community-based intervention on mortality.

I. Home-based health assessment, education and support by community health workers
Four observational studies examined the effectiveness of home-based health assessment, education, and support provided by community health workers on mortality (Fatti 2012; Grimwood 2010; Munoz 2011; Kipp 2012).

Two studies conducted in South Africa showed significant reductions in mortality amongst participants who received home-based health assessment, education, and support by community health workers (Fatti 2012; Grimwood 2010). Grimwood 2010 evaluated a home-based CHW adherence and psychosocial support for caregivers of HIV-infected children under 16 years of age who initiated ART.
this study, there was a statistically significant reduction in mortality at 3 years of follow up amongst children in CHW-supported households compared to children residing in households that did not receive home-based support (RR 0.46, 95% CI 0.26 to 0.82). Fatti 2012 evaluated CHW-provided home-based adherence and psychosocial support for HIV-infected adults on ART. There was a significant reduction in mortality at 5 years of follow up amongst participants in the intervention group compared to those in the control group (RR 0.85, 95% CI 0.81 to 0.89).

Two studies showed no intervention effect on mortality (Kipp 2012; Munoz 2011). Munoz 2011, conducted in Peru, evaluated the effectiveness of tailored home-based support including DOT-HAART, microfinance and/or psychosocial support. Crude mortality was higher amongst participants exposed to the intervention compared to their matched controls at 2 years follow-up, but the difference was not statistically significant (RR 1.18, 95% CI 0.49 to 2.85). Kipp 2012, conducted in Uganda, evaluated outcomes of patients enrolled to care in a community-based ART program compared to patients enrolled to care at a well-established hospital-based ART program. Crude mortality was higher in the community-based cohort compared to the hospital-based cohort, but the difference was not statistically significant (RR 1.5, 95% CI 0.91 to 2.47).

II. mHealth support intervention used by peer health workers at home visits

Two cluster-RCTs conducted in Uganda (Chang 2010; Chang 2011) and one cluster-RCT conducted in Kenya (Selke 2010) examined the efficacy of mHealth-supported home visits on mortality. No significant difference in mortality at 26 months was observed between HIV-infected adults who received home visits by peer health workers using a mobile phone for text messaging or to send home visit data back to a central clinic, compared to HIV-infected adults who received home-based support by a peer health worker not using mHealth support (RR 1.1, 95% CI 0.74 to 1.62, Chang 2010; RR 0.82, 95% CI 0.55 to 1.22, Chang 2011). In Selke 2010, there were no deaths in the intervention or control arms.

III. Socioeconomic support

One observational retrospective cohort study assessed the effectiveness of providing one or more types of socioeconomic support on mortality (Talisuna-Alamo 2012). This study found a significantly decreased risk of mortality follow up at 10 years amongst adults who received two or more types of socioeconomic support compared to adults who received no support (RR 0.49, 95% CI 0.38 to 0.64). However, there was not a statistically significant difference in mortality rates between patients who received one type of socioeconomic support compared to those who received no support (RR 0.96, 95% CI 0.85 to 1.09).

IV. Peer support

One RCT conducted in Nigeria found higher crude mortality amongst HIV-infected adults who received support from a patient-selected treatment partner to participants randomized to standard of care, but the difference was not statistically significant (10.6% vs 6.1%, RR1.74, 95% CI 0.95-3.2) (Taiwo 2010).

V. Directly observed ART (DAART)

One RCT from Mozambique (Pearson 2007) found there to be no difference in mortality amongst HIV-infected adults randomized to receive six weeks of daily peer-delivered, modified directly observed therapy compared to HIV-infected adults who received standard care (RR0.72, 95% CI 0.44-1.18).
3. Viral Failure /Viral suppression

Eleven of the 17 studies (eight RCTs, three observational) provided data regarding the efficacy or effectiveness of a community-based intervention on viral suppression or viral failure.

I. Home-based health assessment, education and support by community health workers

Three studies examined the effectiveness of home-based adherence and health promotion support by community health workers on virologic suppression (Fatti 2012; Kipp 2012; Munoz 2011). One of the three studies showed significant improvements in virologic suppression amongst intervention participants. Fatti 2012 examined the effectiveness of CHW-provided home-based adherence and psychosocial support for HIV-infected adults on ART on viral suppression at 6- and 24-months. There was a significant improvement in viral suppression in the intervention group compared to the control group at 6 months (RR 1.06, 95% CI 1.05 to 1.08), 12 months (RR 1.18, 95% CI 1.15 to 1.21), and 24 months (RR 1.26, 95% CI 1.21 to 1.31). Kipp 2012 found there to be no statistically significant difference in viral suppression between patients enrolled to care in a community-based ART program compared to patients enrolled to care at a well-established hospital-based ART program (RR 1.07, 95% 0.98 to 1.15). Munoz 2011 found there to be no statistically significant difference in viral suppression between participants who received home-based support including DOT-ART, microfinance and/or psychosocial support (RR 1.49, 95% CI 0.97 to 2.29).

II. mHealth support intervention used by peer health workers at home visits

One cluster-RCT conducted in Kenya (Selke 2010), two cluster-RCTs conducted in Uganda (Chang 2010; Chang 2011) and one RCT conducted in the USA (Simoni 2009) examined the impact of mHealth-supported home visits on viral failure or suppression. None showed a significant improvement in virologic suppression or reduction in virologic failure. Chang 2010 showed there to be no effect of the intervention on viral failure when measured at 24 weeks (RR 0.94, 95% CI 0.56 to 1.57) or 48 weeks (RR 0.84, 95% CI 0.5 to 1.42), but did show a significant reduction in viral failure at 96 weeks amongst participants in the intervention arm compared to those in the control arm (RR 0.51, 95% CI 0.29 to 0.92). Chang 2011 also showed there to be no effect of the intervention on viral failure when measured at 24 weeks (RR 1.59, 95% CI 0.91 to 2.79) or 48 weeks (RR 0.95, 95% CI 0.53 to 1.17). Selke 2010 showed there to be no difference in the proportion of patients with viral failure in the intervention compared to those in the control arm (RR 0.81, 95% CI 0.36 to 1.81). 2009 found no statistically significant difference in mean viral load level at 3 months (MD 0.4 lower [1.01% lower to 0.21 higher]) or at 6 months (MD 0 higher [0.62 lower to 0.62 higher]) in the peer+pager group compared to the control group.

III. Socioeconomic support

Not assessed.

IV. Peer support

One RCT conducted in Nigeria (Taiwo 2010) and two RCTs conducted in the USA (Simoni 2007; Simoni 2009) assessed the efficacy of peer-support interventions on mean viral load or viral suppression. None showed an intervention effect on viral load/viral suppression. Taiwo 2010 found there to be no difference in viral suppression amongst HIV-infected adults randomized to receive support from a patient-selected treatment partner compared to participants randomized to standard of care at 24 weeks (RR 1.16, 95% CI 1 to 1.35) or 48 weeks follow up (RR 1.01, 95% CI 0.89 to 1.14). Simoni 2007and
Simoni 2009 showed no statistically significant difference in mean viral load level at three months (MD 0.28 higher [0.27 lower to 0.84 higher]), six months (MD 0.72 higher [0.14 lower to 1.29 higher]), or at nine months (MD 0 higher [0.72 lower to 0.72 higher]).

V. Community-based DAART
Two RCTs conducted in the USA with HIV-infected adult substance users examined the efficacy of community-based DAART on viral suppression (Altice 2007; Macalino 2007). Macalino 2007 showed community-based DAART to be associated with reduced viral load at 3 months follow up in the intervention group compared to the control group (RR 1.71, 95% CI 1.05 to 2.76). A second study (Altice 2007) showed there to be no difference in viral suppression at 6 months follow up (RR 1.24, 95% CI 0.95-1.63).

5. Retention on 1st line regimen
One of the 17 studies (an RCT) provided data regarding the efficacy of a community-based intervention on retention of the 1st line ART regimen. This RCT, conducted in the US, showed there to be no statistically significant difference in retention on first-line regimen at six months amongst HIV-infected injection drug users who received directly observed ART compared to injection drug users who received standard care (RR 1, 95% CI 0.69-1.46) (Altice 2007).

6. Follow-up visits
One of the 17 studies (an observational study) provided data regarding the effectiveness of a community-based intervention on attendance at follow-up medical visits. This non-randomized comparative prospective cohort study conducted in South Africa found no difference in HIV-infected pregnant women’s attendance at follow-up medical visit amongst HIV-infected pregnant women who participated in a peer-mentoring program and an eight-session cognitive behavioral intervention compared to HIV-infected pregnant women who received standard care (RR 1.62, 95% CI 0.94-1.79) (Futterman 2010).

Findings of the 17 studies eligible for GRADE analysis
Overall, findings were a mixture of positive effects and no effects attributable to a range of community-based interventions.

Home-based health assessment, education and support by community health workers. Community-based interventions that included home-based health assessment, education and support by community health workers were shown to be associated with better levels of ART adherence in one of three studies (Kabore 2010), with viral suppression in one of three studies (Fatti 2012), and reduced mortality rates in two of four studies (Fatti 2012; Grimwood 2010).

mHealth support intervention used by peer health workers at home visits. Exposure to an mHealth-supported community-based intervention was shown to be associated with viral suppression at 96 weeks in one study (Chang 2010). However, no significant association between exposure to an mHealth intervention and virologic suppression were observed for earlier time points (Chang 2010; Chang 2011; Selke 2010). None of four studies of mHealth-supported interventions showed an association with ART adherence (Chang 2010; Chang 2011; Selke 2010; Simoni 2009). None of three mHealth studies that
examined mortality showed differences in mortality rates between intervention and control groups (Chang 2010; Chang 2011; Selke 2010).

**Peer support interventions.** One of three peer support interventions showed an association with better adherence (Taiwo 2010). One study of a peer support intervention that examined intervention effect on mortality showed no effect of the intervention on mortality (Taiwo 2010). One study that examined intervention effect on follow up appointments showed no effect (Futterman 2010).

**Socioeconomic support.** The one study of a socioeconomic support intervention showed reduction in mortality amongst participants exposed to the intervention (Talisuna-Alamo 2012).

**Community Based DAART.** Neither of two studies of community-based DAART showed an association with better adherence (Altice 2007; Pearson 2007). One study of community-based DAART that examined mortality did not show an intervention effect on mortality (Pearson 2007). However, one of two studies showed an association between receipt of DAART and reduced mean viral load (Macalino 2007). One study that examined the effect of community-based DAART on retention on 1st line ART regimen showed no effect of the intervention on this outcome (Altice 2007).

**Quality of the evidence**

Sixteen of the 17 studies amenable to GRADE analysis included adult populations, and one of the 17 included children (<10 years old) only. Therefore, the findings of this review may not be generalizable to populations of adolescents. Other concerns that must be addressed are the financial costs of community based strategies for improving health outcomes of HIV-infected populations, as well as consideration on how to optimize adherence to program protocols and quality of care provided by community health workers. There is also the potential for significant implementation challenges of scaling up community-based programs for supporting adherence when there is limited infrastructure for monitoring or supporting community health workers.

In the GRADE system, well-conducted randomized controlled trials (without additional limitations) provide high quality evidence, and observational studies without any special strengths (and without additional limitations) provide low-quality evidence. In this analysis, we found that the 10 RCTs provided low to very low quality evidence for the benefits of community based interventions and for most outcomes very low quality evidence due to the observational nature of the studies, the small number of events reported, and indirectness of the populations studied (i.e. adults, or children <10 years old).

**Home-based health assessment, education and support by community health workers.** Community-based interventions that included home-based health assessment, education and support by community health workers were shown to be associated with better levels of ART adherence in one of three studies (Kabore 2010), with viral suppression in one of three studies (Fatti 2012), and reduced mortality rates in two of four studies (Fatti 2012; Grimwood 2010). The quality of evidence is very low due to serious or very serious imprecision (few or very few events) and serious indirectness (studies did not include adolescents).
mHealth support intervention used by peer health workers at home visits. Exposure to an mHealth-supported community-based intervention was shown to be associated with viral suppression at 96 weeks in one study (Chang 2010). However, no significant association between exposure to an mHealth intervention and virologic suppression were observed for earlier time points (Chang 2010; Chang 2011; Selke 2010). None of four studies of mHealth-supported interventions showed an association with ART adherence (Chang 2010; Chang 2011; Selke 2010; Simoni 2009). None of three mHealth studies that examined mortality showed differences in mortality rates between intervention and control groups (Chang 2010; Chang 2011; Selke 2010). The quality of evidence is very low due to serious or very serious imprecision (few or very few events) and serious indirectness (studies did not include adolescents).

Peer support interventions. One of three peer support interventions showed an association with better adherence (Taiwo 2010). One study of a peer support intervention that examined intervention effect on mortality showed no effect of the intervention on mortality (Taiwo 2010). One study that examined intervention effect on follow up appointments showed no effect (Futterman 2010). The quality of evidence is very low due to serious or very serious imprecision (few or very few events) and serious indirectness (studies did not include adolescents).

Socioeconomic support. The one study of a socioeconomic support intervention showed reduction in mortality amongst participants exposed to the intervention (Talisuna-Alamo 2012). The estimates of effect are very uncertain from this study. The quality of evidence is very low due to very serious imprecision (very few events) and very serious indirectness (retrospective analysis of adult data).

Community Based DAART. Neither of two studies of community-based DAART showed an association with better adherence (Altice 2007; Pearson 2007). One study of community-based DAART that examined mortality did not show an intervention effect on mortality (Pearson 2007). However, one of two studies showed an association between receipt of DAART and reduced mean viral load (Macalino 2007). One study that examined the effect of community-based DAART on retention on 1st line ART regimen showed no effect of the intervention on this outcome (Altice 2007). The quality of evidence is very low due to serious risk of bias in two studies, serious or very serious imprecision (few or very few events), and serious or very serious indirectness (studies did not include adolescents; two of the three studies were based in the United States).

Summary of the 10 studies not amenable to GRADE analysis

Ten studies were identified for inclusion in this review but presented insufficient information needed for GRADE analysis; they reported only odds ratios without numerators (Stubbbs 2009), regression parameters (Igumbor 2011), had no comparator or the comparator was not the comparator of interest (i.e., standard care) (Achieng 2012; Bekker 2006; Chang 2009; Kipp 2010; Kipp 2011; Nglazi 2011; Nglazi 2012; Rich 2012; Stubbbs 2009). Therefore, associations are briefly described below.

Mortality

One observational prospective cohort study of HIV-infected adolescents and adults (>15 years) at a community-based ART clinic in South Africa reported probability of death in the first year of ART (7.9%, 95% CI 7.0% - 8.9%), and cumulative probability of death after 6 years (15.2%, 95% CI 13.1% - 17.6%)
Male sex, lower baseline CD4 cell count, and WHO stage III and IV were associated with higher mortality risk.

One observational study comparing HIV-infected adolescents (9-19 years) and young adults (20-28 years) at a public sector community-based ART program in South Africa reported similar overall mortality rates in adolescents (1.2 [95% CI 0.3-4.8] deaths per 100 person-years) and young adults (3.1 [95% CI 2.4-3.9] deaths per 100 person-years) (Nglazi 2012).

One observational retrospective cohort study conducted in Rwanda reported a low mortality rate (5%) at 2 years following ART initiation amongst HIV-infected adults in care at a community-based ART program (Rich 2012).

One non-randomized prospective cohort study conducted in Uganda compared treatment outcomes and mortality in rural community-based ART program with a hospital-based program in the same district (Kipp 2010). In this study, mortality at six months was not significantly different between both cohorts (11.9% vs. 9.0%).

**Viral Failure or Viral Suppression**

One observational study that evaluated outcomes of patients enrolled to a community-based, comprehensive ARV program staffed by peer health workers and nurses in Uganda reported 86% of active patients (211 or 246 tested) to have a viral load <400 copies/mL (Chang 2009). Virologic failure was significantly associated with lack of CD4 response and any history of prior ARV use. No external comparator was included in the study.

One observational retrospective cohort study of HIV-infected patients in government HIV treatment sites in South Africa showed that a significantly higher proportion of patients with a community-based adherence supporter had viral load <400 copies/mL at 6 months of treatment for a longer period compared to patients without a treatment supporter (Igumbor 2011). Also, a significantly greater proportion of patients in care at sites with community-based adherence supporter services maintained a suppressed viral load for a longer period compared to patients in care at clinics without a community-based adherence supporter service.

One observational prospective cohort study of HIV-infected adolescents and adults (≥15 years) at a community-based ART clinic in South Africa reported high rates of virological suppression by 16 weeks after ART initiation, and to not vary significantly between successive years of recruitment (Nglazi 2011). Lack of virological suppression was associated with younger age (<25 years old), and high baseline viral load (≥5 log₁₀ copies/mL).

One observational study comparing HIV-infected adolescents (9-19 years) and young adults (20-28 years) at a public sector community-based ART program in South Africa reported adolescents to have significantly lower rates of virological suppression at 48 weeks compared to young adults (Nglazi 2012). In addition, adolescents had significantly higher risk of virological failure compared to young adults, though the association was not significant when comparing perinatally infected adolescents and young adults.
One observational retrospective cohort study conducted in Rwanda reported a high rate of virologic suppression at 2 years following ART initiation (97.5% with <500 copies/mL) amongst HIV-infected adults in care at a community-based ART program (Rich 2012).

One observational prospective cohort study conducted in South Africa reported high and sustained rates of virologic suppression (<400 copies/mL) over a 3-year period (100%, 92% and 98% for 2002, 2003, and 2004 cohorts) amongst HIV-infected adults in care at a public-sector community-based ART clinic (Bekker 2006).

One observational retrospective cohort study conducted in Kenya reported that time to treatment failure was significantly longer in patients who participated in peer support groups and/or home visits (Achieng 2012). Further, risk of treatment failure was significantly reduced amongst those who participated in support groups compared to patients who did not.

One non-randomized prospective cohort study conducted in Uganda reported that virologic suppression at six months was not significantly different between patients enrolled to a rural community-based ART program and patients in care at a hospital-based program in the same district (90.1% vs. 89.3%) (Kipp 2010). However, in a later report (Kipp 2011), the authors reported that a greater proportion of patients enrolled to the rural community-based ART program were more likely to achieve viral suppression at 2 years of follow up compared to patients in care at the hospital-based program.

**ART Adherence**

One observational retrospective cohort study of HIV-infected patients in care in government HIV treatment sites in South Africa showed that a significantly higher proportion of patients with a community-based adherence supporter attained a treatment pickup rate of over 95% compared to patients without a treatment supporter (Igumbor 2011).

One observational retrospective cohort study conducted in Mozambique reported that patients who had a treatment partner were significantly more likely to have higher levels of adherence compared to patients who had no treatment partner (Stubbs 2009). No differences in adherence were observed between patients with community-based treatment partners and patients with self-selected treatment partners.

One observational retrospective cohort study conducted in Kenya reported that a significantly greater proportion of patients who participated in support groups achieved higher mean adherence compared to patients who did not participate in support groups (Achieng 2012).

**Retention in Care**

One observational retrospective cohort study of HIV-infected patients in government HIV treatment sites in South Africa showed that the median retention time in care for patients in care at sites with community-based adherence supporter services was significantly greater than retention in care time of patients in care at clinics without a community-based adherence supporter service. (Igumbor 2011).
One observational retrospective cohort study conducted in Rwanda reported a high rate of retention in care two-years after ART initiation (92.3%) among HIV-infected adults in care at a community-based ART program (Rich 2012). In multivariate analysis, attrition was associated with older age (>50 years) and enrollment in 2006. An interaction existed between WHO clinical stage at baseline and sex. Among women, WHO clinical stage was not significantly associated with retention in care. However, men with WHO stage 3 or 4 disease at baseline were more likely to drop out of care compared to men with WHO stage 1 or 2 disease at baseline.

One observational prospective cohort study conducted in South Africa reported low rates of loss to follow up over a 3-year period (2.9%) amongst HIV-infected adults in care at a public-sector community-based ART clinic (Bekker 2006).

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

ANNEX 5: GRADE notation and language

<table>
<thead>
<tr>
<th>GRADE METHODOLOGY NOTATION</th>
<th>INTERPRETATION</th>
<th>LANGUAGE USED IN THE GUIDELINES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong recommendation for</td>
<td>The panel concluded that the availability and quality of relevant scientific evidence, together with data on cost and feasibility issues, and community preferences and values, were enough to categorically support the intervention under review.</td>
<td>We recommend the intervention under review.</td>
</tr>
<tr>
<td>Strong recommendation against</td>
<td>The panel concluded that the availability and quality of relevant scientific evidence, together with data on cost and feasibility issues, and community preferences and values, were enough to categorically recommend against the intervention under review.</td>
<td>We recommend against the intervention under review.</td>
</tr>
<tr>
<td>Conditional recommendation for</td>
<td>The panel concluded that the availability and quality of relevant scientific evidence, together with data on cost and feasibility issues, and community preferences and values, were not enough to categorically support the intervention under review. However, benefits may outweigh costs/risks, and this intervention should be considered in light of locally relevant needs, resources and priorities.</td>
<td>We suggest that the intervention be considered in light of locally relevant needs, resources and priorities.</td>
</tr>
<tr>
<td>Conditional recommendation against</td>
<td>The panel concluded that the availability and quality of relevant scientific evidence, together with data on cost and feasibility issues, and community preferences and values, were not enough to categorically recommend against the intervention under review. However, costs/risks may outweigh benefits, and the decision on whether or not to implement it should be made in light of locally relevant needs, resources and priorities, particularly if better interventions are not available.</td>
<td>We suggest against the intervention under review.</td>
</tr>
</tbody>
</table>
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**ANNEX 6: GRADE Evidence profiles**

**GRADE evidence profiles: PICO 1a – RCTs (HTC)**

<table>
<thead>
<tr>
<th>Quality assessment</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
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<tr>
<td>No of studies</td>
<td>Design</td>
<td>Risk of bias</td>
<td>Inconsistency</td>
<td>Indirectness</td>
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<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
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<td>HIV+ alive at 6 months (follow-up 6 months)</td>
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<td>HIV+ attended HIV clinic (follow-up 6 months)</td>
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<td>Inconsistency</td>
<td>RR</td>
<td>Absolute Effect</td>
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<tr>
<td>Unprotected sex, women, non-primary partner (follow-up 6 months)</td>
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<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious²</td>
</tr>
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</table>

1 Adult population.
2 Very few events
3 Numerators and denominators were back-calculated from the reported OR (95% CI) and assumed equal data availability (89.4%) for each intervention group. These estimates are only used for the absolute effect measure.
4 As estimated from back-calculated OR using available data reported in text.
5 Adult population; intervention and control groups were hospitalised inpatients.
6 Few events.
7 Adult population. Also, outcomes self-reported.

Author(s): Horvath T
Date: 2012-10-15
Question: Should four-session VCT vs wait-list control be used for preventing HIV transmission and improving HIV care in Adolescents?
Settings: Nigeria
Bibliography: Olley 2006

<table>
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<tr>
<th>No of studies</th>
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<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Four-session VCT</th>
<th>wait-list control</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
<th>Quality</th>
<th>Importance</th>
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<tr>
<td>Sexual risk behaviour at 4 weeks (Better indicated by lower values)</td>
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<tr>
<td>1</td>
<td>randomised trials</td>
<td>serious¹</td>
<td>no serious inconsistency</td>
<td>very serious²</td>
<td>very serious³</td>
<td>none</td>
<td>34</td>
<td>33</td>
<td>-</td>
<td>MD 2.47 lower (3.17 to 1.77 lower)</td>
<td>🌟🌟🌟🌟 VERY LOW</td>
<td>CRITICAL</td>
</tr>
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</table>

1 Randomisation process unclear, allocation not concealed, not blinded.
2 Adult population, self-report
3 Very few events.

Depression at 4 weeks (Better indicated by lower values) | | | | | | | | | | | | |
| 1 | randomised trials | serious¹ | no serious inconsistency | very serious² | very serious³ | none | 34 | 33 | - | MD 8.45 lower (9.44 to 7.46 lower) | 🌟🌟🌟🌟 VERY LOW | IMPORTANT |

GRADE evidence profiles: PICO 1b – RCTs (HTC)
**Author(s):** Lindegren ML, Horvath T, Anglemyer A, Rutherford GW  
**Date:** 2011-12-12  
**Question:** Should HIV testing and counselling vs control be used for preventing HIV transmission and improving HIV care in Adolescents?  
**Settings:** Key populations in settings with a low-level epidemic: United Kingdom, United States of America  
**Bibliography:** Apoolla 2011, Bolu 2004

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<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
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<td><strong>STI incidence</strong> (follow-up 12 months)</td>
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<td>Risk of bias</td>
<td>Inconsistency</td>
<td>Indirectness</td>
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<tr>
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<td>randomised trials</td>
<td>serious</td>
<td>no serious inconsistency</td>
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<td><strong>Attended STI clinic</strong> (follow-up 1 week)</td>
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<td>Inconsistency</td>
<td>Indirectness</td>
</tr>
<tr>
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<td>very serious</td>
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<td>serious</td>
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<td><strong>Uptake of HIV, HBV, and HCV testing</strong> (follow-up 1 week)</td>
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<td>Risk of bias</td>
<td>Inconsistency</td>
<td>Indirectness</td>
</tr>
<tr>
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<td>very serious</td>
<td>no serious inconsistency</td>
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<td><strong>Received all 3 doses of HAV and HBV vaccine</strong> (follow-up 1 week)</td>
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1. Counselling intervention only.  
2. Not blinded; Only 5833/13471 (43%) of eligibles consented.  
3. Very few events  
4. Testing intervention only  
5. Not blinded. Sequence generation method and allocation concealment method not described. Only 11% of eligibles consented.  
6. Pre-test discussion, not counselling per se.  
7. Very large effect (97% vs. 11%) but not upgraded for strong association because of multiple downgradings.

**GRADE evidence profiles: PICO 1a/b – observational studies**

**Author(s):** Lindegren ML, Horvath T, Anglemyer A, Rutherford GW  
**Date:** 2011-11-02  
**Question:** Should HIV testing and counselling vs control be used for preventing HIV transmission and improving HIV care in Adolescents?  
**Settings:** Kenya, South Africa, Thailand, United Kingdom, United States of America  
**Bibliography:** Gwadz 2010, Kabiru 2010, Müller 1995, Naughton 2011 (observational studies)
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<td>Linkage to care (generalised) (follow-up 2-14 months)</td>
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<td>23/89 (25.8%)</td>
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<td>1 observational studies</td>
<td>26/160 (16.3%)</td>
<td>8/159</td>
<td>HR 3.18 (1.51 to 6.72)</td>
<td>101 more per 1000 (from 25 more to 243 more)</td>
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<td>7/73 (9.6%)</td>
<td>4/74</td>
<td>HR 1.67 (0.51 to 5.48)</td>
<td>35 more per 1000 (from 26 fewer to 208 more)</td>
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<td>1/60 (1.7%)</td>
<td>2/73</td>
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<td>20/160 (12.5%)</td>
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<td>6/73 (8.2%)</td>
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<td>HR 1.18 (0.33 to 4.16)</td>
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<td>20/60 (33.3%)</td>
<td>7/73</td>
<td>HR 3.54 (1.48 to 8.45)</td>
<td>204 more per 1000 (from 43 more to 477 more)</td>
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<td><strong>Risk of bias</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Inconsistency</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Indirectness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Imprecision</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other considerations</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Had unprotected sex in past 6 months after test, men (generalised) (follow-up 6 months)</strong></td>
<td></td>
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1
2
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6
7
<table>
<thead>
<tr>
<th>1</th>
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<th>no serious risk of bias</th>
<th>no serious inconsistency</th>
<th>very serious</th>
<th>very serious</th>
<th>none</th>
<th>60/160 (37.5%)</th>
<th>61/159 (38.4%)</th>
<th>HR 0.98 (0.75 to 1.28)</th>
<th>6 fewer per 1000 (from 79 fewer to 78 more)</th>
<th>⚠️⚠️⚠️</th>
<th>CRITICAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had unprotected sex in past 6 months after test, ever pregnant women (generalised) (follow-up 6 months)</td>
<td></td>
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<td>observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious</td>
<td>very serious</td>
<td>none</td>
<td>30/73 (41.1%)</td>
<td>50/74 (67.6%)</td>
<td>HR 0.59 (0.47 to 0.75)</td>
<td>190 fewer per 1000 (from 105 fewer to 265 fewer)</td>
<td>⚠️⚠️⚠️</td>
<td>VERY LOW</td>
</tr>
<tr>
<td>2</td>
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<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious</td>
<td>very serious</td>
<td>none</td>
<td>25/60 (41.7%)</td>
<td>19/73 (26%)</td>
<td>HR 1.64 (0.94 to 2.83)</td>
<td>130 more per 1000 (from 14 fewer to 314 more)</td>
<td>⚠️⚠️⚠️</td>
<td>VERY LOW</td>
</tr>
<tr>
<td>Had unprotected sex in past 6 months after test, never pregnant women (generalised) (follow-up 6 months)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Number of sexual partners (N=0-1) (concentrated) (follow-up median 23 months)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>1</td>
<td>observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious</td>
<td>serious</td>
<td>none</td>
<td>198/300 (66%)</td>
<td>109/300 (36.3%)</td>
<td>RR 1.82 (1.53 to 2.15)</td>
<td>298 more per 1000 (from 193 more to 418 more)</td>
<td>⚠️⚠️⚠️</td>
<td>VERY LOW</td>
</tr>
<tr>
<td>2</td>
<td>observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious</td>
<td>serious</td>
<td>strong association</td>
<td>121/300 (40.3%)</td>
<td>32/300 (10.7%)</td>
<td>RR 3.78 (2.65 to 5.39)</td>
<td>297 more per 1000 (from 176 more to 468 more)</td>
<td>⚠️⚠️⚠️</td>
<td>VERY LOW</td>
</tr>
</tbody>
</table>

1 Relative effect not calculable.
2 No control.
3 Very few events
4 Study limitations (testing intervention only)
5 Outcomes based on patient self-report.
6 Adult study population.
7 Not upgraded for large effect because of multiple downgradings.
8 Numerators and denominators were back-calculated from the reported HR (95% CI) and sample sizes. These estimates are only used for the absolute effect measure.
9 Few events.

GRADE evidence profiles: PICO 2 (training)

GRADE evidence profiles were not created for this review.

GRADE evidence profiles: PICO 3a (disclosure)

GRADE evidence profiles were not created for this review.

GRADE evidence profiles: PICO 3b (disclosure)
## CONTROLLED TRIALS – ADOLESCENTS

**Author(s):** Mary Lou Lindegren, Gail Kennedy, Tara Horvath, Alicen Spaulding  
**Date:** 2012-10-16  
**Question:** Should small group discussions among adolescents be used for to support disclosure of HIV status?  
**Settings:** United States  

<table>
<thead>
<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Small group discussions among adolescents</th>
<th>Control</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
</table>
| Disclosed to sex partners at 15 months | 1<sup><sup>1</sup></sup> randomised trials | serious  
no serious inconsistency | serious<sup>2</sup>  
very serious<sup>4</sup> | Pre-ART era | 51/80 (63.8%) | 17/30 (56.7%) | RR 1.12  
(0.79 to 1.6) | 68 more per 1000 (from 119 fewer to 340 more) | □□□□ VERY LOW | CRITICAL |
| Number of missed appointments at 9 months (Better indicated by lower values) | 1<sup>1</sup> randomised trials | serious  
no serious inconsistency | serious<sup>2</sup>  
serious<sup>5</sup> | Pre-ART era | 80  
30 | - | MD 0.6 higher (0.18 to 1.02 higher) | □□□□ VERY LOW | CRITICAL |
| Emotional distress mean score at 9 months (Better indicated by lower values) | 1<sup>1</sup> randomised trials | serious<sup>2</sup>  
no serious inconsistency | serious<sup>3</sup>  
serious<sup>5</sup> | Pre-ART era | 80  
30 | - | MD 0 higher (0.42 lower to 0.42 higher) | □□□□ VERY LOW | CRITICAL |
| Emotional distress mean score at 15 months (Better indicated by lower values) | 1<sup>1</sup> randomised trials | serious<sup>2</sup>  
no serious inconsistency | serious<sup>3</sup>  
serious<sup>5</sup> | Pre-ART era | 80  
30 | - | MD 0 higher (0.42 lower to 0.42 higher) | □□□□ VERY LOW | CRITICAL |
| Physical distress mean score at 15 months (Better indicated by lower values) | 1<sup>1</sup> randomised trials | serious<sup>2</sup>  
no serious inconsistency | serious<sup>3</sup>  
serious<sup>5</sup> | Pre-ART era | 80  
30 | - | MD 0.1 lower (0.52 lower to 0.32 higher) | □□□□ VERY LOW | CRITICAL |
| Unprotected sex at 15 months | 1<sup><sup>1</sup></sup> randomised trials | serious  
no serious inconsistency | serious<sup>2</sup>  
very serious<sup>4</sup> | Pre-ART era | 2/80 (2.5%) | 5/30 (16.7%) | RR 0.15  
(0.03 to 0.73) | 142 fewer per 1000 (from 45 fewer to 162 fewer) | □□□□ VERY LOW | CRITICAL |
| T-cell count at 9 months (Better indicated by higher values) | 1<sup>1</sup> randomised trials | serious  
no serious | serious<sup>2</sup>  
serious<sup>5</sup> | Pre-ART era | 80  
30 | - | MD 8.4 higher | □□□□ CRITICAL |
<table>
<thead>
<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Four session one-on-one counselling intervention among mothers</th>
<th>Control</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious</td>
<td>very serious</td>
<td>none</td>
<td>13/39 (33.3%)</td>
<td>3/41 (7.3%)</td>
<td>RR 4.56 (1.4 to 14.77)</td>
<td>260 more per 1000 (from 29 more to 1000 more)</td>
<td>⊗⊗⊗⊙</td>
<td>VERY LOW</td>
</tr>
</tbody>
</table>

1 Comparison group was standard of care.
2 Non-randomized comparison between intervention attendees and controls.
3 Study was conducted in the United States.
4 Small number of events.
5 Physical health distress score, calculated as a mean of the intensity (range=0-5) of each symptom from among 23 physical symptoms.

**RANDOMIZED CONTROL TRIALS – ADULTS**

Author(s): Mary Lou Lindegren, Gail Kennedy, Tara Horvath, Alicen Spaulding
Date: 2012-10-17
Question: Should four session one-on-one counselling intervention among mothers be used for to support disclosure of HIV status?
Settings: United States

**Disclosure at 9 months follow-up**

<table>
<thead>
<tr>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>13/39 (33.3%)</td>
<td>RR 4.56 (1.4 to 14.77)</td>
<td>⊗⊗⊗⊙</td>
<td>VERY LOW</td>
</tr>
</tbody>
</table>

1 Comparison was standard of care.
2 Study conducted in the United States.
3 Very small number of events.

Author(s): Mary Lou Lindegren, Gail Kennedy, Tara Horvath, Alicen Spaulding
Date: 2012-10-09
Question: Should group sessions among HIV-positive parents and their adolescent children be used for to support disclosure of HIV status?
Settings: United States
<table>
<thead>
<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Group sessions among HIV-positive parents and their adolescent children</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious¹</td>
<td>serious²</td>
<td>Pre-ART era</td>
<td>115/153 (75.2%)</td>
<td>116/154 (75.3%)</td>
<td>RR 1 (0.88 to 1.13)</td>
<td>0 fewer per 1000 (from 90 fewer to 98 more)</td>
</tr>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious²</td>
<td>serious³</td>
<td>Pre-ART era</td>
<td>136/153 (88.9%)</td>
<td>131/154 (85.1%)</td>
<td>RR 1.04 (0.96 to 1.14)</td>
<td>34 more per 1000 (from 34 fewer to 119 more)</td>
</tr>
</tbody>
</table>

**Disclosed status to all children at 12 months**

- **Control**
  - **Relative (95% CI)**
  - **Absolute**

**Disclosed status to at least 1 adolescent at 24 months**

- **Control**
  - **Relative (95% CI)**
  - **Absolute**

**Disclosed status to all children at 24 months**

- **Control**
  - **Relative (95% CI)**
  - **Absolute**

**Parental depression score at 3 months (Better indicated by lower values)**

- **Control**
  - **Relative (95% CI)**
  - **Absolute**

**Parental depression score at 15 months (Better indicated by lower values)**

- **Control**
  - **Relative (95% CI)**
  - **Absolute**

**Parental depression score at 24 months (Better indicated by lower values)**

- **Control**
  - **Relative (95% CI)**
  - **Absolute**

---

¹ Comparison was standard of care intervention.
² HIV-infected parents of uninfected children were the study population; Study conducted in the United States.
³ Small number of events.
**Question:** Should group counselling among MSM be used for to support disclosure of HIV status?

**Author(s):** Mary Lou Lindegren, Gail Kennedy, Tara Horvath, Alicen Spaulding

**Date:** 2012-10-17

**Settings:** United States

**Bibliography:** Serovich JM, Reed S, Grafsky EL, Hartwell EE, Andrist D. An Intervention to Assist Men Who Have Sex with Men Disclose Their Serostatus to Family Members: Results from a Pilot Study. AIDS AND BEHAVIOR. Volume 15, Number 8 (2011), 1647-1653.

<table>
<thead>
<tr>
<th>Quality assessment</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of studies</td>
<td>Design</td>
<td>Risk of bias</td>
<td>Inconsistency</td>
<td>Indirectness</td>
</tr>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>serious¹</td>
<td>no serious inconsistency</td>
<td>very serious²</td>
</tr>
</tbody>
</table>

¹ Comparison group got a delayed version of the same intervention.
² Adult population; Study conducted in the United States; self report.
³ Very small number of events.

**Question:** Should peer led behavioral sessions among MSM be used for to support disclosure of HIV status?

**Author(s):** Mary Lou Lindegren, Gail Kennedy, Tara Horvath, Alicen Spaulding

**Date:** 2012-10-17

**Settings:** United States


<table>
<thead>
<tr>
<th>Quality assessment</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of studies</td>
<td>Design</td>
<td>Risk of bias</td>
<td>Inconsistency</td>
<td>Indirectness</td>
</tr>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious²</td>
</tr>
</tbody>
</table>

¹ Comparison group got a delayed version of the same intervention.
Disclosed HIV status to all partners at 6 months

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious²</td>
<td>serious³</td>
<td>none</td>
<td>136/304 (44.7%)</td>
<td>128/298 (43%)</td>
<td>RR 1.04 (0.87 to 1.25)</td>
<td>17 more per 1000 (from 56 fewer to 107 more)</td>
</tr>
</tbody>
</table>

Unprotected anal intercourse at 6 months

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious²</td>
<td>serious³</td>
<td>none</td>
<td>99/373 (26.5%)</td>
<td>108/354 (30.5%)</td>
<td>RR 0.87 (0.69 to 1.1)</td>
<td>40 fewer per 1000 (from 95 fewer to 31 more)</td>
</tr>
</tbody>
</table>

Consistent condom use during insertive anal intercourse at 6 months

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious²</td>
<td>very serious³</td>
<td>none</td>
<td>61/121 (50.4%)</td>
<td>58/119 (48.7%)</td>
<td>RR 1.03 (0.8 to 1.34)</td>
<td>15 more per 1000 (from 97 fewer to 166 more)</td>
</tr>
</tbody>
</table>

Intervention motivated me to tell my partners about my HIV status: mean score (Better indicated by higher values)

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious³</td>
<td>no serious imprecision</td>
<td>none</td>
<td>413</td>
<td>398</td>
<td>MD 0.57 higher (0.41 to 0.73 higher)</td>
<td>VERY CRITICAL</td>
</tr>
</tbody>
</table>

1 Comparison group received a standard intervention that was briefer in content.
2 Adult population; Study conducted in the United States; self report.

OBSERVATIONAL STUDIES – ADULTS

Author(s): Mary Lou Lindegren, Gail Kennedy, Tara Horvath, Alicen Spaulding
Date: 2012-10-17
Question: Should structured support groups among pregnant women be used for to support disclosure of HIV status?
Settings: South Africa
<table>
<thead>
<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Workshops among women</th>
<th>Control</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious ²</td>
<td>serious ²</td>
<td>none</td>
<td>115/129 (89.1%)</td>
<td>134/150 (89.3%)</td>
<td>RR 1 (0.92 to 1.08)</td>
<td>0 fewer per 1000 (from 71 fewer to 71 more)</td>
<td>☒○○○ VERY LOW</td>
<td>CRITICAL</td>
</tr>
</tbody>
</table>

**Disclosure at 8 months follow-up**

<table>
<thead>
<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Workshops among women</th>
<th>Control</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious ²</td>
<td>serious ²</td>
<td>none</td>
<td>125/129 (96.9%)</td>
<td>123/150 (82%)</td>
<td>RR 1.18 (1.09 to 1.28)</td>
<td>148 more per 1000 (from 74 more to 230 more)</td>
<td>☒/functions</td>
<td>VERY LOW</td>
</tr>
</tbody>
</table>

**Depressed at 8 months follow-up**

<table>
<thead>
<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Workshops among women</th>
<th>Control</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious ²</td>
<td>serious ²</td>
<td>none</td>
<td>125/129 (96.9%)</td>
<td>123/150 (82%)</td>
<td>RR 1.18 (1.09 to 1.28)</td>
<td>148 more per 1000 (from 74 more to 230 more)</td>
<td>☒/functions</td>
<td>VERY LOW</td>
</tr>
</tbody>
</table>

**Quality assessment**

<table>
<thead>
<tr>
<th>Quality assessment</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight of keeping HIV status secret mean score (Better indicated by lower values)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Author(s):** Mary Lou Lindegren, Gail Kennedy, Tara Horvath, Alicen Spaulding

**Date:** 2012-10-17

**Question:** Should workshops among women be used to support disclosure of HIV status?

**Settings:** Mali


**GRADE evidence profiles: PICO 4 (c-b services/decentralization)**

**Author(s):** Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T

**Date:** 2012-10-10

**Question:** Should Peer health workers (PHW) vs Standard care be used for improving outcomes in adolescents with HIV infection?

**Settings:** Uganda

**Bibliography:** Chang 2010
<table>
<thead>
<tr>
<th>Quality assessment</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of studies</td>
<td>Design</td>
<td>Risk of bias</td>
<td>Inconsistency</td>
<td>Indirectness</td>
</tr>
<tr>
<td><strong>Mortality (26 months)</strong></td>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
</tr>
<tr>
<td><strong>Viral failure (&gt;400 copies/mL) (24 weeks)</strong></td>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
</tr>
<tr>
<td><strong>Viral failure (&gt;400 copies/mL) (48 weeks)</strong></td>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
</tr>
<tr>
<td><strong>Viral failure (&gt;400 copies/mL) (96 weeks)</strong></td>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
</tr>
<tr>
<td><strong>less than 95% adherence (26 months)</strong></td>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
</tr>
<tr>
<td><strong>less than 100% adherence (26 months)</strong></td>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
</tr>
</tbody>
</table>

¹ Adult population
² Very few events.

**Author(s):** Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T

**Date:** 2012-10-10

**Question:** Should Peer health workers (PHW) w/ mobile phone support vs PHW without mobile phone support be used for improving outcomes in adolescents with HIV infection?

**Settings:** Uganda

**Bibliography:** Chang 2011
<table>
<thead>
<tr>
<th>Mortality (26 months)</th>
<th>Peer health workers (PHW) w/ mobile phone support</th>
<th>PHW without mobile phone support</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>37/446 (8.3%)</td>
<td>53/524 (10.1%)</td>
<td>RR 0.82 (0.55 to 1.22)</td>
<td>18 fewer per 1000 (from 46 fewer to 22 more)</td>
</tr>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Viral failure (&gt;400 copies/mL) (48 weeks)</td>
<td>Peer health workers (PHW) w/ mobile phone support</td>
<td>PHW without mobile phone support</td>
<td>Relative (95% CI)</td>
<td>Absolute</td>
</tr>
<tr>
<td>1</td>
<td>18/201 (9%)</td>
<td>24/255 (9.4%)</td>
<td>RR 0.95 (0.53 to 1.7)</td>
<td>5 fewer per 1000 (from 44 fewer to 66 more)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Viral failure (&gt;400 copies/mL) (24 weeks)</td>
<td>Peer health workers (PHW) w/ mobile phone support</td>
<td>PHW without mobile phone support</td>
<td>Relative (95% CI)</td>
<td>Absolute</td>
</tr>
<tr>
<td>1</td>
<td>25/203 (12.3%)</td>
<td>20/259 (7.7%)</td>
<td>RR 1.59 (0.91 to 2.79)</td>
<td>46 more per 1000 (from 7 fewer to 138 more)</td>
</tr>
<tr>
<td>less than 95% adherence (26 months)</td>
<td>Peer health workers (PHW) w/ mobile phone support</td>
<td>PHW without mobile phone support</td>
<td>Relative (95% CI)</td>
<td>Absolute</td>
</tr>
<tr>
<td>1</td>
<td>2/401 (0.5%)</td>
<td>10/473 (2.1%)</td>
<td>RR 0.24 (0.05 to 1.07)</td>
<td>16 fewer per 1000 (from 20 fewer to 1 more)</td>
</tr>
<tr>
<td>less than 100% adherence (26 months)</td>
<td>Peer health workers (PHW) w/ mobile phone support</td>
<td>PHW without mobile phone support</td>
<td>Relative (95% CI)</td>
<td>Absolute</td>
</tr>
<tr>
<td>1</td>
<td>101/401 (25.2%)</td>
<td>122/473 (25.8%)</td>
<td>RR 0.98 (0.78 to 1.23)</td>
<td>5 fewer per 1000 (from 57 fewer to 59 more)</td>
</tr>
</tbody>
</table>

1 Adult population
2 Very few events

**Author(s):** Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T

**Date:** 2012-10-10

**Question:** Should HIV+ mentor mother vs Standard care be used for improving outcomes in adolescents with HIV infection?

**Settings:** South Africa

**Bibliography:** Futterman 2010
<table>
<thead>
<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>HIV+ mentor mother</th>
<th>Standard care</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
<th>Quality</th>
<th>Importance</th>
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</thead>
<tbody>
<tr>
<td><strong>Follow-up visits (6 months)</strong></td>
<td>1</td>
<td>observational studies</td>
<td>serious¹</td>
<td>no serious inconsistency</td>
<td>serious²</td>
<td>very serious³</td>
<td>none</td>
<td>23/40 (57.5%)</td>
<td>11/31 (35.5%)</td>
<td>RR 1.62 (0.94 to 2.79)</td>
<td>220 more per 1000 (from 21 fewer to 635 more)</td>
<td>☒ ☒ ☒ ☒ ☐</td>
</tr>
</tbody>
</table>

¹ Very high loss to follow-up.
² Population was pregnant women.
³ Very few events.

**Author(s):** Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T

**Date:** 2012-10-10

**Question:** Should Patient advocates (for paeds) vs Standard care be used for improving outcomes in adolescents with HIV infection?

**Settings:** South Africa

**Bibliography:** Grimwood 2012

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<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Patient advocates (for paeds)</th>
<th>Standard care</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mortality (3 years)</strong></td>
<td>1</td>
<td>observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious¹</td>
<td>very serious²</td>
<td>none</td>
<td>12/323 (3.7%)</td>
<td>259/3240 (8%)</td>
<td>RR 0.46 (0.26 to 0.82)</td>
<td>43 fewer per 1000 (from 14 fewer to 59 fewer)</td>
<td>☒ ☐ ☒ ☒ ☐</td>
</tr>
</tbody>
</table>

¹ Population was children: Median baseline age was 6.3 (IQR 3.3 to 9.5)
² Very few events

**Author(s):** Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T

**Date:** 2012-10-10

**Question:** Should Integrated community-based services vs Standard care be used for improving outcomes in adolescents with HIV infection?

**Settings:** Botswana, Lesotho, Namibia, South Africa

**Bibliography:** Kabore 2010
<table>
<thead>
<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Integrated community-based services</th>
<th>Standard care</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;95% adherence (12 months)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious</td>
<td>no serious imprecision</td>
<td>none</td>
<td>287/429 (66.9%)</td>
<td>250/429 (58.3%)</td>
<td>RR 1.15 (1.03 to 1.27)</td>
<td>87 more per 1000 (from 17 more to 157 more)</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>VERY LOW CRITICAL</td>
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</table>

Author(s): Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T
Date: 2012-10-10
Question: Should Rural community-based ART vs Urban hospital-based ART be used for improving outcomes in adolescents with HIV infection?
Settings: Uganda
Bibliography: Kipp 2012

<table>
<thead>
<tr>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
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</thead>
<tbody>
<tr>
<td>Rural community-based ART</td>
<td>Urban hospital-based ART</td>
<td>Relative (95% CI)</td>
<td>Absolute</td>
</tr>
<tr>
<td>32/185 (17.3%)</td>
<td>23/200 (11.5%)</td>
<td>RR 1.5 (0.91 to 2.47)</td>
<td>58 more per 1000 (from 10 fewer to 169 more)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>VERY LOW CRITICAL</td>
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</tbody>
</table>

Mortality (2 years)

<table>
<thead>
<tr>
<th>Reduced viral load (24 months)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>observational studies</td>
</tr>
<tr>
<td></td>
<td>serious</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Author(s): Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T
Date: 2012-10-10
Question: Should Multi-component community-based care vs Standard care be used for improving outcomes in adolescents with HIV infection?
Settings: Peru
Bibliography: Munoz 2011

<table>
<thead>
<tr>
<th>Quality assessment</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural population probably not comparable to urban population</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2 Adult population
3 Very few events
<table>
<thead>
<tr>
<th>Quality assessment</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortality (1 year)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 randomised trials</td>
<td>no serious risk of bias</td>
<td>serious¹</td>
<td>very serious²</td>
<td>none</td>
</tr>
</tbody>
</table>

| Reduced viral load (2 years) |               |        |         |            |
| 1 randomised trials | no serious risk of bias | serious¹ | very serious² | none | 135/147 (91.8%) | 110/130 (84.6%) | RR 1.09 (0.99 to 1.18) | 76 more per 1000 (from 8 fewer to 152 more) | ☒☺☺☺ VERY CRITICAL |

¹ Adult population
² Very few events.
³ Self-reported adherence.

Author(s): Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T
Date: 2012-10-10
Question: Should Peer-delivered modified DOT vs Standard care be used for improving outcomes in adolescents with HIV infection?
Settings: Mozambique
Bibliography: Pearson 2007
**Question:** Should Treatment-partner assisted therapy vs Standard care be used for improving outcomes in adolescents with HIV infection?

**Settings:** Nigeria

**Bibliography:** Taiwo 2010

<table>
<thead>
<tr>
<th>No of studies</th>
<th>Design</th>
<th>Risk of bias</th>
<th>Inconsistency</th>
<th>Indirectness</th>
<th>Imprecision</th>
<th>Other considerations</th>
<th>Treatment-partner assisted therapy</th>
<th>Standard care</th>
<th>Relative (95% CI)</th>
<th>Absolute</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mortality (1 year)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious(^1)</td>
<td>very serious(^2)</td>
<td>none</td>
<td>26/245 (10.6%)</td>
<td>15/246 (6.1%)</td>
<td>RR 1.74 (0.95 to 3.2)</td>
<td>45 more per 1000 (from 3 fewer to 134 more)</td>
<td>⚫⚫⚫⚫</td>
<td>VERY CRITICAL</td>
</tr>
<tr>
<td>(&gt;95%) adherence (48 weeks)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious(^3), (^4)</td>
<td>serious(^5)</td>
<td>none</td>
<td>199/248 (80.2%)</td>
<td>169/251 (67.3%)</td>
<td>RR 1.19 (1.07 to 1.33)</td>
<td>128 more per 1000 (from 47 more to 222 more)</td>
<td>⚫⚫⚫⚫</td>
<td>VERY CRITICAL</td>
</tr>
<tr>
<td><strong>Reduced viral load (24 weeks)</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious(^1)</td>
<td>serious(^6)</td>
<td>none</td>
<td>153/238 (64.3%)</td>
<td>126/227 (55.5%)</td>
<td>RR 1.16 (1 to 1.35)</td>
<td>89 more per 1000 (from 0 more to 194 more)</td>
<td>⚫⚫⚫</td>
<td>LOW CRITICAL</td>
</tr>
<tr>
<td><strong>Reduced viral load (48 weeks)</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious(^1)</td>
<td>serious(^7)</td>
<td>none</td>
<td>162/234 (69.2%)</td>
<td>149/217 (68.7%)</td>
<td>RR 1.01 (0.89 to 1.14)</td>
<td>7 more per 1000 (from 76 fewer to 96 more)</td>
<td>⚫⚫⚫</td>
<td>LOW CRITICAL</td>
</tr>
</tbody>
</table>

1. Adult population
2. Very few events
3. Self-reported adherence.
4. Few events

**Author(s):** Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T
**Date:** 2012-10-10
**Question**: Should Socio-economic support vs No socio-economic support be used for improving outcomes in adolescents with HIV infection?

**Settings**: Uganda

**Bibliography**: Talisuna-Alamo 2012

<table>
<thead>
<tr>
<th>Quality assessment</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
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</thead>
<tbody>
<tr>
<td>Mortality (10 years): one kind of support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious</td>
<td>no serious imprecision</td>
</tr>
</tbody>
</table>

| Mortality (10 years): two or more kinds of support | | | | |
| 1 observational studies | no serious risk of bias | no serious inconsistency | very serious | very serious | none | 56/698 (8%) | 653/3985 (16.4%) | RR 0.49 (0.38 to 0.64) | 84 fewer per 1000 (from 59 fewer to 102 fewer) | 5000 VERY LOW | CRITICAL |

1. Retrospective records review of adult patients.
2. Very few events
3. Not upgraded for large effect because of multiple down-gradings

**Author(s)**: Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T

**Date**: 2012-10-24

**Question**: Should Community-based adherence support vs standard care be used for improving outcomes for adolescents with HIV?

**Settings**: South Africa

**Bibliography**: Fatti 2012

<table>
<thead>
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<th>Quality assessment</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortality (5 years)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>1 observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious</td>
<td>no serious imprecision</td>
</tr>
</tbody>
</table>

**Retention in care (5 years)**
<table>
<thead>
<tr>
<th>Virologic suppression (6 months)</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious¹</td>
<td>no serious imprecision</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Virologic suppression (12 months)</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
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<td>1 observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious¹</td>
<td>no serious imprecision</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Virologic suppression (24 months)</th>
<th>No of patients</th>
<th>Effect</th>
<th>Quality</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
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<td>1 observational studies</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>serious¹</td>
<td>no serious imprecision</td>
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</table>

¹ Adult population

Author(s): Butler LM, Kennedy GE, Rajan J, Wells G, Spaulding AB, Horvath T
Date: 2012-10-24
Question: Should PDA-supported home visits by PLHA vs standard care for improving outcomes in adolescents with HIV infection?
Settings: Kenya
Bibliography: Selke 2010
<table>
<thead>
<tr>
<th></th>
<th>randomised trials</th>
<th>no serious risk of bias</th>
<th>no serious inconsistency</th>
<th>serious(^1)</th>
<th>very serious(^2)</th>
<th>none</th>
<th>9/96 (9.4%)</th>
<th>13/112 (11.6%)</th>
<th>RR 0.81 (0.36 to 1.81)</th>
<th>22 fewer per 1000 (from 74 fewer to 94 more)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>100% adherence (self-report)</td>
<td></td>
<td>randomised trials</td>
<td>no serious risk of bias</td>
<td>no serious inconsistency</td>
<td>very serious(^3)</td>
<td>serious(^4)</td>
<td>none</td>
<td>76/96 (79.2%)</td>
<td>95/112 (84.8%)</td>
<td>RR 0.93 (0.82 to 1.06)</td>
<td>59 fewer per 1000 (from 153 fewer to 51 more)</td>
</tr>
</tbody>
</table>

\(^1\) Adult population; self-reported adherence
\(^2\) No events in either group
\(^3\) Very few events
\(^4\) Few events
HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV

ANNEX 7: Evidence summaries and findings

PICO 1 - HTC

EVIDENCE SUMMARIES: RCTs

HIV testing and counselling for adolescents in generalised epidemic settings (randomised controlled trials)

Outcome: STI incidence (follow-up 6 months)
- In 1 trial (VCT 2000) with 6 months follow up, STI incidence decreased (non-statistically significant) among those individuals who received VCT compared to standard health information (OR 0.80, 95% CI 0.53 to 1.20). The quality of evidence is very low and was downgraded for indirectness due to an adult population and very serious imprecision (very small number of events).

Outcome: Survival at 6 months (follow-up 6 months)
- In 1 trial (Wanyenze 2011) with 6 months follow-up, fewer hospitalized HIV-positive adults who received VCT as inpatients were still alive, compared to HIV-positive patients referred for VCT post-discharge (RR 0.83, 95% CI 0.68 to 1.0). The quality of the evidence is very low. The evidence was downgraded for indirectness (adult population) and because the population were sick, hospitalized inpatients. The evidence was downgraded for imprecision due to few participants and events. Of note, 171/249 in the control group (VCT referral post discharge) and 3/251 in the inpatient intervention group were not tested for HIV.

Outcome: Attended HIV clinic (follow-up 6 months)
- In 1 trial (Wanyenze 2011) with six months follow-up, fewer HIV-positive patients in the control arm attended a HIV clinic compared to the intervention arm (RR 0.76, 95% CI 0.59 to 0.98). The quality of the evidence is very low. The evidence was downgraded as noted above.

Outcome: Uptake of pre-ARV care (follow-up 5 months)
- In 1 trial (Muhamadi 2011) with five months follow-up, uptake of pre-ARV care increased significantly in adult HIV-positive patients who received the intervention (enhanced post-test counseling by trained staff with combined with home visits by community support agents for extended counseling) compared to standard post-test counseling (RR 1.75, 95% CI 1.44 to 2.14). The quality of the evidence is low. The evidence was downgraded for indirectness (adult population) and for imprecision (few participants and events).

Outcome: Unprotected sex with non-primary partner (follow-up 6 months)
- In 1 trial (VCT 2000) with 6 months follow up, unprotected sexual intercourse with a non-primary partner was significantly decreased among both men (RR 0.74, 95% CI 0.6 to 0.91) and women (RR 0.72, 95% CI 0.56 to 0.93) who received VCT compared to those who received basic health information only. The quality of the evidence is very low. The evidence was downgraded twice for indirectness (adult population, self-reported outcomes), and for imprecision (few
Outcome: Sexual risk behaviour (follow-up 4 weeks)

- In 1 trial (Olley 2006) with 4 weeks follow up, the mean number of adults reporting sexual risk behavior was lower in participants attending four-session VCT, compared to those in the wait-list control group (MD 2.47 lower, 95% CI 3.17 to 1.77 lower). The quality of the evidence is very low. The evidence quality was downgraded for study limitations (randomisation process unclear, allocation not concealed, not blinded), very serious indirectness (adult population, self-reported outcomes), and for very serious imprecision (very few events).

Outcome: Depression (follow-up 4 weeks)

- In 1 trial (Olley 2006) with 4 weeks follow up, the mean number of adults reporting depression was lower in participants attending four-session VCT, compared to those in the wait-list control group (MD 8.45 lower, 95% CI 9.44 to 7.46 lower). The quality of the evidence is very low. The evidence quality was downgraded for study limitations (randomisation process unclear, allocation not concealed, not blinded), very serious indirectness (adult population, self-reported outcomes), and for very serious imprecision (very few events).

HIV testing and counselling for HIV adolescents in low-level epidemic settings (randomised controlled trials)

Outcome: STI incidence (follow-up 12 months)

- In 1 trial (Bolu 2004) with 12 months follow-up, STI incidence decreased in adolescent key populations in settings with a low-level epidemic undergoing HIV counselling vs. control (no counselling) (RR 0.65, 95% CI 0.49 to 0.86). The quality of evidence is low. The evidence was downgraded for significant study limitations, and for serious indirectness (counselling-only intervention).

Outcome: Attended STI clinic

- In 1 trial (Apoola 2011) with 1 week follow-up, attendance at STI clinic increased in adolescent key populations in settings with a low-level epidemic undergoing HIV testing vs. control (no testing) (RR 3, 95% CI 0.91 to 9.88). The quality of evidence is very low. The evidence was downgraded for significant study limitations, for very serious imprecision (very few participants/events), and for serious indirectness (testing-only intervention).

Outcome: Uptake of HIV, HBV, and HCV testing

- In 1 trial (Apoola 2011) with 1 week follow-up, uptake of HIV, HBV, and HCV testing increased in adolescent key populations in settings with a low-level epidemic undergoing HIV testing vs. control (RR 8.77, 95% CI 4.73 to 16.26). The quality of evidence is very low. The evidence was downgraded for significant study limitations, for very serious imprecision (very few participants and events), and for serious indirectness (testing-only intervention). Although the effect size was large, the quality of the evidence was not upgraded due to the significant study limitations and very few participants/events.

Outcome: Received all 3 doses of HAV and HBV vaccines

- In 1 trial (Apoola 2011) with 1 week follow-up, receipt of all 3 doses of HAV and HBV vaccines decreased in adolescent key populations in settings with a low-level epidemic undergoing HIV testing vs. control (RR 0.90, 95% CI 0.43 to 1.85). The quality of evidence is very low. The
evidence was downgraded for significant study limitations, for very serious imprecision (very few participants and events), and for serious indirectness (testing-only intervention).

EVIDENCE SUMMARIES: OBSERVATIONAL STUDIES

HTC for HIV prevention and linkage to care among adols in generalised, concentrated and key population/low-level epidemic settings

**Outcome: Linkage to care, generalised epidemic setting**
- In one observational study (Naughton 2011) with 2-14 months follow-up, none (0%) of the 7 HIV-positive adolescents identified subsequently attended the clinic for care. There was no control group, and the relative effect was not calculable. The quality of the evidence is very low. The evidence was downgraded for serious study design limitations (no comparator), and downgraded for very serious imprecision (very few participants/events).

**Outcome: Linkage to care, key populations**
- In one observational study (Gwadz 2010), 23/89 (26%) HIV-positive adolescents subsequently attended the clinic for care, vs 29/83 (35%) in the control group (RR 0.74, 95% CI 0.47 to 1.17). The quality of the evidence is very low. The evidence was downgraded for serious indirectness (testing-only intervention) and very serious imprecision (very few events).

**Outcome: Concurrent sexual partnership, men, generalised epidemic setting**
- In one observational study (Kabiru 2010) with 6 months follow-up, significantly more men from the intervention group (had an HIV test in past 6 months) reported concurrent sexual partnerships compared to men in the control group (HR 3.18, 95% CI 1.51 to 6.72). Although the evidence was graded up for a strong association, the quality of the evidence is very low. The evidence was downgraded for very serious indirectness (adult population, patient self-report), and very serious imprecision (very few participants/events).

**Outcome: Concurrent sexual partnership, ever pregnant women, generalised epidemic setting**
- In one observational study (Kabiru 2010) with 6 months follow-up, more ever pregnant women (non-statistically significant) from the intervention group (had an HIV test in past 6 months) reported concurrent sexual partnerships compared to women in the control group (HR 1.67, 95% CI 0.51 to 5.48). The quality of the evidence is very low. The evidence was downgraded for very serious indirectness (adult population, patient self-report), and very serious imprecision (very few participants/events).

**Outcome: Concurrent sexual partnership, never pregnant women, generalised epidemic setting**
- In one observational study (Kabiru 2010) with 6 months follow-up, fewer never pregnant women (non-statistically significant) from the intervention group (had an HIV test in past 6 months) reported concurrent sexual partnerships compared to women in the control group (HR 0.69, 95% CI 0.07 to 7.12). The quality of the evidence is very low. The evidence was downgraded for very serious indirectness (adult population, patient self-report), and very serious imprecision (very few participants/events).

**Outcome: “Risky” sexual partner, men, generalised epidemic setting**
- In one observational study (Kabiru 2010) with 6 months follow-up, more men (non-statistically significant) from the intervention group (had an HIV test in past 6 months) reported having had a “risky” sexual partner in the past 6 months, compared to men in the control group (HR 1.11,
95% CI 0.61 to 2.01). The quality of the evidence is very low. The evidence was downgraded for very serious indirectness (adult population, patient self-report), and very serious imprecision (very few participants/events).

Outcome: “Risky” sexual partner, ever pregnant women, generalised epidemic setting
- In one observational study (Kabiru 2010) with 6 months follow-up, more ever pregnant women (non-statistically significant) from the intervention group (had an HIV test in past 6 months) reported having had a “risky” sexual partner in the past 6 months, compared to women in the control group (HR 1.18, 95% CI 0.33 to 4.16). The quality of the evidence is very low. The evidence was downgraded for very serious indirectness (adult population, patient self-report), and very serious imprecision (very few participants/events).

Outcome: “Risky” sexual partner, never pregnant women, generalised epidemic setting
- In one observational study (Kabiru 2010) with 6 months follow-up, significantly more women from the intervention group (had an HIV test in past 6 months) reported having had a “risky” sexual partner in the past 6 months, compared to women in the control group (HR 3.54, 95% CI 1.48 to 8.45). Although the evidence was graded up for a strong association, the quality of the evidence is very low. The evidence was downgraded for very serious indirectness (adult population, patient self-report), and very serious imprecision (very few participants/events).

Outcome: Had unprotected sex in the past 6 months, men, generalised epidemic setting
- In one observational study (Kabiru 2010) with 6 months follow-up, fewer men from the intervention group (had an HIV test in past 6 months) (non-statistically significant) reported having had unprotected sex in the past 6 months, compared to men in the control group (HR 0.98, 95% CI 0.75 to 1.28). The quality of the evidence is very low. The evidence was downgraded for very serious indirectness (adult population, patient self-report), and very serious imprecision (very few participants/events).

Outcome: Had unprotected sex in the past 6 months, ever pregnant women, generalised epidemic setting
- In one observational study (Kabiru 2010) with 6 months follow-up, fewer women (non-statistically significant) from the intervention group (had an HIV test in past 6 months) reported having had unprotected sex in the past 6 months, compared to women in the control group (HR 0.59, 95% CI 0.47 to 0.75). The quality of the evidence is very low. The evidence was downgraded for very serious indirectness (adult population, patient self-report), and very serious imprecision (very few participants/events).

Outcome: Had unprotected sex in the past 6 months, never pregnant women, generalised epidemic setting
- In one observational study (Kabiru 2010) with 6 months follow-up, more women (non-statistically significant) from the intervention group (had an HIV test in past 6 months) reported having had unprotected sex in the past 6 months, compared to women in the control group (HR 1.64, 95% CI 0.94 to 2.83). The quality of the evidence is very low. The evidence was downgraded for very serious indirectness (adult population, patient self-report), and very serious imprecision (very few participants/events).

Outcome: Number of sexual partners (N=0-1), concentrated epidemic setting
- In one observational study (Müller 1995) with a median of 23 months follow-up, adolescents in the intervention group (after VCT) were significantly more likely to report having had fewer sexual partners in the past six months, compared to control (RR 1.82, 95% CI 1.53 to 2.15).
Although the evidence was graded up for a strong association, the quality of the evidence is very low. The evidence was downgraded for indirectness (patient self-report) and for serious imprecision (few participants/events).

**Outcome: Condom use during the last 3 episodes of sexual intercourse, concentrated epidemic setting**

- In one observational study (Müller 1995) with a median of 23 months follow-up, adolescents in the intervention group (after VCT) were significantly more likely to report condom use during the last 3 episodes of sexual intercourse, compared to control (RR 3.78, 95% CI 2.65 to 5.39).

Although the evidence was graded up for a strong association, the quality of the evidence is very low. The evidence was downgraded for indirectness (patient self-report) and for serious imprecision (few participants/events).

## REFERENCES


## PICO 2 – Disclosure

References for PICO 2-4 are found at the end of this annex.

**What is the best way to help adolescents disclose HIV status?**

**CONTROLLED TRIALS - Adolescents**

**Outcome: Disclosed to sex partners at 15 months**

- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001a), adolescents participating in small group discussions were more likely to disclose their HIV status to sex partners (statistically non-significant), compared to those receiving standard care (RR 1.2, 95%
CI 0.79 to 1.6). The quality of evidence is very low. Evidence quality was graded down for risk of bias (non-randomised comparison between intervention attendees and controls), indirectness (study was conducted in the United States), and very serious imprecision (very few events).

Outcome: Number of missed appointments at 9 months
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001a), adolescents participating in small group discussions had more missed appointments, compared to those receiving standard care (MD 0.6 higher, 95% CI 0.18 to 1.02 higher). The quality of evidence is very low. Evidence quality was graded down for risk of bias (non-randomised comparison between intervention attendees and controls), serious indirectness (study was conducted in the United States), and very serious imprecision (very few events).

Outcome: Emotional distress mean score at 9 months
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001a), there was no difference in the mean emotional distress scores (statistically non-significant) of adolescents participating in small group discussions, compared to those receiving standard care (MD 0 higher, 95% CI 0.42 lower to 0.42 higher). The quality of evidence is very low. Evidence quality was graded down for risk of bias (non-randomised comparison between intervention attendees and controls), serious indirectness (study was conducted in the United States), and very serious imprecision (very few events).

Outcome: Emotional distress mean score at 15 months
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001a), there was no difference in the mean emotional distress scores (statistically non-significant) of adolescents participating in small group discussions, compared to those receiving standard care (MD 0 higher, 95% CI 0.42 lower to 0.42 higher). The quality of evidence is very low. Evidence quality was graded down for risk of bias (non-randomised comparison between intervention attendees and controls), serious indirectness (study was conducted in the United States), and very serious imprecision (very few events).

Outcome: Physical distress mean score at 15 months
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001a), there was no difference in the mean physical distress scores (statistically non-significant) of adolescents participating in small group discussions, compared to those receiving standard care (MD 0.1 lower, 95% CI 0.52 lower to 0.32 higher). The quality of evidence is very low. Evidence quality was graded down for risk of bias (non-randomised comparison between intervention attendees and controls), serious indirectness (study was conducted in the United States), and very serious imprecision (very few events).

Outcome: Unprotected sex at 15 months
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001a), adolescents participating in small group discussions were less likely to report unprotected sex, compared to those receiving standard care (RR 0.15, 95% CI 0.03 to 0.73). The quality of evidence is very low. Evidence quality was graded down for risk of bias (non-randomised comparison between intervention attendees and controls), serious indirectness (study was conducted in the United States), and very serious imprecision (very few events).

Outcome: T-cell count at 9 months
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001a), adolescents participating in small group discussions had a higher mean T-cell count (statistically non-
significant), compared to those receiving standard care (MD 8.4 higher, 95% CI 12.58 lower to 29.38 higher). The quality of evidence is very low. Evidence quality was graded down for risk of bias (non-randomised comparison between intervention attendees and controls), serious indirectness (study was conducted in the United States), and very serious imprecision (very few events).

**RANDOMIZED CONTROL TRIALS: Adults**

**Outcome: Unprotected sex at 15 months**
- In one trial (Murphy 2011), adults participating in four-session, one-on-one counselling among other HIV-infected mothers were more likely to disclose their HIV status to sex partners, compared to those receiving standard care (RR 4.56, 95% CI 1.4 to 14.77). The quality of evidence is very low. Evidence quality was graded down for indirectness (study was conducted in the United States), and serious imprecision (very few events).

**Outcome: Disclosed HIV status to all children at 12 months**
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001b), HIV-infected parents participating in small group discussions with their adolescent children were no more likely (statistically non-significant) to disclose HIV status to all children than those receiving standard care (RR 1, 95% CI 0.88 to 1.13). The quality of evidence is very low. Evidence quality was graded down for very serious indirectness (HIV-infected adult parents were study population; study was conducted in the United States), and serious imprecision (few events).

**Outcome: Disclosed HIV status to at least one adolescent at 24 months**
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001b), HIV-infected parents participating in small group discussions with their adolescent children were more likely (statistically non-significant) to disclose HIV status at least one adolescent than those receiving standard care (RR 1.04, 95% CI 0.96 to 1.14). The quality of evidence is very low. Evidence quality was graded down for very serious indirectness (HIV-infected adult parents were study population; study was conducted in the United States), and serious imprecision (few events).

**Outcome: Disclosed HIV status to at least all children at 24 months**
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001b), HIV-infected parents participating in small group discussions with their adolescent children were no more likely (statistically non-significant) to disclose HIV status to all children than those receiving standard care (RR 1, 95% CI 0.91 to 1.1). The quality of evidence is very low. Evidence quality was graded down for very serious indirectness (HIV-infected adult parents were study population; study was conducted in the United States), and serious imprecision (few events).

**Outcome: Parental depression score at 3 months**
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001b), HIV-infected parents participating in small group discussions with their adolescent children had higher mean depression scores than those receiving standard care (MD 0.28 higher, 95% CI 0.06 to 0.5 higher). The quality of evidence is low. Evidence quality was graded down for very serious indirectness (HIV-infected adult parents were study population; study was conducted in the United States).
Outcome: Parental depression score at 15 months
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001b), HIV-infected parents participating in small group discussions with their adolescent children had lower mean depression scores than those receiving standard care (MD 0.22 lower, 95% CI 0.44 lower to 0 higher). The quality of evidence is low. Evidence quality was graded down for very serious indirectness (HIV-infected adult parents were study population; study was conducted in the United States).

Outcome: Parental depression score at 24 months
- In one trial conducted in the pre-antiretroviral therapy era (Rotheram-Borus 2001b), HIV-infected parents participating in small group discussions with their adolescent children had lower mean depression scores (statistically non-significant) than those receiving standard care (MD 0.12 lower, 95% CI 0.34 lower to 0.1 higher). The quality of evidence is low. Evidence quality was graded down for very serious indirectness (HIV-infected adult parents were study population; study was conducted in the United States).

Outcome: Number of family members disclosed to at 3 months follow-up
- In one trial (Serovich 2011), adults (men who have sex with men, MSM) participating in group counselling among other HIV-infected MSM were no more likely to disclose (statistically non-significant) to a higher number of family members than were the wait-list control (RR 1.1, 95% CI 0.91 to 1.34). The quality of evidence is very low. Evidence quality was graded down for very serious indirectness (adult population, study was conducted in the United States, and self-reported data), and very serious imprecision (very few events).

Outcome: Disclosed HIV status to some sex partners at 6 months
- In one trial (Wolitski 2005), adults (men who have sex with men, MSM) participating in peer-led behavioural sessions among other HIV-infected MSM were more likely to disclose (statistically non-significant) to some sex partners, compared to participants receiving standard care (RR 1.06, 95% CI 0.85 to 1.32). The quality of evidence is very low. Evidence quality was graded down for very serious indirectness (adult population, study was conducted in the United States, and self-reported data), and serious imprecision (few events).

Outcome: Disclosed HIV status to all sex partners at 6 months
- In one trial (Wolitski 2005), adults (MSM) participating in peer-led behavioural sessions among other HIV-infected MSM were more likely to disclose (statistically non-significant) to all sex partners, compared to participants receiving standard care (RR 1.04, 95% CI 0.87 to 1.25). The quality of evidence is very low. Evidence quality was graded down for very serious indirectness (adult population, study was conducted in the United States, and self-reported data), and serious imprecision (few events).

Outcome: Unprotected anal intercourse at 6 months
- In one trial (Wolitski 2005), adults (MSM) participating in peer-led behavioural sessions among other HIV-infected MSM were less likely to report (statistically non-significant) unprotected anal intercourse, compared to participants receiving standard care (RR 0.87, 95% CI 0.69 to 1.1). The quality of evidence is very low. Evidence quality was graded down for very serious indirectness (adult population, study was conducted in the United States, and self-reported data), and serious imprecision (few events).
Outcome: Consistent condom use during insertive anal intercourse at 6 months
• In one trial (Wolitski 2005), adults (MSM) participating in peer-led behavioural sessions among other HIV-infected MSM were more likely to report (statistically non-significant) consistent condom use during insertive anal intercourse, compared to participants receiving standard care (RR 1.03, 95% CI 0.8 to 1.34). The quality of evidence is very low. Evidence quality was graded down for very serious indirectness (adult population, study was conducted in the United States, and self-reported data), and serious imprecision (few events).

Outcome: Intervention motivated me to tell my sex partners about my HIV status
• In one trial (Wolitski 2005), adults (MSM) participating in peer-led behavioural sessions among other HIV-infected 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 (MD 0.57 higher, 95% CI 0.41 to 0.73 higher). The quality of evidence is very low. Evidence quality was graded down for very serious indirectness (adult population, study was conducted in the United States, and self-reported data).

OBSERVATIONAL STUDIES: Adults

Outcome: Disclosure at 2 months follow-up
• In one observational study (Mundell 2011), more HIV-infected pregnant women who participated in structured support groups for HIV-infected pregnant women had disclosed their HIV status, compared to before attending the support groups (RR 1.2, 95% CI 1.09 to 1.32). The quality of evidence is very low. Evidence quality was graded down for indirectness (adult population), and serious imprecision (few events).

Outcome: Disclosure at 8 months follow-up
• In one observational study (Mundell 2011), more HIV-infected pregnant women who participated in structured support groups for HIV-infected pregnant women had disclosed their HIV status, compared to before attending the support groups (RR 1.18, 95% CI 1.09 to 1.28). The quality of evidence is very low. Evidence quality was graded down for indirectness (adult population), and serious imprecision (few events).

Outcome: Depression at 8 months follow-up
• In one observational study (Mundell 2011), HIV-infected pregnant women who participated in structured support groups for HIV-infected pregnant women were no different in reporting feeling depressed, compared to before attending the support groups (RR 1, 95% CI 0.92 to 1.08). The quality of evidence is very low. Evidence quality was graded down for indirectness (adult population), and serious imprecision (few events).

Outcome: Weight of keeping HIV status secret at 1-week follow-up
• In one observational study (Otis 2012), HIV-infected women who participated in workshops for HIV-infected women had lower mean scores (statistically non-significant) for the weight of keeping their HIV status a secret, compared to before attending the support groups (MD -1.07 lower, 95% CI -1.3 lower to 0.81 higher). The quality of evidence is very low. Evidence quality was graded down for indirectness (adult population), and serious imprecision (few events).
PICO 3 – Training to support adherence and retention

Training of healthcare providers in adolescent health for improving retention and adherence among ALHIV

EVIDENCE SUMMARY: RCTs

Outcome: MORBIDITY

Asthma symptom days (follow-up 24 months)
- This outcome was defined as the number of days with any asthma symptoms (including cough, wheeze, limitation in activity, or night wakening) in the 14 days preceding contact
- In 1 trial (Lozano 2004) with 24 months of follow-up, children with asthma in the planned care intervention arm condition had 13.3 fewer asthma symptom days compared to the standard care control arm (95% CI -24.7, -2.1; p=0.02) and children in the peer leader intervention arm had 6.5 fewer days compared to the standard care control arm (95% CI -16.9, 3.6; p=0.20).

Oral steroid burst rate (follow-up 24 months)
- This outcome was defined as how frequently this medication was taken the past 4 weeks
- In 1 trial (Lozano 2004) with 24 months of follow-up, children with asthma in the planned care intervention care arm had 39% lower oral steroid burst rate per year compared to the standard care control arm (95% CI 11% to 54%) and children in the peer leader intervention arm had 36% lower oral steroid burst rate per year compared to the standard care control arm (95% CI 11% to 58%).

HbA1c levels (follow-up 12 months)
- This outcome is a laboratory blood test conducted to determine the amount of sugar in the blood that is used to determine the level of diabetes disease control
- In 1 trial (Robling 2012, Gregory 2011) with 12 months of follow-up, children with diabetes in the intervention arm had mean HbA1c levels of 9.7 (SD 1.7) compared to 9.5 (SD 1.7) in the control group and this difference was not statistically significantly different (intervention effect 0.01, 95% CI -0.02 to 0.04, p=0.50).

Outcome: ADHERENCE

Adherence (as measured by quality of life questionnaire)
- In 1 trial (Robling 2012, Gregory 2011) with 12 months of follow-up, children with diabetes in the intervention arm had mean adherence scores of 76.8 compared to 80.6 in the control arm (difference not statistically significant).

PICO 4 – Community-based approaches

Adolescent community-based approaches

RANDOMIZED CONTROL TRIALS – Low-middle income countries

Outcome: Mortality (26 months) in peer health worker interventions
- This outcome is represented by 1 study with 26 months of follow-up (Chang 2010).
• In this one study, the proportion of patients who died was 9.3% in the intervention peer health workers arm compared to 8.5% in the control standard of care arm for a non-statistically significant difference (RR 1.1, 95% CI: 0.74 to 1.62) (Chang 2010).
• The quality of this evidence is very low.

Outcome: Mortality (26 months) in peer health workers interventions with mobile phone support
• This outcome is represented by 1 study with 26 months of follow-up (Chang 2011).
• In this one study, the proportion of patients who died was 8.3% in the intervention peer health worker with mobile phone support arm compared to 10.1% in the control peer health worker arm for a non-statistically significant difference (RR 0.82, 95% CI: 0.55 to 1.22) (Chang 2011).
• The quality of this evidence is very low.

Outcome: HIV-associated mortality (12 months) in peer health workers interventions with personal digital assistant (PDA) support
• This outcome is represented by 1 study with 12 months of follow-up (Selke 2010).
• In this one study, no patients in either study arm had died of HIV-associated causes at 12 months. The relative effect is not estimable. (Selke 2010).
• The quality of this evidence is very low.

Outcome: Viral failure (>400 copies/mL) (24 weeks) in peer health worker interventions
• This outcome is represented by 1 study with 24 weeks of follow-up (Chang 2010).
• In this one study, the proportion of patients with viral failure was 9.7% in the intervention peer health worker arm compared to 10.4% in the control standard of care arm for a non-statistically significant difference (RR 0.94, 95% CI: 0.56 to 1.57) (Chang 2010).
• The quality of this evidence is very low.

Outcome: Viral failure (>400 copies/mL) (24 weeks) in peer health workers interventions with mobile phone support
• This outcome is represented by 1 study with 24 weeks of follow-up (Chang 2011).
• In this one study, the proportion of patients with viral failure was 12.3% in the intervention peer health worker with mobile phone support arm compared to 7.7% in the control standard of care arm for a non-statistically significant difference (RR 1.59, 95% CI: 0.91 to 2.79) (Chang 2011).
• The quality of this evidence is very low.

Outcome: Viral failure (>400 copies/mL) (48 weeks) in peer health worker interventions
• This outcome is represented by 1 study with 48 weeks of follow-up (Chang 2010).
• In this one study, the proportion of patients with viral failure was 9.2% in the intervention peer health worker arm compared to 11% in the control standard of care arm for a non-statistically significant difference (RR 0.84, 95% CI: 0.5 to 1.42) (Chang 2010).
• The quality of this evidence is very low.

Outcome: Viral failure (>400 copies/mL) (48 weeks) in peer health workers interventions with mobile phone support
• This outcome is represented by 1 study with 48 weeks of follow-up (Chang 2011).
• In this one study, the proportion of patients with viral failure was 9% in the intervention peer health worker with mobile phone support arm compared to 9.4% in the control standard of care arm for a non-statistically significant difference (RR 0.95, 95% CI: 0.53 to 1.17) (Chang 2011).
• The quality of this evidence is very low.
Outcome: Viral failure (>400 copies/mL) (96 weeks) in peer health worker interventions
- This outcome is represented by 1 study with 96 weeks of follow-up (Chang 2010).
- In this one study, the proportion of patients with viral failure was 6.5% in the intervention peer health worker arm compared to 12.7% in the control standard of care arm with statistically significant fewer patients in the intervention arm experiencing viral failure (RR 0.51, 95% CI: 0.29 to 0.92) (Chang 2010).
- The quality of this evidence is very low.

Outcome: Detectable viral load (12 months) in peer health workers interventions with personal digital assistant (PDA) support
- This outcome is represented by 1 study with 12 months of follow-up (Selke 2010).
- In this one study, the proportion of patients with viral failure was 9.4% in the intervention peer health worker with mobile phone support arm compared to 11.6% in the control standard of care arm for a non-statistically significant difference (RR 0.81, 95% CI: 0.36 to 1.81) (Selke 2010).
- The quality of this evidence is very low.

Outcome: 100% adherence, self reported (12 months) in peer health workers interventions with personal digital assistant (PDA) support
- This outcome is represented by 1 study with 12 months of follow-up (Selke 2010).
- In this one study, the proportion of patients with viral failure was 79.2% in the intervention peer health worker with mobile phone support arm compared to 84.8% in the control standard of care arm for a non-statistically significant difference (RR 0.93, 95% CI: 0.82 to 1.06) (Selke 2010).
- The quality of this evidence is very low.

Outcome: Less than 95% adherence (26 months) in peer health worker interventions
- This outcome is represented by 1 study with 26 months of follow-up (Chang 2010).
- In this one study, the proportion of patients with less than 95% adherence was 1.4% in the intervention peer health worker arm compared to 2.4% in the control standard of care arm for a non-statistically significant difference (RR 0.57, 95% CI: 0.23 to 1.37) (Chang 2010).
- The quality of this evidence is very low.

Outcome: Less than 95% adherence (26 months) in peer health workers interventions with mobile phone support
- This outcome is represented by 1 study with 26 months of follow-up (Chang 2011).
- In this one study, the proportion of patients with less than 95% adherence was 0.5% in the intervention peer health worker arm compared to 2.1% in the control standard of care arm for a non-statistically significant difference (RR 0.24, 95% CI: 0.05 to 1.07) (Chang 2011).
- The quality of this evidence is very low.

Outcome: Less than 100% adherence (26 months) in peer health worker interventions
- This outcome is represented by 1 study with 26 months of follow-up (Chang 2010).
- In this one study, the proportion of patients with less than 95% adherence was 25.5% in the intervention peer health worker arm compared to 23.3% in the control standard of care arm for a non-statistically significant difference (RR 1.09, 95% CI: 0.87 to 1.37) (Chang 2010).
- The quality of this evidence is very low.

Outcome: Less than 100% adherence (26 months) in peer health workers interventions with mobile phone support
- This outcome is represented by 1 study with 26 months of follow-up (Chang 2011).
• In this one study, the proportion of patients with less than 95% adherence was 25.2% in the intervention peer health worker arm compared to 25.8% in the control standard of care arm for a non-statistically significant difference (RR 0.98, 95% CI: 0.78 to 1.23) (Chang 2011).
• The quality of this evidence is very low.

OBSERVATIONAL STUDIES – Low-middle income countries

Outcome: Mortality (1 year) with peer-delivered modified DOT
• This outcome is represented by 1 study with 1 year of follow-up (Pearson 2007).
• In this one study, the proportion of patients who died was 13.1% in the intervention peer-delivered modified DOT arm compared to 18.3% in the control standard of care arm for a non-statistically significant difference (RR 0.72, 95% CI: 0.44 to 1.18) (Pearson 2007).
• The quality of this evidence is very low.

Outcome: Mortality (1 year) with treatment-partner assisted therapy
• This outcome is represented by 1 study with 1 year of follow-up (Taiwo 2010).
• In this one study, the proportion of patients who died was 10.6% in the intervention treatment-partner assisted therapy arm compared to 6.1% in the control standard of care arm for a non-statistically significant difference (RR 1.74, 95% CI: 0.95 to 3.2) (Taiwo 2010).
• The quality of this evidence is very low.

Outcome: Mortality (2 years) multi-component community-based care
• This outcome is represented by 1 study with 2 years of follow-up (Munoz 2011).
• In this one study, the proportion of patients who died was 10% in the intervention multi-component community-based care arm compared to 8.5% in the control standard care arm for a non-statistically significant difference (RR 1.18, 95% CI: 0.49 to 2.85) (Munoz 2011).
• The quality of this evidence is very low.

Outcome: Mortality (2 years) in rural ART
• This outcome is represented by 1 study with 2 years of follow-up (Kipp 2012).
• In this one study, the proportion of patients who died was 17.3% in the intervention rural-based ART compared to 11.5% in the control urban-based ART arm for a non-statistically significant difference (RR 1.5, 95% CI: 0.91 to 2.47) (Kipp 2012).
• The quality of this evidence is very low.

Outcome: Mortality (3 years)
• This outcome is represented by 1 study with 3 years of follow-up (Grimwood 2010).
• In this one study, the proportion of patients who died was 3.7% in the intervention patient advocates for paeds arm compared to 8% in the control standard of care arm for statistically significantly fewer deaths in the intervention arm (RR 0.46, 95% CI: 0.26 to 0.82) (Grimwood 2010).
• The quality of this evidence is very low.

Outcome: Mortality (5 years)
• This outcome is represented by 1 study with 5 years of follow-up (Fatti 2012).
• In this one study, the proportion of patients who died was 9% in the community-based adherence support arm compared to 10.6% in the control standard of care arm for statistically significantly fewer deaths in the intervention arm (RR 0.85, 95% CI 0.81 to 0.89) (Fatti 2012).
• The quality of this evidence is very low.
Outcome: Mortality (10 years): one kind of support
- This outcome is represented by 1 study with 10 years of follow-up (Talisuna-Alamo 2012).
- In this one study, the proportion of patients who died was 15.7% in the intervention socio-economic support arm compared to 16.4% in the control no socio-economic support arm for a non-statistically significant difference (RR 0.96, 95% CI: 0.85 to 1.09) (Talisuna-Alamo 2012).
- The quality of this evidence is very low.

Outcome: Mortality (10 years): two or more kinds of support
- This outcome is represented by 1 study with 10 years of follow-up (Talisuna-Alamo 2012).
- In this one study, the proportion of patients who died was 8% in the intervention socio-economic support arm compared to 16.4% in the control no socio-economic support arm with statistically fewer deaths in the intervention arm (RR 0.49, 95% CI: 0.38 to 0.64) (Talisuna-Alamo 2012).
- The quality of this evidence is very low.

Outcome: Retention in care (5 years)
- This outcome is represented by 1 study with 5 years of follow-up (Fatti 2012).
- In this one study, the proportion of patients who were retained in care was 79.1% in the community-based adherence support arm compared to 73.6% in the control standard of care arm for statistically significantly fewer deaths in the intervention arm (RR 1.07, 95% CI 1.07 to 1.08) (Fatti 2012).
- The quality of this evidence is very low.

Outcome: Reduced viral load (24 weeks)
- This outcome is represented by 1 study with 24 weeks of follow-up (Taiwo 2010).
- In this one study, the proportion of patients with reduced viral load was 64.3% in the intervention treatment-partner assisted therapy arm compared to 55.5% in the control standard of care arm for a non-statistically significant difference (RR 1.16, 95% CI: 1 to 1.35) (Taiwo 2010).
- The quality of this evidence is very low.

Outcome: Reduced viral load (48 weeks)
- This outcome is represented by 1 study with 48 weeks of follow-up (Taiwo 2010).
- In this one study, the proportion of patients with reduced viral load was 69.2% in the intervention treatment-partner assisted therapy arm compared to 68.7% in the control standard of care arm for a non-statistically significant difference (RR 1.01, 95% CI: 0.89 to 1.14) (Taiwo 2010).
- The quality of this evidence is very low.

Outcome: Reduced viral load (24 months)
- This outcome is represented by 1 study with 24 months of follow-up (Kipp 2012).
- In this one study, the proportion of patients who died was 93% in the intervention rural-based ART compared to 87.3% in the control urban-based ART arm for a non-statistically significant difference (RR 1.07, 95% CI: 0.98 to 1.15) (Kipp 2012).
- The quality of this evidence is very low.

Outcome: Reduced viral load (2 years)
- This outcome is represented by 1 study with 2 years of follow-up (Munoz 2011).
• In this one study, the proportion of patients with reduced viral load was 67.3% in the intervention multi-component community-based care arm compared to 45.2% in the control standard care arm for a non-statistically significant difference (RR 1.49, 95% CI: 0.97 to 2.29) (Munoz 2011).
• The quality of this evidence is very low.

**Outcome: Reduced viral load (6 months)**
• This outcome is represented by 1 study (Fatti 2012).
• In this one study, the proportion of patients with a suppressed viral load was 76.6% in the community-based adherence support arm compared to 72% in the control standard of care arm for statistically significantly fewer deaths in the intervention arm (RR 1.06, 95% CI 1.05 to 1.08) (Fatti 2012).
• The quality of this evidence is very low.

**Outcome: Reduced viral load (12 months)**
• This outcome is represented by 1 study (Fatti 2012).
• In this one study, the proportion of patients with a suppressed viral load was 65.8% in the community-based adherence support arm compared to 55.8% in the control standard of care arm for statistically significantly fewer deaths in the intervention arm (RR 1.18, 95% CI 1.15 to 1.21) (Fatti 2012).
• The quality of this evidence is very low.

**Outcome: Reduced viral load (24 months)**
• This outcome is represented by 1 study (Fatti 2012).
• In this one study, the proportion of patients with a suppressed viral load was 53.1% in the community-based adherence support arm compared to 42.3% in the control standard of care arm for statistically significantly fewer deaths in the intervention arm (RR 1.26 (1.21 to 1.31) (Fatti 2012).
• The quality of this evidence is very low.

**Outcome: >90% adherence (1 year)**
• This outcome is represented by 1 study with 1 year of follow-up (Pearson 2007).
• In this one study, the proportion of patients with >90% adherence was 91.8% in the intervention peer-delivered modified DOT arm compared to 84.6% in the control standard of care arm for a non-statistically significant difference (RR 1.09, 95% CI: 0.99 to 1.18) (Pearson 2007).
• The quality of this evidence is very low.

**Outcome: >95% adherence (48 weeks)**
• This outcome is represented by 1 study with 48 weeks of follow-up (Taiwo 2010).
• In this one study, the proportion of patients with >95% adherence was 80.2% in the intervention treatment-partner assisted therapy arm compared to 67.3% in the control standard of care arm with statistically significantly more adherent patients in the intervention arm (RR 1.19, 95% CI: 1.07 to 1.33) (Taiwo 2010).
• The quality of this evidence is very low.

**Outcome: >95% adherence (12 months)**
• This outcome is represented by 1 study with 12 months of follow-up (Kabore 2010).
• In this one study, the proportion of patients with >95% adherence was 66.9% in the intervention integrated community-based services arms compared to 58.3% control standard arm for
significantly more adherent patients in the intervention arm (RR 1.15, 95% CI: 1.03 to 1.27) (Kabore 2010).

- The quality of this evidence is very low.

**Outcome: >95% adherence (2 years)**
- This outcome is represented by 1 study with 2 years of follow-up (Munoz 2011).
- In this one study, the proportion of patients >95% adherent was 88.5% in the intervention multi-component community-based care arm compared to 83.9% in the control standard care arm for a non-statistically significant difference (RR 1.05, 95% CI: 0.88 to 1.27) (Munoz 2011).
- The quality of this evidence is very low.

**Outcome: Follow-up visits (6 months)**
- This outcome is represented by 1 study with 6 months of follow-up (Futterman 2010).
- In this one study, the proportion of patients with 57.5% in the intervention HIV+ mentor mother arm compared to 35.5% in the control standard of care arm for a non-statistically significant difference (RR 1.62, 95% CI: 0.94 to 2.79) (Futterman 2010).
- The quality of this evidence is very low.

**RANDOMIZED CONTROLLED TRIALS – High-income countries**

**Outcome: ≥80% adherence (6 months)**
- This outcome is represented by 1 study with 6 months of follow-up (Altice 2007).
- In this one study, the proportion of patients with ≥80% adherence was 67% in the intervention community-based ART arm compared to 56.6% in the control self-administered ART arm for a non-statistically significant difference (RR 1.18, 95% CI: 0.9 to 1.56) (Altice 2007).
- The quality of this evidence was very low.

**Outcome: Reduced viral load (6 months)**
- This outcome is represented by 1 study with 6 months of follow-up (Altice 2007).
- In this one study, the proportion of patients with reduced viral load at 6 months was 70.5% in the intervention community-based ART arm compared to 56.6% in the control self-administered ART arm for a non-statistically significant difference (RR 1.18, 95% CI: 0.95 to 1.63) (Altice 2007).
- The quality of this evidence was very low.

**Outcome: Reduced viral load (3 months)**
- This outcome was represented by 1 study with 3 months of follow-up (Macalino 2007).
- In this one study, the proportion of patients with reduced viral load at 3 months was 58.1% in the intervention MDOT outreach worker arm compared to 34.1% in the control standard care arm for a statistically significant higher proportion in the intervention arm (RR 1.71, 95% CI: 1.05 to 2.76) (Macalino 2007).
- The quality of this evidence was very low.

**Outcome: Still on first-line regimen (6 months)**
- This outcome is represented by 1 study with 6 months of follow-up (Altice 2007).
- In this one study, the proportion of patients still on first-line regimen at 6 months 45.5% in the intervention community-based ART arm compared to 45.3% in the control self-administered ART arm for a non-statistically significant difference (RR 1, 95% CI: 0.69 to 1.46) (Altice 2007).
- The quality of this evidence was very low.
Outcome: 100% adherence: electronic drug monitoring (6 months)
- This outcome is represented by 2 studies with 6 months of follow-up (Simoni 2007, Simoni 2009).
- In one study, the mean was 37.7 (SD 36) in the intervention peer-support arm compared to 48.1 (SD 36.3) in the control standard care arm for a non-statistically significant difference (Mean difference -10.40, 95% CI: -22.57 to 1.77) (Simoni 2007).
- In the other study, the mean was 37.2 (SD 44.5) in the intervention peer-support arm compared to 41 (SD 44) in the control standard care arm for a non-statistically significant difference (Mean difference -3.80, 95% CI: -20.05 to 12.45) (Simoni 2009).
- Analyzed together there was no statistically significant difference found between the arms (Mean difference -8.03, 95% CI: -17.77 to 1.71).
- The quality of this evidence was low.

Outcome: ≥90% adherence: MEMS cap (12 months)
- This outcome is represented by 1 study with 12 months of follow-up (Simoni 2009).
- In this one study, the proportion with ≥90% adherence using MEMS cap measures was 21.8% in the community-based home visits arm compared to 14.3% in the control standard care arm for a non-statistically significant difference (RR 1.53, 95% CI: 0.79 to 2.95) (Williams 2006).
- The quality of this evidence was very low.

Outcome: 100% adherence: electronic drug monitoring (9 months)
- This outcome is represented by 1 study with follow-up at 9 months (Simoni 2009).
- In this one study, the mean was 32.3 (SD 42.5) in the intervention peer-support arm compared to 29.1 (SD 39.7) in the control standard care arm for a non-statistically significant difference (Mean difference 3.2, 95% CI: -11.9 to 18.3) (Simoni 2009).
- The quality of this evidence was very low.

Outcome: ≥90% adherence: MEMS cap (12 months)
- This outcome was represented by 1 study with follow-up at 12 months (Williams 2006).
- In this one study, the proportion with ≥90% adherence using MEMS cap measures was 21.8% in the community-based home visits arm compared to 14.3% in the control standard care arm for a non-statistically significant difference (RR 1.53, 95% CI: 0.79 to 2.95) (Williams 2006).
- The quality of this evidence was very low.

REFERENCES

15. Dewo Z et al. Strengthening treatment, care and support to people living with HIV through community-based treatment services. 19th International AIDS Conference: [Abstract no. TUAD0202].
25. International Center for Research on Women (2012). “Study to Evaluate the Effectiveness of WHO Tools – Orientation Programme on Adolescent Health for Health Care Providers and Adolescent Job Aid – in improving the quality of health services provided by health workers provided by health workers to their female adolescent clients in India.” Available from:
44. Otis J et al. Effects of an empowerment program on the ability of women living with HIV (WLHIV) in Mali to manage decisions regarding whether or not to disclose HIV status. : 19th International AIDS Conference: [Abstract no. MOPES02].
47. Pearson CR et al. Randomized control trial of peer-delivered, modified directly observed therapy for HAART in Mozambique. Journal of Acquired Immune Deficiency Syndromes, 2007 46:2, 238-244.
63. Sherman BF et al. When children tell their friends they have AIDS: possible consequences for psychological well-being and disease progression. Psychosomatic Medicine, 2000 62:2, 238–47.
HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV

ANNEX 8: Decision-making tables

<table>
<thead>
<tr>
<th>PICO 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Topic for analysis:</strong></td>
</tr>
<tr>
<td>Should HTC be offered to adolescents from key populations in all settings?</td>
</tr>
<tr>
<td><strong>2. Background:</strong></td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td><strong>3. DRAFT recommendation:</strong></td>
</tr>
<tr>
<td>HIV testing and counseling with linkage to prevention, treatment and care is recommended for adolescents from key affected populations in all settings (generalized, low and concentrated epidemics).</td>
</tr>
<tr>
<td><strong>4. Summary and quality of evidence:</strong></td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>The quality of evidence was VERY LOW. The RCT data was graded down for risk of bias, serious indirectness and very serious imprecision.</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td><strong>5. Risks/benefits</strong></td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td><strong>Risks</strong></td>
</tr>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>
Based on available evidence, overall benefits judged to be potentially greater than potential harms.

6. Acceptability, values and preferences

<table>
<thead>
<tr>
<th>Community</th>
<th>Adolescent participants report strong desire to test, motivations to test and awareness of responsibilities and benefits of testing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health-care workers</td>
<td>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.</td>
</tr>
<tr>
<td>Other</td>
<td>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</td>
</tr>
</tbody>
</table>

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.

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 heath 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.

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.

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

<table>
<thead>
<tr>
<th>PICO 2</th>
</tr>
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<tbody>
<tr>
<td>1. Topic for analysis:</td>
</tr>
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</tr>
<tr>
<td>3. DRAFT recommendation:</td>
</tr>
<tr>
<td>In generalized epidemics, HIV testing and counselling with linkage to prevention, treatment and care is recommended for all adolescents.</td>
</tr>
<tr>
<td>4. Summary and quality of evidence:</td>
</tr>
<tr>
<td>Despite the low quality of evidence, there was strong consensus that based on strong values and preferences, a strong recommendation was warranted.</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>5. Risks/benefits</td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
</tr>
<tr>
<td>One RCT found that HTC reduces STI incidence in the 6 months following HCT.</td>
</tr>
<tr>
<td>One RCT found that HTC reduces reported unprotected sex with a non-primary partner at 6 month after HCT.</td>
</tr>
<tr>
<td>One RCT found that HTC increases uptake of pre-ARV care at 5 months follow-up.</td>
</tr>
<tr>
<td><strong>Risks</strong></td>
</tr>
<tr>
<td>One RCT found that HTC may reduce attendance at HIV clinics and reduce survival at 6 months following HTC.</td>
</tr>
<tr>
<td>Based on available evidence, overall benefits judged to be potentially greater than harms.</td>
</tr>
<tr>
<td>6. Acceptability, values and preferences</td>
</tr>
<tr>
<td><strong>Community</strong></td>
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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

<table>
<thead>
<tr>
<th>Community</th>
<th>Adolescent participants report strong desire to test, motivations to test and awareness of responsibilities and benefits of testing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health-care workers</td>
<td>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.</td>
</tr>
<tr>
<td>Other</td>
<td>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</td>
</tr>
</tbody>
</table>

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

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#### 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:

<table>
<thead>
<tr>
<th>Community (adolescents)</th>
<th>Health-care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Divided opinions:</td>
<td>-- Challenging to discuss disclosure with adolescents, and so often not adequately discussed with adolescents</td>
</tr>
<tr>
<td>-- Disclosure is the right of the individual and should be the decision of the individual</td>
<td>-- Guidance or policy on how to support disclosure is weak or non-existent in many places</td>
</tr>
<tr>
<td>-- Disclosure can be a necessary means of support or it can expose the individual to rejection, marginalization and loss of relationships</td>
<td>-- 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</td>
</tr>
<tr>
<td></td>
<td>-- Need to take into account the willingness and readiness of each adolescent to disclose</td>
</tr>
</tbody>
</table>

**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

<table>
<thead>
<tr>
<th>PICO 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Topic for analysis:</td>
</tr>
<tr>
<td>Should HIV treatment and care programmes include community-based approaches to improve treatment adherence and retention in care of adolescents living with HIV?</td>
</tr>
<tr>
<td>2. Background:</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>3. DRAFT recommendation:</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>4. Summary and quality of evidence:</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>5. Risks/benefits:</td>
</tr>
<tr>
<td><strong>Benefits</strong></td>
</tr>
<tr>
<td>Greater accessibility / acceptability / affordability can also contribute to increased retention in care / reductions in LTFU.</td>
</tr>
<tr>
<td><strong>Risks</strong></td>
</tr>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>
### 6. Acceptability, values and preferences:

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

**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 that 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

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**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:

<table>
<thead>
<tr>
<th>Community (adolescents)</th>
<th>Adolescents mention a number of positive aspects of care that would indicate the potential value of training:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Sensitive and caring treatment;</td>
</tr>
<tr>
<td></td>
<td>• Interactions with providers who convey a sense of hope and optimism in a meaningful and realistic way.</td>
</tr>
<tr>
<td></td>
<td>Adolescents want health-care workers to be sensitive, supportive and attuned to their needs; this can be achieved through training.</td>
</tr>
<tr>
<td></td>
<td>Support for adherence requires other knowledge, including technical knowledge as well as motivation, skills; performance improvement more generally is required and achieved through training.</td>
</tr>
</tbody>
</table>

| Health-care workers | 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 |
### 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 to 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
HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV

ANNEX 9: Review methods

Our methodology in conducting the systematic reviews was based on the guidance of the Cochrane Handbook for Systematic Reviews of Interventions.¹

General inclusion criteria

To be included in the respective systematic reviews and GRADE analyses, an article had to meet the following criteria:

1) Published in a peer-reviewed journal, or presented as a peer-reviewed abstract at a scientific meeting.
2) Include outcome data for an intervention that is pertinent to at least one PICO question of interest.
3) Eligible study designs included randomised controlled trials (RCT), non-randomised controlled trials, pre-post-intervention evaluations, and other observational studies (e.g. cohort studies) with comparators.

Specific inclusion criteria for each review

1. Should HIV testing and counseling (HTC) be offered to adolescents?

Population:
- Adolescents living in countries with a generalised HIV epidemic (HIV prevalence >1% among women attending antenatal clinics)
- Adolescents living in countries with a concentrated HIV epidemic (HIV prevalence >5% among subpopulations but <1% in the general population)
- Key populations of adolescents (e.g. drug users, sex workers, transgender persons, youth with male sex partners of any age, and other populations at higher risk of acquiring or transmitting HIV infection than the general population)

Interventions:
- HIV testing and counselling (HTC)
- HIV testing (without counselling)
- HIV counselling (without testing)

Comparator
- No HTC

Outcomes:
- Change in HIV incidence
- Change in HIV mortality
- Change in HIV morbidity
- Change in STI incidence
• Access to and uptake of health care services
  o HIV care and treatment
  o Uptake of and adherence to antiretroviral therapy
  o Sexually transmitted infections (STI) screening and treatment
• Access to and uptake of prevention services
  o Provision of condoms
  o Male circumcision
  o Prevention of mother-to-child HIV transmission
  o Drug services
  o Other relevant measures
• Behaviour change
  o Increased condom use
  o Reduced sexual risk behaviour
  o Delayed sexual debut
• Psychosocial impact
  o Reduction in mental health symptoms
  o Reduction in stigma and discrimination
  o Increased psychosocial support
  o Improved quality of life

2. Can training of health workers in adolescent health improve retention and adherence among adolescents living with HIV?

Population:
• Adolescents (males and females) 10-19 years old.

Intervention:
• Training of health workers who provide care and treatment to adolescents living with HIV.

Comparator:
• No training of health workers in adolescent health.

Outcomes:
• Mortality
• Morbidity
• Proportion of appointments kept
• Continuation rates for medications/commodities

3. Should adolescents disclose their HIV status to parents, family members, sexual partners, others?

In view of the expected paucity of evidence from studies conducted in adolescents, studies conducted in adults were eligible for inclusion in the first instance.

Population:
• Adolescents (males and females) 10-19 years old.

Intervention:
• Disclosure of HIV status to
  o Parents
o Family members
  o Sexual partners
  o Friends
  o Others

Comparator:
  • No disclosure.

Outcomes:
  • Reduced mortality among adolescents
  • Reduced morbidity among adolescents
  • Improved quality of life
  • Reduced HIV transmission to sexual partners
  • Proportion of patients on ART with suppressed viral load at 3, 6, 12, 24 months
  • Proportion of patients maintained on 1st line therapy
  • Proportion of patients ‘adhering’ by standard adherence measure
  • Proportion of appointments kept
  • Continuation rates for medications/commodities
  • Proportion of adolescents using condoms with sexual partner/s
  • Proportion of adolescents with depression, mental health problems, or proportion of adolescents who rate good on QoL assessment measures

4. What is the best way to support adolescents to disclose their HIV status safely and effectively?

In view of the expected paucity of evidence from studies conducted in adolescents, studies conducted in adults were eligible for inclusion in the first instance.

Population:
  • Adolescents (males and females) 10-19 years old.

Intervention:
  • Support for disclosure by counsellor, health worker, peers

Comparator:
  • No support for disclosure.

Outcomes:
  • Reduced mortality among adolescents
  • Reduced morbidity among adolescents
  • Improved quality of life
  • Reduced HIV transmission to sexual partners
  • Proportion of patients on ART with suppressed viral load at 3, 6, 12, 24 months
  • Proportion of patients maintained on 1st line therapy
  • Proportion of patients ‘adhering’ by standard adherence measure
  • Proportion of appointments kept
  • Continuation rates for medications/commodities
  • Proportion of adolescents using condoms with sexual partner/s
  • Proportion of adolescents with depression, mental health problems, or proportion of adolescents who rate good on QoL assessment measures)
5. Can community-based approaches improve adherence to treatment and retention to care among adolescents?

Population:
- Adolescents (males and females) 10-19 years old.

Intervention:
- Community-based initiatives involving the provision of health services or support by informal caregivers or peers in the home or other community settings including preventive, promotive, therapeutic, rehabilitative or palliative care. Examples include home visits or support groups led by non-professional health workers (e.g., community health workers, lay health workers, volunteer health workers, church volunteers, etc.), peers, or other community members.

Comparator:
- No activities at the community level.

Outcomes:
- Mortality
- Morbidity
- Proportion of patients on ART with suppressed viral load at 3, 6, 12, 24 months
- Proportion of patients maintained on 1st line therapy
- Proportion of patients adhering by standard adherence measure
- Proportion of appointments kept
- Continuation rates for medications/commodities

Search methods and screening process
We searched PubMed, the Cochrane Central Register of Controlled Trials, EMBASE, Web of Science, and WHO's Global Index Medicus. Along with Medical Subject Heading (MeSH) terms and relevant keywords, we used the Cochrane Highly Sensitive Search Strategy for identifying reports of randomised controlled trials, augmented with terms for capturing reports of observational studies, and the Cochrane HIV/AIDS Group's existing strategies for identifying references relevant to HIV/AIDS. The search strategies were iterative, in that references of included studies were searched for additional references. All languages were included. Our core PubMed search strategies were modified as needed for use in the other databases. See Tables 1-4 below.

Using a variety of relevant terms, we also searched the clinical trials registry at the WHO International Clinical Trials Registry Platform, which includes trials from many countries including all trials listed in "ClinicalTrials.gov."

We searched the online abstract archives of relevant conference proceedings, including the Conference on Retroviruses and Opportunistic Infections (CROI), the International AIDS Conference (IAC), and the International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention (IAS). These conferences were searched from their inception dates (1993, 1985, and 2001 respectively) to the most recent conference (2012, 2012 and 2011, respectively). We contacted individual researchers working in the field in an attempt to learn of any research we had not identified.

In each review, after removal of duplicate references and an initial screening by one author to remove clearly irrelevant references, two authors working independently then reviewed the titles, abstracts and descriptor terms of the remaining citations to identify potentially eligible reports. We obtained full text articles for all references identified as potentially meeting inclusion criteria. Two authors reviewed these
full text articles and applied the inclusion criteria to establish each study's eligibility or ineligibility. Studies were reviewed for relevance based on study design, intervention given, types of participants and outcome measures. See Tables 5-8 below.

Data collection and analysis

In each review, after identifying studies for inclusion, two authors working independently examined and extracted data from each study. Two authors separately entered these data into standardised data extraction forms. Extracted data in the forms were then compared. A neutral arbiter stood by in the event of any disagreement or discrepancy.

Extracted data included: Study details, participant details, intervention details, outcome details, and details necessary to assess the risk of bias (in the case of RCTs) or to assess study quality (in the case of observational studies).

In the case of RCTs, we assessed the risk of bias with the Cochrane collaboration's tool. In the case of observational studies, we assessed study quality with a 9-point rigor scale developed by the Johns Hopkins-WHO Synthesizing Intervention Effectiveness Project.

Measures of treatment effect

We used Review Manager 5.2 provided by the Cochrane Collaboration for preparing the review and for statistical analysis. We summarised dichotomous outcomes for effect using risk ratios (RR), with 95% confidence intervals (CI). We calculated summary statistics using meta-analytic methods and present findings in regard to evidence quality in GRADE summary of findings tables, for all outcomes of interest.

Assessment of heterogeneity

We examined heterogeneity between the trials using the $I^2$ statistic. We interpreted an $I^2$ estimate greater than 50% as indicating moderate or high levels of heterogeneity.

Data synthesis

When study populations, interventions, comparators and outcomes were sufficiently similar, we pooled the data across studies and estimated summary effect sizes using a fixed effect model if there was little heterogeneity between the trials, or a random effects model if there were moderate or high levels. We summarised the quality of evidence provided using GRADE evidence profiles.

Assessment of evidence quality by outcome

We graded the quality of evidence for each outcome using the Grades of Recommendation Assessment, Development and Evaluation (GRADE) approach. We used the GRADEpro software, version 3.2, to perform our analyses.

GRADE ranks the quality of evidence on four levels: "high," "moderate," "low" and "very low." Evidence from randomised controlled trials starts at "high," but can be downgraded based on study limitations, inconsistency of results, indirectness of evidence, imprecision or for reporting bias. Evidence from observational studies starts at "low," but can be upgraded if the magnitude of treatment effect is very large, if there is a significant dose-response relation, or if all possible confounders would decrease the magnitude of an apparent treatment effect. Evidence from observational studies can also be downgraded.

Tables 1-4: Core PubMed search strategies (modified as needed for use in the other databases)
<table>
<thead>
<tr>
<th>Search</th>
<th>Table 1: PubMed strategy: Adolescent HTC (1 Jan 1985 – 23 October 2012)</th>
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<td>Search (((#1) AND #2) AND #3)</td>
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<tr>
<th>Search</th>
<th>Table 2: PubMed strategy: Provider training (1 Jan 1980 – 22 May 2012)</th>
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</thead>
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<tr>
<td>#9</td>
<td>Search (#7) OR #8</td>
</tr>
<tr>
<td>#8</td>
<td>Search ((#3) AND #4) AND #6</td>
</tr>
<tr>
<td>#7</td>
<td>Search (((#3) AND #4) AND #5) AND #6</td>
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</tbody>
</table>


<table>
<thead>
<tr>
<th>Search</th>
<th>Table 3: PubMed strategy: Disclosure (1 Jan 1980 – 14 August 2012)</th>
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<td>#5</td>
<td>Search (((#1) AND #2) AND #3) AND #4</td>
</tr>
<tr>
<td>Search</td>
<td>Table 4: PubMed strategy: Community-based approaches (1 Jan 1999 – 17 Sept 2012)</td>
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<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>#5</td>
<td>Search (((#1 AND #2) AND #3) AND #4)</td>
</tr>
<tr>
<td>#2</td>
<td>Search &quot;Patient Compliance&quot;[mh] OR adheren*[tiab] OR retention[tiab] OR (suppress*[tiab] AND &quot;viral load&quot;[tiab])</td>
</tr>
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</table>

Tables 5-8: Screening processes for each review

Table 5: Screening process: Adolescent HTC

<p>| Total of records | 636 |
| Duplicates removed | 17 |
| Records screened | 619 |</p>
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**Table 6: Screening process: Provider training**

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<td>Studies included in review</td>
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**Table 7: Screening process: Disclosure (both questions)**

<table>
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<td>Studies included in review</td>
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<tr>
<td>(“Should adolescents disclose?”)</td>
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<tr>
<td>Studies included in review</td>
<td>16</td>
</tr>
<tr>
<td>(“What is the best way?”)</td>
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**Table 8: Screening process: Community-based approaches**

<table>
<thead>
<tr>
<th>Total of records</th>
<th>656</th>
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<tbody>
<tr>
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<td>Records screened</td>
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<tr>
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<tr>
<td>Full-text articles obtained</td>
<td>79</td>
</tr>
<tr>
<td>Studies included in review</td>
<td>27</td>
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</table>

**References:**

The Voices, Values and Preference of Adolescents on HIV Testing and Counselling

Consultation for the Development of the World Health Organization HIV Testing and Counselling Guidelines for Adolescents

Commissioned by The World Health Organization – Department of HIV and the Department of Maternal, Newborn, Child and Adolescent Health
By: Alice Armstrong, Rachel Baggaley, Jane Ferguson, Anke Van der Kwaak, and Liezel Wolmarans

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Acknowledgements

We would like to thank all adolescents, service providers, youth organisations and local partners for their involvement in and contribution to this consultation. Our special thanks goes to the adolescents, who shared their views and experiences with enthusiasm, honesty and openness. We would also like to particularly acknowledge the local facilitators for all their hard work; Jeffry Acaba, Xolani Mkhize, Tinashe Rufurwadz, Zonke Banjwa, and Tinashe Mhlanga.

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### Abbreviations and acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency</td>
</tr>
<tr>
<td>HTC</td>
<td>HIV Testing and Counselling</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
</tr>
<tr>
<td>NGO's</td>
<td>Non-Governmental Organisations</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother-To-Child Transmission</td>
</tr>
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<td>UNICEF</td>
<td>United Nations Children's Fund</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>YKAP</td>
<td>Young Key Affected Populations</td>
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<td>ZNFPC</td>
<td>Zimbabwean National Family Planning Council</td>
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Executive Summary

Introduction
Adolescents constitute a significant proportion of the current HIV burden. Presently, low levels of HIV testing and counselling access and uptake by adolescents is leading to late diagnosis and late entry into care and treatment and poor uptake of prevention interventions and services; resulting in unacceptable morbidity and mortality and ongoing HIV transmission.

There is an urgent need to increase access to HTC for adolescents, as they are not being adequately supported by current HTC approaches. In response to this, World Health Organization is developing adolescent HTC guidelines.

As part of the development of these guidelines the WHO Guideline Review Committee encourages consultation with different stakeholders including end-users of interventions. To facilitate the inclusion of the voices, values and preferences of adolescents and service providers in the guideline development, a community consultation was undertaken.

Method
Three activities were conducted:
- Ten workshops involving 98 participants, aged 15 – 24 years were conducted in the Philippines, South Africa and Zimbabwe. The workshops were based on participatory learning and action approaches and were carried out with support of local facilitators;
- An online survey focusing on personal experiences of testing was available in four languages and was disseminated through youth organizations. In total, 655 respondents from 92 countries covering all regions completed the survey;
- Sixteen service providers were interviewed from the three selected countries. These included multidisciplinary staff from various settings including primary care, outreach programs, VCT and NGO’s involved in promotion and provision of adolescent HTC services.

Adolescents’ and service providers’ perspectives were explored in relation to five key areas: a) motivations to test; b) barriers to HTC; c) experiences of HTC; d) post-testing experience; and e) strategies to improve access and uptake of HTC by adolescents.

Key Findings
Adolescents
Motivations to test
- Respondents in the online survey that had not yet tested, 66.9 percent indicated the desire to test.
- Assumed sense of responsibility to prevent HIV, the observed benefits of testing, and perceived risk are key HTC motivators.
- Adolescents identified health workers, peers and partners as key influencers in prompting or encouraging adolescents to test.
- Despite the fears and negative association regarding HTC, adolescents expressed their willingness to recommend HTC services to friends.

Barriers to HTC
- Fear of results, the implications of a positive status including psychosocial and practical difficulties, stigma felt from taboos regarding adolescent sexual activity and HIV deter testing.
- Barriers to accessing HTC reported were lack of HTC facilities, difficulty locating them, uninviting facilities and inconvenient operating times.
Adolescents identified judgmental and unsupportive attitudes of service providers, with particular concerns regarding confidentiality. Consent requirements were seen as a deterrent however, some felt that those younger than the testing age were sexually active and should be allowed to test independently. Others were concerned about the ability of younger adolescents to cope and saw consent requirements as a facilitator to subsequent support.

Experiences of HTC (Results from the online survey)
- 40.5 percent had tested within the last six months, 23.6 percent between 6 and 12 months and 22.8 percent more than a year ago.
- For 32.2 percent of those that tested this was their first test; a further 59.8 percent are repeat testers, with females from Africa more likely to repeat test.
- The majority of respondents (62.4 percent) indicated that they attended HTC alone, with friends and girlfriend/boyfriend/partners most common testing companions. Those in Europe were more likely to involve family and those in Africa, friends.
- Respondents were mainly tested in health facilities.
- HIV positive adolescents rated services poorly, have more concerns regarding confidentiality and indicated an unwillingness to recommend services or testing when compared to HIV negative adolescents.
- Respondents from Africa were more likely to have a rapid pin pick test, receive their results immediately and have post-test counseling when compared to Europe and Americas.
- Post-test discussions were less common overall, however, the majority of respondents testing positive for HIV had a post-testing discussion.
- A small number of survey respondents reported being HIV positive, the majority of which considered themselves to be from a young key affected populations.

Post-testing experience
- 69.8 percent of tested survey respondents were not referred to services post-testing. Those who were referred had to initiate contact with other services independently.
- Disclosure is seen as a means of obtaining necessary support.
- Adolescents are considered to have the right to choose to disclosure their HIV status.
- Disclosure to family, especially parents, is encouraged by service providers however this seems to be taken with more caution by other participants.
- In the online survey when comparing HIV positive testers to HIV negative testers no difference in sharing test results (83.9 percent vs 82.6 percent) were reported, however the time taken to disclose is longer.
- The fear of unwilling onward disclosure by others was the main reason not to disclose your status.
- Support groups were viewed as an ideal forum for adolescents to ‘get help’, ‘learn from each other’, ‘share ideas for positive living’ and openly talk about their status.

Strategies to improve access and uptake of HTC by adolescents
- Adolescents want HTC and information strategies within their environment that captivate, inform them and stimulate discussions. Such strategies need to include the whole community to raise awareness to support testing.
- Adolescents are keen to be involved in the promotion of HTC as individuals (peer), in the community (forums, outreach workers) and service delivery levels (HTC providers).
- High value was placed on the environment of service facilities. The importance of having a ‘youth friendly’, ‘relaxed atmosphere’ where adolescents could ‘feel welcome’. The need for friendly, understanding and supportive health providers was raised as a priority.
- Adolescents indicated the desire for HTC to be delivered outside health services with suggestions of integrating HTC services in youth/community venues and door-to-door/mobile testing.
Service providers

- Offering effective HTC services and encouraging adolescents to access them is considered a high priority for service providers as they recognize that adolescents are underserved and at high-risk of HIV infection.
- Essential elements of a HTC service delivery highlighted by providers include maintaining confidentiality, providing accurate and understandable information, facilitating ongoing referral and supporting post-testing including around disclosure.
- Although providers felt confident in delivering HTC services to adolescents many acknowledged the challenges as follows:
  - Present HTC strategies are hindered by insufficient resources, consent requirements, lack of adolescent specific HTC training and policy, and providers' personal feelings about adolescent having sex, and difficulties in communicating effectively.
  - Inconsistencies in the practical application of the law regarding age of consent were noted. Providers highlighted difficulties choosing between following the law and serving the needs of adolescents.
- Suggested areas for improvement, included clarification around legal issues regarding consent, increasing resources and as well as the need for adolescent specific training and policy.

The adolescent workshops and interviews were conducted in South Africa, Zimbabwe and the Philippines and although there were many similarities in the findings there were also significant differences. Further qualitative work exploring adolescent and health workers views in planned in Eastern Europe and Central Asia and it is recommended that other countries and regions consider adolescent and health worker community consultations to support the effective development of HTC services for adolescents.

The e-survey (available in English, French, Spanish and Russian) was a relatively easy and inexpensive way of appraising the views of young people from a large number of countries. However the results have to be interpreted with caution and only represent those who have access to the internet, favoring those with higher education and those who understand the four languages included. The e-survey could be translated into other languages for other countries and an effort to include a more representative sample could potentially be achieved by proving sites with computers (in for example youth facilities, schools or mobile sites) where adolescents could complete the survey.

This community consultation facilitated the participation and the inclusion of adolescents’ and service providers’ voices to explore their values and preferences regarding HTC. Despite its methodological limitations, this is a feasible way of involving end-users valuable views in a short timeframe with limited expenditure.

The findings from these activities will be used as background and supporting information for the guideline development group. They will be considered in conjunction with graded literature and operational approaches to help in the formulation of the guidelines and to direct the guideline process.
1. Introduction

Adolescents contribute significantly to shaping the future course of the HIV epidemic.\(^1\) It is estimated that 4.9 million young people aged 15 to 24 are living with HIV in low and middle income countries.\(^2\) This constitutes a large proportion of the current HIV burden, particularly in developing countries and more specifically in Eastern and Southern Africa.\(^1\)

Acquisition of infection in adolescents can occur through "vertical" mother-to-child transmission, where diagnosis may have been missed due to either loss to follow up or poor prevention of mother-to-child transmission (PMTCT) programme coverage.\(^3,4\) For other adolescents, infection occurs through "horizontal" transmission—either sexually or non-sexually. Risks for acquisition of HIV include early sex, injecting drug use, medical procedures, sexual coercion and abuse, traditional practices and unsafe circumcisions.\(^5\)

HIV testing and counselling (HTC) is the key entry point for many HIV prevention interventions and is essential for access to care and treatment.\(^6\) With the increased availability of antiretroviral therapy (ART) and prevention interventions, early diagnosis can reduce transmission to others and improve health outcomes.\(^7\)

Presently, low levels of HTC access and uptake by adolescents are leading to late diagnosis and late entry into care and treatment.\(^5\) In countries with high prevalence of HIV infection, increasing numbers of adolescents with HIV present late for care \(^3,4\) Knowledge of status is also important so that adolescents can make effective choices about HIV prevention to lessen HIV acquisition and prevent ongoing transmission. In 2009, an estimated 41 percent of new HIV infections among adults occurred in the 15-24 years age group.\(^5\)

Increasing evidence indicates that adolescents face different challenges and needs than children and adults. Existing HTC guidelines do not focus specifically on these challenges.\(^8\) In response to this gap, World Health Organization (WHO) is developing HTC guidelines for adolescents to support increased acceptable access and uptake.

The WHO guidelines development process requires consultation with different stakeholders, including end-users of interventions, to understand their values and preferences.\(^9\) In this case, end-users are defined as the service providers as well as the adolescents. To facilitate the inclusion of the voices, values and preferences of adolescents and service providers in the guideline development, a community consultation was undertaken.

The views portrayed in the community consultation are presented in this report and will be used as background and supporting information for the Guideline Development Group.\(^9\) This group comprised of experts in adolescent health and HIV from various countries and affiliations. The inputs from the community consultations will be considered in conjunction with graded literature and information collected on operational approaches to help in the formulation of the guidelines at a meeting of experts, to be held in 2012.
2. Methodology

2.1 Objectives
The objective of this consultation is to facilitate the participation and inclusion of the voices of the end-users in the development of HTC guidelines for adolescents.

Specific objectives
- To gain an adolescent perspective of HTC and services including the motivations and barriers to testing.
- To have a better understanding of what aspects of care and prevention are important to adolescents when undertaking HTC.
- To explore issues of what would make an adolescent HTC service more accessible and effective.
- To gain the service provider perspective on barriers to providing HTC, important aspects in the delivery of HTC to adolescents, and identify strategies that would make adolescent HTC more accessible and effective.

2.2 Consultation design
The community consultation took place from 31st October 2011 to 12th December 2012 and involved three activities:
- a series of workshops involving adolescents
- an anonymous and voluntary online survey
- interviews with service providers

Three countries, Philippines, South Africa and Zimbabwe, were purposely selected for workshops and interviews based on the following selection criteria: regional spread; inclusion of both generalized HIV epidemic countries (South Africa and Zimbabwe) and a concentrated HIV epidemic country (Philippines); established local partnerships, partners’ capacities, resources and timing existing youth networks. Further community consultations are planned to include adolescents and health workers from Eastern Europe, and Central Asia.

In addition, in an attempt to have a geographic representation of youth voices, an electronic survey was sent to all regions via websites, e-newsletters and blogs of youth organisations and included respondents from 92 countries.

Adolescents are the most knowledgeable about their lives. Knowing how they are viewing and perceiving problems and understanding the reasons behind certain behaviors enables programs and services to be responsive and provide sustainable appropriate solutions. By supporting the inclusion of adolescents and service providers’ views and concerns around HTC important insights relating to HTC for adolescents will be gained. Furthermore, the inclusion of adolescents in this participatory process was perceived by them to be empowering and an important contribution to shaping the guideline development process.

This consultation explores both adolescents and service providers’ perspectives in relation to: a) motivations to test; b) barriers to HTC; c) experiences of HTC; d) post-testing experience; and e) strategies to improve access and uptake of HTC by adolescents. These areas explored are based on previous work in HIV prevention among adolescents and HTC. The mixed method approach allowed for triangulation between adolescents views portrayed in the workshops, those reported in the online survey, and service providers perspectives.
2.2.1 Workshops
Workshops were based on participatory action and learning approaches such as drawings, priority scoring and brainstorming methods. Workshops were chosen for this consultation as they allow interactions and dialogue around a specific set of issues. They also provide multiple answers that help uncover a wide range of views and the development of new ideas. The visual methods used were also helpful in generating discussion from individuals in a group setting and made the process more entertaining and engaging for the adolescents involved. Topics covered in the workshops concentrated on the general perceptions of adolescents regarding HTC, as it permits them to be more open. (Annex 8.1 provides a detailed description of the workshops).

2.2.2 Online survey
An international anonymous online survey was developed to: include greater and diverse numbers of adolescents’ views; learn from other adolescents beyond the scope of the workshop; and to support the workshop findings. The survey was developed and reviewed with the assistance of different stakeholders. It was available in four languages – English, French, Spanish and Russian. Each survey was ‘live’ online and accessible for a period of one month.

The focus of the survey was on adolescents’ personal experience of testing and included: decisions around testing; referral to prevention and care services; barriers to HTC and concerns about HTC; and improvements for testing services (Annex 8.2 provides a detailed description of the online survey and its development).

2.2.3 Service provider interviews
Service providers were interviewed to explore additional perspectives in relation to service delivery aspects. These interviews covered views and experiences of HTC of adolescents; current capacity to provide HTC to adolescents; suggestions for changes to health service delivery to best support adolescents seeking HTC (Annex 8.3 provides a detailed description of the service provider interviews).

Approval for these activities followed the appropriate requirements in each of the countries (Annex 8.4).

2.3 Consultation participants

2.3.1 Workshop participants
Local partners were engaged to help organise the workshops. These included: loveLife in South Africa, the Zimbabwean National Family Planning Council (ZNFPC) and the United Nations Children’s Fund (UNICEF) in collaboration with the NewGen Asia Leadership Short Course* in the Philippines. In total, there were 98 participants involved in 10 workshops (see table 2.1).

The workshops included both males and females regardless of their HIV status or whether they had been tested. Adolescents were invited to be involved in this consultation by local youth workers, through established youth networks and as part of a leadership-training course. Before each workshop, informed consent was gained from all participants.

The selection of participants took into consideration various socio-economic and cultural backgrounds; those in Philippines workshops were largely from young key affected populations (YKAP - men who have sex with men, transgender people, people who inject drugs, people who sell sex, and people living with HIV).

* A five-day course developed for emerging young leaders in the HIV response, many of whom come from key affected populations. It was hosted by the Council for the Welfare of Children and supported by UNICEF Philippines in partnership with the Asia-Pacific Interagency Task Team on HIV.
The workshops were carried out with the support of local facilitators who had experience with conducting workshops with adolescents.

- In South Africa, local facilitators were recruited from loveLife groundBREAKERS program; adolescents trained to become peer educators and leaders in HIV prevention within their communities.
- The National AIDS Council, in Zimbabwe, identified two local facilitators that participate in their youth program.
- In the Philippines, UNICEF engaged a young researcher from Action for Health Initiatives.

Prior to the workshops in South Africa and Zimbabwe local facilitators were provided one-day training in participatory action and learning approaches.

### Table 2.1: Characteristics of workshops

<table>
<thead>
<tr>
<th>Country and Partner</th>
<th>Location</th>
<th>Total no. of participants</th>
<th>Profile of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Africa – loveLife</td>
<td>2 urban workshops in the Eastern Cape</td>
<td>20</td>
<td>10 female 10 male Aged 15 -19 years old</td>
</tr>
<tr>
<td></td>
<td>2 rural workshops in KwaZulu-Natal</td>
<td>20</td>
<td>11 female 9 male Aged 15 -19 years old</td>
</tr>
<tr>
<td>Zimbabwe - ZNFPC</td>
<td>2 urban workshops in Harare City</td>
<td>22</td>
<td>11 female 11 male Aged 15 -19 years old</td>
</tr>
<tr>
<td></td>
<td>2 rural workshops in Mudzi District</td>
<td>20</td>
<td>8 female 12 male Aged 15 – 19 years old</td>
</tr>
<tr>
<td>Philippines – UNICEF</td>
<td>1 female workshop</td>
<td>8</td>
<td>Aged 15-24 years old</td>
</tr>
<tr>
<td></td>
<td>1 male workshop</td>
<td>8</td>
<td>Aged 15-18 years old</td>
</tr>
</tbody>
</table>

### 2.3.2 Online survey respondents

Through the collaboration with youth organisations, the online survey was disseminated to all regions via websites, e-newsletters and blogs (see annex 8.2). Those between the ages of 15-29 years, irrespective of their HIV status or whether they had been tested, were able to take part in the survey. In total **655 people responded** to the online survey with a completion rate of 76.3 percent. Although a number of adolescents supplied only partial or limited information (approximately 23.7 percent) we aimed to present as much of the data on a question-to-question basis. Denominators are therefore clearly specified. Table 2.2 provides a description of the demographic characteristics of 498 online survey respondents (76.3 percent) who had provided complete or almost complete demographical information.

### Table 2.2: Characteristics of online survey respondents

<table>
<thead>
<tr>
<th>Sex</th>
<th>Male</th>
<th>Female</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Total</td>
<td>256</td>
<td>51.4%</td>
<td>239</td>
<td>48.0%</td>
</tr>
<tr>
<td>Age group</td>
<td>Missing data</td>
<td>5</td>
<td>2.0%</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>15 - 18 years old</td>
<td>8</td>
<td>3.1%</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>19 - 21 years old</td>
<td>39</td>
<td>15.2%</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>22 - 24 years old</td>
<td>74</td>
<td>28.9%</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>25 - 29 years old</td>
<td>130</td>
<td>50.8%</td>
<td>88</td>
</tr>
<tr>
<td>Region</td>
<td>Missing data</td>
<td>11</td>
<td>4.3%</td>
<td>6</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------</td>
<td>----</td>
<td>------</td>
<td>---</td>
</tr>
<tr>
<td>Africa</td>
<td></td>
<td>82</td>
<td>32.0%</td>
<td>43</td>
</tr>
<tr>
<td>Americas</td>
<td></td>
<td>58</td>
<td>22.7%</td>
<td>47</td>
</tr>
<tr>
<td>Eastern Mediterranean</td>
<td></td>
<td>13</td>
<td>5.1%</td>
<td>7</td>
</tr>
<tr>
<td>Europe</td>
<td></td>
<td>54</td>
<td>21.1%</td>
<td>114</td>
</tr>
<tr>
<td>South East Asia</td>
<td></td>
<td>13</td>
<td>5.1%</td>
<td>13</td>
</tr>
<tr>
<td>Western Pacific</td>
<td></td>
<td>25</td>
<td>9.8%</td>
<td>9</td>
</tr>
<tr>
<td>Live in</td>
<td>Missing Data</td>
<td>3</td>
<td>1.2%</td>
<td>7</td>
</tr>
<tr>
<td>Rural area</td>
<td></td>
<td>36</td>
<td>14.1%</td>
<td>26</td>
</tr>
<tr>
<td>Urban area</td>
<td></td>
<td>217</td>
<td>84.8%</td>
<td>206</td>
</tr>
<tr>
<td>Level of schooling</td>
<td>Missing data</td>
<td>0</td>
<td>.0%</td>
<td>6</td>
</tr>
<tr>
<td>Primary school</td>
<td></td>
<td>3</td>
<td>1.2%</td>
<td>2</td>
</tr>
<tr>
<td>Secondary/High school</td>
<td></td>
<td>26</td>
<td>10.2%</td>
<td>27</td>
</tr>
<tr>
<td>Tertiary / University</td>
<td></td>
<td>227</td>
<td>88.7%</td>
<td>204</td>
</tr>
<tr>
<td>Do you consider yourself Bisexual</td>
<td></td>
<td>2</td>
<td>.8%</td>
<td>2</td>
</tr>
<tr>
<td>Heterosexual</td>
<td></td>
<td>12</td>
<td>4.7%</td>
<td>9</td>
</tr>
<tr>
<td>Man who has sex with men</td>
<td></td>
<td>91</td>
<td>35.5%</td>
<td>4</td>
</tr>
<tr>
<td>Person who uses drugs</td>
<td></td>
<td>7</td>
<td>2.7%</td>
<td>6</td>
</tr>
<tr>
<td>Sex worker</td>
<td></td>
<td>3</td>
<td>1.2%</td>
<td>5</td>
</tr>
<tr>
<td>Transgender</td>
<td></td>
<td>5</td>
<td>2.0%</td>
<td>5</td>
</tr>
<tr>
<td>Young mother</td>
<td></td>
<td>0</td>
<td>.0%</td>
<td>19</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>2</td>
<td>.8%</td>
<td>6</td>
</tr>
<tr>
<td>None of these</td>
<td></td>
<td>134</td>
<td>52.3%</td>
<td>183</td>
</tr>
</tbody>
</table>

See annex 8.2 for countries of survey respondents per region

With regard to testing data we had 351 (67.9 percent) respondents who reported to be tested for HIV. Of the 32.1 percent that had never tested **66.9 percent indicated a desire to test.** For descriptive statistics and denominators concerning HIV testing data refer to Table 1 and 2 in the annex 8.5.

### 2.3.3 Service provider interviewees

Appropriate programs and services were identified by local partner organisations, departments of health or local WHO and UNICEF offices. Overall, **14 service provider interviews** with 16 people were conducted. These included multidisciplinary staff from various settings including primary care, outreach programs, VCT in both rural and urban areas as well as non-governmental organizations (NGO’s) involved in promotion and advocacy of HTC services for adolescents (see table 2.3).
Table 2.3: Service provider characteristics

<table>
<thead>
<tr>
<th>Country</th>
<th>Location</th>
<th>Profile of program/service</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Africa</td>
<td>Mthatha, Eastern Cape</td>
<td>Regional program leaders for loveLife</td>
</tr>
<tr>
<td></td>
<td>Durban, Kwazulu Natal</td>
<td>YouthAIDS program coordinator at The Society for Family Health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HTC counsellor at the AIDS health foundation</td>
</tr>
<tr>
<td></td>
<td>Cape Town, Western Cape</td>
<td>Managing Director Africa for Grassroots Soccer</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>Harare City, Harare</td>
<td>An nurse/HTC counsellor at a Department of Health Central Hospital</td>
</tr>
<tr>
<td></td>
<td></td>
<td>An nurse/HTC counsellor at a Department of Health Primary Healthcare Clinic</td>
</tr>
<tr>
<td></td>
<td>Mudzi District, Mashonaland East</td>
<td>An nurse/HTC counselor at a Department of Health District Hospital</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Youth program officer at the ZNFC youth center</td>
</tr>
<tr>
<td>Philippines</td>
<td>Davao City, Davao Region</td>
<td>Reproductive Health and Wellness Center Physician at the City Health Department</td>
</tr>
<tr>
<td></td>
<td>Cebu City, Central Visayas</td>
<td>Social Hygiene Clinic Physician at the City Health Department</td>
</tr>
<tr>
<td></td>
<td>Quezon City, Metro Manila</td>
<td>Physician at the City Health Department overseeing three social hygiene clinics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>AIDS Society of the Philippines (ASP) and Online Chatters</td>
</tr>
<tr>
<td></td>
<td>Manila, Metro Manila</td>
<td>Council for the Welfare of Children and Center for Promotion, Advocacy and Protection of the Rights of the Child (Lunduyan Foundation)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A Lawyer commissioned by the Council for the Welfare of Children and UNICEF to look into legal context of HCT</td>
</tr>
</tbody>
</table>

2.4 Limitations
This consultation had certain limitations. These limitations need to be seen in the light of the choice of methodology; the consultation was not developed as a rigorous study, rather as a methodology to facilitate participation of the end users of guidelines in their development.

2.4.1 Workshops and service providers
Firstly, to include views from a variety of settings and epidemics, workshops were conducted in different countries by different facilitators. Possible information bias was reduced through providing preset interview and workshop guides as well as training on the methodology to local facilitators. One facilitator undertook the analysis of data from all three countries’ workshops and from the interviews of service providers. To avoid misinterpretation, the other facilitators and co-authors reviewed the analysis. It is inevitable that the views of the facilitators might have to some extent influenced the findings.

The workshop methodology and structure have their own strengths and weaknesses. On the one hand, participants in workshops are inclined to allow participants to express their opinions as expected ‘social norms’ rather than ones’ actual opinions, especially those that include sensitive topics. On the other hand workshops: a) permit participants to convey their opinions in their own words; b) are more representative of everyday social interaction; and c) are less daunting than individual interviews, particularly for adolescents. However, an uneven number of workshops and interviews across countries could provide an over
representation of certain views. Different workshop structures (mixed and single sex) made it difficult to provide sex comparisons although this was possible in the online survey. The selection of adolescents differed per country. As adolescents were selected through existing youth networks there is a possibility that they were more likely to have been already exposed to HIV and sexual health programmes.

Country specific workshop and service provider findings were considered together and comparisons were made. However the online survey data for the corresponding countries was not formally compared. The online survey was essential to ensuring the inclusion of a greater number of adolescents’ views from a broader context.

As this study only includes the views of a small number of adolescents, the findings cannot be not be generalised and are not necessarily representative of the situation in other locations and cannot be extrapolated to represent countries as a whole.

2.4.2 Online Survey
The survey was voluntary and “self-selecting” in nature and therefore not necessarily representative of all youth testing for HIV or seeking testing in the general population of the participating countries and/or youth networks. Respondents had the option of opting out of the survey at any point resulting in missing or incomplete data, which limits multivariate analysis. Due to small number of respondents from some regions, we could only compare responses from Africa, the Americas and Europe. Overall, we had a ratio of 51:49 of male to female respondents. However, this varied by region, for example, Africa had predominantly male respondents (32 percent) and Europe female (47.7 percent) respondents. We were therefore cautious with the interpretation of regional or sex differences and explored differences within sex and within region.

The online survey is a simple, quick and inexpensive means of gaining youth opinion. However because respondents need be linked into a youth network and have access to computer and internet facilities it results in an unrepresentative sample of young people – reflected in the demographics – the high proportion of respondents with tertiary education and ages skewed towards the older ‘youth’ range. Although ideally a more representative sample would have been preferable, the views of older youth are an important reflection of their experiences during their proceeding years.

Taking these limitations into consideration, the rich data collected during this consultation and the triangulation thereof will make a valuable contribution to the existing understanding of adolescents’ values and preferences of HTC and the development of HTC guidelines for adolescents through ensuring participation. These methods, employed as background for the guidelines development process, cannot be interpreted as rigorous research, but are a feasible way of involving adolescents’ views to inform guideline development in a short timeframe with limited expenditure.
3. Key findings from adolescent workshops and online survey

This section presents the voices, values and preferences of adolescents involved in the workshops in the Philippines, South Africa and Zimbabwe as well as those in the international online survey. It explores their motivations to test; barriers to HTC; experiences of HTC; post-testing experience; and strategies to improve access and uptake of HTC. The findings were preliminarily based on the workshops, with the online survey being used to support and compliment them. However, the online survey provided personal perspectives in relation to experiences of HTC and post-testing.

3.1 Motivations to test

Adolescents attending for HTC are motivated by different factors. Although they identified various barriers, many adolescents also highlighted reasons in favor of HTC that could motivate them. Many online survey respondents indicated a desire to test. Of the one third (32 percent) of respondents that had not tested, two thirds (66.9 percent) indicated that they would like to have a HIV test (see table 1 in annex 8.5). Of these, males (79.2 percent) were more likely to indicate the desire to be tested than females (61 percent).

3.1.1 Benefit

‘You can’t not test just because the health workers aren’t friendly! You are risking your own life.’

[Female, Zimbabwe – Urban]

In all workshop countries, the benefit of knowing your status was the most common reason why adolescents tested for HIV. Similarly, in the online survey, 37.9 percent of tested respondents indicated just wanting to know as a prompt to test (see table 6 in annex 8.5 for regional differences). This was higher for male respondents (44 percent) than females (33.3 percent).

Participants in Zimbabwe saw getting tested as an opportunity to be informed about HIV and other STI’s. It was not only seen as a chance ‘to take control of their lives’ and ‘look after your health’ but get support and advice ‘in order to remain negative’ or ‘take the right steps if you are positive’ (see figure 3.1.1). Similarly those in the Philippines reported that it allowed adolescents to change their behavior especially to ‘practice prevention’.

Figure 3.1.1
Views of why adolescents do attend for HTC

Observing others surviving with HIV and benefiting from ART was also identified as an incentive to get tested. Zimbabwean and South African participants frequently mentioned that ‘you now have access to treatment’ or ‘the medication you need’ to ‘live healthy’, ‘stay strong’ and to ‘have hope’. Despite participants feeling that ‘knowing your status was stressful’ those in the South African workshops reported that it could also give you the benefit of having ‘peace of mind’. One South African rural participant stated: ‘even when you haven’t been tested you worry... worried you could be positive.’

* Multiple answers for this question were possible per respondent
3.1.2 Your Responsibility

‘To know where you stand and to know if you are safe so as not to infect the next person.’

[Male, Zimbabwe – Urban]

Across all countries, although more frequently in Zimbabwe, adolescents considered being tested as a responsibility to ‘prevent the spread of HIV’. In South Africa participants suggested that adolescents would test for HIV prior to ‘engaging in sex’ or ‘starting a new relationship’. This reason was also evident in the online survey with 14.5 percent of respondents that had tested identifying starting a new relationship as a reason to test.*

This motivation to test was also viewed as a responsibility to society, as stated by a Zimbabwean participant: ‘our contribution to a HIV-free generation’, as well as your ‘duty to your loved ones’ (see figure 3.1.2). A rural South African participant felt: ‘You should not think of yourself only. You should think for others next to you and how you will affect them if you don’t get tested.’

‘The trophy of a healthy society
‘I’m going up for the trophy and I am a winner.’

Steps - HIV test, Counselling, Positive living, Hope, HIV Free

[Male, Zim – Urban]

Figure 3.1.2
An adolescent’s drawing of their views of HTC

In Zimbabwe, ‘getting tested to plan for the future’ and ‘in preparation to get married’ were also repeatedly highlighted as a reason to test. A number of drawings and stories told involved couples or families going to test together where no matter the status the outcome was optimistic. One participant stated: ‘Here is a faithful couple that are safe from HIV and AIDS and their future is bright’ and another shared: ‘After some weeks Mark dumped Mary but she doesn’t regret her decision not to sleep with him but was proud that she protected herself and her future’.

Participants in Zimbabwe also viewed getting tested as an opportunity to ‘lead by example’, to ‘be a role model’ and to ‘show solidarity’.

3.1.3 Influenced

‘I lacked self-confidence. My best friend gave me the encouragement to go.’

[Male, Philippines]

Other people play an important role in adolescents going to have a HIV test. In the online survey the most frequent identified prompt to testing was when HTC was offered during a visit to health services (39.9 percent) especially sexual health services (15.1 percent).**(see table 6 in annex 8.5).

* Multiple answers for this question were possible per respondent
Filipino participants fondly mentioned the help provided by peer educators in ‘disseminating information about HIV’ and HTC services, ‘encouraging them to attend’ as well as accompanying them to be tested. Having a testing companion was seen to make them ‘feel braver’. One in six survey respondents indicated encouragement from others, including peers and partners, as a key prompt to test (see table 6 in annex 8.5). This was also raised in each workshop.

Although a third did not respond to this question, of those 442 that responded only 2.4 percent would not would encourage other adolescents to test. In the workshops, this influence of peers was occasionally viewed negatively as ‘pressure’, as stated by a rural South African participant: ‘you want to fulfill friends’.

A number of participants in South Africa mentioned that adolescent may test due to ‘feeling forced to’ primarily by parents or by partners (see figure 3.1.3). One urban participant told of the pressure from health care centers to test: they don’t treat you if you don’t get tested when you are sick’. Other requirements to test that were mentioned were: prior to MC; university entrance; commencement of employment. Survey respondents also specified that requirements (8.3 percent) for jobs, medical procedures and travel as reasons for having a HIV test.

Figure 3.1.3
A view of why adolescents do attend for HTC

3.1.4 Perceived need

‘This time in life is very, very, very, risky if you don’t know your status.’

[Male, South Africa – Rural]

The need to test for HIV was closely associated to one’s perceived exposure as a result of their behaviors or risks they had taken. Although this was also seen as a barrier, in each workshop this was mentioned as a reason why adolescent test. Likewise tested respondents in the online survey, 19.4 percent indicated that having an experience that may have exposed them to HIV is what prompted them to test (see table 6 in annex 8.5). A number of those in the Philippines workshops felt that they had ‘already assessed their risk’ and that this had caused them to test. Some participants in Zimbabwe and South Africa thought that ‘being a young person and sexually active is enough to put you at risk’ of getting HIV and therefore requiring a test.

Zimbabwean adolescents mentioned having a parent or partner that was unwell or had been diagnosed with HIV as driving factors to test. While those in South Africa felt that ‘feeling sick’, ‘losing weight’, or ‘having unusual diseases’ were all reasons to have a HIV test.

‘This teenage girl fell sick and made a decision to go and take a HIV test.’

[Male, South Africa – Urban]

* Offered in a health service includes: offered part of my care when I was pregnant, offered as part of a visit to obtain contraceptives, offered by a healthcare worker, part of a sexually transmitted infection screen
† Multiple answers for this question were possible per respondent
3.2 Barriers to HTC

Adolescents experience a variety of barriers in relation to HIV testing and counselling. These barriers could be categorised as personal, social, cultural or service related. These are factors that, alone or combined, can often override the adolescent’s desire to attending HTC. Although they may not completely deter the adolescent from using HTC services, such barriers can make the process more difficult. In the online survey, 17 percent of respondents who had tested reported barriers.* Those from Europe reported experiencing fewer barriers with no differences seen between sex (see table 3.2 – Q36).

3.2.1 Fear

'I just don’t want to talk about HIV or HIV testing cause I’m afraid of it and it’s so scary I feel like crying.’

[Male, South Africa – Urban]

The notion of ‘fear’ or ‘being afraid’ was the most frequently identified barrier to having a HIV test in all workshops. 19.8 percent of survey respondents, who had not yet tested but wanted to, specified fear of the result as a reason why they did not test.* For the survey respondent in Africa, this was more evident with 52.9 percent identifying this reason (see table 4 in annex 8.5). Fifty-five percent of those who had been tested also indicated this as their biggest concern when deciding to test.

The 'fear of death’ was very apparent in the South African workshops. Despite a number of adolescents having good understanding that ‘you can now take medication and live positively’ many involved expressed that anxiety around testing was mainly due to its association with death. As stated by one participant: ‘You feel anxiety because you think what if I’m positive, maybe then I'll die’. A number of the drawings of their views of HTC involved coffins or people on their deathbed (see figure 3.2.1).

For some participants in the Zimbabwe workshops, the fear of death came from seeing those around them suffer from HIV/AIDS. One participant stated that: ‘I want to go and get tested but I am afraid because my parents died and they were very sick.’

In the Philippines, being 'scared of the injection’ or 'afraid of the pain from the needle’ was viewed as the number one reason why adolescent do not get tested (see figure 3.2.1). Another common fear mentioned in the Philippines workshops was of ‘parents reaction’ or of ‘parents finding out’. A participant stated: ‘They (parents) will scold you, and get angry with you. It's also possible that they will hurt you physically’. In the online survey, 8.5 percent of tested men who have sex with men (MSM), more than double the rate of other respondents, indicated that they are afraid that their parents will be informed” (see table 9 in annex 8.5).

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* Multiple answers for this question were possible per respondent
The stress of finding out that you are HIV positive was raised repeatedly in all workshops. A number of adolescents felt that ‘just knowing you are positive would make you sick’ and that if they found out that they were positive they would ‘commit suicide’. It was felt that a positive status was ‘demoralising’, that one would ‘stay stressed’, that ‘you could never be happy’. Those in the Philippines felt that there was ‘no hope’ as ‘once you get HIV it doesn’t go away’. They felt that ‘HTC seems so burdened with negatives’ that acted as a deterrent to testing.

The emotional difficulty of coping with a HIV positive result was evident in a number of the participant’s drawings and stories. In Zimbabwe, participants shared stories of people killing themselves as a result of being HIV positive (see figure 3.2.2). Their stories all involved people feeling that there was ‘no point surviving’ or that it was ‘no hope’.

In contrast to the other countries, South African adolescents viewed the changes that one has to make to their life as a result of a positive status as a burden. As a result of health promotion messages participants felt that you would be forced to do things that you may not want to do like wear a condom, take ART, eat healthy food and attend clinic (see figure 3.2.3). A male participant stated: ‘A real man eats meat, not vegetables’. Another stated ‘what now I have to wear a condom? .. eishh... this is a tough thing’. This participant later finished his presentation by saying: ‘These are the things that are on my mind when I think about testing and this is why I don’t want to (get tested).’
Zimbabwean participants frequently mentioned concerns about the effect of a positive status on their future. These concerns mainly focused on the impact and disruption it would have on their education and on future relationships. While those in the Philippines conveyed their anxiety about the implication and effect their status would have on their families.

Zimbabwean participants felt that they ‘did not want to have to think about such things’ that ‘thinking about it made life too serious’. One male participant felt that ‘to live like that, it’s no fun! Eventually you are going to die so you may as well have fun.’ Similarly, in the South African workshops participants felt that they ‘would rather die without knowing’ their status as knowing that you are going to die would be too stressful and that they would prefer a ‘nice life’.

‘I will be positive and not live my normal life.’

[Male, South Africa – Rural]

### 3.2.3 Association with bad and high-risk behavior

‘Those taking the test are automatically branded as immoral.’

[Female, South Africa – Urban]

In each workshop adolescents highlighted that, in general, a HIV test ‘indicated to society’ that you were involved in what is generally viewed as bad behavior. Adolescents in the Philippine workshops expressed the difficulty of not only having to disclose that you were sexually active, but also admit you are involved in high – risk behavior such as sex work. They felt that this was an added deterrent to testing.

A number of participants across all workshops viewed this negative association with HTC testing as a result of society’s view towards adolescent being sexually active. This negative association is also highlighted by the difficulty mentioned in engaging parents and adults in discussions regarding sexual health.

‘In their mind, you are still a child but already engaging in sex.’

[Female, Philippines]

‘There is a huge bridge between parents and young people; they do not discuss issues about sex. But the reality is that young people are having sex.’

[Female, Zimbabwe – Urban]

‘Any talk about HIV and AIDS and other things about sex, especially at a young age, is considered taboo in the Philippines.’

[Male, Philippines]

### 3.2.4 Stigma and its consequences
‘They would gossip … “Behold her, she has HIV. Don’t ever go near her.’

[Male, Philippines]

One of the main deterrents from HTC that emerged in all the workshops was the potential to experience stigma and discrimination. Adolescents viewed that stigma and its consequences were entrenched in societies’ views on HIV. This was also evident in the online survey where 18.8 percent of tested respondents (n=351) also listed being afraid of what other may think as a concern when deciding to test. This concern was more evident for those who considered themselves as MSM (n=82), with 26.8 percent indicating this compared 16.4 percent of other tested respondents *(see table 9 in annex 8.5).

![Figure 3.2.4](image)

**Figure 3.2.4**
An adolescent’s drawing of their views of HTC

The consequence of being rejected by friends, family and the community was repeatedly mentioned as a hindrance to HTC by workshop participants (see figure 3.2.4). In South Africa the notion of ‘loss of relationship’ was very common. Potentially being ‘disowned by your parents’, ‘losing all your friends’ or ‘being left alone’ was viewed as ‘not worth knowing your status’. When asked about their general views of HTC a number of participants drew and told stories of broken relationships as a result of a positive HIV test. One participant stated: ‘Who will be with you if you are positive?’

Feelings of shame or fear of not being accepted by your family was specifically highlighted by adolescents in the Philippines. Participants, told stories of other adolescents running away from home as a result of shame and parents negative reactions to a positive status.

Stigma as a result of rumors and gossip were mentioned in all workshops, however this was particularly evident in South Africa. Adolescents were worried about ‘what people will say’ whether their friends would laugh at them or that they ‘would be subject to gossip’. Some felt that the discrimination around HIV was so strong that even if ‘you lose weight people start talking like you have HIV’. Comparably in the Philippines workshops, participants on a number of occasions commented on the assumption that if you attend for testing you must already be HIV positive. As stated by a female participant: ‘When you ask others to join you to get tested, and they will quickly react; Why, are you (HIV) positive?’

### 3.2.5 Information

‘Lack of information’, ‘being misinformed’, or ‘not understanding HIV’ were all identified as an obstruction to testing. In Zimbabwean workshops participants felt that the misconceptions and ignorance surrounding HIV, which often led to fear, was a result of not having enough information (see figure 3.2.5).

* Multiple answers for this question were possible per respondent
Likewise in the Philippines one participant stated: ‘I get all nervous because this is a virus, and I’m clueless about what will happen to me if ever I get it’. Other Filipino participants expressed the fact that there is lack of knowledge and therefore ‘insufficient awareness in the community’.

In contrast, those in South Africa just having more of it but to better understanding of HIV.’

3.2.6 Perceived risk

‘In their (adolescents’) hearts they that’s why they don’t want to be know they may test positive for HIV, tested.’ [Female, Philippines]

Drawings regarding their general views of HTC revealed that some participants were aware of the routes and risk of HIV transmission (see figure 3.2.6). In each workshop adolescent reported different behaviours or lifestyles that would put one at risk of contracting HIV. They felt that such behaviours increased the possibility of a positive result, which further contributed to fear and ultimately their choice not to test. This was particularly evident in the Philippines where both male and female participants reported ‘suspecting that you are already positive’ and therefore being ‘afraid of having this confirmed’.

‘People perish from a lack of knowledge.’ [Male, Zimbabwe – Rural]
Apart from the identified risky behavior, some participants highlighted others that were beyond their control. No clear indication was given whether these further hindered adolescents to test.

'It’s not your fault if you are raped.’

[Female, South Africa – Rural]

'None of us wished it upon ourselves: “when I grow up, I want to be a prostituted child, or, I want to be a prostituted woman”. But because of poverty, we are now in this situation.’

[Female, Philippines]

Adolescents in the South African and Zimbabwe workshops, who perceived their risk as limited or absent, believed that they had a reduced need for HTC. However, some raised concerns about adolescents finding themselves to be HIV positive in an ‘non-understandable way, that you don’t understand how you got HIV’. One participant highlighted that it ‘can be confusing because some people were born with HIV’ while another told a story of a young boy ‘whose parents never tested therefore no one understood him getting HIV’.

'I don’t have to get tested, there is no point because I have never slept with anyone.’

[Female, Zimbabwe – Rural]

For non-testers in the online survey, who do not want to test, perceived low or no risk was also a reason why they had not been tested in the past. Fifty percent indicated that they had no reason to need a test, 43.8 percent that they had minimal risk (i.e: no multiple partners, no unprotected sex, or never injected drugs) and 29.2 percent indicated that they felt healthy* (see table 5 in annex 8.5).

3.2.7 Denial

Workshop participants particularly in South Africa and Zimbabwe mentioned denial about HIV as a barrier to adolescents testing. Participants were concerned that many people in their communities ‘believe the disease [HIV] doesn’t exist’. They felt that denial caused people to not want to test and furthermore discourage other people from testing. As highlighted by one participant: ‘some religious groups are not allowing for such activities [HTC] to happen’.

A number of participants highlighted that HTC was not a priority for many adolescents as they had ‘no interest in knowing their status’, that they were ‘too lazy to be bothered to test’ or ‘were bored of having to discuss HIV again’. Similarly among non-tested online survey respondents that wanted to test the most frequently indicated reason (35.1 percent) for not testing was because HTC was not a priority* (see table 4 in annex 8.5 for regional differences).

3.2.8 Attitudes of Health Providers

'If I come to get tested because I have unprotected sex they will shout ‘why have you done that?’

[Female, South Africa – Urban]

In the workshops and the online survey, interactions with and attitudes of HTC service providers were frequently discussed and noted as a major reason why adolescent do not test. The most frequent indicated experienced barrier by survey respondents that had tested was unfriendly health providers (41 percent) and being worried about their reaction (45.9 percent).* These barriers were more common for males than females (see table 8 in annex

*Multiple answers for this question were possible per respondent
† Multiple answers for this question were possible per respondent
With 20.7 percent of tested MSM (n=82) indicating being worried about the reactions of healthcare workers when deciding to test, compared to 16.4 percent of other tested respondents (see table 9 in annex 8.5). Despite this, the HTC provided by health workers was rated as above average (average, good, excellent) by the majority (66.4 percent) of tested respondents. More males in Africa (77.9 percent) rated services higher compared to males overall (71.4 percent) and females (64.1 percent).

Adolescents in the workshops expressed ‘feeling ignored’, ‘looked down upon’ and felt that service providers were ‘not supportive’. Many participants voiced their concerns of being interrogated and judged by providers. Such concerns were more apparent in both the Philippines and South African workshops. One South African participant stated: ‘they ask many questions like, why are you having sex? and why can’t you wait’ while another in the Philippines said: ‘you need to argue with clinic staff to convince them that you want to get tested’.

Some are sometimes overheard to say “You again?” [Male, Philippines]

A large element of the adolescents concerns about service providers was regarding confidentiality. Participants expressed the fear of other finding out their results through ‘those (service providers) that they are supposed to trust’. Some participants in South Africa were apprehensive as these ‘staff are their neighbors’ and that their ‘result would end up at home’.

3.2.9 Accessing HTC services

According to the participants, there are many barriers to accessing HTC services. Among workshop participants these barriers were experienced at different levels in the different countries. Location, costs, long waiting times, and opening hours were identified as key access barriers to HTC.

Across all workshops the lack of testing facilities was raised as a problem. In the Philippines workshop they repeatedly mentioned the difficulty locating HTC services. As one male participated mentioned: ‘I will not know what to do. I am unaware of the services available or what organisations to approach’. Similarly in the online survey, those that would like to get tested did not know where to get tested (27 percent) or hadn’t had the opportunity to test (34.2 percent)† (see table 4 in annex 8.5 for regional differences).

Service provision at inconvenient times (29.5 percent) and locations (24.6 percent) were also indicated by tested online respondents who experienced barriers (n=61)†. This was also a highlighted obstacle in the Philippines, particularly for those attending school.

Furthermore, the cost of transport to testing centers was seen as a major limiting factor, especially for those from rural areas. Zimbabwean participants raised the barrier of having a double cost of both testing and transport.

Unlike the other workshops, in Zimbabwe the concern for lack of resources to provide testing went beyond having a place to test. Next to more facilities, they highlighted the need for more staff to provide the testing. Some felt that there were not enough resources to tend to

* Five rating options were provided: excellent, good, average, fair and poor
† Multiple answers for this question were possible per respondent
all those that needed help. One participant stated: ‘I think one of the biggest challenges in our hospitals is that nurses have lots to deal with’.

Another access barrier was the perceived waiting time. Workshop participants in South Africa expressed ‘being tired of the process involved testing’, and that they ‘had other things to do rather than waiting in queues all day’.

3.2.10 Consent requirements

‘I don’t think there can be an age. It’s your decision. It’s me that is going to be affected so I should be the one to decide.’

[Male, Zimbabwe – Urban]

The need for parental/guardian consent for adolescent HTC differs between countries. In South Africa the age is 12 years old, however in Zimbabwe and the Philippines it is higher, respectively, 16 and 18 years old. Therefore, formal consent as a barrier to testing only emerged in Zimbabwe and the Philippines.

The requirement of having your parent or guardians permission was a substantial deterrent to having a HIV test. In the Philippines fear of discrimination by your parents after disclosing high-risk behavior was a point of concern. While in Zimbabwe participants felt restricted by the fact that ‘many of us don’t have parents or guardians to take us for testing’ (see figure 3.2.7).

Figure 3.2.7
An adolescent’s drawing of their views of HTC

Workshop participants had conflicting views regarding the age of consent to test. The majority agreed that ‘their consent is what should be considered’ not that of their parents. A number across all workshops felt that consent to ‘testing should be at a younger age,’ as adolescents ‘as young as 13 years old’ were having sex and are at risk. Other participants voiced concerns of ‘being too young’ or ‘not mature enough to cope with a positive status alone’. Parent or guardian consent was viewed as a source of support.

‘Bottom line is how people would be able to handle the situation when informed that they tested positive.’

[Female, Philippines]

3.3 The HIV testing and counselling experience

The anonymous nature of the online survey allowed for questions regarding adolescents’ personal experiences of attending HTC. Overall, 68 percent of the 517 respondents who
answered the question on ever been tested indicated that they had been tested for HIV. Regional and sex variation are given in the table below.

This section refers to the **351 respondents** (68 percent) insight into their testing experience.

*(Note: Of the 351 tested, 23 respondents’ country and/or sex unknown)*

### Table 3.3: Number and percentage of respondents who ever tested for HIV by sex and region

<table>
<thead>
<tr>
<th>Sex and Region</th>
<th>Have you ever had an HIV test</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Male</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Africa               |                               | 68 | 82.9%
| Americas             |                               | 49 | 84.5%
| Eastern Mediterranean|                               | 2  | 15.4%
| Europe               |                               | 33 | 61.1%
| South East Asia      |                               | 7  | 53.8%
| Western Pacific      |                               | 16 | 64.0%
| **Total**            |                               | 175| 71.4%|
| **Female**           |                               |    |      |
| Africa               |                               | 35 | 81.4%
| Americas             |                               | 37 | 78.7%
| Eastern Mediterranean|                               | 3  | 42.9%
| Europe               |                               | 71 | 62.3%
| South East Asia      |                               | 4  | 30.8%
| Western Pacific      |                               | 3  | 33.3%
| **Total**            |                               | 153| 65.7%|
3.3.1 When last did they test?
Of the 351 tested respondents 40.5 percent had tested within the last six months, 23.6 percent between 6 and 12 months and 22.8 percent more than a year ago. In fact, more women (28.8 percent) tested between 1-5 years ago than men (18.8 percent), the remainder (7.7 percent) did not respond.

Graph 3.1: Time since last HIV test by sex

3.3.2 First time or repeat tester
For 32.2 percent of those that tested this was their first test; a further 59.8 percent are repeat testers and 8 percent did not answer.

The almost 60 percent repeat testers are made up of those who tested once before (16.5 percent) yearly (19.7 percent), every 3 months (8.3 percent), every 6 months (6.3 percent) and 1-5 years ago (9.1 percent).

Our data showed regional and sex differences when we compared first and repeat testers. Proportionally more females (41.9 percent) are first time testers than men (30 percent). The ratio of first time to repeat testers of 30:70 for males were seen across countries (note we had small samples in South East Asia, Eastern Mediterranean and Western Pacific). However, for females, when compared to females from other countries, more females in Africa are repeat testers (74.3 percent, all women 58.1 percent) and more females in Europe are first time testers (50.7 percent, overall 41.9 percent). Also refer to table 3 in annex 8.5.

Graph 3.2: Number of first time and repeat testers by sex and region
3.3.3 Who accompanied those who tested
Although 62.4 percent of respondent reported not being accompanied by anyone to test, our data demonstrated regional differences in those that were accompanied. In Africa, more testers were accompanied (38.1 percent) when compared to Europe (31.7 percent) or Americas (14.9 percent). More MSM went on their own (71.7 percent).

Respondents could indicate multiple people in a question on who accompanied them when getting tested. For those that were accompanied (37.6 percent) the majority attended with a friend (43.7 percent), a boyfriend/girlfriend/partner (39.8 percent), a parent (12.6 percent), a youth worker (8.7 percent) or a family member (5.8 percent). We saw no differences between males and females. Regionally, we could only compare Europe with Africa due to small numbers for other countries. In Europe, more parents (27.3 percent) accompany a tester when compared to Africa (5 percent) as is illustrated below.

Graph 3.3: Reported testing companions by region

3.3.4 Where did they test? *
Respondents’ test were undertaken in a HIV testing center (29.1 percent), general practitioner/local clinic/health post (23.4 percent), a hospital (22.5 percent), a sexual health center (9.4 percent), a venue i.e. music concert or sports venue (8.3 percent), youth center (6.3 percent) or other places (9.4 percent) which included school, family planning clinic, home, or somewhere far away from home. 66.1 percent felt that their test was conducted in a private place. The statistical test for regional, sex or sexual orientation differences for where the test took place and whether the test was private were not significant.

3.3.5 Giving consent, pre-test and post-test counselling
79.2 percent indicated that their full consent/permission explicitly prior to their test was given. In regards to a pre-test discussion 29.3 percent indicated that they had a full discussion with time for questions, 24.5 percent reported moderate time with some discussion, 11.1 percent very short discussion with no explanation and 24.8 percent indicated that they received no pre-test discussion. Regional and sex differences were seen, with significantly more female testers not having a pre-test discussion with a health worker (32.7 percent) than males (19 percent), and more females in Europe indicating no pre-test discussion (45.1 percent) when compared to Americas (32.4 percent) and Africa (14.3 percent).

*Multiple answers for this question were possible per respondent
In regards to a post-test discussion 20.2 percent indicated that they had a full discussion with time for questions, 22.8 percent moderate time with some discussion, 16 percent very short discussion with no explanation and 29.6 percent indicated that received no post-test discussion. 11.4 percent did not answer this question. Again, regional and sex differences occurred, with significantly more female testers not having a post-test discussion with a health worker (35.9 percent) than males (25.5 percent). More males and females in Africa indicated to have a post-test discussion (76.5 percent and 82.9 percent respectively) compared to the overall of 59 percent.

Graph 3.5: Percentage of testers receiving a post-test discussion by sex and region
3.3.6 Type of test
Needle and syringe (45.9 percent) and rapid pin prick (34.2 percent) were the most common types of tests experienced by respondents, some also mentioned an oral swab (3.4 percent) and 6.3 percent did not know which test was used. We found regional differences: more respondents from Africa had the rapid pin prick test (56.1 percent) compared to Americas (32.2 percent) and Europe (22.1 percent), and less needle and syringe (28.6 percent) than the Americas (51.7 percent) and Europe (58.7 percent).

Graph 3.6: Type of test by region

3.3.7 Receiving test results
Of the 351 testers, 40.7 percent were able to receive their results immediately, with a further 14 percent within a day and 26.8 percent in a week, and 7.1 percent more than one week. 11.4 percent did not answer the question. Regional differences are demonstrated with our data with proportionally more respondents, both males (69.1 percent) and females (80.8 percent) in Africa receiving their results immediately (72.4 percent for Africa).

Overall 63 percent of tested respondents felt confident that the service provider would not share their result without their permission, 21.7 percent did not feel confident and 15.4 percent did not answer. No regional or sex differences existed in our data.

3.3.8 HIV positive respondent experiences
Of those who tested, 8.8 percent were HIV positive (n=31), 76.9 percent HIV negative (n=270) and the remainder of 14.2 percent did not want to say or chose not to answer the question (n= 50). When compared to HIV negative testers, HIV positive testers no regional differences were demonstrated. However, males (13.6 percent) when compared to females (6.6 percent) were more likely to be positive. Our data showed high percentage of HIV positives among those who consider themselves MSM at 26.8 percent, sex workers at 25 percent*, transgender at 14.3 percent*, and people who use drugs at 30 percent*.

Differences were also observed in their testing experience. Overall HIV positive testers (25.8 percent vs. 7 percent) were more inclined to rate services as poor. HIV negative testers were more confident that their result would not be shared by the service provider without their permission (73.3 percent vs. 54.8 percent).

* These figures should not be quoted due to small number of respondents
More HIV positive testers received post-test counselling with 32.3 percent indicating a full discussion with time for questions and 16.1 percent indicating no-post discussion, compared to 21.9 percent and 35.2 percent for HIV negative testers.

3.4 Post-testing experiences

A significant component of HTC is post-test counselling. This includes providing referral to prevention services for those that are negative as well as ensuring appropriate links to care and treatment for those testing positive. This section provides insights into the post-testing care and adolescents' experiences and perceptions of them. It also addresses the importance of discussing disclosure, and providing or facilitating psychological support for those testing positive.

3.4.1 Referral and linkage to care

Referral and linkage to care could only be purposely explored with adolescents in the online survey as the questions were focused on their personal testing experiences. Of those in the online survey, 69.8 percent of the 351 respondents that tested for HIV indicated that they were not referred to any services, 17.4 percent were referred and 12.8 percent did not answer the question.

67.7 percent of HIV positive testers (n=31) compared to 14.4 percent HIV negative testers were referred to post-testing services. HIV positive testers were more likely to be referred to HIV care services with 42.9 percent being referred treatment advice and support, 33.3 percent counselling, 33.3 percent for blood tests, and 23.9 to PLHIV networks.*

The data showed no regional differences. However, more males were referred (22.3 percent) than females (12.8 percent). This is possibly due to more males reporting a HIV positive status. For those that were referred (n=61, 17.4 percent) the most frequent indicated service referral was to HIV care services (44.3 percent), to counselling (42.6 percent)* and other services as indicated in the graph below.

Graph 3.7: Services referred to by sex for those testing positive and negative

The main referral mechanism indicated involved the adolescent being given the detail of services to initiate contact independently (50.8 percent), an appointment made on their behalf (23 percent) or in the case of 19.7 percent they were accompanied to services.

* Multiple answers for this question were possible per respondent
3.4.2 Disclosure

‘Once you hide your HIV status from your friends, they wouldn’t know when you needed help, when you need their support.’

[Female, Zimbabwe – Urban]

Across all workshops, disclosing your HIV status was acknowledged as the decision or right of an individual. However opinions regarding whether you should share your status or who to share it with were divided. In all countries some participants held the view that ‘you should share your status with those you can trust’ as this provided a ‘necessary means of support’ especially in accepting your status. Other participants, notably those in South Africa and the Philippines, felt that ‘it was better to keep it (HIV status) to yourself’. One South African participant stated that: ‘Telling someone your status is like digging your own grave.’ This view was closely related to adolescents concerns that ‘someone could use your status against you in the future’, or ‘spread it around to others without your permission’ or result in rejection and loss of relationship (see box 3.4 for a discussion during the workshop that was generated in response to a question regarding disclosure).

Box 3.4 – Discussion among urban South African participants

| Boy 1: Who will be with you if you are positive? |
| Girl 1: Someone will want to be with me. |
| 3 boys: No one will want to be with you!!! |
| Girl 1: Why? |
| Boy 1: They may say they love you but they will run away if they know you are positive. |
| Girl 1: Will you tell your girlfriend if you are HIV positive? |
| Boy 1: No not at all. |
| Girl 1: So you will just rather infect her. |
| Boy 1: Safety first. The minute you tell her it will go all wrong. |
| Boy 2: Yeah she would rather get infected. |
| Girl 1: You must go together to get tested. |
| Boy 1: Ok yeah you can get tested but what do you do if I am positive and you are negative what do you do? Will you keep on being with me? |
| Girl 1: If I really loved you. |
| Boy 2: Ah love whatever. |
| Boy 1: We are all about facts. What they talk about is what they see on movies! |
| Boy 1: The question says you have this boyfriend and you want to have kids, a week down the line when you start to date him you find out |
| Boy 2: That he is positive, are you asking for kids or a relationship? |
| Boy 1: No I am asking if you will still date him even if he's positive. |
| Girl 2: Maybe they do not know the meaning of love because if you love someone, you love them even if they are sick. |
| Girl 3: You don't understand girls. That's the problem. |
| Boy 2: Whatever. |
| Boy 1: Personally speaking if you told me you where HIV positive I don't want to lie but I would pack my bags and leave. |

When asked about disclosure, 72.9 percent of tested respondents (n=351) in the online survey indicated that they had told someone their result, 16.2 percent did not tell anyone and 10.8 percent did not answer. A friend (60.5 percent) was the most frequently identified person that they disclosed their status to, followed by a boyfriend/girlfriend/partner (53.9 percent), a sexual partner (30.1 percent), a family member (27 percent), a parent (23.4 percent) or a youth worker (9.4 percent).*

* Multiple answers for this question were possible per respondent
We found slight regional differences – In Africa, significantly more testers reported to have disclosed to youth workers (17.1 percent) when compared to the Americas (1.6 percent) or Europe (7.3 percent).

For those who did disclose their result (n=57), 87.5 percent told someone in less than one week of receiving their result. For those who did not disclose their status the main reason was due to feeling that they could manage by themselves (50.9 percent).* Males were more inclined to express this reason than females (65.7 and 27.3 percent respectively). Refer to table 7 in annex 8.5.

When comparing HIV positive testers to HIV negative testers no difference in percentages sharing test results (83.9 percent vs 82.6 percent) were reported. However, there were differences in time taken to share the result and whom they disclosed their status to. HIV positive testers took longer to share their results; within one week, 53.8 percent disclosed compared to 91.5 percent of HIV negative testers. A further 15.4 percent of HIV positive testers disclosed within one month, 7.7 percent within three months, and 23.1 percent took more than three months.

Even though both HIV positive and negative testers mentioned to most often disclosed to friends (61.5 and 60.5 percent respectively), HIV negative testers (57.4 percent) were more likely to share with a boyfriend/girlfriend/partner compared to HIV positive testers (30.8 percent).* Being scared that their results would be told to others if they disclosed, as a reason not to disclose, was also more evident among HIV positive testers (40 percent) than HIV negative testers (6.5 percent).*

### 3.4.3 Having support

![Figure 3.4.1: An adolescent's drawing of their views of HTC](image)

A key incentive to disclose your status was to receive support. Workshop participants in all countries felt that ‘those who tested positive for HIV need encouragement’ and support from family, peers, service providers and other people living with HIV. In Zimbabwe and South Africa, a number of drawings and stories ended with those who were found to be positive joining support groups (see figure 3.4.1). Support groups were viewed as an ideal forum for adolescents to ‘get help’, ‘learn from each other’, ‘share ideas for positive living’ and openly talk about their status.

### 3.5 Suggestions for improving access to and uptake of HTC

Knowing the reasons to test and barriers that deter adolescents from using HTC services, adolescents in the workshops provided their unique perspective to offer suggestions and strategies to improve uptake of HTC among their age group. Adolescents provided ideas and strategies to encourage more adolescents to access HTC. The suggestions were made at four different levels; the role of the community, the role of the health service provider, the environment in which HTC services take place as well as improvements to the health system.

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* Multiple answers for this question were possible per respondent
3.5.1 Engaging the community
In South Africa and Zimbabwe, the majority of ideas on how to encourage adolescents to test included activities conducted in their environment. Awareness raising events, education, performances and campaigns in schools, sporting fields, nightclubs and churches were viewed as ways to *captivate young people*, *to make testing less scary* and *more interesting* (see figure 3.5.1). In the online survey, using mass media (41.7 percent) and having education in schools (52.8 percent) were regarded as main strategies to encourage adolescents to test*). More males (74.2 percent) were in favor of education in schools as a strategy compared to females (64.4 percent). Refer to table 10 in annex 8.5.

![Figure 3.5.1](image1.png)
**Drawings of strategies to encourage more adolescents to test**

Adolescents in Zimbabwe strongly felt that *openly discussing HIV* and *publicly testing would motivate others to test* (see figure 3.5.1). That by involving celebrities or people that adolescents *lookup to*, *admire* and *follow* in such activities, adolescents would *start to have a different view about HIV and would want to get tested* (see figure 3.5.2).

![Figure 3.5.2](image2.png)
**Drawings of strategies to encourage more adolescents to test**

’*Have singers or the celebrities come out and say I’m tested and negative or I’m positive and I’m living positively.*’

[Male, Zimbabwe – Urban]

Having those already living with HIV, especially adolescents, *’share their story of how they live their life normally’* was desired by a number of participants. Adolescents viewed this as *’a way to encourage others’* to get tested, *’learn more about HIV’* and to *’get society to begin to accept it (HIV).’* While this view was shared in all countries Zimbabwean participants again emphasised that this should be done publically:

’*Here we have a story in Zimbabwe about a girl who is HIV positive and she even goes in schools teaching people about HIV.*’

[Female, Zimbabwe – Rural]

* Multiple answers for this question were possible per respondent
'Videos of young positive people from all over the world should be made, even ones that show people how to disclose (their status).'

[Male, Zimbabwe – Urban]

Other strategies suggested by Zimbabwean adolescents had particular emphasis on ‘ensuring information was available and accessible’. They felt that this could be achieved through ‘mass campaigns’, ‘posters and pamphlets’, ‘involving social media’, ‘having sections in libraries’ and ‘edutainment like dramas’. Paying attention to how information regarding HIV and HTC services is delivered was noted to be essential to adolescents in the Philippines. They suggested that messages and advertisements were youth friendly; that they had ‘a positive message’ and ‘not syringes’. To ensure that this was achieved, participants felt that adolescents should be involved in ‘designing posters and information’.

‘On posters information you can put in there regarding HIV, it should be precise, concise or direct to the point.’

[Male, Philippines]

Adolescents in all settings expressed the need for societies to change its views on HIV. Talking more about HIV and HTC was viewed as a ‘necessity’ by many in the South African workshops. Such discussions were seen as a way to ‘increase understanding’ in the general community and to decrease stigma. A Zimbabwean participant stated: ‘we need to have a culture of accepting that there is HIV’. This was echoed in the South African rural workshop: ‘society needs to treat it like a chronic disease or a headache. Why do we have to make a big deal out of it?’ Similarly, discussions regarding HIV were also offered as additional ways to encourage adolescent to test by online survey respondents.

Participants suggested that such discussion happen at schools, workplaces, through workshops, at community forum with young and old people as well as in support groups for those who are already positive. One participant felt discussions around HIV would help future disclosure. He stated that: ‘I think parents should talk to their kids about this disease so that it would be easier for them to talk to their parents when they know their status.’ The need for the entire community to be oriented to issues around HIV was also mentioned in the Philippines.

3.5.2 Role of the Health Service Provider

Involving adolescents as peer educators, outreach workers, and as HTC service providers was repeatedly suggested in all workshops as a way to encourage adolescents to test. A common view shared was that they ‘could relate’ and had ‘more understanding of a young person’s way of life’ and therefore contributed to ‘less fear of being tested’. Suggestions also included involving those who were HIV positive and those from most affected populations. This was also an additional suggestion given by online survey respondents.

‘This is a health worker employed but also a young person. He wants to share with you his life story: "I was tested positive but I am healthy and strong."’

[Male, Zimbabwe – Urban]

A number of participants in the Philippines spoke highly of their experience with peer educators; of how they made them ‘feel very welcome every time’ they attended services. These peer educators were also seen to bridge the gap between adolescents and health services.

'When you enter you don't get any adverse treatment whatsoever, no unkind words said... I really wish that this would be possible.'

[Male, Philippines]
The need for friendly, understanding and supportive health providers was raised as a priority by workshop participants. Having health providers who are welcoming, professional and able to communicate effectively with adolescents was highly valued and viewed as an important requirement to providing HTC. Similarly, 51.7 percent of survey respondents felt that youth-friendly (or non-judgmental services) was important to encouraging adolescents to test.* In figure 3.5.3 a Zimbabwean participant portrays an example of good communication and ‘how a good counselor should be’.

*Multiple answers for this question were possible per respondent.

![Figure 3.5.3](image)

**Drawings of strategies to encourage more adolescents to test**

‘Big ears to listen, small mouth with less to say.’

[Female, Zim – Urban]

‘If nurses were more understanding young people would test more.’

[Male, South Africa– Rural]

The notion of ‘being treated with respect’ and ‘being accepted’ by service providers emerged in every workshop. Those in the Philippines particularly raised concerns regarding discrimination or being treated differently to others. One female participant expressed her desire for service providers to ‘be open-minded enough and be able to accept that we too are part of the population’. While another requested that they were ‘aware of the issues confronting the youth, like us who are into prostitution, so that they will understand why we are in their facility’.

Another form of respect voiced by adolescents was their right to confidentiality. This was very evident in the South African workshops, where participants even advocated for those who were found to breach confidentiality to suffer some sort of consequence.

Additionally, Zimbabwean participants thought that the role of HTC service providers was ‘not just to test’ but also to provide them with advice and information especially regarding sexual health and prevention. One male participant stated: ‘We want condom demonstration when we get tested’.

### 3.5.3 The delivery of HTC services

High value was placed on the environment of service facilities. The importance of having a ‘youth friendly’, ‘relaxed atmosphere’ where adolescents could ‘feel welcome’ was evident in all workshops. Adolescents recommended that such an environment could be achieved by services ‘being clean’, ‘colorful’, by ‘having music in the waiting area’, ‘activities to do while you wait’ and ‘being open at a time when youth could attend’. In the Philippines, particular emphasis was placed on having separate areas or different service times exclusively for adolescents. While in the rural South African workshops the recommendation of offering food and drinks in HTC services as an incentive to test was repeatedly voiced.

‘Testing should be inside the community clinics then people won’t know why you are there.’

[Female, Philippines]
The appropriate place for testing to be conducted differed in each workshop country. Having HTC and sexual health clinics integrated within other services, such as a village health centers, was recommended in the Philippines. Adolescents in Zimbabwe, especially those in the rural workshops, suggested that HTC be ‘provided in youth centers’ alongside other activities including income-generating projects (see figure 3.5.4).

![Figure 3.5.4](image)
**Drawings of strategies to encourage more adolescents to test**

Another common suggestion mentioned by Zimbabwean participants was for testing to be ‘carried out by mobile services’ at universities, schools and community centers. In South Africa a number of participants felt that HTC should be provided ‘privately at home’ some even suggested that a ‘at-home test kits should be provided to do the testing yourself’. Going ‘door to door to provide testing and give information’ regarding HTC would not just help adolescents but also adults especially ‘grandmas and grandpas that don’t always understand’ the importance of testing (see figure 3.5.5). This was seen as solution to costs associated with travelling to get tested but also ‘to reduce discrimination’.

In contradiction to their desire to be tested in the privacy of their home, South African participants equally recommended that testing should be conducted in venues ‘where young people can be found’ (see figure 3.5.6).

![Figure 3.5.6](image)
**Drawings of strategies to encourage more adolescents to test**

In the online survey 36 percent of respondents also suggested that having HTC available in venues other than health services.* They additionally suggested the option of having mobile and integrated HTC services as ways to encourage adolescent to test.

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* Multiple answers for this question were possible per respondent
3.5.4 Improvements to the health system

‘Testing centers need to be closer to people they can test more.’
[Female, Zimbabwe – Rural]

Increasing the number of HTC services available was voiced by a number of participants in each workshop (see figure 3.5.7). Participants suggested that this would decrease the ‘struggle to find services’ and increase the likelihood that you would attend. Those in the Zimbabwe particularly mentioned ensuring greater access to services in rural areas. Providing transport to HTC centers as well as reducing the cost of testing or making it for free were viewed as necessary solutions to overcome health system barriers (see figure 3.5.7). The availability of free testing was also indicated by 47.8 percent of survey respondents as a strategy to encourage adolescents to test.* Proportionally more males were in favor of free testing compared to females (see table 6 in annex 8.5).

Figure 3.5.7
Drawings of strategies to encourage more adolescents to test

In South Africa other suggestions included providing incentives or rewards such as T-shirts, vouchers, and airtime (mobile phone credit). While those in the Philippines thought having referral systems from organisations and village health clinics could also contribute to greater uptake of testing by adolescents.

* Multiple answers for this question were possible per respondent
4. **Key findings from service provider interviews**

In this section, the views of providers are highlighted, presenting the perspective of those involved in proving HTC services to adolescents. The 16 service providers presented their perceptions of barriers to HTC for adolescents, the important elements in HTC provision and strategies for improving access to and uptake of HTC.

Offering effective HTC services and encouraging adolescents to access them is considered to be a high priority for service providers as they recognise that adolescents are at high-risk of HIV infection. According to a number of providers, services and policies around HTC are not often geared specifically towards adolescents and their needs are underserved.

4.1 **Barriers to HTC**

Service providers identified different types of barriers: the perceived barriers faced by adolescents in attending HTC and the problems preventing providers from reaching adolescents more effectively. Though providers address these issues on different fronts, they are often interrelated, creating barriers for both providers and the adolescents they are trying to serve.

4.1.1 **Cultural attitudes and information**

‘Most of the Filipinos won’t be talking about this with the kids because of our culture.’

[Service provider - Philippines]

One of the key barriers identified in all countries was societal, or cultural views surrounding HIV and sex. Particularly in Zimbabwe and the Philippines, providers highlighted the significant influence of religious and parental opinions and their effect on adolescents’ decision around HTC. Service providers noted that parents avoid engaging their children in discussions about sex due to the cultural ‘taboo placed on sex at a young age’. Some providers felt this lack of discussion leads to the spread of misinformation and a culture of discrimination.

In the Philippines, providers particularly noticed that awareness within the general community about HIV was very poor and the majority of the country had not received even basic HIV information. Some providers felt that this lack of understanding caused adolescents and parents to be uninformed about HTC, the seriousness of HIV and its consequences. One provider stated: ‘Since knowledge of HIV is not being talked about at schools or discussed in the house, these adolescents are really at risk’.

These factors together, said providers, prevented adolescents from seeking out testing or being encouraged to do so by their parents.

4.1.2 **Discrimination and stigma**

“We find that people are cursed, they are chased away, they have to leave their homes, they have nowhere to go.”

[Service provider - South Africa]

Another major barrier mentioned by service providers was the discrimination and stigma that can often accompany testing or a positive status. ‘Fear of discrimination’ and the ‘danger of being ostracized’ were especially prevalent among many interviewees in South Africa. A number of service providers told of stories of adolescents ‘being chased away’ or ‘removed from school by parents after a positive HIV diagnosis’. Parents declining to bring their children in for testing was also mentioned as a result of negative attitudes towards those with HIV.
4.1.3 Interactions between service providers and adolescents

The relationship between service providers and adolescents was noted by interviewees as a main barrier to providing services. Though most of those interviewed had experience with adolescents and said they felt confident dealing with them, many still acknowledge that these interactions were ‘emotionally tiring’ and at times ‘very challenging’.

In all countries, service providers highlighted the empathy they felt for adolescents especially those with a positive diagnosis, with a number contributing this to the challenge of providing HTC to adolescents. Providers were especially concerned about the ‘negative impact’ of a positive result and an adolescent’s ability to cope or manage their diagnosis.

‘I get nervous – for young people it’s not about their status its about the consequences that they will face.’

[Service provider - Zimbabwe]

‘When the result comes reactive I feel sorry for them, for that boy, because he is still so young.’

[Service provider - Philippines]

‘There is a lot to handle with the medication required if they get sick. They know that life is not going to be the same as yesterday.’

[Service provider – South Africa]

In the Philippines and South Africa, concerns were raised about the attitudes of other staff members towards adolescents. South African service providers talked of moral judgment that discourages adolescents to attend for HTC. Personal feelings about adolescents having sex were seen to create an intimidating or judgmental atmosphere with a number of South African interviewees commenting on adolescents being ‘shouted at’ or ‘called names’. One service provider in the Philippines particularly noted the stigma experienced by those from key affected populations especially ‘inter sexual adolescents’.

‘Sometimes the nurse will forget that it is my duty to provide a service, not to be a mother to this child.’

[Service provider – South Africa]

Filipino providers noted problems with effective communication by staff. One provider told stories of others having difficulties in providing counselling to seemingly inattentive or unreceptive adolescents. While another expressed the difficulty of delivering the information ‘in such a way that it is not as dramatic as it really is’.

A number of providers in all countries noted this to be partially due to ‘lack of training around adolescent HTC’. Although all providers had been given training for adult HTC, most felt there was a large gap in providing adolescent specific training. Those that had undertaken some sort of adolescent training still felt that this was not sufficient. One provider in the Philippines felt that lack of trained provider was specifically restricting their ability to set up dedicated adolescent HTC services.

‘You may want to spend more time with them but you know that the queue is so long.’

[Service provider - Zimbabwe]

In Zimbabwe, various providers also mentioned understaffing as a problem, resulting in stressed and agitated health service providers who felt they could not spend enough time thoroughly counselling adolescents who attended for HTC and follow up.
4.1.4 Service-related barriers

Many of the hurdles service providers said they face were logistical or practical concerns. Providers in the Philippines reported that clinics were on at inconvenient times ‘when most people have work or school’. They also noted that clinics are also situated in uninviting locations, places that are not convenient for adolescents or spots that are well known for catering specifically to sex workers. This, some providers thought, limited which adolescents would attend. Not having specific testing centers for adolescents, or clinical setting that were ‘inviting’ or ‘welcoming for adolescents’ was noted as a barrier by providers in all countries.

‘When there is a lot of work, shortage of staff there is not enough time to have with the client and other nurses get frustrated.’

[Service provider - Zimbabwe]

Staff resources were again identified as a barrier in Zimbabwe. One provider stated that, although they had a youth-friendly corner, they rarely had enough staff to facilitate it. Other Zimbabwean providers told of when they conducted outreach in the community, giving people specific times to come into the clinic because the need overwhelmed the available staff. While others noted that the long queues and extended waiting time at their clinics, they believed, put off adolescents from wanting to test.

4.1.5 Consent

Provider-related challenges are not just limited to staff attitudes and availability. Being hindered by and clearly understanding, the law surrounding consent for HTC was also a commonly mentioned problem. This was particularly mentioned in Zimbabwe and the Philippines, where the age of consent is higher than in South Africa.

'[We] need to do testing, because all of the most at risk populations are below 18 years old, and they have the right to HIV testing.’

[Service provider - Philippines]

Service providers felt that the higher age for individual consent was restrictive and often detrimental to adolescents who need help. In the Philippines, where the age of consent is highest, some providers felt that this was excluding those most at-risk. In contrast, other providers understood the importance of the age constraints; in the case of a positive diagnosis, an adolescent would require the support parents/guardians could give, even in relation to logistical concerns such as how to get to the hospital if the adolescent falls ill.

In each country, even in South Africa, where adolescents can get tested on their own from age 12, inconsistencies in the practical application of the law were evident. Some providers mentioned the age of consent in their facilities as being higher than that of the law while others told of specific occasions when they had acted in defiance to the law ‘to do what is best for the adolescent.’ These providers voiced concerns over being put in a vulnerable and compromising position of choosing to adhere to the law or test an underage adolescent and suffering the possible consequences of both.

‘You are not the one testing, we are the ones who will be the ones put in prison.’

[Service provider - Philippines]

A number of providers also highlighted grey areas within the legislation. Concerns were raised regarding adolescents with no parent or guardian, and those who arrived with another adult, claiming to be their parent. Filipino providers also noted another inconsistency; an adolescent must be 18 for HTC without parental consent, but only 16 to donate blood, which is then tested for HIV often without appropriate counselling.
In Zimbabwe, several providers said parents’ dishonesty about their own status causes problems, especially when adolescents want to get tested themselves. In some cases not only were parents not supportive of adolescents testing, but actively worked against it for fear their own status being disclosed.

‘If they know that maybe the young person could be positive they will close the ways of that young person getting tested.’

[Service provider - Zimbabwe]

4.2 Important aspects of HTC provision

There are certain aspects of HTC that consistently came up as priorities in all three countries; confidentiality was highly valued, providing accurate, understandable information, and ongoing support after testing including disclosure and linkage to care.

4.2.1 Confidentiality

In South Africa, many service providers said the assurance of confidentiality was key to adolescents seeking HTC. Similarly in the Philippines providers highlighted that in attending services adolescents were particularly ‘scared somebody would know them and tell the parents’.

Despite most providers in all countries acknowledging confidentiality as a right, some providers felt that ‘parents needed to know’ and noted certain circumstances where breaking confidentiality was sometimes necessary. One gave an example of how from testing one adolescent; the y were able to diagnose an entire family with HIV, although her confidentiality was broken.

In providing confidential services, service providers focused on the need to explicitly inform adolescents about their right to confidentiality. In Zimbabwe, some service providers saw this as a step towards empowering them. In the Philippines, it was routine informational practice.

4.2.2 Information

The importance of providing information was a theme across countries. A number of providers felt that providing the right information was their key responsibility. They highlighted the importance for adolescents to not just know their status, but to ‘understand what it means’, and ‘what they can do about it’. Some providers mentioned that even when they were unable to provide testing, mainly due to consent restrictions, they still provide pre-test counselling to deliver key information.

For those in Zimbabwe, felt that the role of service providers was to assist adolescents overcome fear surrounding HTC, to be aware of ongoing support, and to understand that a full life with HIV – including children - is possible. Providers expressed the need to talk to adolescents about safer sex, about issues surrounding sexuality as a whole, not only HTC. With explanation and information, they said they want to bring a message of hope to adolescents, who can view a positive status as a ‘death sentence.’

‘Always tell them there is hope because if you know your status - you get services, treatment and care.’

[Service provider - Zimbabwe]

A provider in the Philippines felt that delivering good information that had a lasting impact was essential but often challenging. It requires the time of the provider to build rapport and deliver effective counselling. Having the communication skills to deliver these messages was also highlighted:
'You need to work with the age of an adolescent and speak the language they understand.'
[Service provider - South Africa]

'How do you really make a person to open up, it’s sometimes a skill which we learn along the way or maybe if one has the heart of a counselor.'
[Service provider - Philippines]

### 4.2.3 Linkage to Care and Post-Testing Support

Once an adolescent makes the decision to get tested, following up and linking them to ongoing support, treatment and care is a vital step in the HTC process, according to a number of service providers in all three countries. However, some noted that guidance on whose responsibility it is to provide this link to care and the procedures involved are often unclear.

'The testing may not really be a problem, but in terms of when we do have a positive status, who will follow through with this case?'
[Service provider - Philippines]

Steering adolescents into support groups was highlighted by providers, as it helps reinforce that they are not alone, that there are others their age going through the same things. Many saw it as an alternative for adolescents without families or those who do not have support, a position especially held in Zimbabwe.

Particularly in South Africa, providers identified the need for the 'decentralisation of services' – bringing them into a more local, familiar, easy-to-reach setting – and the grouping services together, so that testing and support could be found in the same place.

'As we are all in the same building we have strong links and can easily refer a young person to care and the support group.'
[Service provider - South Africa]

Providers in the Philippines took a collaborative approach, partnering closely with other organisations, including social care and NGO’s, to ensure that adolescents are supported, linked to care and other prevention services.

### 4.2.4 Disclosure

Intertwined with ongoing support is the challenge of disclosure to friends and family. Service providers noted issues around disclosure to be very challenging to discuss and was often not properly addressed in pre or post-test counselling. In the Philippines, some interviewees felt that this was due to unclear or no guidance or no policy available to assist them to advise adolescents through this difficult process. Overall, disclosure was seen as the adolescents’ choice. Most providers felt that it was the adolescent’s right to keep it private, however a number of providers in all countries do advocate for the disclosure to parents if only for the necessary practical support; ‘what will they do if they are ill’, ‘who can take them to hospital’, ‘who can get medication for them’. Some providers counselled adolescents to recognise the need to disclose to someone that they trust and discuss the benefits of disclosing. One provider stated that ‘disclosure to parents needs to be based on trust between the adolescent and parent if there’s no relationship, we can’t encourage it.’ Others highlighted the need to take into account the willingness and readiness of the adolescents.

In Zimbabwe especially, family disclosure was encouraged, not just from the adolescent but from the parents as well. One provider told of an adolescent whose parents withheld their status from them, causing anger in the adolescent. This provider felt that some barriers to them taking medications were due to unresolved issues regarding disclosure.
'They are angry, they are bitter. Why didn’t my father and mother tell me this? Why did I have to learn about it in a clinic with a stranger?'

[Service provider - Zimbabwe]

Among South African service providers, the view of disclosure seems to be more cautionary. Providers are very aware of the negative repercussions of disclosing, and while they encourage it, they also counsel discretion about when and to whom adolescents disclose their status.

'I usually encourage people to disclose to the right people, at the right time, when they feel like it.'

[Service provider - South Africa]

4.3 Strategies for improving access to and uptake of HTC

Though there are a number of barriers and challenges inherent to providing HTC services to adolescents, service providers also highlighted a range of existing successful strategies and made recommendations for new strategies to improve access and uptake of HTC among adolescents.

4.3.1 Education

In all countries, education was named as a strategy that would encourage adolescents to attend HTC. This was especially evident in Zimbabwe, providers felt that ‘if adolescents had the knowledge, they would test’. Campaigns that raised awareness among adolescents, bringing HIV and the availability of HTC services to the public in a way that isn’t frightening or intimidating was proposed by providers. In South Africa, service providers told of using hip-hop and soccer competitions to raise awareness, to provide information and to engage adolescents to test.

The need for increased awareness among the general population was also highlighted by those in Zimbabwe and the Philippines. Several service providers felt that without wider uptake of information, no cultural attitude shift toward HTC and HIV will happen. Providers suggested that more could be achieved through education by partnering with schools, using edutainment, involving parents and increasing access to information regarding HTC in local communities.

'Schools should also be used as tools, or an institution that would provide information on sexual health education especially regarding HIV.'

[Service provider - Philippines]

4.3.2 Delivery of HTC services

'A facility with people and information, where we can be sure that children and young people are safe.'

[Service provider - Philippines]

Providers in all countries mentioned the importance of the testing facility environment. Having an environment that was comfortable, safe and welcoming was viewed as key to encouraging adolescent to test. A number recommended that HTC should take place in community or youth centers, free from the hospital environment due to negative association of hospitals being places for those who are sick.
Those in South Africa saw attitude change among service providers themselves as a greater strategic need. Some suggested a greater focus on privacy and confidentiality, and a push to eradicate the culture of judgment they felt was often found in clinics, especially in regard to adolescents and sexual health. Providers acknowledged that dealing with adolescents requires expertise and that training was required to assist service providers in relating to adolescents and providing ‘youth friendly’ services. They recommended that training also included multidiscipline workers such as social workers and social services.

‘We need to fight for adolescents to be treated equally and for there to be a smile.’
[Service provider - South Africa]

A number of clinics reported already implementing several of strategies, including separate opening hours for adolescents or special testing times that target high-risk groups of adolescents. In Zimbabwe, youth-friendly corners have been installed in hospitals and local clinics.

In putting more of these strategies into practice, many providers mentioned the need for collaboration and stronger links among health care services, NGO’s, civil society and other groups that target adolescents. Much work is also being done in the Philippines to reach out to establishments catering to YKAP, bringing community leaders into collaboration with service providers, and the use of online chat rooms to disseminate basic information on sexual health and HTC. In South Africa collaborations between NGO’s and local clinics has led to the implementation of in clinic adolescent representatives whose role is ‘to speak to and assist others in feeling comfortable’.

Despite existing strategies, providers noted the need for more innovative ways to engage a broader range of adolescents, such as offering services at less stigmatized locations and bringing testing, counselling and peer education under one roof.

4.3.3 Involving adolescents

‘We really need to involve young people. They really have a lot of things to say. I think we need to consult with them more rather than imposing on young people.’
[Service provider - Zimbabwe]

The meaningful participation of adolescents was a strategic suggestion for all countries. Some service providers felt that by engaging with adolescents and meeting them where they are, providers could train them to be leaders among their friends, encouraging other adolescents to learn about services and build networks.

Currently in the Philippines, they are operating a peer educator strategy among YKAP, doing youth-friendly outreach to identify and refer adolescents who need to be tested. That approach is part of a national plan that many providers felt works well. It provides an avenue for adolescents to take advantage of HTC services without having to do it alone. Similarly in South Africa, adolescents are trained as peer educators and conduct outreach through youth centers, schools, youth groups and clinics.

4.3.4 Legislation
In addition to collaboration on strategies, a large number of service providers said they need clarification on legal issues especially regarding consent, with some advocating for legislative change.

‘We want clean cut provision that says adolescents can take HIV testing and counselling, and if there’s no parents, then a service provider can do it.’
[Service provider - Philippines]
In all three countries, providers have said that there is limited to no policy or guidance for them and other organisations providing HTC to adolescents. For some, the problem was that while there may be specific direction and policy surrounding children and HTC or adults and HTC, adolescents fall into the undefined middle. They felt that this left them to interpret the law, which could be to their detriment if interpreted wrongly. Many providers found this limited what services they could provide and how they could provide them.

‘While we are protecting children we are also protecting the service providers.’

[Service provider - Philippines]

In the Philippines, for example, there is a push to make legislation more encompassing 'to cover all children, especially those with difficult circumstances.' But particularly there and in Zimbabwe, where the age of consent still excludes all but older adolescents, understanding how to apply the law and simultaneously serve the adolescent is challenging.
5. Discussion

The findings from this consultation show that involving adolescents can give a unique perspective of their values and preferences regarding HTC services and enable them to provide appropriate solutions to improve access and uptake of HTC by adolescents. The findings also provide a picture of existing HTC provision and experiences in relation to resources, policy, legislation and training.

Overall, common themes are evident among adolescents’ values and preferences and service providers’ perspective, however distinct a few differences exist between them and across countries. These differences potentially are the result of context specificities (political, cultural, social, and economic), the type of epidemic, and the individual country’s response to HIV. This discussion will focus on the five main areas that this report explores.

5.1 Motivations to test

Respondents in the online survey indicated the desire to test. Their motivation to test was both a result of intrinsic and external factors. Adolescents identified encouragement to test by health workers, peers and partners as well as their assumed sense of responsibility to prevent HIV, the observed benefits, and their perceived risk as key HTC motivators.

A number of contradictions also existed. Despite the fears and negative association regarding HTC, the general view of adolescents was that HTC should be promoted, supported and available. With a number of adolescents rating the HTC delivered by service provider as above average and expressing their willingness to recommend HTC services to friends.

5.2 Barriers

Fear surrounding HTC was shared in all countries although the type of fear expressed varied significantly. In South Africa and Zimbabwe fear was strongly related to the association with death. While the influence of, or fear of, parents’ reaction was noted by those in the Philippines and MSM in the online survey.

The influence of HTC messages and how they are conveyed could also be seen as a barrier. Those in the Philippines noted a particular fear of injections as a barrier, which led adolescents to suggest youth friendly positive messages in HTC advertising – i.e. not having needles in them. Similarly adolescents in South Africa were very aware of the changes they would have to make to their lives if they did test positive, thus causing them to view these changes as a burden. Some of these changes are real and important although many were not evidence based.

Societal views of and the stigma attached to HIV and adolescent sex are seen as key barriers by adolescents and service providers. In the Philippines and Zimbabwe lack of information and community awareness were raised as contributors to these views. However those in South Africa viewed this as a result of not discussing issues around HIV or understanding the information already received.

Several barriers to accessing services were mentioned by all respondents, which included lack of testing facilities, difficulties locating them, uninviting facilities and inconvenient operating times. Particularly in Zimbabwe, access was further obstructed due to limited human resources.

Providers and adolescents all highlighted service providers’ attitudes as a barrier. Adolescents identified judgmental and unsupportive attitudes of service providers, with particular concerns regarding confidentiality. Providers stated that their personal feelings about adolescents’ sex, difficulties in communicating effectively, insufficient training and resources negatively impacted on their interactions with adolescents.
Consent requirements were also seen as deterrent however, views of the age of consent were divided in both groups. Service providers and adolescents felt that those younger than the testing age were sexually active and should be allowed to test independently. However both were concerned about the ability of younger adolescents to cope and saw consent as a facilitator to subsequent support. Service providers additionally highlighted inconsistencies in practical application of the law regarding consent as laws on consent for HIV testing vary widely between countries, and the difficulties in choosing between following it and serving the needs of adolescents.

5.3 HTC experiences

Many respondents in the online survey reported that they tested did so recently, although some had tested up to five years previously. As these respondents were older, this highlights late entry into testing and therefore the ongoing need for HTC services to reach younger adolescents.

A higher proportion of repeat testers were seen, with females from Africa more likely to repeat test. This is a desirable strategy for adolescents in countries with high HIV incidence, like South Africa and Zimbabwe – and also for adolescents from key populations with ongoing potential risk – where annual testing is recommended. This has implication for reaching universal coverage of HTC, if re-testing is not captured in data collection about numbers of adolescents tested.

The majority of respondents indicated that they attended HTC alone raising concerns regarding individual support mechanisms. Peers are seen to be instrumental in providing motivation to test and support for testing, with friends and girlfriend/boyfriend/partners most common testing companions. Those in Europe were more likely to involve family and those in Africa friends. This could be an important consideration in strategies to improve uptake.

Respondents were mainly tested in health facilities. Those in the survey and the workshops indicated the desire for HTC to be delivered outside health services with suggestions of integrated services, HTC in youth venues and door-to-door /mobile testing. Self-testing was also mentioned as a potential way of facilitating adolescents to know their status.

Many HIV positive adolescents rated services poorly, have more concerns regarding confidentiality and indicated an unwillingness to recommend services or testing. This raises questions around the capacities of service providers to deal with an adolescent with a HIV positive result. Service providers also acknowledged that dealing with positive HIV results is challenging. Despite small number of respondents, high HIV positive rates amongst YKAP were observed in the online survey, highlighting enhancement, and the need for, targeted and inclusive strategies. This need was also highlighted among workshop participants and service providers in the Philippines. Similarly, high rates observed among males indicate attention for gender issues.

Respondents from Africa were more likely to have a rapid pin pick test, receive their results immediately and have post-test counseling when compared to Europe and Americas. This may reflect the greater use of rapid tests in countries with mature generalised epidemics where same day testing is often more frequently available. However, issues regarding quality of services were still highlighted i.e. – waiting times, lack of testing facilities, service provider attitudes and lack of human resources.

Post-test discussions were less common over all, although the majority of respondents testing positive for HIV had a post-testing discussion. Despite this being more important for HIV positive adolescents, the missed prevention opportunity for those that test negative cannot be under estimated.
5.4 Post-testing
Service providers recognised referral to prevention and care services as an important component of service provision although clear procedures especially regarding responsibility were often lacking. In the online survey data regarding referrals indicated significant gaps with the majority of respondents not being referred to services after testing. Additionally, those referred had to initiate contact with other services independently. The decentralized or collaborative approach mentioned by service providers was not reflected. The important role of support groups was evident. However in the online survey, only a small number of HIV positive participants were referred to PLHIV support services.

Disclosure is seen as a necessary means of support and as the adolescents’ choice and right. Disclosure to family especially parents is encouraged by service providers however this seems to be taken with more caution by participants in South Africa. In the online survey, HIV positive testers are sharing their results however the time taken to disclose is longer. This could indicate support and guidance needed during this period of non-disclosure. The fear of unwilling onward disclosure by others was highlight by both HIV positive respondents and workshops participants as a reason not to disclose your status.

5.5 Strategies for improving access to and uptake of HTC
Adolescents and service providers both highlighted the need for information and education. This was seen as an important strategy to encourage adolescents to test but also to raise awareness within communities and stimulate discussion to support testing. A number of the participants’ views were related to HIV as a whole rather than explicitly to HTC, emphasizing the need for HTC specific education.

Specific service delivery differences among countries highlights the need for formative research in individual countries. Despite these differences adolescents placed a particular priority on having information and services to be delivered in a way that would captivate and involve them. They desired to be involved in the promotion of HTC as individuals (peer), in the community (forums, outreach workers) and service delivery levels (HTC providers). Service providers ultimately supported this meaningful involvement of adolescents.

Both adolescents and service providers suggested the need for testing environments and providers that were welcoming requiring a change in providers’ attitudes. For providers key suggested strategies, involved clarification around legal issues regarding consent, increasing resources and as well as the need for adolescent specific training and policy.
6. Conclusion

In the development of the service delivery guidelines, consultation with end users is key to directing implementation discussions. This community consultation facilitated the participation and the inclusion of adolescents’ and service providers’ voices to explore their values and preferences regarding HTC.

Adolescents indicated the desire to be tested however several barriers exist. These barriers need to be further understood, addressed and overcome. To shape HTC provision, if it is to be acceptable and effective, adolescents need to be involved. Overall they suggested strategies that are within their environment, that captivate, inform them and stimulate discussions. Such strategies need to include the whole community to raise awareness to support testing.

Significant gaps in post-testing discussions and referrals highlight missed opportunities for prevention and support especially around disclosure. There is a need for clear referral procedures and policy, with particular focus on strategies for HIV positive adolescents and YKAP. Guidance on how to best support adolescents to disclose safely and beneficially to family members, sexual partners and others is required.

Although providers felt confident in delivering HTC services to adolescents many acknowledged the challenge. Inconsistencies in the practical application of the law regarding consent and difficulties choosing between following the law and serving the needs of adolescents were noted. Additional support and training especially regarding communication for service providers as well as attention to the legal and adolescent specific policy will be important if increased uptake of HTC to adolescents is to occur. An assessment of current practice on age of consent and guidance on appropriate consent policy is therefore required.

Overall, the findings were consistent however distinct differences among end users and across countries were apparent. To address these differences at a service delivery level guidance needs to be country specific relating to its context and the type of epidemic, with individual country undertaking formative type of research to further explore end-users voices, values and preferences.

This consultation builds upon previous existing guideline processes, giving a wider voice to end-users. Despite its limitations, this is a feasible way of involving adolescents’ views in a short timeframe with limited expenditure. All findings raised will be presented to the guideline development group and be used to inform the guideline development process.
7. References


8. **Annex**

**8.1 Workshops**

**8.1.1 Workshop Location**

South Africa
- Workshops were held at loveLife Y-Centre, multi-purpose facilities for adolescents, providing a range of recreational and educational opportunities, as well as sexual health information, clinical services, and skills development.

Zimbabwe
- They were conducted in youth centers run by the Zimbabwe National Family Planning Council who offer family planning services, life skills training, and recreation services.

Philippines
- Participants were identified from the NewGen Asia Leadership Short Course. A five-day course for emerging young leaders in the HIV response, many of whom come from key affected and was attended by adolescents from various youth networks and organisations from around the country. The course was hosted by the Council for the Welfare of Children and supported by UNICEF Philippines in partnership with the Asia-Pacific Interagency Task Team on HIV and YKAP.

**8.1.2 Workshop Description**

Each workshop followed a preset guide and lasted around 120 minutes. They were conducted using participatory learning and action approaches, such as drawings, priority scoring and brainstorming methods. The adolescents were asked to: a) draw their thoughts, feelings and what they had heard regarding HTC; b) come up with and prioritize reasons why adolescents do and don’t get tested for HIV; c) brainstorm and discuss the ways in which access to HTC and the experience of HTC could be improved for adolescents and how adolescents could be encouraged to have a HIV test; and d) discuss issues around consent, confidentiality and disclosure.

These visual methods provided a unique way to facilitate expression. The concrete nature of images lends itself to reaching grounding questions and therefore discussion. These visual methods took up approximately half the time spent in the workshop. After each workshop adaptations were made to questions and activities to refine them for the next session.

Prior to the workshops the importance of confidentiality was emphasized. The public nature of workshop means that this cannot be guaranteed. Adolescents attending the workshop were encouraged not to disclose any sensitive or private information. To further ensure confidentiality within the workshop participants were also given the option to use an alias name. Further opportunity to ask questions and the option to stop involvement at any time was also given.

All participants received a small token of gratitude, through the provision of lunch. Participants in South Africa and Zimbabwe workshops received approximately US $4 towards the cost of transport. Those in the Philippines received no remunerations were provided to participants as they were already on-site however calendars and pens provided as appreciation for their participation.

To overcome any bias from the facilitator and to ensure the quality of the consultation, a run through of the workshop and interview content was conducted with youth center workers and local facilitators. After each workshop adaptations were made to questions/activities to refine them for the next workshop. The facilitators and translators were recruited from local partners and were selected based on experience of workshops with adolescents.
8.1.3 Workshop guide

1. Introduction (15 mins)
   - Facilitator introduction to topic, aim, purpose and limitations to benefit
   - Discussion regarding confidentiality and anonymity of workshop's
   - Ground rules for the workshop to be made together and to be put up to be observed during discussion
   - Ice breaker and introduction exercise

2. Group task 1 - Current view of AHTC (15 mins)
   - What do you think of when you hear people discussing HIV testing?
   - Individual or in groups, draw your feelings, thoughts, conversations you have had.
   - Prompt: If you have been tested you could draw your thoughts and feelings of this experience.
   - Each group/individual to present their drawing - discuss to be generated by presentations

3. Group task 2 - Reasons to test or not to test (10 mins)
   - Write down the reasons why adolescents DO get tested?
   - Write down the reasons why adolescents DON'T get tested?
   - Prioritize the top 5 for both and present the reasons behind your choice

4. Group task 3 - Making AHTC more adolescent-friendly (equitable, accessible, acceptable, appropriate and effective) (20 mins)
   - How do you think access to HTC and the experience of HTC could be improved for adolescents? What could be encouraged adolescents to have a HIV test?
   - Draw your response
   - Each group to present changes to their drawings
   - Prompt: What environment/setting would be the most appropriate to be tested? What could health services do to improve the testing experience of adolescents?

5. Discussion (20 mins)
   - Do you think all adolescents should be offered HTC? Or only some adolescents? Why?
   - Should you or an adolescent share their result? Who should they share it with?
   - What would make it easier for adolescents to share their results? What support should be given to adolescents to share their result?
   - It is important that adolescents are involved with giving their permission to test. At what age do you think a young person can decide on their own to test for HIV?

6. Conclusion/Debrief (20 mins)
   - Each participant is given a chance to add anything else
   - Develop and agree on workshop outcomes and recommendation
   - How can we improve the group activity for next time?
   - Thank participants

8.1.4 Consent procedures
For those aged 15 to 17, individual assent as well as written consent from parents/guardian was obtained. Only written consent was obtained for those aged 18 and for those aged 15 to 17 years who are not living under the control of a parent/guardian (i.e. those looking after siblings or own children or married). All information was provided in both English and in the appropriate local language.
Hello, I am working on behalf of the World Health Organization. I am helping them to explore adolescents’ views about HIV testing and counselling as part of the development of international guidelines. We would like to speak to about 20 adolescents between the ages of 15 and 19.

You are being invited to consider if you would like to be a part of a workshop. If you want to participate, you will spend a morning or afternoon taking part in a group workshop with about 8-10 other adolescents. The workshop will involve activities and a discussion and will be held at your youth center. You don’t need to have had a HIV test to be involved - we would just like to hear your views about HIV testing and counselling and services.

Being a part of this workshop is up to you. If you participate, you can change your mind at any time. You can decide how much information you would like to share. No one will be upset if you don’t want to participate, if you choose to stop or if you refuse to answer some questions.

Everything in this workshop will be kept strictly confidential. Your names will not be used in any reports and you can even give an alias name to introduce yourself. However if something is said that makes me concerned about your safety, such as someone causing you physical harm, I may have to talk to someone about it but I will not do this without discussing it with you first.

You may know some of the adolescents in the group but we ask that you protect their confidentiality as they should protect yours. Unfortunately we are unable to guarantee this and therefore requested that you don’t disclose any sensitive or personal information of your own.

Once the workshop is finished, we will let the World Health Organization know what we discussed. We hope that this will help to develop adolescent HIV testing services that are appropriate and will support adolescents’ needs. However, it is important to note that changes to your local services are not up to us but by participating in this workshop will ensure that your thoughts and opinions are heard.

You will not be paid for participating but you will be given the equivalent of USD 4 to cover your travel costs. We will also serve snacks and some drinks at the workshop.

This workshop has been approved by the ______________.

If you have any questions or are unsure of anything to do with the workshop you can contact us at: (local organisation or WHO office)

Yes, I want to take part in this workshop. I ______________________________________ have been informed about the workshop entitled: HIV testing and counselling - Voices, values and preference of adolescents

- I understand the workshop that has been explained to me
- I have been given an opportunity to ask questions about the workshop and have had answered clearly.
- I understand that my participation in this workshop is voluntary
- I understand that I can change my mind to participate and no one will be upset at me
- I understand that I do not have to answer any of the questions if I do not want to
- I understand that everything I say will be kept private and that my name will not be used in any reports
- I understand that if I have any questions or concerns about the workshop I can contact the facilitator at anytime
• I understand that if I have any questions or concerns about my rights as a workshop participant, or if I am worried about the workshop or the facilitators then I may contact:

____________________                               ________   
Signature of Participant                          Date

____________________                             __________________ 
Signature of Witness                               Date

____________________                             __________________ 
Signature of Translator (Where applicable)        Date

8.1.5 Data management and analysis
With the explicit consent of participants, digital voice recordings and field notes were made of workshops. Hand written notes were made for those who did not feel comfortable being recorded. All recordings and field notes were uploaded onto a password protected computer. With the assistance of the local facilitators all voice recordings were translated and transcribed into English. No identifiable information on service providers or adolescents was used in the transcribed document. After transcription all voice recordings were deleted to ensure confidentiality.

The transcripts and field notes were analyzed using qualitative content analysis. After reading the transcripts several times, they were divided into meaning units. Considering the context, the meaning units were condensed into a close account of the original transcript and the interpretation of the underlying meaning. The condensed text was examined for ‘threads of meaning’.

These were further divided into sub-themes. On reflection and discussion with co authors the sub-themes were unified into themes underneath the key areas that were intended to be explored. All transcripts and field notes were reviewed at the end of the analysis process to ensure no relevant data is missed. Salient quotes will be identified to illustrate the each sub-theme and theme.

8.2 Online survey
8.2.1 Online survey Description
Respondents were invited to participate in the survey by following a web link. The survey was conducted online with the assistance of “survey monkey”. The survey took approximately 20 minutes to complete. It included questions demographic information (e.g. sex, age, education level, country) and as well as personal experience related to HTC. Topics on personal experience included decisions around testing, referral to prevention and care services, barriers and concerns, and improvements for testing services. All participants were able to exit the survey at any time. No identifiable information was requested to ensure that it is anonymous and no IP addresses were recorded.

The English version of the online survey was launched first. To further distribute the survey and include non-English speaking adolescents, youth organisations translate the survey into Russian, Spanish and French. Each translated version was checked by at least three other native tongue professionals working as editors, translators, researchers and postgraduate students. The following were involved in the review of the survey:

- WHO, EMRO, AFRO, EURO and PAHO representatives from the HIV treatment and care, adolescent and HIV prevention departments.
- UNAIDS and UNESCO representatives from headquarters and the Asia regional office.
- Young people between 15 and 19 years old attending a sexual health service in London.
- Interns at WHO headquarters between the ages of 20 and 29; representing 7 different countries.

8.2.2 Consent procedures
Electronic information and consent forms were provided for those using the online survey. For those under the age 18 a separate option was provided for the consent of parents/guardians.

8.2.3 Distribution of the survey
A number of international and regional youth organisations were contacted to assist in the distribution of the survey. These included those involved in advocacy, LGBT, people who inject drugs, young people living with HIV, and SRH and HIV education. Twenty-one organisations agreed to distribute the survey to their networks through websites, e'newsletters and blogs. Many of these organisations are part of larger networks of local youth organisations. For example Dance4Life has disseminated the survey to local partners in 28 countries and Global Youth Coalition on HIV/AIDS network reaches 6229 people in 173 countries. Further distribution of the survey was carried out by regional WHO representative to local youth organisations within their region.


8.2.4 Countries of survey respondents

**Americas:** Argentina, Barbados, Bolivia, Brazil, Canada, Chile, Costa Rica Colombia, Dominican Republic, Ecuador, El Salvador, Grenada, Guyana, Haiti, Jamaica, Mexico, Panama, Paraguay, Peru, United States, and Venezuela.

**Eastern Mediterranean:** Egypt, Lebanon, Jordan, Oman, Sudan, and Syria.

**Europe:** Armenia, Austria, Azerbaijan, Belgium, Bosnia and Herzegovina, Bulgaria, Cyprus, Denmark, Estonia, France, Georgia, Germany, Kazakhstan, Kyrgyzstan, Moldova, Netherlands, Norway, Poland, Romania, Russia, Serbia, Switzerland, Turkey, United Kingdom, Ukraine and Uzbekistan.

**South East Asia:** Bangladesh, Bhutan, India, Indonesia, Maldives, Nepal, Pakistan, Sri Lanka, and Thailand.

**Western Pacific:** Australia, Brunei, China, Cambodia, Fiji, Malaysia, Philippines Singapore, Tuvalu and Vietnam.
8.2.5 Data analysis

The data collected from the online survey were exported from survey monkey into SPSS where after we merged the different language subsets into one dataset. The open ended questions (the only non-numerical data in the combined dataset), were translated into English and coded. We further checked for inconsistencies and whether skip patterns were followed. For the latter, we created filters to ensure that the analysis uses the correct denominators (i.e. analysis for testing experiences were filtered on those who tested). Missing data are reported in all tables. We did not impute missing data values since multivariate analysis (dependent on complete cases for variables used during analysis) was not performed. Descriptive statistics were compiled for all variables and presented in frequency tables. New variables were generated to summarize responses to multiple-choice questions, to combine responses to multiple questions and for any required recoding.

We tested, on a 5 percent level of significance, for statistical differences for most variables, by:
- regions as specified in the previous section,
- sex (males and females) and
- sexual orientation (i.e. those who identified themselves as msm versus all other responses combined).

We are aware that this is not a rigorous study design; statistical testing of differences was based on distribution free tests since all our consultation data categorical in nature. For analysis of categorical variables, cross tabulations were analysed using statistical tests such as Pearson’s chi-square or Z-test for proportions for predetermined associations and comparisons of interest. For regional comparisons, we focused on the comparison of three regions (Africa, the Americas and Europe) due to small numbers of respondents from the other countries.

8.3 Service provider interviews

8.3.1 Interview Description

Appropriate service providers were be identified by local WHO offices and contact via email with information regarding the consultation and were asked to express interest in being involved. In South Africa and Zimbabwe interviews were organized in both rural and urban area in the vicinity of the workshops. Service providers in the Philippines were selected to represent the three major islands.

Each interview followed as preset guide and lasted approximately 30 minutes. Topics covered in the interviews include: views and experiences of HTC of adolescents; current capacity to provide HTC to adolescents; suggestions for changes to health service delivery to best support adolescents seeking HTC. Prior to the interview service providers were informed about the purpose of the consultation. Consent to participate was gained after all questions were answered.

8.3.2 Interview guide
- M/F  Age  Years experience
- What is your background?
- What setting do you work in?
- Have you had any special training in adolescents?
- Does your setting offer adolescents HTC?
- Can you explain the process involved in offering an adolescent HTC?
- In your role, how are you involved in adolescent HTC?
- What is your experience of testing adolescents for HIV?
- How do you feel about this? Prompt: Do you feel confident/competent or nervous/under prepared?
- Could you tell me about a recent encounter/consultation that involved providing an adolescent testing and counselling for HIV?
- How do you feel about the way in which HTC is provided to adolescents both in your setting and in general?
- In what circumstance would an adolescent be offered HTC?
- In what circumstance would an adolescent NOT be offered HTC?
- Do you have anything in your service to make HTC more suitable/acceptable for adolescents?
- What is the current capacity of your setting/service to provide HTC to adolescents?
- In your experience, what do you feel are important considerations when offering AHTC?
- What do you think are the main barriers around adolescent testing for HIV?
- What do you think could be done in your setting and in general to make HTC more accessible and acceptable for adolescents?
- Do you have a national or clinical policy regarding AHTC?
- Have you had any training in relation to its provision? If so what?
- Do you have any supervision? If so what?
- What guidance does it have around consent and disclosure?
- What guidance does it have around parental involvement?

8.3.3 Organisations involved in service provider interviews

South Africa

- **loveLife** - provide testing at their Y-Centers, outreach HTC and groundBREAKER support in local DOH clinics.
- **The Society for Family Health** - provide New Start HTC centers and conduct the YouthAIDS peer educator project
- **AIDS health foundation** - provide clinic and outreach based HTC
- **Grassroots Soccer** – an NGO that uses the soccer as a tool for HIV prevention, education and community mobilization

Zimbabwe

- **Zimbabwe National Family Planning Council** - provide family planning services, life skills training, and recreation services in youth centers and family planning clinics
- **Department of Health Zimbabwe** – government services providing HTC in primary health care clinic, district and central hospital in urban and rural areas

Philippines

- **City Health Department** – government services for registered, establishment-based females in sex work, men who have sex with men and people who inject drugs through social hygiene clinics with regular education, STI screening, and offer of HTC. Recently, HTC outreach also started in prison settings and with child-caring institutions.
- **AIDS Society of the Philippines (ASP)**
- **Online Chatters** - NGO’s providing outreach, including HTC, and online information to MSM
- **Council for the Welfare of Children** - the government agency for children’s protection, welfare and development
- **Center for Promotion, Advocacy and Protection of the Rights of the Child (Lunduyan Foundation)** - implements project targeting children living with HIV, including developing their life skills, and undertakes advocacy so that child rights can be promoted and protected
8.3.4 Interview data management and analysis
As per workshops

8.4 Approval requirements
In each country the requirements for approval to carry out the consultation differed. Within South Africa national and provincial departments of health were informed by WHO country office and by local partners and organizing institute prior to carrying out the activities. Approval in Zimbabwe was arranged by the WHO country office and granted by the Ministry of Health. As this was a community consultation a waiver was given by the Medical Research Council Zimbabwe

8.5 Online survey findings tables
Notes on tables:
We tested for statistical significant differences on region, sex, and sexual orientation for most of the variables in our online survey. Where we found regional differences, tables are presented by region, for differences between males and females, tables are presented by sex and a similar approach for sexual orientation where we tested for differences between MSM and other orientations. Where no statistical significant differences were found, only frequencies for the particular variable are given. Highlighted rows indicate the statistical significance per table.

<table>
<thead>
<tr>
<th>Table 1: Descriptive statistics for HIV testing data:</th>
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<tbody>
<tr>
<td>Description</td>
</tr>
<tr>
<td>Ever tested</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Never tested and would like to test</td>
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<td>Total</td>
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Table 2: Have you ever had a HIV test? (Q9)

<table>
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<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
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<tr>
<td>Total</td>
<td>517</td>
<td>78.9</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>655</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3: Sex and regional distribution of first and repeat testers (Q15)

<table>
<thead>
<tr>
<th>Region</th>
<th>Q15 First time and repeat testers</th>
<th>First time tester</th>
<th>Repeat tester</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>Row Valid N %</td>
<td>Count</td>
</tr>
<tr>
<td>Male Region</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Africa</td>
<td>13</td>
<td>20.6%</td>
<td>50</td>
</tr>
<tr>
<td>Americas</td>
<td>17</td>
<td>36.2%</td>
<td>30</td>
</tr>
<tr>
<td>Eastern Mediterranean</td>
<td>0</td>
<td>.0%</td>
<td>2</td>
</tr>
<tr>
<td>Europe</td>
<td>11</td>
<td>33.3%</td>
<td>22</td>
</tr>
<tr>
<td>South East Asia</td>
<td>4</td>
<td>57.1%</td>
<td>3</td>
</tr>
<tr>
<td>Western Pacific</td>
<td>2</td>
<td>18.2%</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>47</td>
<td>28.8%</td>
<td>116</td>
</tr>
<tr>
<td>Female Region</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Africa</td>
<td>9</td>
<td>25.7%</td>
<td>26</td>
</tr>
<tr>
<td>Americas</td>
<td>14</td>
<td>38.9%</td>
<td>22</td>
</tr>
<tr>
<td>Eastern Mediterranean</td>
<td>1</td>
<td>33.3%</td>
<td>2</td>
</tr>
<tr>
<td>Europe</td>
<td>34</td>
<td>50.7%</td>
<td>33</td>
</tr>
<tr>
<td>South East Asia</td>
<td>3</td>
<td>75.0%</td>
<td>1</td>
</tr>
<tr>
<td>Western Pacific</td>
<td>1</td>
<td>33.3%</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>62</td>
<td>41.9%</td>
<td>86</td>
</tr>
</tbody>
</table>
Table 4: Q11 Reasons for not testing in the past (for those who answered no to “Have you ever had a HIV Test?” and yes to “Would you like to have a test?” (n=111)) by Region

<table>
<thead>
<tr>
<th>Region</th>
<th>Africa</th>
<th>Americas</th>
<th>Eastern Mediterranean</th>
<th>Europe</th>
<th>South East Asia</th>
<th>Western Pacific</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Total</td>
<td>1</td>
<td>100.0</td>
<td>18</td>
<td>100.0</td>
<td>3</td>
<td>100.0</td>
</tr>
<tr>
<td>Afraid of the results</td>
<td>9</td>
<td>52.9%</td>
<td>4</td>
<td>22.2%</td>
<td>3</td>
<td>23.1%</td>
</tr>
<tr>
<td>Afraid that they will inform my parents</td>
<td>0</td>
<td>.0%</td>
<td>2</td>
<td>11.1%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Couldn’t afford it</td>
<td>0</td>
<td>.0%</td>
<td>2</td>
<td>11.1%</td>
<td>1</td>
<td>7.7%</td>
</tr>
<tr>
<td>Didn’t know where to get tested</td>
<td>1</td>
<td>5.9%</td>
<td>7</td>
<td>38.9%</td>
<td>3</td>
<td>23.1%</td>
</tr>
<tr>
<td>Don’t trust services</td>
<td>4</td>
<td>23.5%</td>
<td>3</td>
<td>16.7%</td>
<td>2</td>
<td>15.4%</td>
</tr>
<tr>
<td>Haven’t had the opportunity</td>
<td>3</td>
<td>17.6%</td>
<td>9</td>
<td>50.0%</td>
<td>6</td>
<td>46.2%</td>
</tr>
<tr>
<td>It’s not a priority</td>
<td>8</td>
<td>47.1%</td>
<td>6</td>
<td>33.3%</td>
<td>8</td>
<td>61.5%</td>
</tr>
<tr>
<td>Low risk</td>
<td>1</td>
<td>5.9%</td>
<td>0</td>
<td>.0%</td>
<td>1</td>
<td>7.7%</td>
</tr>
<tr>
<td>Scared of what others may think</td>
<td>3</td>
<td>17.6%</td>
<td>3</td>
<td>16.7%</td>
<td>2</td>
<td>15.4%</td>
</tr>
</tbody>
</table>
Table 5: Q12 Reasons for not testing (for those who answered no to “Have you ever had a HIV Test?” and no to “Would you like to have a test?” (n=48))

<table>
<thead>
<tr>
<th>Reason</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afraid of the result</td>
<td>48</td>
<td>100.0%</td>
</tr>
<tr>
<td>I feel healthy</td>
<td>2</td>
<td>4.2%</td>
</tr>
<tr>
<td>I feel that I have minimal risk</td>
<td>14</td>
<td>29.2%</td>
</tr>
<tr>
<td>(no multiple partners, no unprotected sex, or never injected drugs)</td>
<td>21</td>
<td>43.8%</td>
</tr>
<tr>
<td>No reason to need one</td>
<td>24</td>
<td>50.0%</td>
</tr>
<tr>
<td>Scared of what others may think</td>
<td>2</td>
<td>4.2%</td>
</tr>
</tbody>
</table>
Table 6: Q16 What prompted you to have this test (for those who answered yes to “Have you ever had a HIV Test?” (n=351))

<table>
<thead>
<tr>
<th>Region</th>
<th>Africa</th>
<th>Americas</th>
<th>Eastern Mediterranean</th>
<th>Europe</th>
<th>South East Asia</th>
<th>Western Pacific</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Total</td>
<td>105</td>
<td>100.0%</td>
<td>87</td>
<td>100.0%</td>
<td>5</td>
<td>100.0%</td>
</tr>
<tr>
<td>Be an example</td>
<td>2</td>
<td>1.9%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Done without my knowledge or consent</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Encouraged by a friend</td>
<td>11</td>
<td>10.5%</td>
<td>5</td>
<td>5.7%</td>
<td>5</td>
<td>4.8%</td>
</tr>
<tr>
<td>Encouraged by family</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Encouraged by my partner</td>
<td>16</td>
<td>15.2%</td>
<td>9</td>
<td>10.3%</td>
<td>1</td>
<td>20.0%</td>
</tr>
<tr>
<td>Felt unwell</td>
<td>5</td>
<td>4.8%</td>
<td>6</td>
<td>6.9%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Had an experience that may have exposed me to HIV</td>
<td>16</td>
<td>15.2%</td>
<td>18</td>
<td>20.7%</td>
<td>2</td>
<td>40.0%</td>
</tr>
<tr>
<td>Just wanted to know</td>
<td>49</td>
<td>46.7%</td>
<td>33</td>
<td>37.9%</td>
<td>2</td>
<td>40.0%</td>
</tr>
<tr>
<td>New relationship</td>
<td>12</td>
<td>11.4%</td>
<td>14</td>
<td>16.1%</td>
<td>1</td>
<td>20.0%</td>
</tr>
<tr>
<td>Offered as part of a visit to obtain contraceptives (birth control)</td>
<td>1</td>
<td>1.0%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Offered as part of my care when I was pregnant</td>
<td>8</td>
<td>7.6%</td>
<td>2</td>
<td>2.3%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Offered by a health care worker</td>
<td>20</td>
<td>19.0%</td>
<td>22</td>
<td>25.3%</td>
<td>1</td>
<td>20.0%</td>
</tr>
<tr>
<td>Part of a sexually transmitted infection screen</td>
<td>10</td>
<td>9.5%</td>
<td>14</td>
<td>16.1%</td>
<td>1</td>
<td>20.0%</td>
</tr>
<tr>
<td>Requirement</td>
<td>8</td>
<td>7.6%</td>
<td>9</td>
<td>10.3%</td>
<td>0</td>
<td>0.0%</td>
</tr>
</tbody>
</table>
Table 7: Q30 Reasons that has prevented disclosure (for those who answered yes to “Have you ever had a HIV Test?” and no to “Did you tell anyone your result” (n=57)) by sex

<table>
<thead>
<tr>
<th>Reason</th>
<th>Sex</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100.0%</td>
<td>22</td>
</tr>
<tr>
<td>Afraid of the consequences</td>
<td>2</td>
<td>5.7%</td>
<td>1</td>
</tr>
<tr>
<td>Don’t have anyone supportive to tell</td>
<td>6</td>
<td>17.1%</td>
<td>2</td>
</tr>
<tr>
<td>I can manage by myself</td>
<td>23</td>
<td>65.7%</td>
<td>6</td>
</tr>
<tr>
<td>It was negative, so it was not necessary</td>
<td>4</td>
<td>11.4%</td>
<td>5</td>
</tr>
<tr>
<td>Not a priority</td>
<td>1</td>
<td>2.9%</td>
<td>1</td>
</tr>
<tr>
<td>Scared that they will tell others</td>
<td>3</td>
<td>8.6%</td>
<td>3</td>
</tr>
<tr>
<td>Still dealing with it myself</td>
<td>2</td>
<td>5.7%</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 8: Q36 Barriers to testing (for those who answered yes to “Have you ever had a HIV Test?” and yes to “Have you experienced any barriers in getting a HIV test?” (n=61)) by sex

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Sex</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Total</td>
<td>37</td>
<td>100.0%</td>
<td>24</td>
</tr>
<tr>
<td>Afraid that other people will see me go into the clinic</td>
<td>10</td>
<td>27.0%</td>
<td>5</td>
</tr>
<tr>
<td>Cost</td>
<td>7</td>
<td>18.9%</td>
<td>1</td>
</tr>
<tr>
<td>Did not know where to get tested</td>
<td>8</td>
<td>21.6%</td>
<td>7</td>
</tr>
<tr>
<td>Scared of what others may think</td>
<td>12</td>
<td>32.4%</td>
<td>4</td>
</tr>
<tr>
<td>Services at inconvenient locations</td>
<td>9</td>
<td>24.3%</td>
<td>6</td>
</tr>
<tr>
<td>Services at inconvenient times</td>
<td>11</td>
<td>29.7%</td>
<td>7</td>
</tr>
<tr>
<td>Unfriendly health workers</td>
<td>16</td>
<td>43.2%</td>
<td>9</td>
</tr>
<tr>
<td>Worried about the reaction of health workers</td>
<td>21</td>
<td>56.8%</td>
<td>7</td>
</tr>
</tbody>
</table>
**Table 9: Q37** Biggest concerns when deciding to have a HIV test (for those who answered *yes* to “Have you ever had a HIV Test?” (n=351)) by MSM and others

<table>
<thead>
<tr>
<th>Concern</th>
<th>Man who has sex with men</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Total</td>
<td>82</td>
<td>100.0%</td>
</tr>
<tr>
<td>Afraid of the results</td>
<td>45</td>
<td>54.9%</td>
</tr>
<tr>
<td>Afraid that they will inform my parents</td>
<td>7</td>
<td>8.5%</td>
</tr>
<tr>
<td>Couldn't afford it</td>
<td>5</td>
<td>6.1%</td>
</tr>
<tr>
<td>Didn't know where to get tested</td>
<td>7</td>
<td>8.5%</td>
</tr>
<tr>
<td>Scared of what others may think</td>
<td>22</td>
<td>26.8%</td>
</tr>
<tr>
<td>The reaction of health workers</td>
<td>17</td>
<td>20.7%</td>
</tr>
</tbody>
</table>

**Table 10: Q45** What could be done to encourage other adolescents to test for HIV (n=650) by sex. Note: Although 650 answered this question. sex was missing for 160 adolescents

<table>
<thead>
<tr>
<th>What could be done to encourage other adolescents to test for HIV</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Total</td>
<td>252</td>
<td>98.4%</td>
</tr>
<tr>
<td><strong>Available free of charge</strong></td>
<td>176</td>
<td>68.8%</td>
</tr>
<tr>
<td>Available in venues other than health services</td>
<td>132</td>
<td>51.6%</td>
</tr>
<tr>
<td>Discussions*</td>
<td>2</td>
<td>.8%</td>
</tr>
<tr>
<td><strong>Education in schools</strong></td>
<td>190</td>
<td>74.2%</td>
</tr>
<tr>
<td>Incentives</td>
<td>0</td>
<td>.0%</td>
</tr>
<tr>
<td>Integrated</td>
<td>2</td>
<td>.8%</td>
</tr>
<tr>
<td>Involve people on influence</td>
<td>1</td>
<td>.4%</td>
</tr>
<tr>
<td>Involve youth*</td>
<td>2</td>
<td>.8%</td>
</tr>
<tr>
<td>Mass media</td>
<td>148</td>
<td>57.8%</td>
</tr>
<tr>
<td>Mobile</td>
<td>1</td>
<td>.4%</td>
</tr>
<tr>
<td>Offered by health care providers</td>
<td>83</td>
<td>32.4%</td>
</tr>
<tr>
<td>Peer educators/workers</td>
<td>3</td>
<td>1.2%</td>
</tr>
<tr>
<td>Remove legal barriers</td>
<td>1</td>
<td>.4%</td>
</tr>
<tr>
<td>Youth friendly (or non-judgmental) services</td>
<td>170</td>
<td>66.4%</td>
</tr>
</tbody>
</table>

*Additional items mentioned by adolescents*
Care and treatment values, preferences, and attitudes of adolescents living with HIV

A survey for the development of WHO guidelines for HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV: recommendations for a public health approach
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Written by Kathleen Fox, Department of HIV, World Health Organization, Geneva.

Survey developed and/or analyzed by Kathleen Fox, Rachel Baggaley, Katherine Noto, and Gonçalo Figueiredo Augusto of the Department of HIV, WHO; and Jane Ferguson of the Department of Maternal, Newborn, Child, and Adolescent Health, World Health Organization, Geneva.
Abbreviations and acronyms

AIDS  acquired immune deficiency syndrome
ALHIV  adolescents living with HIV
ANC  antenatal care
ART  antiretroviral therapy
ARVs  antiretrovirals
CDC  U.S. Centers for Disease Control and Prevention
CHTC  couples HIV testing and counselling
DHS  Demographic and Health Surveys
FBOs  faith-based organizations
HIV  human immunodeficiency virus
HTC  HIV testing and counselling
MCH  maternal and child health
M&E  monitoring and evaluation
MMC  medical male circumcision
MSM  men who have sex with men
NGOs  non-governmental organizations
OST  opioid substitution therapy
PEPFAR  U.S President’s Emergency Plan for AIDS Relief
PITC  provider-initiated testing and counselling
PMTCT  prevention of mother-to-child transmission
PrEP  pre-exposure prophylaxis
PWID  people who inject drugs
RCT  randomized controlled trial
STI  sexually transmitted infection
SW  sex workers
TB  tuberculosis
UN  United Nations
UNAIDS  Joint United Nations Programme on HIV/AIDS
UNICEF  United Nations Children’s Fund
UNFPA  United Nations Population Fund
USAID  United States Agency for International Development
VCT  voluntary HIV testing and counselling
WHO  World Health Organization
YKAP  young key-affected population
Executive Summary

Globally, more than two million adolescents aged 10–19, and five million young people aged 15–24 are living with HIV. Many factors contribute to this: from low levels of testing and linkage to care and prevention, to poor retention in care and adherence to antiretroviral treatment (ART). By increasing adolescent-focused treatment and care services, adolescents and young people (10–24 years) will be more likely to be better engaged in care and treatment, thus reducing morbidity and mortality in this greatly underserved population.

A scoping exercise of published literature relating to the care and treatment values and preferences of adolescents living with HIV (ALHIV) was conducted using PubMed, Google scholar and Google. The search method employed combinations of terms for adolescents, HIV, care, service, and values and preferences. Studies were categorized and qualified by topic, study design type, and income level. This informed the content of an e-survey of 36 questions that was disseminated in six languages through various international and youth organizations (379 respondents aged 10–24 years from 46 countries completed the survey in full).

The scoping exercise highlighted eleven major themes, chief amongst them were access to care and medication, psychological/mental health support, transition and continuity of care services and support, learning materials about HIV, opportunities to participate in or be responsible for their own health care, and health-care provider knowledge, attitudes, and confidentiality. Data collected from the survey revealed that 72% of ALHIV had either some or significant difficulty accessing health care, but about 87% felt comfortable asking health providers about either their general health (85%) or HIV (88%). Open-ended questions underscored the importance of staff and peer support (~72%). Respondents suggested better or more education (~37%) and age-appropriate support (~35%) as areas for improvement.

Adolescents need to be engaged in their HIV care and treatment. Governments and organizations need to tailor services to meet the specific needs of adolescents and support the development of responsibilities aimed at self-care. At the same time, governments must identify and address barriers to acceptable and effective provision of services to adolescents, including the training of service providers to better communicate with this unique and underserved population.
1. Introduction

Globally, over two million adolescents aged 10–19, and five million young people aged 15–24 are living with HIV. Many factors contribute to this high prevalence: from low levels testing and linkage to care and prevention, to poor retention in care and adherence to antiretroviral treatment (ART) in this population. By increasing adolescent-focused treatment and care services, adolescents (10–19 years) and young people (20–24 years) will be more likely to be better engaged in care and treatment, thus reducing morbidity and mortality in this greatly underserved population.

Adolescents living with HIV (ALHIV) have been infected with HIV through one of two pathways: through vertical transmission, from mother to child via pregnancy or breastfeeding, or through horizontal transmission, from either sexual (i.e. consensual or non-consensual penetrative sex) or non-sexual methods (e.g. injecting drug use, exposure to infected blood, medical procedures).

Systematic reviews have been conducted to examine a range of relevant studies on adolescent-related topics from the availability of HIV testing and counselling services for adolescents to the provision of and access to HIV care and treatment services for ALHIV. These reviews have indicated significant barriers and facilitators to improving the provision of and access to health care and HIV services for ALHIV: however, few of the studies discussed in these reviews have included the values, preferences, and perceptions of the adolescents themselves.

The WHO guidelines development process requires consultation with stakeholders engaged at all levels: this survey was developed to understand the values, preferences, and attitudes of the end-users—adolescents and young people living with HIV—of various types of HIV care and treatment services and interventions. A survey was conducted to facilitate the inclusion of those voices into the guidelines process.

The results of the survey are presented in this report and will be used as supporting information for the Guideline Development Group (GDG). The GDG is comprised of experts in adolescent health and HIV from various countries and affiliations, including civil society. The data and results of the survey will be considered in conjunction with graded literature to aid the development of the guidelines at a meeting of experts to be held in October and November 2012.

2. Objectives

A study of the values and preference of adolescents was conducted to facilitate the participation of those who will be most affected by HIV care and treatment services for adolescents living with HIV and the inclusion of their voices in the guidelines development process. The key objectives of this study were:

- To gain an adolescent perspective of HIV care and treatment services including the benefits and barriers to accessing services and remaining retained in care;
- To have a better understanding of what aspects of care and treating are important to adolescents when seeking, initiating, and remaining in care;
- To explore accessibility and effectiveness of services from adolescents’ viewpoints.

3. Methodology

3.1 Survey design

The development of the survey was conducted in two distinct phases. First, a scoping review of published and gray literature (37 sources, descriptive studies, and reports were identified during the
literature review) was conducted to look at current discussions of and studies examining the values, preferences, and attitudes of adolescents and young people living with HIV (10–24 years) regarding their health and HIV care. The scoping exercise identified eleven key themes to be addressed in the community survey:

- Access to care and medication – broadly defined to include not only physical access to treatment and care, but also financial and social support (including provider and community stigma which were found to be major barriers to utilization of available services);
- Structure of health-care services;
- Availability of youth-friendly or adolescent-only services;
- Opportunities to participate in or be responsible for one’s own health care;
- Transition and continuity of care services and support – from paediatric and/or adolescent services to adult health- or HIV-care services;
- Psychosocial/mental health support – from access to counsellors to skills development;
- Peer, community, and social support;
- HIV education and knowledge- and skills-building services;
- Sexual and reproductive health education and services;
- Knowledge, attitudes, and confidentiality of health-care providers;
- Confidentiality, disclosure, and privacy.

Based on the findings of scoping exercise, examination of published and unpublished HIV-related surveys, and discussion with WHO and GNP+ (Global Network of People living with HIV) colleagues, a draft of the survey was developed. With the assistance of GNP+ the survey was pilot tested by seven members of Y+, a network within GNP+, comprised of adolescents and young people living with HIV—from Africa, South America, and Asia, and feedback was provided through GNP+, thus maintaining the anonymity of the young people. Based on that feedback and further discussions with Georgina Caswell at GNP+, a second draft was developed and then pilot tested by five young people in a group at the Mortimer Market and Archway Centres in London.

The final survey was comprised of thirty-six questions: thirty-three close-ended and three open-ended. Only three of the questions were required: The first asking for the respondent to consent to take the survey, another asking the respondent’s age, and the last asking for the respondent’s HIV status. The last two questions served to disqualify those who did not fall within the defined survey population—adolescents and young people living with HIV (10–24 years).

The survey asked respondents to provide demographic data regarding their age, sex, location, occupation, and HIV status. If they indicated they were HIV-positive, they then answered questions about what types of services providers they access and how often, how they felt about the services available to them, what types of services they would like, and how responsible they were for their own health—from making their own appointments to remembering to take their medication. The approximate completion time was twelve to fifteen minutes (depending on length of answers provided for open-ended questions).

The survey was translated by volunteers into five languages—Spanish, French, Russian, Thai, and Arabic, and, along with the English version, were uploaded to the internet.

3.2 Distribution of the survey

Information about the survey was provided to a wide range of international, national, and regional networks working with adolescents living with HIV, asking them to circulate the survey in either digital
or paper form. A few of the community-based networks and groups also assisted with the administration of the survey.

3.3 Ethical considerations

Anonymity of participants

The survey was designed to keep the identities of the respondents anonymous. No identifiable information was requested and no IP addresses were stored. Where computer access was lacking or limited at best, the survey was administered on paper in a manner suitable to the context (e.g. placed in envelopes that were then sealed and shipped to WHO), while retaining the anonymity of the respondents as best as possible. In cases where the respondents required assistance or translation by an administrator was required, survey administrators gained verbal consent from the adolescent respondents.

Opt in, opt out

One group from Lesotho, administering the survey verbally on an individual basis, chose to eliminate the question asking if the respondents knew how they got HIV because the administrators felt that the question was too sensitive for their group of young people. Adolescents and young people taking the e-survey were able to skip almost all of the questions provided, with the exception of the three questions asking for their consent to take the survey, their age, and if they are living with HIV. The latter two questions were used to disqualify respondents who did not fall within the required age range of 10–24 years and were not currently living with HIV. For those respondents within the qualifying age range, who chose not to disclose their HIV status, the disqualification message reemphasized the purpose of the survey: “We are looking for the opinions and experiences of young people (ages 10–24) living with HIV who know they are living with HIV and are willing to disclose their status. If you are living with HIV and would like to complete the full survey, please start again.” On every page of the survey respondents were provided an exit button, enabling them to leave the survey at any point they wished.

3.4. Survey consultation respondents

The survey consultation was available in both electronic and paper versions in order to reach as many adolescents and young people as possible.

A total of 830 people started the online surveys—available in English, Spanish, French, Thai, and Russian—after which 376 were disqualified because of age or because they exited the survey and 116 were disqualified because they indicated they were not HIV positive or did not know or did not wish to disclose their status. The disqualification statement explained we were looking for opinions from young people living with HIV regarding their care and invited those who were disqualified to complete the survey by disclosing their status. 338 respondents remained within this group.

An additional 111 adolescents and young people completed paper versions of the survey, 2 of which were disqualified because they answered ‘I don’t know’ regarding their HIV status. 109 respondents remained within this group.

A total of 447 adolescents and young people completed the full survey.

- Ages: 10–12 (26), 13–14 (39), 15–16 (47), 17–18 (63), 19–20 (91), 21–22 (82), 23–24 (99)
- 57 countries represented
  - The greatest number of respondents come from Cameroon (55), India (50, evenly distributed amongst the age groups), Nigeria (50, mainly between 17 and 22 years), Thailand (28, evenly distributed amongst age groups), Ghana (25, mainly between 17
and 22 years), Lesotho (18, between 10 and 18 years), Philippines (17, between 19 and 24 years), Malawi (15, mainly between 14 and 20 years), Zimbabwe (15, mainly between 21 and 24 years), Mexico (13, between 19 and 24 years) and Rwanda (12, fairly evenly distributed amongst the age groups)

- Eight countries had between 5 and 10 respondents, while the remaining countries had between 1 and 3 respondents.
- Several adolescent-focused NGOs were very successful gaining participants in Cameroon, India, Lesotho, Malawi, and Rwanda. Surprisingly, teen club participation, even at the individual level, was very low or nonexistent in Swaziland (1) and Botswana (0).

**Table 1. Characteristics of survey respondents by age, sex, and country [including non-responses]**

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3.5. Limitations of the survey consultation

While the survey was circulated globally, adolescents already actively engaged in HIV care and treatment provided the highest number of respondents. For this reason, the survey results were limited and not representative of all adolescents living with HIV who may not be linked to networks or receiving care. In general, the adolescents receiving care described being happy with their care, however a significant proportion—between 72 and 74%—were not.

For these reasons, any quantitative data collected must be perceived as limited at best. However, the research does provide us with some understanding of adolescents, particularly those in areas where participation in the survey was higher: New Delhi, India (India HIV/AIDS Alliance); Maseru, Lesotho (Sentebale); Malawi (unknown teen club); Cameroon (Positive Action for Treatment Access and an unknown adolescent support group); Kigali, Rwanda (UNICEF country team).

4. Key findings from survey consultation

Ease of access to services. Most of the adolescents and young people who took the survey expressed that access to care and attending health-care appointments were either very easy or not a significant challenge. Twenty-nine per cent of respondents (63 male and 50 female) reported that it was very easy to access services, 62% (105 male and 139 female) reported variability in the ease of access and 10% (26
male and 10 female) reported that it was very difficult to access their health-care services. Twenty-six per cent of respondents felt that attending health-care appointments did not interfere with their lives at all, however 59% felt that it sometimes interfered and 15% felt that attending health-care services interfered with their lives a great deal.

Twenty-six per cent of those who responded to the open-ended question asking what they liked the most about the care they receive, stated that access to treatment—from availability and cost of regular health check-ups and drug treatment (ART) services to proximity of services, short lines/queues, and specialized health-care workers—was a major factor in their positive experience with their current health-care and HIV services. Several mentioned the importance of NGOs in supporting the provision of life-saving drugs and services.

“I like the way they help us in treatment by free of cost.” 10-12, Female, India

“The supports provided by some of the NGOs like medicine support, education support and psychological support.” 15-16, Male, India

“About HIV care and treatment given by govt. hospitals and other NGOs working in the field.” 19-20, Female, India:

“The clinic is not far from my dormitory…” 21-22, Female, Thailand

“Poder tener la atención cuando la necesito y también la medicación” [“Having the attention when I need it and also the medication”] 23-24, Male, Argentina:

“That I freely access the ARVs and it’s very rare to find drug stock outs at the clinic as its in the city center.” 23-24, Male, Uganda

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

“Yo soy Uruguayo y tuve que venirme a tratar a Argentina porque aquí casi todo el tratamiento y la medicación es gratuita. En Uruguay no, hay una extrema ignorancia desde todos los puntos de vista, ni la medicación es gratuita, ni la facilitan, ni el tratamiento en sí.” [“I’m from Uruguay and I had to come to Argentina to get treatment because here almost all treatment and medication is given for free. In Uruguay it’s not like that. There is a lot of ignorance and medication and treatment are not free or facilitated.”] 21-22, Male, Uruguay

“Comprehensive health services, including SRH [sexual and reproductive health] and no stigma discrimination” 21-22, Female, Indonesia

“Make it easier to get meds and pick them up at other locations.” 23-24, Male, Argentina

“Need to improve on attendance time by the doctor when I or other young people visit a health facility due to stigma. Need pharmacy attendance to be sensitized on how they handle young YPLWHIV at the counter.” 23-24, Female, Kenya

“The health centers should have youth friendly stuff to cater for our needs, also privacy is an issue, not all of us are ready to disclose, there is a problem at our hospitals when we queue at a window written ARVs everyone can see that we are HIV positive and that makes the stigma to be worse.” 23-24, Female, Swaziland
Interactions with providers. In the survey, most of the respondents indicated they had good experiences interacting with health-care providers and felt comfortable asking both general health- and HIV-related questions. Eighty-five per cent of respondents reported moderately good to very good interactions (51% moderately good and 34% very good) with their providers in terms of comfort in asking general health-related questions. However, 15% did not report good interactions with their health-care providers. Eighty-eight per cent of respondents reported moderately good to very good interactions (51% moderately good and 38% very good) with their providers in terms of comfort in asking HIV-related questions. Thirty-five per cent reported that a provider contacts them if they miss an appointment.

“Я могу спокойно разговаривать с ними обо всём, включая и свое заболевание. Могу открыто излагать свои потребности.” [“I can calmly talk to my care givers about everything, including my condition. I can openly express my needs.”] 15-16, Male, Kazakhstan

“The way the doctors care for us as patients, they show love and care.” 15-16, Female, Malawi

“Everyone at the clinic is so understanding and they are willing to help me with any problems I come across. I can really trust them.” 17-18, Female, USA

“Friendly environment with the care givers in the health centres.” 19-20, Male, India

“I suggest if the attitude of health care providers could be changed, it will help we the young people have access to the care services we need. Their attitude towards young people seeking treatment is very poor. They usually judge why young people seek treatment or contraceptives and this affects how they help the young even if he/she is at risk. We need a youth-friendly environment that can attract and serve the young who may be embarrassed or intimidated to seek HIV care.” 23-24, Female, The Gambia

Transition to adult services. The survey revealed that a majority of adolescents and young people either do not receive paediatric or adolescent services, or, if they do, have never discussed transitioning to adult services. The age distribution of the 40% who answered they had not discussed transition with their health-care providers was evenly distributed throughout the 10 to 24 year age range. Of the respondents who said they are currently receiving paediatric or adolescent services, 38% had discussed a transition to adult care with their provider on at least one occasion, 40% had discussed it two to three times with their provider, and 22% had discussed it more than three times with their provider.

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

- **Making one's own appointment** (34%–never; 7%–not now, but would like to; 32%–sometimes; 22%–all the time; 4% not applicable);
- **Attending appointments alone** (13%–never; 17%–not now, but would like to; 27%–sometimes; 41%–all the time; 2% not applicable);
- **Asking the provider questions** (7%–never; 18%–not now, but would like to; 44%–sometimes; 30%–all the time; 1% not applicable);
- **Helping to choose one's own treatment plan** (28%–never; 22%–not now, but would like to; 24%–sometimes; 20%–all the time; 6% not applicable);
- **Picking up one's own medication** (16%–never; 10%–not now, but would like to; 22%–sometimes; 48%–all the time; 4% not applicable);
- Remembering to take one’s medication (34%–never; 7%–not now, but would like to; 32%–sometimes; 22%–all the time; 4% not applicable);
- Seeking other types of care as desired or needed (3%–never; 3%–not now, but would like to; 10%–sometimes; 81%–all the time; 3% not applicable).

The most positive aspects of care reported by respondents included sensitive and caring treatment by providers; home visits; opportunities for meeting other ALHIV to share experiences and to feel empathy with others; and interactions with providers who preserve a sense of optimism and hope, and explain that all of life’s experiences and dreams are open to ALHIV.

Twenty-three per cent of those who responded to the open-ended question asking what they liked most about the care they receive, valued the support the received from peer groups, teen clubs, and peer mentors:

“I enjoy being with other children because I learn about good adherence.” 13-14, Female, Lesotho

“Having the to be a part of a support group (teen club) Having mentors who have so much information on HIV.” 15-16, Male, Malawi

“การเรียนรู้เรื่องการดูแลสุขโดยผ่านการท ากิจกรรมกลุ่ม มากกว่าการนั่งฟังข้อมูลอย่างเดียว” [“Learning through group activities, rather than sit and listen to the same information...”] 15-16, Male, Thailand

“People like us should have counselling and we should counselling others were should make them be comfortable.” 15-16, Female, Lesotho

“Supportive friends and other PLHIV including a presence by PLHIV volunteers at the hospital.” 17-18, Female, Nepal

“Que se explique las oportunidades de seguir viviendo con calidad de vida, testimonios de personas que han superado la etapa de diagnostico de ser PVV” [“I like that the opportunities of living with quality of life are explained, and testimonials of people who have overcome the diagnosis of HIV are shared.”] 21-22, Male, Venezuela

“Avoir des séances de soutiens entre pairs, avoir des formations pour mieux se prendre en charge dans le futur sans que mon statut s’y affecte. J’aimerais aussi avoir un traitement de qualité basé sur une éducation sexuelle adaptée à mon âge” [“I like to have the group support sessions, to have training to better take care of myself in the future without being affected by my status. I would also like to have a quality treatment based on appropriate sex education for my age.”] 21-22, Female, Senegal

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

Thirty-one per cent of those who provided suggestions on how to improve services indicated the need for age-appropriate support—from the separation of adolescent and adult services by location, day, or time, to the provision of peer support in the forms of groups, mentoring, teen clubs, or camps.

“Не хочу чтобы меня видели в очереди другие взрослые больные” [“I do not want to be seen in same line as the adult patients.”] 13-14, Male, Moldova
“Have Teen Clubs at every health centre (Support groups for ALHIV...” 17-18, Male, Malawi

“Our peers should be trained to support more of our friends because entering the clinic the first time I really suffered.” 19-20, Female, Uganda

“Want to keep a special day for young people.” 21-22, Male, India

“Having more HIV peer group activities such as camp. Support the educational funds for who needed.” 21-22, Female, Thailand

“Right now in Zimbabwe, many children suffer stigma and discrimination, so naturally I would say if it were possible to shield them from such harsh treatment as it sometimes leads to suicide. If maybe there could be an adolescent/youth friendly corners all over the country where I do not have to be shy to ask about Adolescent Sexual Reproductive Health.” 21-22, Female, Zimbabwe

“I would like to suggest you or others people in charge of this to find for us young people living with HIV a time for appointment not different to adult” 23-24, Female, Rwanda

5. Discussion

The findings from this survey consultation show that adolescents and young people are not only interested in communicating their care and treatment values, preferences, and attitudes, but also are willing to provide solutions to current inadequacies in services. While the results are limited and therefore not necessarily representative of all adolescents living with HIV globally, the data did highlight five key areas where providers of adolescent services should focus.

First, and most importantly, that services for adolescents living with HIV should be offered. How those services are manifested is largely dependent upon context and availability of resources. If adolescent-specific facilities cannot be created, then possible solutions are adolescent-specific days or times at existing facilities. Regardless of the type of facility, a youth-friendly environment with accessible and communicative health-care providers is necessary to provide a physically and emotionally supportive space where ALHIV can feel safe and protected. Finally, the provision of supportive activities, such as teen clubs, peer mentoring training, and ALHIV camps, offer ALHIV environments where they feel ‘normal’, yet have peers who understand what it is like to live with HIV.

6. Conclusion

Adolescents need to be engaged in their HIV care and treatment. Governments and organizations need to tailor services to meet the specific needs of adolescents and support the development of responsibilities aimed at self-care. At the same time, governments must identify and address barriers to acceptable and effective provision of services to adolescents, including the training of service providers to better communicate with this unique and underserved population.
7. Appendices

7.1 Survey text in English

[Directions for the survey]

1) This question requires an answer.
2) Thank you for your help with our survey.
   We are looking for the opinions and experiences of young people (ages 10 - 24) living with HIV who know they are living with HIV and are willing to disclose their status.
   If you are living with HIV and would like to complete the full survey, please start again.

[Survey Title]
What do you want and need from your health care as a young person living with HIV?

[Introductory Page Content]
Welcome!
The World Health Organization is developing international guidelines on health care for young people living with HIV. We believe it is very important that the voices of young people living with HIV be included in the development of these guidelines.

The survey:
If you are between the ages of 10 and 24 and living with HIV, we ask that you answer the questions in this survey so we can better understand what you want and need from your HIV care.

We hope that the survey will take about 15 minutes to do. Most of the questions will only need you to tick/check an answer; but several questions have boxes where you can write an answer to the question or just tell us your thought and opinions.

Answering the survey is absolutely voluntary – if you feel uncomfortable with a question, you can skip that question or end the survey altogether. However, for us, the more questions you answer, the more we will be able to learn from you.

Your privacy:
The survey starts by asking for some basic information about you. We only ask for that information so we have a basic description – age, sex, country, education – of those who have given us input. We will not be collecting any information about you (or your computer, if you are taking this online) that will link your answers to you – your answers are completely anonymous. This is a safe environment for you to tell us about your thoughts and experiences as a young person living with HIV.

Your thoughts and opinions will help us develop international guidelines for HIV care for young people living with HIV. The guidelines will help organizations and your government understand how to improve services for you.

Please feel free to share the link to this survey with other young people living with HIV. The more voices we hear, the better!

If you have any questions about the survey, please email Kathi (foxka@who.int), Jane (fergusonj@who.int), or Rachel (baggaleyr@who.int).
Thank you so much for your help!

[Consent Title Page]
Do you consent/agree to take this survey?

[Consent Page Content]
Please tick/check the circle below, to confirm that:
The purpose of the survey was described to me. I am volunteering to take this survey and understand that, at any point, I can choose to not answer a question or to leave the survey. I understand that my answers will be anonymous (cannot be linked to me in any way). If I have any questions or concerns about the survey, I can email Kathi (foxka@who.int), Jane (fergusonj@who.int), or Rachel (baggaley@who.int).

1. I understand the points above, and consent to participate in this survey.
   ○ Yes

[Demographic Information Title]
Demographic Information

[Demographic Information Content]
2. As of today, how old are you?
   ○ <10 years of age
   ○ 10-12 years of age
   ○ 13-14 years of age
   ○ 15-16 years of age
   ○ 17-18 years of age
   ○ 19-20 years of age
   ○ 21-22 years of age
   ○ 23-24 years of age
   ○ >24 years of age

3. Are you:
   ○ Male
   ○ Female
   ○ Transgender
   ○ Other (please specify)

4. In what country do you currently live?
   [Survey Monkey will provide answers, or give me a list of countries and I will configure the survey to include only them, and an ‘other’ option]

5. What is the highest level of education that you have completed?
   ○ Primary
   ○ Secondary (high school)
   ○ Tertiary (college, university, or vocational training)
6. Are you currently a student (at any level)?
   - Yes
   - No

7. Are you currently working at a job or volunteering?
   - No, I am too young to work
   - No, I am unemployed
   - Yes, I work or volunteer part-time
   - Yes, I work or volunteer full-time

8. Where do you live?
   - Homeless
   - Orphanage/care home
   - Live with friends
   - Live with family
   - Live alone
   - Other (please specify)

9. Which of the following people give you emotional and practical support? (check all that apply)
   - Family
   - Friends
   - Religious/faith community
   - Health-care provider(s)
   - Peer support group with other young people living with HIV
   - Other (please specify)

10. Are you living with HIV?
    - Yes
    - No
    - I do not know
    - I do not wish to disclose

[Access to Care Title]
Access to Care

[Access to Care Content]
11. How do you think that you got HIV?
    - From my mother
    - Through sexual activities
    - Through drug use (contaminated needle or syringe)
    - From a blood transfusion, exposure to infected blood, or a medical procedure (injections, etc.)
    - I do not know
    - Other (please specify)

12. How often do you visit a health-care provider for your HIV?
    - Never
13. Where do you receive your health care for HIV? (check all that apply)
   - I do not receive care for HIV
   - General health centre
   - HIV clinic
   - Visiting/mobile health workers
   - Other (please specify)

14. How do you pay for your health care? (check all that apply)
   - I attend a free clinic
   - I pay
   - My parents/family pay
   - My insurance company pays
   - The government pays
   - I do not know
   - Other (please specify)

15. My health-care provider(s) primarily care for:
   - Children only
   - Adolescents only
   - Families only
   - Adults only
   - All
   - I do not know
   - Other (please specify)

16. If you are currently receiving paediatric or adolescent services, has/have your health-care provider(s) discussed how you will move to adult services?
   - Never
   - Once
   - Two or three times
   - More than three times
   - I do not receive paediatric or adolescent services

17. What type of health-care provider do you see and how often do you see them?

<table>
<thead>
<tr>
<th>Health-care provider</th>
<th>At least once a month</th>
<th>Every 1-3 months</th>
<th>Over 3 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical doctor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Community health worker</td>
<td></td>
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<td></td>
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<tr>
<td>Lay counsellor/ health advisor</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Traditional provider</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
21. If other, please specify

18. How easy is it for you to access your health care?
   - Very easy
   - Sometimes easy, sometimes difficult
   - Very difficult

19. How long do you have to travel to get to your health-care provider(s)?
   - Under 15 minutes
   - 15 – 30 minutes
   - 30 minutes – 1 hour
   - More than 1 hour

20. Do you feel that attending appointments with health-care providers interferes with your life?
   - Not at all
   - Sometimes
   - Very much

21. If you miss an appointment with a health-care provider, does someone contact you to see why?
   - No
   - Yes, by phone call or SMS
   - Yes, by letter
   - Yes, by contacting my parents
   - Yes, by sending someone to my home
   - Other (please specify)

[Health-care Services Title]
Health-care Services

[Health-care Services Content]
22. How comfortable do you feel asking any of your health-care providers questions about your general health?
   - Not at all comfortable
   - Sometimes comfortable
   - Very comfortable

23. How comfortable do you feel asking any of your health-care providers questions about HIV?
   - Not at all comfortable
   - Sometimes comfortable
   - Very comfortable

24. How comfortable do you feel asking any of your health-care providers questions about sex and reproductive health?
   - Not at all comfortable
   - Sometimes comfortable
   - Very comfortable
25. Does your clinic provide sexual and reproductive health services? (check all that apply)
   - No
   - Yes, they provide condoms
   - Yes, they provide contraceptive methods (pill, IUD, etc.)
   - Yes, they provide screening and treatment for sexually transmitted infections (STIs)
   - Yes, they provide education/information
   - Yes, they provide counselling

26. I would like more information, education, or counselling about: (check all that apply)
   - HIV
   - Drug treatment (ART)
   - Opportunistic infections/ other health problems linked to your HIV
   - Sexually transmitted infections (STIs)
   - Contraception methods
   - Condom use and negotiation skills
   - Relationships with people who are HIV-negative/transmission risk
   - Getting pregnant and having children
   - Prevention of mother-to-child transmission of HIV
   - Disclosure of HIV status/ telling others about your HIV status
   - Harm reduction
   - Legal status
   - Education
   - Jobs
   - Other (please specify)

27. Do you already use the following services?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>No</th>
<th>No, but I would like to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational sessions</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Group meetings for HIV-positive people of all ages led by a professional</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group activities (sports, social gatherings, etc.) for young people living with HIV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer support groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual counselling/mentoring (in person, on the phone, etc.)</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

28. Does the place you go to for your HIV services provide ways for you to give feedback?
   - I do not receive care for HIV
   - No
   - Yes, they have a suggestion box
   - Yes, they do surveys
   - Yes, through a support group
   - Yes, other (please specify)

[Participation in Care Title]
Participation in Care
[Participation in Care Content]

29. Are you responsible for doing the following?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Not now, but would like to be</th>
<th>Sometimes</th>
<th>All the time</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making your own appointments</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending appointments on your own</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asking questions to your health-care provider(s)</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Helping to choose your own treatment plan</td>
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<td></td>
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<tr>
<td>Picking up your own medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remembering to take your medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeking other types of care when you want or need it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

30. If you currently take medication for HIV, do you feel you adequately understand why you are taking it?
   - Not at all
   - Sometimes
   - Very much
   - I do not take medication for HIV

31. Do you feel that there is stigma and discrimination towards people living with HIV in your community?
   - Not at all
   - Sometimes
   - Very much

32. Do you feel more should be done in your community to address stigma and discrimination towards people living with HIV?
   - Not at all
   - Sometimes
   - Very much

33. How satisfied are you with your care for HIV?
   - Not at all
   - Somewhat
   - Very much
   - I do not receive care for HIV

[Comments and Suggestions about Your HIV Care Title]

Comments and Suggestions about Your HIV Care

[Comments and Suggestions about Your HIV Care Content (open-ended questions)]
34. What do you like the most about the HIV care you receive?

35. What suggestions do you have to improve HIV care for yourself or other young people?

36. Is there anything else that you would like to tell us?

[Thank you very much! Title]
Thank you very much!

[Thank you very much! Content]
Thank you very much for sharing your thoughts and experiences with us!
If you have any questions or comments about the survey, email Kathi (foxka@who.int), Jane (fergusonj@who.int), or Rachel (baggaley@who.int).

7.2 Key survey findings in table form
Table 1. Final survey population by age (447/447)

<table>
<thead>
<tr>
<th>Age range</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>10–12</td>
<td>26</td>
</tr>
<tr>
<td>13–14</td>
<td>39</td>
</tr>
<tr>
<td>15–16</td>
<td>47</td>
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<td>17–18</td>
<td>63</td>
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<td>19–20</td>
<td>91</td>
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<tr>
<td>21–22</td>
<td>82</td>
</tr>
<tr>
<td>23–24</td>
<td>99</td>
</tr>
<tr>
<td>Total</td>
<td>447</td>
</tr>
</tbody>
</table>

Table 2. Final survey population by gender/sex (447/447)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>213</td>
</tr>
<tr>
<td>Female</td>
<td>215</td>
</tr>
<tr>
<td>Transgender</td>
<td>9</td>
</tr>
<tr>
<td>Other (gay male, gay men, bisexual)</td>
<td>3</td>
</tr>
<tr>
<td>NR</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>447</td>
</tr>
</tbody>
</table>

Table 3. “If you are currently receiving paediatric or adolescent services, has/have your health-care provider(s) discussed how you will move to adult services?” (Q 16)

<table>
<thead>
<tr>
<th>Answer</th>
<th>Number of responses</th>
<th>Age range</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Never</td>
<td>157 (39.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-12</td>
<td>9</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td>13-14</td>
<td>11</td>
<td>12</td>
<td>-</td>
</tr>
<tr>
<td>15-16</td>
<td>14</td>
<td>12</td>
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</tr>
<tr>
<td>17-18</td>
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<td>17</td>
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<td>19-20</td>
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<tr>
<td>21-22</td>
<td>5</td>
<td>9</td>
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<tr>
<td>23-24</td>
<td>18</td>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td>total</td>
<td>71</td>
<td>80</td>
<td>1</td>
</tr>
</tbody>
</table>

Answer | Number of responses | Age | Gender |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>157 (39.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-12</td>
<td>9</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td>13-14</td>
<td>11</td>
<td>12</td>
<td>-</td>
</tr>
<tr>
<td>15-16</td>
<td>14</td>
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### Table 4. “How easy is it for you to access your health care?” (Q18)

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<th>O</th>
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Table 5. “Do you feel that attending appointments with health-care providers interferes with your life?” (Q20)

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Table 6. “If you miss an appointment with a health-care provider, does someone contact you to see why?” (Q21)

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Total | 250

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<td>1 (‘j’attends le prochain RDV)</td>
<td>2 (Do not miss appointments without calling)</td>
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<td>19-20</td>
<td>1 (once missed you need to take an other appointment for the next visit)</td>
<td>3 (I never missed any appointment; relatives)</td>
<td>1 (once missed you need to take an other appointment for the next visit)</td>
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<td>1 (I have never tried, so I don’t know)</td>
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Table 7. “How comfortable do you feel asking any of your health-care providers questions about your general health?” (Q22)

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<td></td>
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<td>60 (14.8%)</td>
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Table 8. “How comfortable do you feel asking any of your health-care providers questions about HIV?” (Q23)

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<td>M</td>
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<td>59 (14.5%)</td>
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<td>206 (50.7%)</td>
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Table 9. “Are you responsible for the following:” (Q29)
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<th>Sometimes 167 (44.0%)</th>
<th>All the time 115 (30.2%)</th>
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7.3 Responses to open-ended questions (by age and gender)

Responses to community consultation survey open-ended questions* (all languages)
*The answers have not been edited — they are the exact responses given by the respondents. Translations for the Russian and Thai responses were made using Google Translate, and may have errors.

Final survey population: 447

7.3.1 “What do you like most about the HIV care you receive?” (Q34)

10–12 years

**Male:**
- Male, Cameroon: “Je me sens bien grâce aux médicaments” [”I feel good with drugs”]
- Male, Cameroon: “les médicaments que le docteur me donne et les conseils et explications qu’on nous donne à la classe thérapeutique” [”drugs the doctor gives me advice and explanations given to us and to the therapeutic class”]
- Male, Cameroon: “les médicaments, les classes thérapeutiques, les causeries avec la psychologue,” [”drugs, therapeutic classes, talks with the psychologist,”]
- Male, Cameroon: “Pour ma santé le soutien médical, psychologique, classe thérapeutique” [”For my health medical, psychological, therapeutic class”]
- Male, India: “No Comment”
- Male, India: “Care provided at my home along with my friends.”
- Male, Lesotho: “Ke thusoe ka lilibisi”
- Male, Lesotho: “I like the fact that the medication I receive reduces the HIV virus in my body”
- Male, Rwanda: “Supporting group”
- Male, Rwanda: “supporting group”
- Male, South Africa: “My healthcare Worker looks out for me everyday and checks that I take my meds properly. The nurse looks after me when I am sick and provides all my medicine and my doctor visits me in the village to take my blood and check on me”

**Female:**
- Female, Cameroon: “je suis contente des classes thérapeutiques, des médicaments” [”I am happy with the therapeutic classes, the drugs”]
- Female, India: “Health monitoring”
- Female, India: “Regular drug treatment”
- Female, India: “About the HIV care, i like the nutrition support given by some of the NGOs,”
- Female, India: “I like the way they help us in treatment by free of cost.”
- Female, India: “About drug treatment”
- Female, India: “No comment”
- Female, Lesotho: “Ke rata herato le kele huoang mona.”
- Female, Malawi: “they treat me with love”

13–14 years

**Male:**
- Male, Cameroon: “ça m’aide à être en bonne santé” [”It helps me to be healthy”]
- Male, India: “Services provided by NGO is far better than in Govt. hospitals as there is always rush.”
- Male, India: “Regular health check up and drug treatment”
- Male, India: “Education/Information”
- Male, Lesotho: “I enjoy going to the network club because that is where I get more information about HIV and more support”
- Male, Moldova: “Внимание моего доктора. Она часто звонит маме” [”I would like my doctor to pay attention to me. She very often calls her mother during my appointment”]
- Male, Moldova: “НПО” [”NGOs”]
- Male, Thailand: “ไม่มีเพื่อนใหม่” [”No new friends”]
- Male, Thailand: “ไม่รู้” [”Do not know”]
- Male, NR: “To keep healthy and get stronger.”

**Female:**
- Female, Cameroon: “les classes thérapeutiques, la causerie avec le psychologue,” [”therapeutic classes, chat with the psychologist,”]
- Female, Cameroon: “les conseils m aident à ne pas tomber malade” [”The advice to help m getting sick”]
- Female, Cameroon: “Les médicaments pour ne pas tomber malade” [”The drugs do not get sick”]
Female, Cameroon: “les médicaments, les informations de la classe thérapeutique, la psychologue” [“drugs, therapeutic class information, the psychologist”]

Female, India: “Health Care”
Female, India: “Health check up and counselling”
Female, India: “No Comment”
Female, India: “Regular health check up and education”
Female, India: “No comment”
Female, India: “ART medicines provided by Govt. hospitals.”
Female, Lesotho: “Ke rala hobane litlare tseo ke linoang li mpha bopelo”
Female, Lesotho: “I like my HIV receive/care that my life is still safe and I feel fully supported”
Female, Lesotho: “I enjoy being with other children because I learn about good adherence”
Female, Malawi: “The medical treatment I get. Teen Club - a peer support group for adolescents living with HIV.”
Female, Namibia: “When you are have HIV CARE you feel love and take good care of. That way teen must join different grond which give good at HIV”
Female, Uzbekistan: “to that ko me relate very well, and I am not afraid of HIV” [“I like] how they treat me and the fact I am not afraid of HIV”
Female, South Africa: “i like that i am bieng take care by the nurses and doctor that is all”
Female, Zimbabwe: “the staff are really caring and if you are not feeling well their treatment is really good, you can easily be seen by the Doctor There is also easy access to the medication”
Female, NR: “i like the way i am welcomed at the clinic i like that the clinic provides phsychosocial support for us which is teen club”
Female, NR: “nothing”
Female, NR: “HIV care and drug treatment.”

15–16 years
Male: 
Male, Cameroon: “Me donne la santé, le courage grâce à la classe thérapeutique” [The therapy class gives me health and courage]
Male, India: “Health check up and drug treatment”
Male, India: “HIV education and counselling”
Male, India: “I can’t say”
Male, India: “Regular health check up and care by Doctors”
Male, India: “The supports provided by some of the NGOs like medicine support, education support and phsychological support.”
Male, India: “Free education, free general medicine and free health investigation”
Male, Kazakhstan: “Я могу спокойно разговаривать с ними обо всём, включая и свое заболевание. Могу открыто излагать свои потребности.” [“I can calmly talk to my care givers about everything, including my condition. I can openly express my needs.”]
Male, Lesotho: “Health professionals teach us how to take a good care of ourselves while still leaving with HIV and AIDS.”
Male, Lesotho: “teen club”
Male, Malawi: “Having the to be a part of a support group (teen club) Having mentors who have so much information on HIV.”
Male, Malawi: “the care which they give to us”
Male, Namibia: “doctors and nurses are very kind and do not discriminate or abuse their power”
Male, Thailand: “การทำกิจกรรมร่วมกัน” [“The activities we do together”]
Male, Thailand: “การเรียนรู้เรื่องการดูแลสุขโดยผ่านการทำกิจกรรมกลุ่ม” [“Learning through group activities, rather than sit and listen to the same information. The effects of the drug are not felt continuously.”]
Male, Thailand: “การทำกิจกรรมร่วมกัน” [“I’m taking a long time. Then get in touch with me first. I attend a lot of events.”]
Male, Uruguay: “Nothing”
Male, NR: “I like the tretment that they give me and they must keep it up. and the are doing a good job”

Female: 
Female, Cameroon: “Les médicaments” [“Drugs”]
Female, Cameroon: “Les médicaments m’aident à ne pas tomber beaucoup malade, le soutien avec les classes thérapeutiques” [“The drugs help me not to get sick a lot, with the support therapeutic classes”]
Female, Cameroon: “les médicaments m’aident à soigner ma maladie” [“medicines help me cure my disease”]
Female, Cameroon: “les médicaments, les activités de la classe thérapeutique” [“drugs, therapeutic class activities”]
Female, Lesotho: “I like the HIV care receive because I have someone help me.”
Female, Lesotho: “People like us should have counselling and we should counseling others were should make them be comfortable”
Female, Lesotho: “They provide us with service for HIV and they also educate us about HIV.”
Female, Malawi: “The care I get The Support group (Teen Club) Chatting with my friends”
Female, Malawi: “The group activities we have. Group discussions we have.”
Female, Malawi: “The way the doctors care for us as patients, they show love and care. We have an adolescent support group (Teen Club) where we have discussions on how to live with HIV as adolescents.”
Female, Thailand: “การให้คำปรึกษา” [“The counselling”]
Female, Thailand: “การใส่ใจของผู้ดูแลในการรักษา” [“The attention of the administrators”]
Female, NR: “Health care investigations at Hospitals.”

17–18 years
Male:
Male, Cameroon: “ça me donne la forme ,je n’ai plus de petites maladies,je suis un peu comme les autres” [“It gives me the form, I have more minor illnesses, I’m a bit like the other”]
Male, Cameroon: “les médicaments” [“drugs”]
Male, Cameroon: “les médicaments m’aident à soigner ma maladie,quand j’assiste à la classe thérapeutique ça m’aide à comprendre ma maladie” [“medicines help me cure my illness, when I attend the therapeutic class it helps me understand my disease”]
Male, India: “Maintaining confidentiality and free health check up”
Male, India: “Drug treatment on ART”
Male, India: “Health check up and drug treatment”
Male, India: “Health check ups and drugs therapy”
Male, Lesotho: “I like being with other children and my health care providers at the club”
Male, Lesotho: “Ba na le nako ea rona, ba ra retsotella ha ba re lieisi.”
Male, Lesotho: “It really helped me a lot and I do not have any comment on how it saved my life because before I get tested I was a very sick person. I really appreciate everything that it had to me because if it wasn’t it I would be nothing to other people.”
Male, Malawi: “I fill good about it.”
Male, Malawi: “We are treated very well at our clinic. There is rivacy at the clinic. We get goot treatment.”
Male, Namibia: “i mostly like the suppot group that we have and were we get to meet other young people”
Male, NR: “access to medication”

Female:
Female, Cameroon: “le soutien psychologique et médical” [“the medical and psychological support”]
Female, India: “Regular health check up”
Female, India: “Drug treatment on ART”
Female, Lesotho: “Helps in accepting the status and live a positive life.”
Female, Malawi: “The care and treatment I recieve. Being a part of a support group (teen Club).”
Female, Namibia: “when am told to go and take my medications”
Female, Namibia: “meeting up with fellow peers and having a discussion.”
Female, Namibia: “to get more support and care from the communities an servers that suprport people living with hiv”
Female, Nepal: “supportive friends and other PLHIV including a presence by PLHIV volunteers at the hospital”
Female, Rwanda: “Good service Counselling services”
Female, Thailand: “ได้ลงโทษ ได้รับ ใจที่ดีในการช่วยเหลือ” [“To have the knowledge to help others find no expression.”]
Female, Thailand: “เป็นกันเอง” [“Friendly”]
Female, Thailand: “การตรวจสุขภาพ” [“Health”]
Female, Thailand: “มีเพื่อนมาก” [“Have many friends”]
Female, USA: “Everyone at the clinic is so understanding and they are willing to help me with any problems I come across. I can really trust them.”
Female, USA: “Feel comfortable there and have built a relationship with staff.”
Female, NR: “I like the supporting group for young people”
Female, NR: “Drug treatment on ART by govt. hospitals and some of the medicine support provided by NGOs through care and support programs from the foreign funding agencies.”

Transgender:
Transgender, Afghanistan: “fuck”
19–20 years

Male:
Male, India: “Friendly environment with the care givers in the health centres”
Male, Malawi: “playing football with my friends at teen club iam welcomed well”
Male, Malawi: “their is more support”
Male, Malawi: “when they talk abou it and the say tht you live with it”
Male, Mexico: “La orientación, el apoyo y las terapias de educación” [“[I like] the orientation, support and educational therapies”]
Male, Mexico: “La atención psicológica” [“[I like] the psychological support”]
Male, Nepal: “Treatment, Care and Support with Advocacy from the care home”
Male, Paraguay: “El espacio en el que se brinda, en un servicio comunitario. No me siento cómo yendo a clínicas ni centros de salud. Me gusta más el centro comunitario de testeo y asesoramiento en VIH.” [“[I like] that the care is provided in a community service. I don’t feel like a go to clinics or healthcare centers. I like more the community center for testing and counseling”]
Male, Rwanda: “I like counselling services and other services I receive from the clinic”
Male, UK: “The close relationship I have developed with my health workers since my diagnosis. They are always happy to listen and assist me in any way possible at any time. They have made it a lot easier for me”
Male, NR: “im loving it so far because i have people around who love and care for me”

Female:
Female, India: “Health check up and counselling at the health cares centres.”
Female, India: “About HIV care and treatment given by govt. hospitals and other NGOs working in the field”
Female, India: “Drug treatment on ART and regular health check up.”
Female, Kenya: “we are many but the health care providers are trying their best to give us their best”
Female, Macau: “THEY OWEZ TREAT IN A VERY SPEACIAL WAY AND THEY ARE DOING A TRAMENDOUS WORK”
Female, Malawi: “It helps to keep me in good health. The adolescent peer support group encourages me to keep strong because it helps me to know that I am not the only one living with HIV”
Female, Malawi: “the care givers are so supportive and are doing there best to help us live a positive life”
Female, Moldova: “я не получаю таких услуг, в них не нуждаюсь” [“I do not receive these services , I do not need them.”]
Female, Namibia: “its that we are looking healthy on our bodies and just look like all the negative children around.”
Female, Thailand: “The doctor ask questions about health status. And asks about the drug. I can feel his support. I have to eat next.”
Female, Thailand: “Have friends and knowledge.”
Female, Uganda: “Am getting more friends living positive through the YPLHIV Network and at the clinic.”
Female, Zambia: “I only just found out about my status, so I am still in the stage where I simply just need someone to talk to. Help me understand things and gain a positive attitude towards it.”
Female, Zimbabwe: “Im proud of it because im being helpeld”
Female, NR: “I like that there is Teen club here at the clinic for us as teens”

Other:
Other (gay men), Cambodia: “ARV free”

21–22 years

Male:
Male, Argentina: “La atención y comprensión de mi infectologa. Que me ayuda a estar tranquilo.” [“[I like] the support and understanding from my infectiologist, who helps to make me calm.”]
Male, India: “Freindly environment in the health care centres.”
Male, India: “most of the care for HIV are focus on prevention, I totally need good food and some one who care for us as I am an orphan”
Male, India: “Maintaining confidentiality.”
Male, India: “Drug therapy (ART) provided by govt. hospitals and support given by some of the NGOs related to HIC care and support.”
Male, India: “Treatment of drugs, counselling and Doctor’s activities”
Male, India: “Regular health check up and treatment on ART”
Male, Malaysia: “They are very professional”
Male, Mexico: “Cuando entra uno a consulta, hay entre tres y cuatro personas con el médico que lo atiende a uno, la asistente y a veces hasta tres pasantes de medicina que hacen su servicio, eso hace que no podamos expresar al médico, las preguntas que necesitamos hacer, es muy incómodo ademas.” [“When I have an appointment at the clinic, there are three to four people with the doctor: the assistant and sometimes three interns. All this makes it uncomfortable to ask the doctor everything we would like to.”]
Male, Philippines: “Free consultation, accommodating staff”
Male, Philippines: “I like that the health care professionals who give me HIV care are very nice and very practical as well.”
Male, Philippines: “I like the fact that they support poor PLHIV. Free ARVs. I hope, free medications also for treatment and curing of infections.”
Male, Rwanda: “The way healthcare providers understand my problems. I like when a healthcare provider call me on the phone to remind me to go to the health centre to take my medication”
Male, Ukraine: “я не получаю этих услуг” [“I do not receive these services”]
Male, Uruguay: “Yo soy Uruguayo y tuve que venirme a tratar a Argentina porque aquí casi todo el tratamiento y la medicación es gratuita. En Uruguay no, hay una extrema ignorancia desde todos los puntos de vista, ni la medicación es gratuita, ni la facilitan, ni el tratamiento en sí.” [“I’m from Uruguay and I had to come to Argentina to get treatment because here almost all treatment and medication is given for free. In Uruguay it’s not like that. There is a lot of ignorance and medication and treatment are not free or facilitated.”]
Male, USA: “The doctors and counselors are very informative and make sure that all my questions are answered. They follow up with me all the time and ensure that my privacy is protected.”
Male, Venezuela: “Que se explique las oportunidades de seguir viviendo con calidad de vida, testimonios de personas que han superado la etapa de diagnostico de ser PVV” [“I like that the opportunities of living with quality of life are explained, and testimonials of people who have overcome the diagnosis of HIV are shared”]
Male, Zimbabwe: “that it will only be me and the nurse in the counseling room and that patience are not grouped at the dispensary.”
Male, NR: “adolescent friendly”

Female:
Female, India: “Drug treatment, counselling and education.”
Female, Indonesia: “sharing times, people listen to me”
Female, Kenya: “How the health workers treat me when I visit the clinic.”
Female, Kenya: “The services are free”
Female, Senegal: “Avoir des séances de soutiens entre pairs, avoir des formations pour mieux se prendre en charge dans le futur sans que mon statut s’y affecte. J’aimerai aussi avoir un traitement de qualité basé sur une éducation sexuelle adaptée à mon âge” [“I like to have the group support sessions, to have training to better take care of myself in the future without being affected by my status. I would also like to have a quality treatment based on appropriate sex education for my age.”]
Female, Thailand: “The clinic is not far from my dormitory. The staff have the service mind.”
Female, Zambia: “YOUTH FRIENDLY SERVICES”
Female, Zimbabwe: “some can not see it”
Female, Zimbabwe: “that the doctors and nurses take time to sit down with me and discuss about life, furthering my education, how i can have that dream job or about having children someday or even being in a relationship with an uninfected partner, and how i do not have to be pressurized into having sex simply because i want to remain in a relationship”
Female, Zimbabwe: “they encourage us to be confident enough and stand for c”
Female, NR: “The health providers are caring and always want to know how we are progressing. when you do not turn up for your appointment they will always follow up and know what the problem is. For those who are unable to reach the facility due to various reasons the health providers go to wherever they are and assist them.”
Female, NR: “Health care and check up and monitoring”

Transgender:
Transgender, Bhutan: “As of now I don't receive any medical care for HIV but I would like it be free and with out much hassles”

23–24 years

Male:
Male, Argentina: “Poder tener la atencion cuando la necesito y tambien la medicacion” [“Having the attention when I need it and also the medication”]
Male, Belize: “its free”
Male, Colombia: “Información clara teniendo en cuenta que no manejo lenguaje médico.” [“I would like] clear information to be given to me, having in mind that I don’t dominate medical terms.”]Male, Denmark: “I don’t take medical treatments for my HIV... I try to prevent it (if possible) with healthy food, positive thinking, meditation, talking sessions and more...”
Male, Denmark: “Its the best”
Male, Denmark: “That it is free, so that everybody have access to the HIV care.”
Male, Germany: “good health care system in Germany, lot of support groups, information, specialized doctors etc.”
Male, India: “Counseling”
Male, India: “Counselling, testing facilities for HIV”
Male, India: “Counselling on HIV/AIDS”
Male, India: “Drug Therapy (ART) treatment”
Male, Indonesia: “- drugs impact related on hiv treatment - information regarding on SRH for young people living with hiv”
Male, Jamaica: “is that i always have different option/ place to visiting the health care center, when am out of fun. ”
Male, Malaysia: “Its still support by goverment and easy access to id clinics”
Male, Malaysia: “they give support in term of social and emotional and also give information”
Male, Mexico: “The possibility to meet other YPLWHIV and share experiences, so then i see my concerns reflected in some one else”
Male, Mexico: “El trato de los médicos y personal de salud, son respetuosos. En ocasiones he acudido a urgencias y siempre he recibido atención.” [“Doctors and health professionals treat us respectfully. Sometimes I had an emergency and I have been always assisted.”]
Male, Mexico: “El trato personalizado de mi preparador de servicio.” [“[I like] the personalized care provided to me.”]
Male, Mexico: “El trato hacia las nosotros sin ninguna discriminación o gesto incómodo.” [“[I like] the way how they treat us, without any discrimination or strange behavior.”]
Male, Philippines: “Basic counseling”
Male, Philippines: “It’s free and health care workers have a sense of urgency towards us which makes me feel secure.
Male, Philippines: “My doctor is very supportive and generous.”
Male, Philippines: “We would like to have a cheaper or at least more free laborotory services”
Male, Philippines: “what i like the most with regard to my medication is that somehow, it boosts my immunity, which in turn helps me avoid infections.”
Male, Russia: “все в одном месте” [“I like that everything is concentrated in one place”]
Male, Russia: “группа взаимопомощи” [“I like the support group”]
Male, Spain: “La profesionalidad de mis médicos” [“I like the professionalism of my doctors.”]
Male, Uganda: “they give me free treatment .they carriage me. not to lose hop”
Male, Uganda: “The care is average though lack cohesion and wide coverage which leads to drug scacity and drug stockouts in Health centers.”
Male, Uganda: “that i freely access the ARVs and it’s very rare to find drug stock outs at the clinic as its in the city center. also most the medical personnels at the clinic don’t seem old and this gives me a youth friendly environment.”  
Male, USA: “the friendly people i meet”
Male, Zambia: “Fee treatment”
Male, NR: “I like all services”

Female:
Female, Ethiopia: “on stigma and discrimination, access free OI Drug and other activities focused on prevention services.”
Female, The Gambia: “My ARV drugs and the nutritional support i sometimes receive quarterly when available.”
Female, Guyana: “Confidentiality”
Female, India: “Maintaining confidentiality and counselling process.”
Female, India: “Love and care supported by NGO, adherence on ART process”
Female, Kazakhstan: “Отношение моего лечащего врача СПИД-центра” [“I like the attitude of my doctor at the AIDS clinic”]
Female, Kenya: “RECEIVE COUNSELLING RECEIVE MEDICATION AND KNOWLEDGE WHEN I NEED IT”
Female, Rwanda: “What I like about the HIV I receive is to take medecin. I mean ART”
Female, Senegal: “Développer la recherche pour trouver le vaccin ou des médicaments beaucoup plus performant” [“[I wish] one vaccine could be developed or more effective medications could be made.”]
Female, South Africa: “point-of- care CD4 machine - no long waits”
Female, South Africa: “I like the fact that my medication is always available and people really care for me here, in their hearts. we are all one.”
Female, Swaziland: “It is quite accessible in terms of distance”
Female, Uganda: “Everything”
Female, Uganda: “Well it is free for starters and qualified persinnel work on me.”
Female, Zambia: “Free treatment.”
Female, Zambia: “HEALTH CARE PROVIDERS PROVIDE ADEQUATE IMFORMATION”
Female, Zimbabwe: “To discus about sexual activities, STIS and how to prevent unwanted pregnence”
Transgender, Other, and No sex or gender specified:
Transgender, USA: “I like the open and honest relationship I have built with my providers.”
Other (bisexual), Philippines: “The Trust and responsibilities”
Other (gay male), Philippines: “it’s confidential and ready.”
NR, Kenya: “The life saving drugs provided”
NR, Philippines: “I like it when my doctor also consider my financila capability especially when i was hospitalized because of arv side effects.”

7.3.2 “What suggestions do you have to improve HIV care for yourself or other young people?” (Q35)
10–12 years
Male:
Male, Cameroon: “Outils de rappel des médicaments, les livres, les cahiers, les vêtements, la nourriture” [“Tools drug recall, books, notebooks, clothing, food”]
Male, Cameroon: “améliorer les choses, les jeux, les formation” [“improve things, games, training”]
Male, Cameroon: “Il faut qu’on trouve le médicament qui tue définitivement le VIH, avoir les livres pour mieux apprendre, aider les jeunes qui n’ont plus leur parents, nous soutenir beaucoup” [“We need to find the drug that kills definitively HIV have books to learn better, helping young people who no longer have their parents support us a lot”]
Male, Cameroon: “trouver le médicament qui guerit, les outils de formation pour les non scolarisé, ...” [“find the medication that geruit, tools for training of school ...”]
Male, India: “No comment”
Male, India: “No comment”
Male, Lesotho: “There should be adequate medication at the hospital”

Female:
Female, Cameroon: “Développer des activités, avoir des outils, trouver le médicaments qui tue le VIH” [“Developing activities, have tools, finding the drug that kills HIV”]
Female, India: “No comment”
Female, India: “To provide nutritional support in order to stay healthy.”
Female, India: “Treatment education and positive living education”
Female, India: “To provide education support”
Female, India: “No Comment”
Female, India: “Awareness drug side effects so that people can take care of their health”
Female, Lesotho: “Nkarata ho bolElla bana hore HIV e ea bolAha ha o sa ithbomele.”
Female, Malawi: “we should cooperate”

13–14 years
Male:
Male, Cameroon: “Améliorer les médicaments pour que la maladie puisse finir, nous soutenir encore quand on nous insulte” [“Better medicines for the disease can finally support us again when we are insulted”]
Male, India: “Provide more informations on HIV”
Male, India: “To make available of the professional Doctors in the field of HIV”
Male, India: “Want to make available other general medicines too like ART in the future.”
Male, Lesotho: “I suggest for public gatherings”
Male, Moldova: “Не хочу чтобы меня видели в очереди другие взрослые больные” [“I do not want to be seen in same line as the adult patients.”]
Male, Thailand: “[The doctor to follow up.]”
Male, Thailand: “[Nothing.]”
Male, NR: “To encourage others with HIV to take meds correctly”

Female:
Female, Cameroon: “avoir les manuels pour bien comprendre et évoluer avec notre maladie, aider les orphelins, nous aider” [“have the manuals to understand and evolve with our sickness, help orphans, help us”]
Female, Cameroon: “recevoir le soutien, les livres, aller à l’école, être comme les autres qui ne sont pas malades” [“receive support, books, go to school, to be like others who are not sick”]
Female, Cameroon: “Soutenir les enfants, les orphelins, avoir les outils qui vont nous aider à mieux comprendre le VIH” [“Supporting children, orphans, have the tools that will help us to better understand HIV”]
Female, Cameroon: “je voudrais qu’on n’est un espace pour nous sentir aussi comme les autres, avec une bibliothèque pour ceux qui ne savent pas lire et qui ne vont pas à l’école, le matériel pour nous faciliter certaines, choses, le soutien,et
qu’on trouve le médicament qui tue le virus VIH,” [“I wish that there is a space for us also feel like the others, with a library for those who can not read and do not go to school, the equipment we facilitate certain, things, support, and found the drug that kills the HIV virus.”]
Female, India: “To provide more information, education and counselling in sexual health and rights”
Female, India: “Awareness on HIV and reducing stigma and discrimination.”
Female, India: “Reduce stigma and discrimination.”
Female, India: “No Comment”
Female, India: “No Comment”
Female, India: “No Comment”
Female, Lesotho: “I suggest the nurses should make home visits”
Female, Lesotho: “Youths that are already taking medication should adhere to their medication. And others must get tested after every three month to reduce spread of HIV.”
Female, Lesotho: “Nka ja hantle ke kene sekolo ke tsebe ho pela bopelo bo monate”
Female, Malawi: “if they could be phoning us”
Female, Malawi: “Is that do not treat people living with HIV different from other people.”
Female, South Africa: “to take care of them selves”
Female, Uzbekistan: “чтобы услуги для подростков были по всей стране, чтобы они были регулярными” [“I would like treatment and care for young people with HIV to be all over the country and to be more regular.”]
Female, Zimbabwe: “To take more care of themselves, take medication as prescribed and avoid sex mainly unprotected sex because you expose yourself to lots of different diseases which is very unhealthy because your immunity is already compromised”
Female, NR: “ART centre should be open ill all the health centres in the state.”

15–16 years
Male:
Male, Cameroon: “Trouver le médicament qui guerit le vih,avoir les structures pour éduquer ,soutenir les orphelins, nous sommes insultés et parfois on ne nous accepte pas à l’école,les livres, les vêtements,” [“Find the medication Guerrit hiv structures have to educate, support orphans, we are insulted and sometimes it does not accept to school, books, clothing.”]
Male, India: “Awareness and treatment education”
Male, India: “To make a proper hygiene and sanitation”
Male, India: “Mass awareness to all the community.”
Male, India: “Awareness about the preventive measures and reducing stigma and discrimination.”
Male, India: “Opening of free clinic only for children”
Male, India: “To improve HIV care services and would like to improve our support in medicine support not the ART but other general medicine.”
Male, Kazakhstan: “Участвовать в спортивных мероприятиях вместе на бесплатной основе и чтобы нас там не дискриминировали.” [“I would like young people living with HIV to be able to do sports without being discriminated by their peers.”]
Male, Lesotho: “The service providers must be on time. They are sometimes late. - Toilets be cleaned.”
Male, Malawi: “the health care people should open up to people”
Male, Namibia: “not much at all”
Male, Thailand: “บริการจุดเดียวหมอจ่ายยาพยาบาลให้ค าแนะน าการดูแลสุขภาพ เพื่อนผู้ติดเชื้อให้ค าปรึกษาและท ากลุ่มระหว่างรอพบแพทย์และติดตามเพื่อการรักษาที่ ต่อเนื่อง” [“Offers a single point of dispensing doctors, nurses and health care instructions. Friends HIV counselling and group awaiting treatment. Follow friends and keep the continuity.”]
Male, Uruguay: “More information, education, goverment does not provide any type of information to the people
Male, NR: “that they must always take ther medicins and nevar skip a day”
Female:
Female, Cameroon: “trouver le médicament qui guerit, les livres, les activités,les formations” [“find the medication that Guerrit, books, activities, training”]
Female, Cameroon: “je voudrais qu’on trouve le médicament qui tue le VIH,qu’on aide aussi les autres enfants qui n’ont plus leur parents à aller à l’école,” [“I would found the drug that kills HIV, it also helps other children who do not have their parents to go to school,”]
Female, Lesotho: “The should get test first before the could have sex and they should use condoms. As for me I not doing that.”
Female, Lesotho: “They should give support to young people living with HIV.”
Female, Malawi: “Pay school fees for them. Give free medical services and treatment. Give them guidance and counselling.”
Female, Thailand: “ขอรู้จักกันให้มาก” [“Want friends together a lot”]
Female, NR: “No idea”

17–18 years
Male:
Male, Cameroon: “je voudrais qu’on nous apporte une aide matérielle, qu’on nous forme à un travail, qu’on nous apporte des documents pour ne pas se sentir à côté” [“I wish that we provide material assistance, which we form a work that brings documents to not feel side”]
Male, Cameroon: “trouver le vaccin contre le VIH, nous apporter du soutien sur tout les plans” [“find a vaccine against HIV, we provide support on all plans”]
Male, Cameroon: “je voudrais qu’on est les documents qu’on nous remet à la classe, qu’on ajoute les activités et nous soutenir, avoir beaucoup de choses pour nous aider” [“I would like is that the documents we deliver to the class is added activities and support us, have a lot of things to help us”]
Male, India: “Sometimes, there is ART out stock. Let’s not make such things happen repeatedly. Requested young generations to have good and nutritious foods.”
Male, India: “Provide for medicine support”
Male, India: “Adolescene programe needs to implement.”
Male, India: “More awareness on sexually reproductive health and rights”
Male, Lesotho: “Ke rata ho baruta ka HIV hobane ba tsebe ho ja hantle.”
Male, Lesotho: “I suggest that there should be peer support groups”
Male, Lesotho: “I think there has to be more support to people living with HIV/AIDS.”
Male, Malawi: “not much i woul change but i would say that they have to keep on what they are doin to help others as well.”
Male, Malawi: “Have Teen Clubs at every health centre (Support groups for ALHIV) Provide free nutritious foods to adolescents as well.”
Male, Namibia: “to reduce the number of tablets intake day by day”
Male, NR: “Government should allocate funds for ART”

Female:
Female, Cameroon: “Améliorer la disponibilité des ARV, Ecouter plus ceux qui sont malades, soutien financier surtout pour les orphelins, les formations” [“Improve the availability of ARV Play over those who are sick, especially financial support for orphans, training”]
Female, India: “Providing proper counselling to the young people on SRHR”
Female, India: “Free treatment and free education”
Female, Lesotho: “Health providers should be punctual at all times.”
Female, Namibia: “faunds should be made because at times we experiencing difficulty with transport to collect our medication.”
Female, Namibia: “young childrens should get more support like school fees for them school uniforms care for foods and clothes as wwell must be treated good like at the clinics need help with a thier gflow up to the doctors an need better develop pmnt with the lp of the goverment as well as the ather support groups”
Female, Namibia: “for the young peopl who are haveing hiv to stop drinking alcohol and to stop haveing so mach sex partners.”
Female, Nepal: “this needs to focus on young people more”
Female, Thailand: “ไม่มี” [“Nothing.”]
Female, Thailand: “ตั้งสถานที่เฉพาะในการนัดตรวจก็น่าจะดี” [“If there is a specific place to make an appointment”]
Female, USA: “Be educated! Know simple things that you can do in order to stay healthy, and if you’re unsure of something, ask someone!”
Female, USA: “I feel there needs to be a lot more education in schools.”
Female, NR: “To stay healthy, we need a good food. Thus, nutrition support is very much necessary.”
Female, NR: “To improve the stigma and discrimination”

Transgender:
Transgender, Afghanistan: “fuck”
19–20 years
Male:
- Male, India: “Mass awareness on the sexually reproductive health and rights for adolescents”
- Male, Malawi: “just take my my drops everyday and eat more”
- Male, Mexico: “Las terapias alternativas micronutrientes, la medicación y pruebas que se hacen para los avances tecnológicos del VIH” (“Alternative therapies with micronutrients, medication and tests done for HIV technological advances.”)
- Male, Mexico: “Pediría medicamentos que no sean tan cómodos.” (“I would ask for less painful medication.”)
- Male, Moldova: “нет предложений” (“No suggestions”)  
- Male, Nepal: “We know the side effects of the ART but still we are using it...”
- Male, Paraguay: “Expandir los servicios comunitarios de testeo, tratamiento y contención para jóvenes viviendo con VIH. Las estrategias comunitarias que ayuden a conocer más sobre VIH son las que generan cambio real de comportamiento a nivel local y regional.” (“[I would suggest] to expand community services of testing, treatment and containment for young people living with HIV. Community strategies that help to learn more about HIV are generating real behaviour change local and regional level.”)
- Male, Rwanda: “I would like to ask you to put more force on your young people living with HIV, try to give us hope for our life”
- Male, UK: “More opportunities to meet other young people in my area with HIV”
- Male, NR: “educate more young people on HIV, AIDS, STI, STD.”

Female:
- Female, India: “More improvement in awareness on youths about sex and sexuality.”
- Female, India: “To organise talent show for the PLHIV”
- Female, India: “No comment.”
- Female, Kenya: “set aside date for us or better still our own clinic, friendly clinic according to our ages, be given choices of treatment and allow us to choose, all the drugs that have fatal side effects to be burned immediately by the government, most of our medication are donor funded so the government should consider putting some measures in case the donors pull out we can continue with medication, last but not least consider a trippler for all of us especially paediatrics.”
- Female, Macau: “THEY SHOULD ALWAYS SUPPORT US BECAUSE WE DEPEND ON THEM AND ALSO ENCOURAGE US TO DO WAT IZ BEST FOR US AND DISCOURAGE US NOT TO DO WHAT THEY FELT IS BAD FOR US”
- Female, Malawi: “There should continue to give free medicat services to ALHIV.”
- Female, Namibia: “they should introduce another cure that does not make us feel dizzy, because with this now some of us feel dizzy in the morning when taking our medication.”
- Female, Thailand: “มีกลุ่มเพื่อนๆรุ่นเดียวกันและให้การพัฒนาสนับสนุนอย่างต่อเนื่อง” (“A group of friends. Same model and the development of ongoing support.”)
- Female, Thailand: “พยาบาลควรพูดดีไม่ตะคอกใส่คนไข้และควรซักถามอาการและมีสีหน้าที่ยิ้มแย้ม” (“Nurses should speak well. Not yell at patient. And symptoms should be questioned. And the expression should be a smile”)
- Female, Uganda: “Our peers shld be trained to support more of our friends because entering the clinic the first time i really suffered.”
- Female, Zambia: “More doctors offices would mean less and shorter queues”
- Female, Zimbabwe: “Teach them more about HIV/Aids”
- Female, NR: “i would like to improve in education by telling how school is important.”

Other:
- Other (gay men), Cambodia: “We need to have more nutrition and family acceptance about our status. Good services for OI, and ARV.”

21–22 years
Male:
- Male, Argentina: “Generar varias sedes de retiro de medicamentos. Más centros de salud con más infectologos. Menor exposición de datos y miradas del personal de salud. Mayoras campañas de concientización, prevención, mayores programas sobre el VIH. Grupos de reflexión de jóvenes.” (“[My suggestion] is to generate multiple drug withdrawal points; to have more health centers with more specialists in infectious diseases; to reduce the exposure of confidential data to health personnel; to make bigger awareness and prevention campaigns; to make wider, higher HIV programs; to create focus groups of youth people.”)
- Male, India: “To improve HIV care and suggested to give supply for medicine and other related support for the welfare of the community.”
- Male, India: “Proper counselling on the issue.”
- Male, India: “Mass awareness on the issue.”
Female, India: “Want to keep a special day for young people.”
Female, India: “To have a free zone for sexual health and rights, HIV care orvisher should provide information especially for young people.”
Female, Indi: “IEC mete rails with photo picture, more component of children in the HIV program, more good nutrition etc”
Male, Malaysia: “saperate the appointment session with adolescence”
Male, Mexico: “Que la atención sea personalizada entre médico y paciente.” “[I would like] personalized care between doctor and patient.”
Male, Philippines: “Give free medications, increase the number of treatment hubs”
Male, Philippines: “Education. Forums and seminars to public. This is epidemic.”
Male, Rwanda: “To improve services for other young people around the country because they are some young people who don’t receive good services because of how they are (poor) Good services for all!!!!”
Male, Ukraine: “я не полюsha этих услуг.” “[I do not get these services.]”
Male, Uruguay: “El tratamiento en todas partes del mundo debe ser gratuito, tanto el tratamiento como la medicación y la contención, hay personas que no pueden pagar lo y no por eso merecen estar en riesgo. Creo que se tienen que hacer más campañas de información, de educación. La ciencia avanza, la sociedad no.” “Treatment around the world should be free, not only treatment, but also medication and containment. There are people who cannot pay and don’t deserve to be at risk just because of that. I think more information and education campaigns are needed. Science goes ahead, but not the society.”
Male, USA: “I would just advise young people who are responsible for scheduling their own appointments, to make sure that they actually schedule the appointments AND attend them. It’s important for our health to be tracked and monitored.”
Male, Venezuela: “Que se elimine la discriminación y estigma social” “[I would like] discrimination and social stigma to be eliminated.”
Male, Zambia: “youth services to the community”
Male, Zimbabwe: “Nurses be in the health sector because they love it not of being forced or pushed by the love of money.”
Male, Zimbabwe: “there must be free heathier foods for all children so that their healthy improve”
Male, NR: “mainstream the young people in the fight against the HIV pandemic more especially those who are infected

Female:
Female, India: “Current facilities provided by NGOs and govt. are not for a longer period. We want a long term policy to save the lives of the PLHIV.”
Female, Indonesia: “Komprehensif health services, including SRHR and no stigma discrimination”
Female, Kenya: “None”
Female, Kenya: “There is need to have people trained to work with HIV positive adolescents. People who really and truly understand HIV positive adolescent. A separate clinic for HIV positive adolescents with games and sports. And also adolescents groups activities - trips and exchange. Maybe a conference for HIV positive adolescents.”
Female, Rwanda: “I would like to ask those who are in charge of health can to put in/ add on a service of communicating someone who don’t respect the appointment”
Female, Senegal: “Plus d’informations sur la santé avec les nouveaux outils de l’information (internet, document électroniques etc…) Des sites de rencontres et d’échanges entre pairs et des club de rencontre pour se divertir et oublier les soucis qui présent.” “[I would like the new information tools to be used for health information (internet, e-documents…). I also would like] places where people could meet, share experiences and have fun, just to forget the troubles of their lives.”
Female, Thailand: “Having more HIV peer group activities such as camp. Support the educational funds for who needed.”
Female, Thailand: “มีศูนย์เยี่ยมแคมเพญให้ผู้เยี่ยมแคมเพญ - อยากให้ภาระเยี่ยมแคมเพญไปด้วย - มีศูนย์เยี่ยมแคมเพญเป็นส่วนสำคัญเลยคะ” “[There are only young blood - the blood draw would not hurt - especially the adolescent clinic is safe.]”
Female, Zambia: “Need for SRH INFORMATION AMONG YOUTHS”
Female, Zimbabwe: “take thing as it is do not discriminate your self”
Female, Zimbabwe: “right now in Zimbabwe, many children suffer stigma and discrimination so naturally i would say if it were possible to shield them from such harsh treatment as it sometimes leads to suicide. in many hospitals and clinics in my country there is shortage of ARVs, this is a major problem as it affects adherence to their medication so if there was improved supply of these drugs it would go a long way - to access medication a person has got to travel to get such help and some of us do not have the money maybe if there could be distribution of the drug whereby you take it and it lasts for six months that would be a great help, because most infected age group is children and in turn their parents as well, let us say for example they get different appointment dates, the child cannot travel alone hence increased bus fare! - if maybe there could be an adolescent/youth friendly corners all over the country where i do not have to be shy to ask about Adolescent Sexual Reproductive Health”
Female, NR: “All the young people infected should have a group where they meet frequently to discuss the problems that they are facing. The group will also help them to encourage each other and always look out for each other.”
Female, NR: “Mass awareness on the issue.”

44
**23–24 years**

**Male:**
- Male, Argentina: “Que haya una difusión más grande sobre el tema y que se haga incapaz un fuerte sobre el hecho de hacerse los estudios, y más que nada cuidarse siempre.” [“There is a larger diffusion on the subject and is made stronger stress upon the fact hacerce studies, and most of all take care always”]
- Male, Argentina: “MAKE IT EASIER TO GET MEDS AND PICK THEM UP AT OTHER LOCATIONS”
- Male, Belize: “free of stigma”
- Male, Colombia: “Como aprender a manejar las relaciones sexuales con personas cero negativas” [“I would like] to learn how to handle sexual intercourse with HIV-negative people.”
- Male, Denmark: “Groups of talking...! Here in Denmark we have a group - YouthGroup of HIV people in Denmark... I've gone there for about 8 years now - And my life would be completely different if that group hadn't existed”
- Male, Denmark: “Smile”
- Male, Denmark: “More groups for PLHIV.”
- Male, Germany: “More detailed information about the side effects. HIV chems are no fun!”
- Male, India: “Treatment education about HIV”
- Male, India: “Mass awareness about the issue to all the people and advocacy for legal rights of the PLHIV”
- Male, India: “more awareness through media, sensitization to local people and specially to stakeholders.”
- Male, India: “Education about sexual health and rights of the young people.”
- Male, India: “Since, we feel shy to ask about our sexual health, we need a separate caregiver in the field of SRHR.”
- Male, Indonesia: “the health services provider should be more widely available for young peoples who living with hiv without any barrier on addressed STI information for youth.”
- Male, Indonesia: “the health services provider should be more widely available for young peoples who living with hiv without any barrier on addressed STI information for youth.”
- Male, Jamaica: “my aim is to encourage young people living with HIV/AIDS (YPWHIV) is to adhere to your medication, live up take full responsibility of your own action, be strong, and think positively and get involve.”
- Male, Jamaica: “proper nutrition n medication”
- Male, Malaysia: “More education about how hiv spread among teenagers as this is not a disease spread by prostitute only as everyone have risk if do not care.”
- Male, Malaysia: “they should give information how the young people living with HIV can live with HIV”
- Male, Mexico: “I think we need (in Mexico) more youth-friendly information related to ARV treatment and secondary effects. Moreover, health providers and young people need to think together on a specific timeline in our healthcare since our need and expectations are different from adult people. Finally we need youth sexual and reproductive health services and information in clinics and care centers for YPLWHIV.”
- Male, Mexico: “Gestionar la erradicación del estigma por VIH SIDA.” [“I would like] the eradication of stigma against HIV/AIDS to be carried out.”
- Male, Mexico: “Realizar MIPA” [“To adopt Meaningful Meaningful Involvement of People Living with HIV.”]
- Male, Mexico: “Mayor información general, sobre los cuidados en casa, como por ejemplo si se pueden tener mascotas o no. O si para alguien con VIH es viable adoptar hijos.” [“I would like] more general information about home care of people living with HIV: for example, if they can have pets, or if it is possible for them to adopt children.”
- Male, Mexico: “Tratamiento, uso de preservativos, una adecuada alimentación, hacer ejercicio, comunicación entre familiares.” [“Treatment, condom use, balanced nutrition, physical exercise, communication among relatives and family would improve the quality of my care”]
- Male, Philippines: “Basic HIV 101 Referral to shc for testing or referral mechanisms to stakeholders and partners RA8504”
- Male, Philippines: “Focus more on the psychological well-being of people living with HIV. Offer a support group program led by a professional (preferably someone who has lived with HIV for many years) as part of the treatment plan. ”
- Male, Philippines: “Never lose faith and keep fighting. Everything happens for a reason.”
- Male, Philippines: “We need the availability of generic once daily dosage of ARV available to help with Adherence during medication as I believe it is still not available here in the Philippines”
- Male, Philippines: “1. an environment/institution where HIV-infected people like me could freely express ourselves. 2. an awareness campaign to those who are HIV-negative to mold their perceptions about HIV. 3. a survey directed to those who are sexually active to gauge their awareness to HIV which could lead to a campaign on how they could be carriers so they would know went to stop spreading the disease. 4. strangely enough, I personally would want a cure that would totally revert my status back to being HIV-negative.”
- Male, Rwanda: “consider that young people are growing up and need improved services for their age group”
- Male, Russia: “волонтерские программы, обучение” [“Volunteer programs, training”]
- Male, Russia: “все сложно” [“It’s complicated”]
Male, Uganda: "It’s very much important that medical workers learn to listen to the young people living with HIV as sometimes they judge them by their acts and always blame them for their poor health. This lowers their self-esteem and sometimes forces them to abandon treatment as they don’t want to run into those individuals. It happened to me onetime, therefore am speaking from experience. Okay I know they are aware of this, but they need also to realise that as young positives, we also grow up and nature takes course as well. They should stop blaming us when we decide to have children when we come of age because they tend to take us as still young even when we are above the adult age."

Male, Uganda: "I would suggest that u proved more ARVS or u extend the services to the rule areas were people luck information"

Male, Uganda: "Ugandan government health sector should change from PUSH SYSTEM OF DRUG DISTRIBUTION to PULL SYSTEM SO THAT CLIENTS CAN ACCESS DRUGS. Also NATIONAL MEDICAL STORES SHOULD BE STREAMLINED SO THAT IT DOESN'T TAKE LONG TO DISTRIBUTE DRUGS TO HEALTH CENTRES IN THE VILLAGE HEALTH CENTRES UPCOUNTRY""}

Male, USA: "None"

Male, Zambia: "Nil"

Male, NR: "Looking for how to fight stigma and discrimination against"

Female:
Female, Ethiopia: “access of job to improve economic support, should be focus to tackle new infection, Prevention activities should be more important.”

Female, The Gambia: “I suggest if the attitude of health care providers could be changed, it will help we the young people have access to the care services we need. Their attitude towards young people seeking treatment is very poor. They usually judge why young people seek treatment or contraceptives and this affects how they help the young even if he/she is at risk. We need a youth-friendly environment that can attract and serve the young who may be embarrassed or intimidated to seek HIV care.”

Female, Guyana: “More support groups and interactive activities with other PLWHIV”

Female, India: “To improve HIV care by providing professional health care service providers.”

Female, India: “Awareness in order to reduce stigma and discrimination.”

Female, Kazakhstan: “Обеспечить бесперебойное поступление препаратов АРВТ” ["I would like the ARV drugs to be accessible for everybody.”]

Female, Kenya: “NEED TO IMPROVE ON ATTENDANCE TIME BY THE DOCTOR WHEN I OR OTHER YOUNG PEOPLE VISIT A HEALTH FACILITY DUE TO STIGMA NEED PHARMACY ATTENDANCE TO BE SENSITIZED ON HOW THEY HANDLE YOUNG YPLWHIV AT THE COUNTER”

Female, Rwanda: “I would like to suggest you or others people in charge of this to find for us young people living with HIV a time for appointment not different to adult”

Female, Senegal: “Je suggère à ce que des médecins soit spécialisés pour prendre en compte les aspects des adolescent et adolescentes. Il faudrait aussi que les adolescents vivant avec le VIH puissent avoir des espaces de rencontres et d'échanges.” ["I suggest those who make drugs to have adolescent boys and girls in mind. I also would like young people living with HIV to have a place to meet and share experiences.”]

Female, South Africa: “decrease stigma”

Female, South Africa: “I would enjoy if I could freely talk about about my sexual health with health care providers and have ways to feel as if I'm more part of the community.”

Female, Swaziland: “The health centers should have youth friendly stuff to cater for our needs, also privacy is an issue, not all of us are ready to disclose, there is a problem at our hospitals when we que at a window written ARVs everyone can see that we are HIV positive and that makes the stigma to be worse.”

Female, Uganda: “We need more dictors. Standing on a line for ages is not fine!”

Female, Uganda: “Help young people living meet with other young positives in different countries”

Female, Zambia: “They is need for more youths friendly service facilities.”

Female, Zambia: "Need for establishment of youths friendly clinics"

Female, Zimbabwe: “To teach them the important of taking ARVS drugs”

Transgender, Other, and No sex or gender specified:

Transgender, USA: “Do not be afraid to take an active stance in your health care. Be informed. Know you can say "No". And stay open-minded.”

Other (bisexual), Philippines: “More on education of safe sex”

Other (gay male), Philippines: “education”

NR, Kenya: “Lets talk about the varied needs of young people and Recognition for the diversity within young people eg needs to - Sexual and Reproductive Health and Rights - Access to treatment, prevention, care and support services - Access to education, skills and livelihood support - Stigma, discrimination and human rights Challenges around disclosure - Transitional care for adolescents living with HIV - Involvement and leadership -”

NR, Philippines: “Here in the Philippines the stigma one to be consider by a HIV positive. All we want is a clinic/hub that will make sure that our identity will not be exposed.”
7.3.3 “Is there anything else that you would like to tell us?” (Q36)

10–12 years

Male:
- Male, Cameroon: “Non”
- Male, Cameroon: “Je voudrais ne plus être malade”
- Male, Cameroon: “Non. Merci”
- Male, Cameroon: “RAS”
- Male, India: “Free education, nutrition and free general medicines”
- Male, India: “Nutrition support”
- Male, Lesotho: “None”
- Male, Rwanda: “No, thank you”
- Male, Rwanda: “no, thank you”

Female:
- Female, Cameroon: “je ne suis pas contente d’avoir le VIH”
- Female, India: “Free medicine support and nutritional support”
- Female, India: “No comment”
- Female, India: “Education support and nutrition”
- Female, India: “Education, nutrition support and general medicines”
- Female, India: “lack of nutrition support in the state, free education and provision for general medicines”
- Female, India: “To provide free education and increase community care centre for children”
- Female, Lesotho: “Ha o ithlo komela hantle o __ ja hantle o phela nako etelele”
- Female, Malawi: “promote htc for those who have not tested”

13–14 years

Male:
- Male, Cameroon: “Non”
- Male, India: “N/A”
- Male, India: “Free nutrition for healthy life of the PLHIV”
- Male, India: “Required nutritional support and awareness on the legal rights of the PLHIV”
- Male, Lesotho: “No”
- Male, Moldova: “Только + может понять +” [“Only HIV positive can understand HIV positive people”]
- Male, Moldova: “Я боюсь что кончатся таблетки для меня.” [“I’m afraid that I run out of pills.”]
- Male, Thailand: “I want to recover from the infection”
- Male, Thailand: “I want to hide this disease from others”
- Male, NR: “I am very thankful for ARV-care.”

Female:
- Female, Cameroon: “Non”
- Female, Cameroon: “Je suis orphelin et je suis mal”
- Female, Cameroon: “Non”
- Female, Cameroon: “Non”
- Female, India: “Provision for free education, free nutrition and general medicines”
- Female, India: “Free education system”
- Female, India: “No Comment”
- Female, India: “Provision for free education and nutrition support”
- Female, India: “Free education and free nutrition support”
- Female, Lesotho: “No, except for thanking the Nurses and Bathabales who see to it that we are happy and health.”
- Female, Lesotho: “No”
- Female, Lesotho: “Ke batla motho emong le emong a tsebe hore na noa litlare hobaneng”
- Female, Malawi: “nothing”
- Female, Namibia: “Nothing much, then just saying THANK YOU VERY MUCH FOR ALL YOU HAVE DONE OF USE”
- Female, South Africa: “no”
- Female, Uzbekistan: “хотелось чтобы услуги для молодых людей были адаптированы для национальных групп (узбекоговорящей молодежи- так как основные материалы для подростков и детей либо на русском либо на
"It would be desirable that services for young people have been adapted for national groups (young Uzbeks) and have as well basic materials for teenagers and children either in Russian or on Uzbek."

Female, NR: “Increase no of medical Doctors in the field of HIV care and treatment.”

15–16 years

Male:
Male, Cameroon: “Merci”
Male, India: “Free education, Free nutrition and free general medicines”
Male, India: “Nutrition support”
Male, India: “Free education, free nutrition and provision for general medicines”
Male, India: “Legal rights of the PLHIV”
Male, India: “lack of proper education, education support and scholarships for PLHIV”
Male, India: “Good nutrition support and legal procedures on the rights of the PLHIV.”
Male, Malawi: “nothing”
Male, Namibia: “I would like to thank the world health organisation for letting to express my feelings and poit of view abot my status”
Male, Thailand: “I am very glad I could grow up”
Male, Thailand: “[Why force a child to take a blood test? If you detect HIV were deprived in the course, such as doctors, nurses, public health, pharmacy, etc...]”
Male, Uruguay: “Yes, In Uruguay, There are no complete access to HAART, This mean that if you need a certain ARVs, you will not get it since the goverment does not provide them.”

Female:
Female, Cameroon: “non”
Female, Cameroon: “non”
Female, Kazakhstan: “[I want to ask: How long will still have to wait for a vaccine against AIDS. And when can we have ART therapy once a day?”
Female, Lesotho: “If you get your self HIV you should not be ashamed coz their are people living with HIV”
Female, Lesotho: “They should also educate young people living HIV about HIV”
Female, Lesotho: “No”
Female, Malawi: “Its very difficult to take ART at boarding school. Teachers should be educated on how they can provide treatment support so that people are not stigmatised.”
Female, Thailand: “[I’m proud in being open with my doctor and knowing he won’t tell anyone else.”
Female, Thailand: “[Want access to care like this. I understand we are not the same.”
Female, NR: “Provision for free educations”

17–18 years

Male:
Male, Cameroon: “Non”
Male, Cameroon: “RAS”
Male, India: “special space for child counselling”
Male, India: “Free education, free nutrition, OIs medicine and general medicine’
Male, India: “Good nutrition support needed.”
Male, India: “No comment”
Male, Lesotho: “No”
Male, Lesotho: “I have nothing to say but what gave me a confidence is my psychologist and other children living with HIV so I really thank them a lot.”
Male, Lesotho: “Tla sa bophelo bona ba HIV ke bona ke phela hantle tla sa hlokromelo Ra batsoali baka.”
Male, Malawi: “well i would only say that you just need to make more surey for more young people understand the importance learning more about HIV”
Male, Namibia: “yeah, i woul like you guys to reduce any questions about HIV (status) on application forms and what not......”
Male, NR: “no”
Male, NR: “No”
Female:
Female, India: “Free education”
Female, India: “Legal rights of PLHIV”
Female, Namibia: “discrimination in our country its too much,something needs to be done to stop stigma and discrimination.”
Female, Namibia: “the workers who works at the pharmacies they dont have cofidential amongst themself.”
Female, Namibia: “doctors should be working very hard an peple with hiv should not give up drinking their medictions”
Female, Thailand: “ขอบคุณค่ะ” [“Thank you.”]
Female, Thailand: “อยากให้วัยรุ่นทุกคนที่มีเชื้อหรืออยู่ในความเสี่ยงได้เข้าถึงการบริการที่ถูกต้องและสะดวกใจ” [“Care and treatment should be available to everyone at risk of HIV”]
Female, NR: “Here in my country we have two sessions for young people under 19 years and for adult so I would like to ask you for adolescents”

Transgender:
Transgender, Afghanistan: “fuck”

19–20 years
Male:
Male, India: “Provision for free education , health investigations specially Hep-C and nutrition support.”
Male, Malawi: “give us young people what we need care and jobs or parts time jobs”
Male, Mexico: “Gracias por preocuparse por la atencion a pacientes con VIH” [“Thank you for caring for people living with HIV”]
Male, Mexico: “¿Qué tan probable es que encuentren una cura?” [“How likely is that a cure is found?”]
Male, Nepal: “We nepali and might be other countries as well always have to suffer somewhere from european union because of increase of tax in medicine which increases the rate of medicine...so why dont WHO suggest them after all its about the public health around the world. ”
Male, Rwanda: “No, thank you”
Male, NR: “No”

Female:
Female, India: “Provision for free education support, nutrition and general medicines”
Female, India: “Provision for nutrition support and free education system from the government.”
Female, India: “Nutritional support for staying healthy”
Female, Kenya: “yes,please work on disclosing to the children who were born with hiv\those who have taken medication from a very tender age,they have the right to know the truth,engage them in most of the things that involve their medication because they also have something to say.”
Female, Macau: “YOU SHOULD KEEP ON SUPPORTING US BECAUSE WE DEPEND ON U TO PERFPM PERFECTLY”
Female, Malawi: “i like the care am getting”
Female, Moldova: “побольше бы делали мероприятий для развития активизма среди ВИЧ-позитивных подростков, молодёжи и молодых людей. Различные семинары, тренинги и т.д. это очень необходимо для нас.” [“We need to develop activism among HIV-positive teenagers, adolescents and young men. We need several seminars, trainings, etc.”.]
Female, Namibia: “yes, that on follow upsor pharmacyday we should not meet in the same day with adults because it use to be full and we spend a lot of hours there,and sometimes we go at the hospital after school and we are hungry.”
Female, Thailand: “ส่งเสริมให้ประชาสัมพันธ์วิธีการป้องกันโรควิวัฒน์กับเรื่องที่เกี่ยวกับการดูแลตนเองอย่างจริงจัง” [“Encourage the government to develop and provide the appropriate knowledge about HIV proactive seriously.”]
Female, Zimbabwe: “Be positive about nagative”
Female, NR: “yes being positive doesnt mean you near to die but you can live longer like any one else”

Other:
Other (gay men), Cambodia: “we need support from all of you , and stop use D4T.”

21–22 years
Male:
Male, India: “what about me and my sister who is born with HIV? no education no good food”
Male, India: “Free general medicines, free health investigations.”
Male, India: “Provision for free education, free health investigation and nutrition support for the PLHIVs”
Male, India: “Today, young people are facing most of the problem on health care. So in order to stay healthy, we need information, education and communication.”

Male, India: “Yes, educational sessions, youths sexual health and rights, about sex and sexuality.”

Male, India: “No comment”

Male, Malaysia: “Mt family didnt know yet.... Teach us how to discuss with family”

Male, Mexico: “Que los grupos de autoapoyo sean mas solidarios con las personas con VIH, ya que muchas veces solo manejan los intereses de ellos, y no de las personas que viven con VIH/SIDA”

Male, Rwanda: “Good services for all young people”

Male, Ukraine: “Я хочу просто жить своей жизнью. Мне не нужно светится на телевидении или как то еще быть известным всем. Поэтому я боюсь ходить на разные группы поддержки. Но у меня есть друзья, тоже инфицированные, и я как могу помогаю им, а они помогают мне. И мой бой Freund очень меня поддерживает. Меня очень беспокоит слухи про то, что лекарства от СПИДа постоянно задерживаются. Если я начну принимать эти лекарства, я боюсь, что они не будут работать потому что их нужно принимать без перерыва, но врач не всегда сможет мне дать их.”

Male, Uruguay: “Gracias, ojalá sirva de algo esto.”

Male, USA: “No”

Male, Venezuela: “¿Donde buscar información real, con testimonios de jóvenes que viven con el virus, con calidad de vida?”

Female, India: “Porvide Life skill education session to all the young people which is focussed on the sexual health and rights.”

Female, Kenya: “The survey questions were good and I hope that something useful and helpful will come out of this survey to help HIV positive adolescents.”

Female, Rwanda: “No, thank you”

Female, Thailand: “I want a treatment developed to cure for HIV infection”

Female, Zambia: “Nil”

Male, Zimbabwe: “In as ART is concerned why can't we be given only one type of medication with the same name and everything.”

Female, Zimbabwe: “hiv is not a crime, to marry a nagative girl is not a crime”

Female, NR: “People living with the virus should not be treated differently from the rest rather they should be loved and cared for.”

Female, NR: “Free education, provision for nutrition support , other health investigations and free provison for general medicines.”
Female, The Gambia: “Adolescent health is greatly affected by not only the inadequate provision of reproductive and sexual health services but to a major extent, by factors outside the control of the health system, such as religious and socio cultural issues and values. The Gambia’s culture and traditions such that parents rarely discuss with their adolescent children and in particular girls, on issues related to their growing up, puberty, sex, etc. As young people, we need information about the physiological changes in our bodies, and the implications of sexual activity in order to make responsible and conscious decisions about our health. The opposing view is that, providing adolescents with information about their sexual and especially, with reproductive health services will encourage early sexual activity and promiscuity.”

Male, Colombia: “Fomentar espacios de educación tanto a cero positivos como negativos al igual sensibilizar frente al estigma y la discriminación” [“Promoting education spaces both to HIV-positive and -negative and also mobilize people against stigma and discrimination.”]

Male, Demark: “Yeah - Have a look on the Danish YouthGroup... The work they do - Health providers and young people in collaboration is worth copying... As a part of that group I can honestly say, that the work we do in the group have saved me many times!”

Male, Ethiopia: “We are in sil...”

Female

Male, USA: “No”

Male, Uganda: “UGANDA HEALTH SYSTEM STILL STIGMATISES AND DISCRIMINATES YOUNG PEOPLE LIVING WITH HIV BECAUSE OF BEUROCRATIC DRUG ACCESS SCHEDULE I RECOMEEND WHO TO ADVICE UGANDA HEALTH MINISTRY TO PUT A FRAMEWORK AND SCHEDULE SPECIFICALLY FOR ACCESS TO DRUGS BY YPLHIV AND PEDIATRICS RATHER THAN BEING INCLUDED IN GENERAL ROASTER PLANN.”

Male, Uganda: “Basically i think i have said everything though i would like the government of my country to decentralise ARV distribution to at least all health center IVs because at least these are in most communities. however i have traveled in various parts of the country in my line of work, but still these health centers are in poor conditions.”

Male, USA: “no”

Male, Zambia: “Nil”

Male, NR: “I just want to thank you for this survey”

Female:

Female, Ethiopia: “We are in silent but the spread of HIV infection is till running, the some solutions that has been done has its own scar and needs to see unexpected hidden problems. thank u”

Female, The Gambia: “Adolescent health is greatly affected by not only the inadequate provision of reproductive and sexual health services but to a major extent, by factors outside the control of the health system, such as religious and socio cultural issues and values. The Gambia’s culture and traditions such that parents rarely discuss with their adolescent children and in particular girls, on issues related to their growing up, puberty, sex, etc. As young people, we need information about the physiological changes in our bodies, and the implications of sexual activity in order to make more responsible and conscious decisions about our health. The opposing view is that, providing adolescents with information about their sexual and especially, with reproductive health services will encourage early sexual activity and promiscuity.”
Female, Guyana: “More interest should be paid to teenagers”
Female, India: “Free health investigation”
Female, Kenya: “THEY NEED TO IMPROVE ON NETWORKING YPLWHIV SO AS TO ENSURE THEY CAN FOLLOW UP ON US SINCE SOME DISAPPEAR DUE TO BEING ORPHANS OR DEATH.”
Female, Rwanda: “I want just to thank you for all thing you try to do for us (getting medicin (ART), to be treated by free). Thankyou very much.”
Female, Senegal: “Trouver des stratégies pour l’insertion des jeunes séropositives dans l’emploi et améliorer leurs conditions de vie.” [“I think it is important to find strategies of integration of young people living with HIV on the job market and improve their conditions of life.”]
Female, Swaziland: “There is too much discrimination of HIV positive youth in my community, also the issue of privacy is crucial especially in public hospitals”
Female, Uganda: “Am just looking at helping other young positives.”
Female, USA: “We need a plan to fight stigma!”
Female, Zambia: “Changing the system on getting drugs, like every after six month especially for those who are adhering well to treatment. Unlike the visitation of every three months.”
Female, Zambia: “Nil”
Female, Zimbabwe: “No”
Female, Zimbabwe: “pliz if there is any help we could get on having medication that we could take once a day that would be of help as one young people die because of defaulting, it takes a disciplined someone to drink their meds but if someone doesn’t understand why this had to fall on them and why they should keep drinking their meds it will be difficult to consistently take their meds. Of which thats the stage i am at”

Transgender, Other, and No sex or gender specified:
Transgender, USA: “Nope”
Other (bisexual), Philippines: “Job opportunities with people who has HIV”
NR, Kenya: “The experiences of YPLHIV are unique to their age and stages of development. The desires and dreams of a young person living with HIV will differ according to their age, their social and economic background, their sexuality, their religion, their gender and so many other factors.”
NR, Philippines: “We all know that Philippines is not a wealthy country, one big problem of HIV positive here in the Philippines is the cutting of free ARV support of a private company. It will be a burden for us to pay for our ARV which is very expensive.”

7.4 Responses to open-ended questions (by theme)

7.4.1 “What do you like most about the care you receive?” (Q34) (229/447) 51.2% (NR=218)

Medication and testing is readily available and helps them feel better: 71/229 (31.0%)

Feel better: 12/71 (16.9%)
10-12, Male, Cameroon: “je me sens bien grâce aux médicaments” [“I feel good with drugs”]
10-12, Male, Lesotho: “I like the fact that the medication I receive reduces the HIV virus in my body”
13-14, Male, Cameroon: “ça m’aide à être en bonne santé” [“It helps me to be healthy”]
13-14, Male, NR: “To keep healthy and get stronger.”
15-16, Female, Cameroon: “les médicaments m’aident à soigner ma maladie” [“medicines help me cure my disease”]
15-16, Male, Thailand: “การเรียนรู้เรื่องการดูแลสุขโดยผ่านการท ากิจกรรมกลุ่มมากกว่าการนั่งฟังข้อมูลอย่างเดียว เช่น ผลกระทบจากการไม่กินยาต้านไม่ต่อเนื่อง ผลข้างเคียงของยา” [“Learning through group activities, rather than sit and listen to the same information. The effects of the drug are not felt continuously.”]
17-18, Female, Thailand: [“Health”]
17-18, Male, Cameroon: “les médicaments m’aident à soigner ma maladie...” [“medicines help me cure my illness”]
17-18, Male, Malawi: “i fill good about it.”
19-20, Female, Namibia: “its that we are looking healthy on our bodies and just look like all the negative children around.”
19-20, Female, Malawi: “It helps to keep me in good health...”
23-24, Male, Philippines: “what i like the most with regard to my medication is that somehow, it boosts my immunity, which in turn helps me avoid infections.”
Access (not including cost): 41/71 (57.7%)
10-12, Female, India: “Health monitoring”
10-12, Female, India: “Regular drug treatment”
13-14, Female, Cameroon: “Les médicaments pour ne pas tomber malade” ["The drugs do not get sick"]
13-14, Female, India: “Health Care”
13-14, Female, India: “Health check up and counselling”
13-14, Female, India: “Regular health check up and education”
13-14, Female, India: “ART medicines provided by Govt. hospitals.”
13-14, Female, Zimbabwe: “...There is also easy access to the medication”
13-14, Female, NR: “HIV care and drug treatment.”
13-14, Male, India: “Regular health check up and drug treatment”
15-16, Female, Lesotho: “They provide us with service for HIV and they also educate us about HIV.”
15-16, Female, NR: “Health care investigations at Hospitals.”
15-16, Male, India: “Health check up and drug treatment”
15-16, Male, India: “Regular health check up and care by Doctors”
17-18, Female, India: “Regular health check up”
17-18, Female, India: “Drug treatment on ART”
17-18, Female, NR: “Drug treatment on ART by govt. hospital....”
17-18, Male, India: “...free health check up”
17-18, Male, India: “Drug treatment on ART”
17-18, Male, India: “Health check up and drug treatment”
17-18, Male, India: “Health check ups and drugs therapy”
17-18, Male, NR: “access to medication”
19-20, Female, India: “Health check up and counselling at the health cares centres.”
19-20, Female, India: “About HIV care and treatment given by govt. hospitals and other NGOs working in the field”
19-20, Female, India: “Drug treatment on ART and regular health check up.”
21-22, Female, Thailand: “The clinic is not far from my dormitory...
21-22, Female, NR: “Health care and check up and monitoring”
21-22, Male, India: “Regular health check up and treatment on ART”
23-24, Female, The Gambia: “My ARV drugs and the nutritional support i sometimes receive quarterly when available.”
23-24, Female, Kenya: “RECEIVE COUNSELLING RECEIVE MEDICATION AND KNOWLEDGE WHEN I NEED IT”
23-24, Female, South Africa: “point-of- care CD4 machine - no long waits”
23-24, Female, South Africa: “I like the fact that my medication is always .... ”
23-24, Female, Swaziland: “It's quite accessible in terms of distance”
23-24, Male, Argentina: “Poder tener la atencion cuando la necesito y tambien la medicacion” [“Having the attention when I need it and also the medication”]
23-24, Male, Germany: “good health care system in Germany, lot of support groups, information, specialized doctors etc."
23-24, Male, India: “Drug Therapy (ART) treatment”
23-24, Male, India: “Drug therapy on ART by govt. hospitals...”
23-24, Male, Malaysia: “Its still support by goverment and easy access to id clinics”
23-24, Male, Uganda: “that i freely access the ARVs and it's very rare to find drug stock outs at the clinic as its in the city center....”
23-24, NR, Kenya: “The life saving drugs provided”
23-24, NR, Philippines: “I like it when my doctor also consider my financila capability especially when i was hospitalized because of arv side effects.”

Cost: 18/71 (25.3%)
10-12, Female, India: “I like the way they help us in treatment by free of cost.”
15-16, Male, India: “...free general medicine and free health investigation”
19-20, Other (gay men), Cambodia: “ARV free”
21-22, Female, Kenya: “The services are free”

21-22, Male, Philippines: “Free consultation....”
21-22, Male, Philippines: “... Free ARVs. I hope, free medications also for treatment and curing of infections.”
21-22, Transgender, Bhutan: “As of now I don’t receive any medical care for HIV but I would like it be free and with out much hassles”
23-24, Female, Ethiopia: “... access free Ol Drug....”
23-24, Female, Uganda: “Well it is free for starters ....”
23-24, Female, Zambia: “Free treatment.”
23-24, Male, Belize: “its free”
23-24, Male, Denmark: “That it is free, so that everybody have access to the HIV care.”
23-24, Male, Philippines: “It’s free...
23-24, Male, Philippines: “We would like to have a cheaper or at least more free laboratory services”
23-24, Male, Uganda: “that i freely access the ARVs and it’s very rare to find drug stock outs at the clinic as its in the city center.
23-24, Male, Uganda: “they give me free treatment ...
23-24, Male, Zambia: “[free treatment”
23-24, NR, Philippines: “[I like it when my doctor also consider my financila capability especially when i was hospitalized because of arv side effects.”

Support: 143/229 (62.4%)
Good relationship with and great support from the staff (not including counselors or psychologists) (trust, confidence, professionalism): 61/143 (42.6%)

10-12, Female, Malawi: “they treat me with love”
10-12, Male, South Africa: “My healthcare Worker looks out for me everyday and checks that I take my meds properly. The nurse looks after me when I am sick and provides all my medicine and my doctor visits me in the village to take my blood and check on me”
13-14, Female, Lesotho: “I like how my HIV receive/care that my life is still safe and I feel fully supported”
13-14, Female, Namibia: “When you are have HIV CARE you feel love and take good care of. That way teen must join different groud which give good at HIV”
13-14, Female, Uzbekistan: “то что ко мне относятся хорошо, и я не чувствую страх из ВИЧ” “[I like how they treat me and the fact I am not afraid of HIV”
13-14, Female, Zimbabwe: “the staff are really caring and if you are not feeling well their treatment is really good, you can easily be seen by the Doctor...”
13-14, Female, South Africa: “i like that i am bieng take care by the nurses and doctor that is all”
13-14, Female, Zimbabwe: “the staff are really caring and if you are not feeling well their treatment is really good, you can easily be seen by the Doctor...”
13-14, Female, NR: “i like the way i am welcomed at the ...
15-16, Female, Lesotho: “I like the HIV care receive because I have someone help me.”
15-16, Female, Malawi: “The way the doctors care for us as patients, they show love and care.”
15-16, Female, Thailand: “[The attention of the administrators]”
15-16, Male, Kazakhstan: “Я могу спокойно разговаривать с ними обо всем, включая и свое заболевание. Могу открытно излагать свои потребности.” “[I can calmly talk to my care givers about everything, including my condition. I can openly express my needs.”
15-16, Male, Lesotho: “Health professionals teach us how to take a good care of ourselves while still leaving with HIV and AIDS.”
15-16, Male, Malawi: “the care which they give to us”
15-16, Male, Namibia: “doctors and nurses are very kind and do not discriminate or abuse their power”
15-16, Male, Thailand: “[The medical doctor]”
15-16, Male, NR: “[like the treatment that they give me and they must keep it up. and the are doing a good job”
17-18, Female, Lesotho: “Helps in accepting the status and live a positive life.”
17-18, Female, Malawi: “The care and treatment I receive... ”
17-18, Female, Thailand: “[Friendly”
17-18, Female, USA: “Everyone at the clinic is so understanding and they are willing to help me with any problems I come across. I can really trust them.”
17-18, Female, USA: “Feel comfortable there and have built a relationship with staff. ”
17-18, Male, Malawi: “We are treated very well at our clinic. There is rivacy at the clinic. We get goot treatment. ”
19-20, Female, Kenya: “we are many but the health care providers are trying their best to give us their best”
19-20, Female, Macau: “[THEY OWEZ TREAT IN A VERY SPEACIAL WAY AND THEY ARE DOING A TRAMENDOUS WORK”
19-20, Female, Malawi: “the care givers are so supportive and are doing there best to help us live a positive life”
19-20, Female, Thailand: “[The doctor ask questions about health status. And asks about the drug. I can feel his support. I have to eat next.”]
19-20, Female, Zimbabwe: “I’m proud of it because im being helpeld”
19-20, Male, India: “Friendly environment with the care givers in the health centres”
19-20, Male, Nepal: “Treatment, Care and Support with Advocacy from the care home”
19-20, Male, Mexico: “La orientacion, el apoyo y las terapias de educacion” “[I like the orientation, support and educational therapies”
19-20, Male, UK: “The close relationship I have developed with my health workers since my diagnosis. They are always happy to listen and assist me in any way possible at any time. They have made it a lot easier for me”
21-22, Female, Kenya: “How the health workers treat me when I visit the clinic.”
21-22, Female, Thailand: “... The staff have the service mind.”
21-22, Female, Zimbabwe: “that the doctors and nurses take time to sit down with me and discuss about life, furthering my education, how i can have that dream job or about having children someday or even being in a relationship with an uninfected partner, and how i do not have to be pressurized into having sex simply because i want to remain in a relationship”

21-22, Female, Zimbabwe: “they encourage us to be confident enough and stand for c”

21-22, Female, NR: “The health providers are caring and always want to know how we are progressing. when you do not turn up for your appointment they will always follow up and know what the problem is. For those who are unable to reach the facility due to various reason the health providers go to wherever they are and assist them.”

21-22, Male, Argentina: “La atención y comprensión de mis infectologa. Que me ayuda a estar tranquilo.” [“I like the support and understanding from my infectologist, who helps to make me calm.”]

21-22, Male, Malaysia: “They are very professional”

21-22, Male, Philippines: “I like that the health care professionals who give me HIV care are very nice and very practical as well.”

21-22, Male, Philippines: “… accommodating staff”

21-22, Male, Rwanda: “The way healthcare providers understand my problems. I like when a healthcare provider call me on the phone to remind me to go to the health centre to take my medication”

21-22, Male, USA: “The doctors and counselors are very informative and make sure that all my questions are answered. They follow up with me all the time…”

23-24, Female, Kazakhstan: “Отношение моего лечащего врача СПИД-центра” [“I like the attitude of my doctor at the AIDS clinic”]

23-24, Female, South Africa: “I like the fact that people really care for me here, in their hearts. we are all one.”

23-24, Female, Uganda: “…qualified persinnel work on me.”

23-24, Female, Zambia: “HEALTH CARE PROVIDERS PROVIDE ADEQUATE INFORMATION”

23-24, Female, Zimbabwe: “To discuss about sexual activities, STIS and how to prevent unwanted pregnences”

23-24, Male, Malaysia: “they give support in term of social and emotional and also give information”

23-24, Male, Mexico: “El trato de los médicos y personal de salud, son respetuosos. En ocasiones he acudido a urgencias y siempre he recibido atención.” [“I like the professionalism of my doctors.”]

23-24, Male, Argentina: “La atención y comprensión de mi infectologa.” [“I like the attitude of my doctor at the AIDS clinic”]

23-24, Female, USA: “The doctors and counselors are very informative and make sure that all my questions are answered. Sometimes I had an emergency and I have been always assisted.”

23-24, Male, Mexico: “El trato personalizado de mi preparador de servicio.” [“I like the personalized care provided to me.”]

23-24, Male, Mexico: “El trato hacia las nosotros sin ninguna discriminación o gesto incómodo.” [“I like the way how they treat us, without any discrimination or strange behavior.”]

23-24, Male, Philippines: “… health care workers have a sense of urgency towards us which makes me feel secure.”

23-24, Male, Philippines: “My doctor is very supportive and generous.”

23-24, Male, Spain: “La profesionalidad de mis médicos” [“I like the professionalism of my doctors.”]

23-24, Male, Uganda: “… they carried me. not to lose hop”

23-24, Male, Uganda: “…also most the medical personnel at the clinic don’t seem old and this gives me a youth friendly environment.”

23-24, Transgender, USA: “I like the open and honest relationship I have built with my providers.”

23-24, Other (bisexual), Philippines: “The Trust and responsibilities”

23-24, NR, Philippines: “I like it when my doctor also consider my finacial capability especially when i was hospitalized because of arv side effects.”

Privacy, Confidentiality: 9/143 (6.3%)

17-18, Male, India: “Maintaining confidentiality…”

17-18, Male, Malawi: “We are treated very well at our clinic. There is rivacy at the clinic. We get goot treatment.”

21-22, Male, India: “Maintaining confidentiality.”

21-22, Male, USA: “The doctors and counsellors…ensure that my privacy is protected.”

21-22, Male, Zimbabwe: “that it will only be me and the nurse in the counseling room and that patience are not grouped at the dispensary.”

23-24, Female, Guyana: “Confidentiality”

23-24, Female, India: “Maintaining confidentiality and counselling process.”

23-24, Male, Jamaica: “the privacy you receive”

23-24, Other (gay male), Philippines: “it’s confidential and ready.”

Talks with the counsellor, psychologist, psychosocial support: 14/143 (9.8%)

[including those mentioned in combination therapy: 27/143 (18.9%)]

13-14, Female, Cameroon: “les classes thérapeutiques, la causerie avec le psychologue,” [“therapeutic classes, chat with the psychologist,”]

15-16, Female, Lesotho: “People like us should have counselling and we should counseling others were should make them be comfortable”
Teen club or other peer support (group activities, having support of others living with HIV) : 33/143 (23.1%)
21-22, Male, Venezuela: “Que se explique las oportunidades de seguir viviendo con calidad de vida, testemonios de personas que han superado la etapa de diagnostico de ser PVV” ["I like that the opportunities of living with quality of life are explained, and testimonials of people who have overcome the diagnosis of HIV are shared”].

23-24, Male, Germany: “good health care system in Germany, lot of support groups…”

23-24, Male, Mexico: “The possibility to meet other YPLWHIV and share experiences, so then I see my concerns reflected in some one else”

23-24, Male, Russia: “группа взаимопомощи” ["I like the support group"]

Combination of medicine, health check ups, therapeutic classes, and psychologist: 13/143 (9.1%)

10-12, Male, Cameroon: “les médicaments que le docteur me donne et les conseils et explications qu'on nous donne à la classe thérapeutique” ["drugs the doctor gives me advice and explanations given to us and to the therapeutic class”]

10-12, Male, Cameroon: “les médicaments, les classes thérapeutiques, les causeries avec la psychologue,” ["drugs, therapeutic classes, talks with the psychologist,”]

10-12, Male, Cameroon: “Pour ma santé le soutien médical, psychologique, classe thérapeutique” ["For my health medical, psychological, therapeutic class”]

13-14, Female, Cameroon: “les médicaments, les informations de la classe thérapeutique, la psychologue” ["drugs, therapeutic class information, the psychologist”]

15-16, Female, Cameroon: “Les médicaments m'aident à ne pas tomber beaucoup malade, le soutien avec les classes thérapeutiques” ["The drugs help me not to get sick a lot, with the support therapeutic classes”]

15-16, Female, Cameroon: “les médicaments, les activités de la classe thérapeutique” ["drugs, therapeutic class activities”]

15-16, Male, India: “The supports provided by some of the NGOs like medicine support, education support and psychological support.”

17-18, Female, Cameroon: “le soutien psychologique et médical” ["the medical and psychological support ”]

19-20, Female, India: “Health check up and counselling at the health cares centres.”

19-20, Male, Rwanda: “I like counselling services and other services I receive from the clinic”

21-22, Female, India: “Drug treatment, counselling and education.”

21-22, Male, India: “Treatment of drugs, counselling and Doctor's activities”

23-24, Male, NR: “I like all services”

Community support 3/143 (2.1%)

17-18, Female, Namibia: “to get more support and care from the communities an servers that support people living with hiv”

19-20, Male, Paraguay: “El espacio en el que se brinda, en un servicio comunitario. No me siento como yendo a clínicas ni centros de salud…” ["[I like] that the care is provided in a community service. I don't feel like a go to clinics or healthcare centers…"]

23-24, Male, NR: “I like all services”

Other support 3/143 (2.1%)

17-18, Female, Namibia: “when am told to go and take my medications”

19-20, Male, NR: “I'm loving it so far because i have people around who love and care for me”

21-22, Male, India: “most of the care for HIV are focus on prevention, i totally need good food and some one who care for us as i am an orphan”

NGOs 7/143 (4.9%)

10-12, Female, India: “About the HIV care, I like the nutrition support given by some of the NGOs”

13-14, Male, India: “Services provided by NGO is far better than in Govt. hospitals as there is always rush.”

13-14, Male, Moldova: “HFI” ["NGOs”]

15-16, Male, India: “The supports provided by some of the NGOs like medicine support, education support and psychological support.”

17-18, Female, NR: “…some of the medicine support provided by NGOs through care and support programs from the foreign funding agencies.”

23-24, Female, India: “Love and care supported by NGO, adherence on ART process”

23-24, Male, India: “… services provided by NGOs.”

HIV testing: 2/229 (1.0%)

17-18, Male, Lesotho: “It really helped me a lot and I do not have any comment on how it saved my life because before I get tested I was a very sick person. I really appreciate every thing that it had to me because if it wasn’t it I would be nothing to other people.”

19-20, Male, Paraguay: “…Me gusta más el centro comunitario de testeo y asesoramiento en VIH.” ["I like more the community center for testing and counseling”]
Education, Advice: 8/229 (3.5%)
13-14, Female, Cameroon: “les conseils m aident à ne pas tomber malade” ["The advice to help m getting sick"]
13-14, Male, India: “Education/Information”
15-16, Male, India: “Free education...”
15-16, Male, Lesotho: “Health professionals teach us how to take a good care of ourselves while still leaving with HIV and AIDS.”
21-22, Female, Zimbabwe: “that the doctors and nurses take time to sit down with me and discuss about life, furthering my education, how i can have that dream job or about having children someday or even being in a relationship with an uninfected partner, and how i do not have to be pressurized into having sex simply because i want to remain in a relationship”
21-22, Male, Zambia: “They give adequate information”
23-24, Female, Ethiopia: “on stigma and discrimination, access free OI Drug and other activities focused on prevention services.”
23-24, Male, Indonesia: “- drugs impact related on hiv treatment - information regarding on SRH for young people living with hiv”

Clinical and support services structure: 6/229 (2.6%)
19-20, Male, Paraguay: “El espacio en el que se brinda, en un servicio comunitario. No me siento como yendo a clínicas ni centros de salud. Me gusta más el centro comunitario de testeo y asesoramiento en VIH.” [“I like that the care is provided in a community service. I don’t feel like a go to clinics or healthcare centers. I like more the community center for testing and counseling”]
21-22, Female, Zambia: “YOUTH FRIENDLY SERVICES”
21-22, Male, NR: “adolescent friendly”
23-24, Male, Jamaica: “is that i always have different option/ place to visiting the health care center, when am out of fun.”
23-24, Male, Russia: “...everything is concentrated in one place”
23-24, Male, Uganda: “…most the medical personnels at the clinic don’t seem old and this gives me a youth friendly environment.”

7.4.2 “What suggestions do you have to improve care for yourself or other young people?” (Q35)
206/447 (46.08%) NR=241

Education 43/206 (20.8%)
Education, books, notebooks, training, games (in general) 10/43 (23.3%)
10-12, Female, Cameroon: “Développer des activités, avoir des outils…” [“Developing activities, have tools...”]
10-12, Female, India: “To provide education support”
10-12, Male, Cameroon: “Outils de rappel des médicaments, les livres, les cahiers, les vêtements, la nourriture” [“Tools drug recall, books, notebooks...”]
10-12, Male, Cameroon: “… avoir les livres pour mieux apprendre, aider les jeunes qui n’ont plus leur parents, nous soutenir beaucoup” [“...have books to learn better, helping young people who no longer have their parents support us a lot”]
10-12, Male, Cameroon: “…les outils de formation pour les non scolarisé, …” [“...tools for training of school...”]
13-14, Female, Cameroon: “I wish that there is a space for us also feel like the others, with a library for those who cannot read and do not go to school, the equipment we facilitate certain, things, support…”
13-14, Female, Cameroon: “recevoir le soutien, les livres, aller à l’école, être comme les autres qui ne sont pas malades” [“receive support, books, go to school, to be like others who are not sick”]
15-16, Female, Malawi: “Pay school fees for them.”
17-18, Female, India: “… free education”
19-20, Female, NR: “i would like to improve in education by telling how school is important.”

Education and tools to better understand HIV or living with HIV (range of subtopics) 33/43 (76.7%)
10-12, Female, India: “Treatment education and positive living education”13-14, Female, Uzbekistan: “хотелось чтобы услуги для молодых людей были адаптированы для национальных групп (узбекоговорящей молодежи- так как основные материалы для подростков и детей либо на русском либо на англи.языках” [“It would be desirable that services for young people have been adapted for national groups (young Uzbeks) and have as well basic materials for teenagers and children either in Russian or on Uzbek.”]
10-12, Female, India: “Awareness drug side effects so that people can take care of their health”
13-14, Female, Cameroon: “avoir les manuels pour bien comprendre et évoluer avec notre maladie...” [“have the manuals to understand and evolve with our sickness...”]
13-14, Female, Cameroon: “...avoir les outils qui vont nous aider à mieux comprendre le VIH” [“...have the tools that will help us to better understand HIV”]
13-14, Female, India: “To provide more information, education and counselling in sexual health and rights”
13-14, Male, India: “Provide more informations on HIV”
15-16, Female, Cameroon: “...les livres, les activités, les formations” [“...activities, training”]
15-16, Female, Cameroon: “le soutien pour tous les adolescents, les livres...” [“support for all teens, books ...”]
15-16, Male, Cameroon: “Trouver le médicament qui guerit le vih, avoir les structures pour éduquer...” [“Find the medication Guerit hiv structures have to educate...”]
15-16, Male, India: “Awareness and treatment education”
15-16, Male, India: “To make a proper hygiene and sanitation”
15-16, Male, India: “Awareness about the preventive measures...”
15-16, Male, Uruguay: “More information, education, goverment does not provide any type of information to the people”
17-18, Female, USA: “I feel there needs to be a lot more education in schools.”
17-18, Male, Cameroon: “je voudrais qu’on est les documents qu’on nous remet à la classe, qu’on ajoute les activités et nous soutenir, avoir beaucoup de choses pour nous aider” [“I would like is that the documents we deliver to the class is added activities and support us, have a lot of things to help us”]
17-18, Male, India: “More awareness on sexually reproductive health and rights”
19-20, Female, Moldova: “побольше бы делали мероприятий для развития активизма среди ВИЧ-позитивных подростков, молодёжи и молодых людей. Различные семинары, тренинги и т.д.это очень необходимо для нас.” [“We need to develop activism among HIV-positive teenagers, adolescents and young men. We need several seminars, trainings, etc.”]
19-20, Male, NR: “educate more young people on HIV, AIDS,STI, STD. ”
21-22, Female, Senegal: “Plus d’informations sur la santé avec les nouveaux outils de l’information (internet, document électroniques etc...) ... [“I would like the new information tools to be used for health information (internet, e-documents....)”]
21-22, Female, Zambia: “Need for SRH INFORMATION AMONG YOUTHS”
21-22, Male, Philippines: “Education. Forums and seminars to public. This is epidemic.”
23-24, Male, Colombia: “Como aprender a manejar las relaciones sexuales con personas cero negativas” [“I would like] to learn how to handle sexual intercourse with HIV-negative people.”]
23-24, Male, Germany: “More detailed information about the side effects. HIV chems are no fun!”
23-24, Male, India: “Treatment education about HIV”
23-24, Male, India: “Education about sexual health and rights of the young people.”
23-24, Male, Malaysia: “they should give information how the young people living with HIV to live with HIV”
23-24, Male, Malaysia: “More education about how hiv spread among teenagers as this is not a disease spread by prostitute only as everyone have risk if do not care.”
23-24, Male, Mexico: “Mayor información general, sobre los cuidados en casa, como por ejemplo si se pueden tener mascotas o no. O si para alguien con VIH es viable adoptar hijos.” [“I would like] more general information about home care of people living with HIV: for example, if they can have pets, or if it is possible for them to adopt children.”
23-24, Male, Mexico: “Tratamiento, uso de preservativos, una adecuada alimentación, hacer ejercicio, comunicación entre familiares.” [“Treatment, condom use, balanced nutrition, physical exercise, communication among relatives and family [would improve the quality of my care]”]
23-24, Male, Philippines: “Basic HIV 101...”
23-24, Other (bisexual), Philippines: “More on education of safe sex”
23-24, Other (gay male), Philippines: “education”

Age-appropriate Support (primarily social with adolescent focus) 45/206 (21.8%)

10-12, Male, Cameroon: “...doucement on the young people who no longer have their parents support us a lot”
13-14, Male, Moldova: “Не хочу чтобы меня видели в очередь другие взрослые больные” [“I do not want to be seen in same line as the adult patients.”]
13-14, Female, Malawi: “if they could be phoning us”
13-14, Female, Uzbekistan: “чтобы услуги для подростков были по всей стране, чтобы они были регулярными” [“I would like treatment and care for young people living with HIV to be all over the country and to be more regular.”]
15-16, Female, Lesotho: “They should give support to young people living with HIV.”
15-16, Female, Thailand: “Want friends together a lot”
15-16, Male, India: “Opening of free clinic only for children”
17-18, Female, Nepal: “this needs to focus on young people more”
17-18, Male, India: “Adolescence programe needs to implement.”
17-18, Male, Lesotho: “I suggest that there should be peer support groups”
17-18, Male, Malawi: “Have Teen Clubs at every health centre (Support groups for ALHIV) Provide free nutritious foods to adolescents as well.”
19-20, Female, India: “More improvement in awareness on youths about sex and sexuality.”
19-20, Female, India: “To organise talent show for the PLHIV”
19-20, Female, Kenya: “set aside date for us or better still our own clinic, friendly clinic according to our ages, be given choices of treatment and allow us to choose, all the drugs that have fatal side effects to be burned immediately by the government...last but not least consider a trip for all of us especially paediatrics.”
19-20, Female, Thailand: “[a group of friends. Same model and the development of ongoing support.”
19-20, Female, Uganda: “Our peers shld be trained to support more of our friends because entering the clinic the first time i really suffered.”
19-20, Male, Paraguay: “Expandir los servicios comunitarios de testeo, tratamiento y contención para jóvenes viviendo con VIH. Las estrategias comunitarias que ayuden a conocer más sobre VIH son las que generan cambio real de comportamiento a nivel local y regional.” [“I would suggest] to expand community services of testing, treatment and containment for young people living with HIV. Community strategies that help to learn more about HIV are generating real behaviour change local and regional level.”
19-20, Male, UK: “More opportunities to meet other young people in my area with HIV”
21-22, Female, Kenya: “There is need to have people trained to work with HIV positive adolescents. People who really and truly understand HIV positive adolescent. A separate clinic for HIV positive adolescents with games and sports. And also adolescents groups activities - trips and exchange. Maybe a conference for HIV positive adolescents.”
21-22, Female, Senegal: “… Des sites de rencontres et d'échanges entre pairs et des club de rencontre pour se divertir et oublier les soucis qui present.” [“...I also would like] places where people could meet, share experiences and have fun, just to forget the troubles of their lives.”
21-22, Female, Thailand: “Having more HIV peer group activities such as camp. Support the educational funds for who needed.”
21-22, Female, Zimbabwe: “right now in Zimbabwe, many children suffer stigma and discrimination so naturally i would say if it were possible to shield them from such harsh treatment as it sometimes leads to suicide. ...if maybe there could be an adolescent/youth friendly corners all over the country where i do not have to be shy to ask about Adolescent Sexual Reproductive Health”
21-22, Female, NR: “All the young people infected should have a group where they meet frequently to discuss the problems that they are facing. The group will also help them to encourage each other and always look out for each other.”
21-22, Male, India: “To have a free zone for sexual health and rights, HIV care orvinder should provide information especially for young people.”
21-22, Male, India: “IEC mete rails with photo picture, more component of children in the HIV program...”
21-22, Male, Malaysia: “saperate the appointment session with adolescence”
21-22, Male, Rwanda: “To improve services for other young people around the country because they are some young people who don't receive good services because of how they are (poor) Good services for all!!!”
21-22, Male, Zambia: “youth services to the community”
21-22, Transgender, Bhutan: “Come with innovatie methods to get engaged with youth living with HIV”
23-24, Female, The Gambia: “I suggest if the attitude of health care providers could be changed, it will help we the young people have access to the care services we need. Their attitude towards young people seeking treatment is very poor. They usually judge why young people seek treatment or contraceptives and this affects how they help the young even if he/she is at risk. We need a youth-friendly environment that can attract and serve the young who may be embarrassed or intimidated to seek HIV care.”
23-24, Female, Guyana: “More support groups and interactive activities with other PLHIV”
23-24, Female, Rwanda: “I would like to suggest you or others people in charge of this to find for us young people living with HIV a time for appointment not different to adult”
23-24, Female, Senegal: “Je suggère à ce que des médecins soient spécialisés pour prendre en compte les aspects des adolescent et adolescentes. Il faudrait aussi que les adolescents vivant avec le VIH puissent avoir des epace de rencontres et d'échanges.” [“I suggest those who make drugs to have adolescent boys and girls in mind. I also would like young people living with HIV to have a place to meet and share experiences”]
23-24, Female, Swaziland: “The health centers should have youth friendly stuff to cater for our needs, also privacy is an issue, not all of us are ready to disclose, there is a problem at our hospitals when we que at a window written ARVs everyone can see that we are HIV positive and that makes the stigma to be worse.”
23-24, Female, Uganda: “Help young people living meet with other young positives in different countries”
23-24, Female, Zambia: “They is need for more youths friendly service facilities.”
23-24, Female, Zambia: “Need for establishment of youths friendly clinics”
23-24, Male, Denmark: “Groups of talking...! Here in Denmark we have a group - YouthGroup of HIV people in Denmark... I've gone there for about 8 years now - And my life would be completely different if that group hadn't existed”
23-24, Male, Denmark: “More groups for PLHIV.”
23-24, Male, Indonesia: “the heal services provider should be more widely available for young people living with hiv without any barrier on addressed STI information for youth.”
23-24, Male, Jamaica: “my aim is to encourage young people living with HIV/AIDS (YPWHIV) to adhere to your medication, live up take full responsibility of your own action, be strong, and think positively and get involve.”

23-24, Male, Mexico: “I think we need (in Mexico) more youth-friendly information related to ARV treatment and secondary effects. Moreover, health providers and young people need to think together on a specific timeline in our healthcare since our need and expectations are different from adult people. Finally we need youth sexual and reproductive health services and information in clinics and care centers for YPLWHIV.”

23-24, Male, Rwanda: “consider that young people are growing up and need improved services for their age group”

23-24, Male, Uganda: “It’s very much important that medical workers learn to listen to the young people living with HIV as sometimes they judge them by their acts and always blame them for their poor health. This lowers their self esteem and sometimes forces them to abandon treatment as they don’t want to run into those individuals. It happened to me onetime, therefore am speaking from experience. Okay I know they are aware of this, but they need also to realise that as young positives, we also grow up and nature takes course as well. They should stop blaming us when we decide to have children when we come of age because they tend to take us as still young even when we are above the adult age.”

23-24, NR, Kenya: “Let’s talk about the varied needs of young people and Recognition for the diversity within young people eg needs to - Sexual and Reproductive Health and Rights - Access to treatment, prevention, care and support services - Access to education, skills and livelihood support - Stigma, discrimination and human rights Challenges around disclosure - Transitional care for adolescents living with HIV - Involvement and leadership -”

**Medications, access to ARVs, ART, etc.**

| 10-12, Female, Cameroon: | “…trouver le médicaments qui tue le VIH” [“…, finding the drug that kills HIV”] |
| 10-12, Male, Lesotho: | “There should be adequate medication at the hospital” |
| 13-14, Male, Cameroon: | “Améliorer les médicaments pour que la maladie puisse finir, nous soutenir encore quand on nous insulte” [“Better medicines for the disease can finally support us again when we are insulted”] |
| 13-14, Male, India: | “Want to make available other general medicines too like ART in the future.” |
| 13-14, Male, NR: | “To encourage others with HIV to take meds correctly” |
| 15-16, Female, Malawi: | “… Give free medical services and treatment. Give them guidance and counselling.” |
| 17-18, Female, Cameroon: | “Améliorer la disponibilité des ARV…” [“Improve the availability of ARV Play over those who are sick…”] |
| 17-18, Female, India: | “Free treatment…” |
| 17-18, Female, Namibia: | “young childrens…must be treated good like at the clinics need help with a thier medication carean their gflow up to the doctors an need better devloppment with the lp of the goverment as well as the ather support groups” |
| 17-18, Male, India: | “Sometimes, there is ART out stock. Let’s not make such things happen repeatedly…” |
| 17-18, Male, India: | “Provide for medicine support” |
| 17-18, Male, Namibia: | “to reduce the number of tabslets intake day by day” |
| 17-18, Male, NR: | “Government should allocate funds for ART” |
| 19-20, Female, Kenya: | “…all the drugs that have fatal side effects to be burned immediately by the government, most of our medication are donor funded so the government should consider putting some measures in case the donors pull out we can continue with medication, last but not least consider a tripper for all of us especially paediatrics.” |
| 19-20, Female, Namibia: | “they should introduce anoher cure that does not make us feel dizzy, because with this now some of us feel dizzy in the morning when talking our medication.” |
| 19-20, Male, Mexico: | “Las terapias alternativas micronutrientes, la medicación y pruebas que se hacen para los avances tecnológicos del VIH” [“Alternative therapies with micronutrients, medication and tests done for HIV technological advances.”] |
| 19-20, Male, Mexico: | “Pediría medicamentos que no sean tan incómodos.” [“I would ask for less painful medication”.] |
| 19-20, Male, Nepal: | “We know the side effects of the ART but still we are using it…” |
| 21-22, Female, Zimbabwe: | “…in many hospitals and clinics in my country there is shortage of ARVs, this is a major problem as it affects adherence to their medication so if there was improved supply of these drugs it would go a long way - to access medication a person has got to travel to get such help and some of us do not have the money maybe if there could be distribution of the drug whereby you take it and it lasts for six months that would be a great help…” |
| 21-22, Male, India: | “To improve HIV care and suggested to give supply for medicine and other related support for the welfare of the community.” |
| 21-22, Male, Philippines: | “Give free medications…” |
| 21-22, Male, Uruguay: | “El tratamiento en todas partes del mundo debe ser gratuito, tanto el tratamiento como la medicación y la contención, hay personas que no pueden pagar y no por eso merecen estar en riesgo. Creo que se tienen que hacer mas campañas de información, de educación. La ciencia avanza, la sociedad no.” [“Treatment around the world should be free, not only treatment, but also medication and containment. There are people who cannot pay and don’t deserve to be at risk just because of that. I think more information and education campaigns are needed. Science goes ahead, but not the society.”]
23-24, Female, Kazakhstan: “Обеспечить бесперебойное поступление препаратов APVT” [“I would like the ARVs to be accessible for everybody.”]
23-24, Male, Argentina: “MAKE IT EASIER TO GET MEDS AND PICK THEM UP AT OTHER LOCATIONS”
23-24, Male, Philippines: “We need the availability of generic once daily dosage of ARV available to help with Adherence during medication as I believe it is still not available here in the Philippines”
23-24, Male, Uganda: “I would suggest that u proved more ARVs or u extend the services to the rule areas were people luck information”
23-24, Male, Uganda: “Ugandan government health sector should change from PUSH SYSTEM OF DRUG DISTRIBUTION to PULL SYSTEM SO THAT CLIENTS CAN ACCESS DRUGS.Also NATIONAL MEDICAL STORES SHOULD BE STREAMLINED SO THAT IT DOESNOT TAKE LONG TO DISTRIBUTE DRUGS TO HEALTH CENTRES IN THE VILLAGE HEALTH CENTRES UPCOUNTRY”

Stigma, discrimination, exposure, privacy issues  23/206 (11.2%)
13-14, Female, India: “Awareness on HIV and reducing stigma and discrimination.”
13-14, Female, India: “Reduce stigma and discrimination.”
15-16, Male, India: “Mass awareness to all the community.”
15-16, Male, India: “…reducing stigma and discrimination.”
15-16, Male, Kazakhstan: “Участвовать в спортивных мероприятиях вместе на бесплатной основе и чтобы нас там не дискриминировали.” [“I would like young people living with HIV to be able to do sports without being discriminated by their peers.”]
17-18, Female, NR: “To improve the stigma and discrimination”
19-20, Other (gay men), Cambodia: “We need...family acceptance about our status....
21-22, Female, Indonesia: “Komprehensif health services, including SRHR and no stigma discrimination”
21-22, Female, Zimbabwe: “right now in Zimbabwe, many children suffer stigma and discrimination so naturally i would say if it were possible to shield them from such harsh treatment as it sometimes leads to suicide. ...”
21-22, Female, Zimbabwe: “take thing as it is do not discriminate your self”
21-22, Male, Venezuela: “Que se elimine la discriminación y estigma social” [“I would like] discrimination and social stigma to be eliminated.”
23-24, Female, India: “Awareness in order to reduce stigma and discrimination.”
23-24, Female, Kenya: “NEED TO IMPROVE ON ATTENDANCE TIME BY THE DOCTOR WHEN I OR OTHER YOUNG PEOPLE VISIT A HEALTH FACILITY DUE TO STIGMA NEED PHARMACY ATTENDANCE TO BE SENSTIZED ON HOW THEY HANDLE YOUNG YPLWHIV AT THE COUNTER”
23-24, Female, South Africa: “decrease stigma”
23-24, Female, Swaziland: “The health centers should have youth friendly stuff to cater for our needs, also privacy is an issue, not all of us are ready to disclose, there is a problem at our hospitals when we que at a window written ARVs everyone can see that we are HIV positive and that makes the stigma to be worse.”
23-24, Male, Belize: “free of stigma”
23-24, Male, Mexico: “Gestionar la erradication del estigma por VIH SIDA.” [“I would like] the erradication of stigma against HIV/AIDS to be carried out”.]
23-24, Male, Russia: “Я ВИЧ положительный гей. И я часто сталкиваюсь с тем что среди ЛЖК ко мне тоже плохо относятся” [“I am a HIV positive gay. I often come face discrimination from people living with HIV.”]
23-24, Male, Uganda: “it’s very very important that medical workers learn to listen to the young people living with HIV as sometimes they judge them by their acts and always blame them for their poor health. this lowers their self esteem and sometimes forces them to abandon treatment as they don’t want to run into those individuals. it happened to me onetime, therefore am speaking from experience. okay I know they are aware of this, but they need also to realise that as young positives, we also grow up and nature takes course as well. they should stop blaming us when we decide to have children when we come of age because they tend to take us as still young even when we are above the adult age. ”
23-24, Male, NR: “Looking for how to fight stigma and discrimination against”
23-24, NR, Philippines: “Here in the Philippines the stigma one to be consider by a HIV positive. All we want is a clinic/hub that will make sure that our identity will not be exposed.”
23-24, NR, Kenya: “Lets talk about the varied needs of young people and Recognition for the diversity within young people eg needs to - Sexual and Reproductive Health and Rights - Access to treatment, prevention, care and support services - Access to education, skills and livelihood support - Stigma, discrimination and human rights Challenges around disclosure - Transitional care for adolescents living with HIV - Involvement and leadership - ”
23-24, NR, Philippines: “Here in the Philippines the stigma one to be consider by a HIV positive. All we want is a clinic/hub that will make sure that our identity will not be exposed.”

Responsibility for self/self-reliance  16/206 (7.76%)
10-12, Female, Malawi: “we should cooperate”
13-14, Female, Lesotho: “Youths that are already taking medication should adhere to their medication...
13-14, Female, South Africa: “to take care of them selves”
13-14, Female, Zimbabwe: “To take more care of themselves, take medication as prescribed and avoid sex mainly unprotected sex because you expose yourself to lots of different diseases which is very unhealthy because your immunity is already compromised”
15-16, Female, Lesotho: “The should get test first before the could have sex and they should use condoms. As for me I not doing that”
15-16, Male, NR: “that they must always take their medicines and never skip a day”
17-18, Female, Namibia: “for the young people who are having hiv to stop drinking alcohol and to stop having so much sex partners.”
17-18, Female, USA: “Be educated! Know simple things that you can do in order to stay healthy, and if you’re unsure of something, ask someone!”
19-20, Male, Malawi: “just take my my drops everyday and eat more”
21-22, Female, Zimbabwe: “take thing as it is do not discriminate your self”
21-22, Male, USA: “I would just advise young people who are responsible for scheduling their own appointments, to make sure that they actually schedule the appointments AND attend them. It’s important for our health to be tracked and monitored.”
23-24, Female, Zimbabwe: “To teach them the important of taking ARVS drugs”
23-24, Male, Jamaica: “my aim is to encourage young people living with HIV/AIDS (YPWHIV) is to adhere to your medication, live up take full responsibility of your own action, be strong, and think positively and get involve.”
23-24, Male, Jamaica: “proper nutrition n medication”
23-24, Transgender, Philippines: “Do not be afraid to take an active stance in your health care. Be informed. Know you can say "No". And stay open-minded.”

**Activism, active involvement in community**
20/206 (4.85%)
19-20, Male, India: “Mass awareness on the sexually reproductive health and rights for adolescents”
21-22, Female, NR: “Mass awareness on the issue.”
21-22, Male, India: “Mass awareness on the issue.”
23-24, Female, India: “Awareness in order to reduce stigma and discrimination.”
23-24, Male, India: “Mass awareness about the issue to all the people and advocacy for legal rights of the PLHIV”
23-24, Male, India: “more awareness through media, sensitization to local people and specially to stakeholders.”
23-24, Male, Malaysia: “More education about how hiv spread among teenagers as this is not a disease spread by prostitute only as everyone have risk if do not care.”
23-24, Male, Mexico: “Realizar MIPA” (“To adopt Meaningful Involvement of People Living with HIV”).
23-24, Male, Russia: “волонтерские программы, обучение” (“Volunteer programs, training”)
23-24, Male, Philippines: “…an awareness campaign to those who are HIV-negative to mold their perceptions about HIV. 3. a survey directed to those who are sexually active to gauge their awareness to HIV which could lead to a campaign on how they could be carriers so they would know went to stop spreading the disease...”

**Better facility structure, access to services**
20/206 (9.7%)
13-14, Male, India: “To make available of the professional Doctors in the field of HIV”
13-14, Female, NR: “ART centre should be open ill all the health centres in the state.”
15-16, Male, Thailand: “บริการดูแลหาย หมอทำยา หมอให้ค าแนะน าการดูแลสุขภาพ เพื่อผู้ติดเชื้อให้การปรึกษาและส่งต่อผู้ติดเชื้อผู้มีอาการ ไข้ติดเชื้อไวรัสเอดส์” (“Offers a single point of dispensing doctors, nurses and health care instructions. Friends HIV counseling and group awaiting treatment. Follow friends and keep the continuity.”)
15-16, Male, Thailand: “อยากให้มีที่ศูนย์เดียวสำหรับกำจัดกรรมเรื่องการกินยาอะไรๆ” (“This would provide all HIV-infected drug activity on the lot.”)
15-16, Male, Lesotho: “The service providers must be on time. They are sometimes late. - Toilets be cleaned.”
17-18, Female, India: “Providing proper counselling to the young people on SRHR”
17-18, Female, Namibia: “faunds should be made because at times we experiencing difficulty with transport to collect our medication.”
17-18, Female, Thailand: “ถ้ามีสถานที่เฉพาะในการนัดตรวจก็น่าจะดี” (“If there is a specific place to make an appointment”) 19-20, Female, Macau: “THEY SHOULD ALWAYS SUPPORT US BECAUSE WE DEPEND ON THEM AND ALSO ENCOURAGE US TO DO WHAT IS BEST FOR US AND DISCOURAGE US NOT TO DO WHAT THEY FELT IS BAD FOR US”
19-20, Female, Malawi: “There should continue to give free medicat services to ALHIV.”
21-22, Female, Rwanda: “I would like to ask those who are in charge of health can to put in/ add on a service of communicating someone who don’t respect the appointment”
21-22, Male, India: “Want to keep a special day for young people.”
21-22, Male, Philippines: “…increase the number of treatment hubs”
23-24, Female, Rwanda: “I would like to suggest you or others people in charge of this to find for us young people living with HIV a time for appointment not different to adult”
23-24, Male, Argentina: “MAKE IT EASIER TO GET MEDS AND PICK THEM UP AT OTHER LOCATIONS”
23-24, Male, Philippines: “... Referral to shc for testing or referral mechanisms to stakeholders and partners RA8504”
23-24, Male, Philippines: “Focus more on the psychological well-being of people living with HIV. Offer a support group program led by a professional (preferably someone who has lived with HIV for many years) as part of the treatment plan.”
23-24, Male, Philippines: “1. an environment/institution where HIV-infected people like me could freely express ourselves…”
23-24, Male, Uganda: “i would suggest that u proved more ARVS or u extend the services to the rule areas were people luck information”
23-24, Male, Uganda: “Ugandan government health sector should change from PUSH SYSTEM OF DRUG DISTRIBUTION to PULL SYSTEM SO THAT CLIENTS CAN ACCESS DRUGS.Also NATIONAL MEDICAL STORES SHOULD BE STREAMLINED SO THAT IT DOES NOT TAKE LONG TO DISTRIBUTE DRUGS TO HEALTH CENTRES IN THE VILLAGE HEALTH CENTRES UPCOUNTRY”

Better care and support (including professional behaviour of staff) 17/206 (8.3%)
13-14, Female, Malawi: “if they could be phoning us”
13-14, Male, Thailand: “ไปตามด้วยกันwicklung” “[The doctor to follow up.”]
15-16, Male, India: “To improve HIV care services and would like to improve our support in medicine support not the ART but other general medicine.”
15-16, Male, Malawi: “the health care people should open up to people”
15-16, Male, Thailand: “เข้าใจที่ทำให้ใจหายใจไม่เป็นอย่างไร” “[Explain more”]
15-16, Male, Thailand: “อย่างไรก็ตามผู้มีพฤติกรรมการบริโภคยาติดเชื้อไวรัส” [“This would provide all HIV-infected drug activity on the lot.”]
17-18, Female, Lesotho: “Health providers should be punctual at all times.”
17-18, Male, Lesotho: “I think there has to be more support to people living with HIV/AIDS.”
19-20, Female, Thailand: “มีเพื่อนๆที่รู้ว่าที่สุดกับที่มีความสุขกับสุขภาพ” [“A group of friends. Same model and the development of ongoing support.”]
19-20, Female, Thailand: “ถ้ามีเพื่อนๆ ที่รู้ว่าที่สุดกับที่มีความสุขกับสุขภาพ” [“A group of friends. Same model and the development of ongoing support.”]
19-20, Female, Thailand: “ความรุ้วและสุขภาพในมายังจะให้ความสุขกับสุขภาพ” [“Nurses should speak well. Not yell at patient. And symptoms should be questioned. And the expression should be a smile.”]
21-22, Male, Mexico: “Que la atención sea personalizada entre médico y paciente.” “[I would like] personalized care between doctor and patient.”
21-22, Male, Zimbabwe: “Nurses be in the health sector because they love it not of being forced or pushed by the love of money.”
23-24, Female, The Gambia: “I suggest if the attitude of health care providers could be changed, it will help we the young people have access to the care services we need. Their attitude towards young people seeking treatment is very poor. They usually judge why young people seek treatment or contraceptives and this affects how they help the young even if he/she is at risk. We need a youth-friendly environment that can attract and serve the young who may be embarrassed or intimidated to seek HIV care.”
23-24, Female, India: “To improve HIV care by providing professional health care service providers.”
23-24, Female, South Africa: “I would enjoy if i could freely talk about about my sexual health with health care providers and have ways to feel as if im more part of the community.”
23-24, Female, Uganda: “We need more dictors. Standing on a line for ages is not fine!”
23-24, Male, India: “Since, we feel shy to ask about our sexual health, we need a separate caregiver in the field of SRHR.”

Possible interventions or structural considerations 10/206 (4.85%)
13-14, Female, Lesotho: “I suggest the nurses should make home visits”
13-14, Male, Lesotho: “I suggest for public gatherings”
19-20, Male, Mexico: “Las terapias alternativas micronutrientes, la medicación y pruebas que se hacen para los avances tecnológicos del VIH” [“Alternative therapies with micronutrients, medication and tests done for HIV technological advances.”]
19-20, Male, Paraguay: “Expandir los servicios comunitarios de testeo, tratamiento y contención para jóvenes viviendo con VIH. Las estrategias comunitarias que ayuden a conocer más sobre VIH son las que generan cambio real de comportamiento a nivel local y regional.” [“I would suggest] to expand community services of testing, treatment and containment for young people living with HIV. Community strategies that help to learn more about HIV are generating real behaviour change local and regional level.”]
19-20, Other (gay men), Cambodia: “… and good services for OI, and ARV,”
21-22, Female, India: “Current facilities provided by NGOs and govt. are not for a longer period. We want a long term policy to save the lives of the PLHIV.”
21-22, Male, Argentina: “Generar varias sedes de retiro de medicamentos. Más centros de salud con más infectologos. Menor exposición de datos y miradas del personal de salud. Mayores campañas de concientización, prevención, mayores programas sobre el VIH. Grupos de reflexión de jóvenes.” “[My suggestion] is to generate multiple drug withdrawal points; to have more health centers with more specialists in infectious diseases; to reduce the exposure [of confidential] data to health personnel; to make bigger awareness and prevention campaigns; to make wider higher HIV programs; to create focus groups of youth people”.

21-22, Male, NR: “mainstream the young people in the fight against the HIV pandemic more especially those who are infected”


23-24, Male, Russia: “волонтерские программы, обучение” “[Volunteer programs, training]”

Material Support (e.g. clothing, food/good nutrition; support orphans) 19/206 (9.2%) 10-12, Female, India: “To provide nutritional support in order to stay healthy.”

10-12, Male, Cameroon: “…les vêtements, la nourriture” “[…clothing, food]”

10-12, Male, Cameroon: “…aider les jeunes qui n’ont plus leur parents, nous soutenir beaucoup” “[…helping young people who no longer have their parents support us a lot]”

13-14, Female, Cameroon: “…aider les orphelins, nous aider” “[…help orphans, help us]”

13-14, Female, Cameroon: “Soutenir les enfants, les orphelins…” “[Supporting children, orphans…]”

13-14, Female, Cameroon: “je voudrais qu’on n’est un espace pour nous sentir aussi comme les autres, avec une bibliothèque pour ceux qui ne savent pas lire et qui ne vont pas à l’école, le matériel pour nous faciliter certaines choses, le soutien, et qu’on trouve le médicament qui tue le virus VIH,” “[I wish that there is a space for us also feel like the others, with a library for those who can not read and do not go to school, the equipment facilitate certain things, support, and found the drug that kills the HIV virus,”]

15-16, Female, Cameroon: “je voudrais qu’on trouve le médicament qui tue le VIH, qu’on aide aussi les autres enfants qui n’ont plus leur parents à aller à l’école.” “[I would found the drug that kills HIV, it also helps other children who do not have their parents to go to school,”]

15-16, Female, Cameroon: “plus de soutien, apport du matériel pour nos activités. aider les orphelins et adolescents sur tous les plans” “[more support, supply of equipment for our activities. aid orphans and youth at all levels]”

15-16, Female, Malawi: “Pay school fees for them…”

15-16, Male, Cameroon: “…soutenir les orphelins, nous sommes insultés et parfois on ne nous accepte pas à l’école, les livres, les vêtements.” “[… support orphans, we are insulted and sometimes we are not accepted at school, books, clothing,]”

17-18, Female, Cameroon: “Ecouter plus ceux qui sont malades, soutien financier surtout pour les orphelins, les formations” “[Listen to those who are sick, especially financial support for orphans, training]”

17-18, Female, Namibia: “young childrens should get more support like school fees for them school uniforms care for foods and clothes…”

17-18, Female, NR: “To stay healthy, we need a good food. Thus, nutrition support is very much necessary.”

17-18, Male, Cameroon: “je voudrais qu’on nous apporte une aide matérielle, qu’on nous forme à un travail, qu’on nous apporte des documents pour ne pas se sentir à côté” “[I wish that we provide material assistance, which we form a work that brings documents to not feel side]”

17-18, Male, India: “…Requested young generations to have good and nutritionous foods.”

19-20, Other (gay men), Cambodia: “We need to have more nutrition…”

21-22, Male, India: “… more good nutrition etc”

21-22, Male, Zimbabwe: “there must be free heathier foods for all children so that their healthy improve”

23-24, Female, Ethiopia: “access of job to improve economic support…”

Blood 1/206 (0.5%) 21-22, Female, Thailand: “- ถึงได้จะขอเลือดเฉพาะกลุ่มวัยรุ่น - นอกจากจะเกี่ยวข้องไม่ได้ค้าตัว - มีผลิตภัณฑ์จะ┱รูปเป็นลำดับ ปลอดภัย” “[There are only young blood - the blood draw would not hurt - especially the adolescent clinic is safe.”]

Testing and Prevention 2/206 (1.0%) 13-14, Female, Lesotho: “… And others must get tested after every three month to reduce spread of HIV.”

23-24, Female, Ethiopia: “…should be focus to tackle new infection, Prevention activities should be more important”

7.4.3 “Is there anything else that you would like to tell us?” (Q36) 143/447 (31.9%) NR=304

Thank you, thankful 15/143 (10.4%) 13-14, Female, Lesotho: “No, except for thanking the Nurses and Bathabales who see to it that we are happy and health.”

13-14, Female, Namibia: “Nothing much, then just saying THANK YOU VERY MUCH FOR ALL YOU HAVE DONE OF USE”
13-14, Male, NR: “I am very thankful for ARV-care.”
15-16, Male, Namibia: “I would like to thank the world health organisation for letting to express my feelings and poit of veiw abot my status”
17-18, Female, Thailand: “ขอบคุณมาก” [“Thank you.”]
17-18, Male, Lesotho: “I have nothing to say but what gave me a confidence is my psychologist and other children living with HIV so I really thank them a lot.”
19-20, Female, Macau: “YOU SHOULD KEEP ON SUPPORTING US BECAUSE WE DEPEND ON U TO PERFPM PERFECTLY”
19-20, Female, Malawi: “I like the care am getting”
19-20, Male, Mexico: “Gracias por preocuparse por la atencion a pacientes con VIH” [“Thank you for caring for people living with HIV”]
21-22, Female, Kenya: “The survey questions were good and I hope that something useful and helpful will come out of this survey to help HIV positive adolescents.”
21-22, Female, Thailand: “Thank you for let us participate on this guideline”
21-22, Male, Uruguay: “Gracias, ojalá sirva de algo todo esto.” [“Thank you. I hope this will be useful.”]
23-24, Female, Rwanda: “I want just to thank you for all thing you try to do for us (getting medecin (ART), to be treated by free). Thankyou very much.”
23-24, Male, Argentina: “Sigan con estas preguntas y estadisticas ya que la gente que tiene este diagnosticito se siente mas incluida mas cuando es reciente el mismo, tambien que sigan asi que el genial poder contar con ustedes! gracias!” [“Keep up these questions and statistics because people with this diagnosis feel more included but when it is recent, so also continue the great to have you! thank you!”]
23-24, Male, NR: “I just want to thank you for this survey”

Growing up 2/143 (1.4%)
13-14, Male, Thailand: “อยากให้สิทธิทางอยาต่างอย่าง” [“Want to recover from the infection”]
15-16, Male, Thailand: “ต้องมีความเข้าใจว่าคุณได้มา” [“I am very glad I could grow up”]

Legal rights 8/143 (5.6%)
13-14, Female, India: “Legal rights of PLHIV…”
13-14, Male, India: “… aware on the legal rights of the PLHIV”
15-16, Male, India: “… legal procedures on the rights of the PLHIV.”
15-16, Male, India: “Legal rights of the PLHIV”
15-16, Male, Thailand: “ทำไมเราต้องการให้ได้รับยาที่มีประสิทธิภาพสำหรับโรคให้กับผู้ที่มีการติดเชื้อไวรัสตับอหิวาติ” [“Why force a child to take a blood test? If you detect HIV were deprived in the course, such as doctors, nurses, public health, pharmacy, etc.”]
17-18, Female, India: “Legal rights of PLHIV”
21-22, Male, Zimbabwe: “hiv is not a crime, to marry a negatve girl is not a crime”
23-24, Male, Philippines: “Imposed the Implementation of Republic Act 8504- The Philippine Aids Law and never say that testing should not be mandatory..”

Medication and adherence 26/143 (18.2%)
Access and regimen 13/26 (50.0%)
13-14, Male, Moldova: “Я боюсь что кончатся таблетки для меня…” [“I’m afraid that I run out of pills.”]
15-16, Female, Kazakhstan: “…И когда можно будет АРТ-терапию один раз в сутки.” [“...And when can we have ART therapy once a day?”]
15-16, Male, Uruguay: “Yes, In Uruguay, There are no complete access to HAART, This mean that if you need a certain ARVs, you will not get it since the goverment does not provide them.”
19-20, Male, Nepal: “We nepali and might be other countries as well always have to suffer somewhere from european union because of increase of tax in medicine which increases the rate of medicine..so why dont WHO suggest them after all its about the public health around the world.”
19-20, Other (gay men), Cambodia: “we need support from all of you, and stop use D4T.”
21-22, Male, Zimbabwe: “In as ART is concerned why can’t we be given only one type of medication with the same name and everything.”
23-24, Female, Zimbabwe: “pliz if there is any help we could get on having medication that we could take once a day that would be of help as one young people die because of defaulting, it takes a disciplined someone to drink their meds but if someone doesn’t understand why this has to fall on them and why they should keep drinking their meds it will be difficult to consistently take their meds. of which thats the stage i am at”

23-24, Female, Zambia: “Changing the system on getting drugs, like every after six month especially for those who are adhering well to treatment. unlike the visitation of every three months.”

23-24, NR, Philippines: “We all know that Philippines is not a wealthy country, one big problem of HIV positive here in the philippines is the cutting of free ARV support of a private company. It will be a burden for us to pay for our ARV which is very expensive.”

Free medication 13/26 (50.0%)
10-12, Female, India: “Free medicine support …”
10-12, Female, India: “… general medicines”
10-12, Female, India: “…free … provision for general medicines”
10-12, Male, India: “… free general medicines”
13-14, Female, India: “Provision for free…general medicines”
13-14, Female, India: “…general medicines.”
15-16, Male, India: “… and free general medicines”
15-16, Male, India: “Fre …provision for general medicines”
17-18, Female, NR: “To provide other general medicines besides ART”
17-18, Male, India: “Free ... Ols medicine and general medicine”
19-20, Female, India: “Provision for free...medicines”
21-22, Female, NR: “Free ... other health investigations and free provision for general medicines.”
21-22, Male, India: “Free general medicines, free health investigations.”

Service provision 12/143 (8.4%)
13-14, Female, NR: “Increase no of medical Doctors in the field of HIV care and treatment.”
17-18, Female, Thailand: “อยากให้วัยรุ่นทุกคนที่มีเชื้อหรืออยู่ในความเสี่ยงได้เข้าถึงการบริการที่ถูกต้องและสะดวกใจ [“Care and treatment should be available to everyone at risk of HIV”]
17-18, Male, India: “special space for child counselling”
19-20, Male, India: “Provision for free...health investigations specially Hep-C and nutrition support.”
21-22, Male, India: “Provision for...free health investigation ... for the PLHIVs”
23-24, Female, India: “Free health investigation”
23-24, Female, Kenya: “THEY NEED TO IMPROVE ON NETWORKING YPLWHIV SO AS TO ENSURE THEY CAN FOLLOW UP ON US SINCE SOME DISAPPEAR DUE TO BEING ORPHANS OR DEATH. ”
23-24, Female, Zambia: “Changing the system on getting drugs, like every after six month especially for those who are adhering well to treatment. unlike the visitation of every three months.”
23-24, Male, India: “… free insurance and other health investigation like Hep-C”
23-24, Male, India: “Availability of free ...health investigation ...”
23-24, Male, India: “Services provided by the NGO should also implement even in the government set up also.”
23-24, Male, Philippines: “I think there’s a lot of NGOs out there that aims to prevent the spread of HIV and to make people aware of the risks but not one aims to help us live with HIV. It’s all just us trying to connect so we have a sort of a peer support group.”

Lack of access to services. 4/143 (2.8%)
15-16, Female, Thailand: “อยากให้วัยรุ่นทุกคนที่มีเชื้อหรืออยู่ในความเสี่ยงได้เข้าถึงการบริการที่ถูกต้องและสะดวกใจ [“Want access to care like this. I understand we are not the same.”]
17-18, Female, Thailand: “อยากให้วัยรุ่นทุกคนที่มีเชื้อหรืออยู่ในความเสี่ยงได้เข้าถึงการบริการที่ถูกต้องและสะดวกใจ [“Care and treatment should be available to everyone at risk of HIV”]
21-22, Male, Uruguay: “Yo soy Uruguayo y tuve que venirme a tratar a Argentina porque aqui casi todo el tratamiento y la medicación es gratuita. En Uruguay no, hay una extrema ignorancia desde todos los puntos de vista, ni la medicación es gratuita, ni la facilitan, ni el tratamiento en sí.” [“I’m from Uruguay and I had to come to Argentina to get treatment because here almost all treatment and medication is given for free. In Uruguay it’s not like that. There is a lot of ignorance and medication and treatment are not free or facilitated.”]
23-24, Male, Uganda: “Basically i think i have said everything though i would like the government of my country to decentralise ARV distribution to at least all health center IVs because at least these are in most communities. however i have traveled in various parts of the country in my line of work, but still these health centers are in poor conditions.”
Adolescent Stigma and discrimination

Attitudes and training of health-care providers 2/143 (1.4%)  
13-14, Male, Moldova: “Я ВИЧ положительный гей. И я часто сталкиваюсь с тем что среди ЛЖВ ко мне тоже плохо относится” [“I am HIV positive gay. I often come face discrimination from people living with HIV.”]
17-18, Female, Namibia: “I want to hide this disease from others”

Privacy confidentiality 2/143 (1.4%)  
15-16, Female, Thailand: “Its very difficult to take ART at boarding school. Teachers should be educated on how they can provide treatment support so that people are not stigmatised.”
15-16, Female, Malawi: “I am proud in being open with my doctor and knowing he won’t tell anyone else.”

Stigma and discrimination 12/143 (8.4%)  
13-14, Male, Moldova: “Только ВИЧ + может понять ВИЧ+” [“Only HIV positive can understand HIV positive people”]
13-14, Male, Thailand: “Я ВИЧ положительный гей. И я часто сталкиваюсь с тем что среди ЛЖВ ко мне тоже плохо относится” [“I am a HIV positive gay. I often come face discrimination from people living with HIV.”]

Adolescent-specific needs 15/143 (10.5%)  
10-12, Female, India: “To ... increase community care centre for children”
13-14, Female, Uzbekistan: “хотелось чтобы услуги для молодых людей были адаптированы для национальных групп (узбеков находится подростки, так как основные материалы для подростков и детей либо на русском либо на англ. языках)” [“It would be desirable that services for young people have been adapted for national groups (young Uzbeks) and have as well basic materials for teenagers and children either in Russian or on Uzbek.”]
17-18, Female, NR: “Here in my country we have two sessions for young people under 19 years and for adults so I would like to ask you for adolescents”

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10-12, Female, India: “To ... increase community care centre for children”
13-14, Female, Uzbekistan: “хотелось чтобы услуги для молодых людей были адаптированы для национальных групп (узбеков находится подростки, так как основные материалы для подростков и детей либо на русском либо на англ. языках)” [“It would be desirable that services for young people have been adapted for national groups (young Uzbeks) and have as well basic materials for teenagers and children either in Russian or on Uzbek.”]
17-18, Female, NR: “Here in my country we have two sessions for young people under 19 years and for adults so I would like to ask you for adolescents”
19-20, Female, Thailand: “сейчас у нас есть проект, который поможет молодежи в борьбе с вирусом” [“Encourage the government to develop and provide the appropriate knowledge about HIV proactive seriously.”]
19-20, Female, Thailand: “сейчас у нас есть проект, который поможет молодежи в борьбе с вирусом” [“Want to have a manual to help young people. Some people have suggested, but did not dare.”]
19-20, Female, Namibia: “yes, that on follow up at pharmacy we should not meet in the same day with adults because it use to be full and we spend a lot of hours there, and sometimes we go at the hospital after school and we are hungry.”
21-22, Female, Zimbabwe: “please help support youth led projects in my country as I am a product of such an a programme, you fail due to not attending classes because of illness, you find yourself with nothing to do and wait for someone to take notice of you which never happens, how you wish you could further your education but because you do not have the funds, you are not given that chance of making someone's life different from all the sufferings”
21-22, Male, Rwanda: “Good services for all young people”
23-24, Female, Guyana: “More interest should be paid to teenagers”
### Activism, community engagement

<table>
<thead>
<tr>
<th>Code</th>
<th>Country</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>19-20</td>
<td>Moldova</td>
<td>“намного было делать мероприятий для развития активизма среди ВИЧ-положительных подростков, молодежи и молодых людей. Различные семинары, тренинги и так далее необходимо для нас.” [&quot;We need to develop activism among HIV-positive teenagers, adolescents and young men. We need several seminars, trainings, etc.&quot;]</td>
</tr>
<tr>
<td>23-24</td>
<td>Uganda</td>
<td>“Am just looking at helping other young positives.”</td>
</tr>
</tbody>
</table>

### Self-care, attitude

<table>
<thead>
<tr>
<th>Code</th>
<th>Country</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>17-18</td>
<td>Namibia</td>
<td>“doctors should be working very hard an people with hiv should not give up drinking their medicitions”</td>
</tr>
<tr>
<td>19-20</td>
<td>Zimbabwe</td>
<td>“Be positive about negavite”</td>
</tr>
<tr>
<td>19-20</td>
<td>NR</td>
<td>“yes being positive doesnt mean you near to die but you can live longer like any one else”</td>
</tr>
<tr>
<td>23-24</td>
<td>Philippines</td>
<td>“HIV/AIDS is not to be considered as a deadly disease.”</td>
</tr>
<tr>
<td>23-24</td>
<td>Philippines</td>
<td>“I am hoping the cure to this is coming. I would want a better future, so as my HIV-infected peers. I don’t want to live in fear and damnation. :(&quot;</td>
</tr>
</tbody>
</table>

### Disclosure

<table>
<thead>
<tr>
<th>Code</th>
<th>Country</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>13-14</td>
<td>Thailand</td>
<td>“я хочу убрать это болезнь от себя” [&quot;I want to hide this disease from others&quot;]</td>
</tr>
<tr>
<td>19-20</td>
<td>Kenya</td>
<td>“yes,please work on disclosing to the children who were born with hiv\those who have taken medication from a very tender age,they have the right to know the truth,engage them in most of the things that involve their medication because they also have something to say.”</td>
</tr>
<tr>
<td>21-22</td>
<td>Malaysia</td>
<td>“Mt family didnt know yet.... Teach us how to discuss with fmily”</td>
</tr>
</tbody>
</table>

### Cultural challenges

<table>
<thead>
<tr>
<th>Code</th>
<th>Country</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>21-22</td>
<td>Bhutan</td>
<td>“As our is very cultural context coming out is big issue...”</td>
</tr>
<tr>
<td>23-24</td>
<td>Ethiopia</td>
<td>“We are in silent but the spread of HIV infection is till running, the some solutions that has been done has its own scar and needs to see unexpected hidden problems. thank u”</td>
</tr>
<tr>
<td>23-24</td>
<td>Gambia</td>
<td>“Adolescent health is greatly affected by not only the inadequate provision of reproductive and sexual health services but to a major extent, by factors outside the control of the health system, such as religious and socio cultural issues and values. The Gambia’s culture and traditions such that parents rarely discuss with their adolescent children and in particular girls, on issues related to their growing up, puberty, sex, etc. As young people, we need information about the physiological changes in our bodies, and the implications of sexual activity in order to make more responsible and conscious decisions about our health. The opposing view is that, providing adolescents with information about their sexual and especially, with reproductive health services will encourage early sexual activity and promiscuity.”</td>
</tr>
</tbody>
</table>

### HIV-specific education (including living with HIV)

<table>
<thead>
<tr>
<th>Code</th>
<th>Country</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>13-14</td>
<td>Uzbekistan</td>
<td>“хотелось чтобы услуги для молодых людей были адаптированы для национальных групп (узбекоговорящий молодежи- так как основные материалы для подростков и детей либо на русском либо на англи.языках)” [&quot;It would be desirable that services for young people have been adapted for national groups (young Uzbeks) and have as well basic materials for teenagers and children either in Russian or on Uzbek.”]</td>
</tr>
<tr>
<td>15-16</td>
<td>Lesotho</td>
<td>“They should also educate young people living HIV about HIV”</td>
</tr>
</tbody>
</table>
21-22, Female, India: “Porvide Life skill education session to all the young people which is focussed on the sexual health and rights.”
21-22, Male, India: “Today, young people are facing most of the problem on health care. So in order to stay healthy, we need information, education and communication.”
21-22, Male, India: “Yes, educational sessions, youths sexual health and rights, about sex and sexuality.”
23-24, Male, Colombia: “Información clara teniendo en cuenta que no manejo lenguaje médico.” [“I would like] clear information to be given to me, having in mind that I don’t dominate medical terms.”
21-22, Male, Mexico: “Que los grupos de autoapoyo sean más solidarios con las personas con VIH, ya que muchas veces solo manejan los intereses de ellos, y no de las personas que viven con VIH/SIDA” [“I wish] support groups to be more solidary with people living with HIV, because often they only serve their interests and not those who are living with HIV.”
21-22, Male, Ukraine “Я хочу просто жить своей жизнью. Мне не нужно светится на телевидении или как то еще быть известным всем. Поэтому я боюсь ходить на разные группы поддержки. Но у меня есть друзья, тоже инфицированные, и я как могу помогаю им, а они помогают мне. И мой бойfriend очень меня поддерживает…” [“I just want to live their lives. I do not need lights on TV, or as something else to be known to all. So I’m afraid to go to different support groups. But I have a friend, also infected, and how can I help them and they help me. And my fight friend really supports me.”]
21-22, Male, Venezuela: “¿Donde buscar información real, con testimonios de jóvenes que viven con el virus, con calidad de vida?” [“Where to find real information, with testimonies of young people living with the virus, with quality of life?”]

**Support, Testimonies 3/143 (2.1%)**

21-22, Male, Mexico: “Que los grupos de autoapoyo sean más solidarios con las personas con VIH, ya que muchas veces solo manejan los intereses de ellos, y no de las personas que viven con VIH/SIDA” [“I wish] support groups to be more solidary with people living with HIV, because often they only serve their interests and not those who are living with HIV.”
21-22, Male, Ukraine “Я хочу просто жить своей жизнью. Мне не нужно светится на телевидении или как то еще быть известным всем. Поэтому я боюсь ходить на разные группы поддержки. Но у меня есть друзья, тоже инфицированные, и я как могу помогаю им, а они помогают мне. И мой бойfriend очень меня поддерживает…” [“I just want to live their lives. I do not need lights on TV, or as something else to be known to all. So I’m afraid to go to different support groups. But I have a friend, also infected, and how can I help them and they help me. And my fight friend really supports me.”]
21-22, Male, Venezuela: “¿Donde buscar información real, con testimonios de jóvenes que viven con el virus, con calidad de vida?” [“Where to find real information, with testimonies of young people living with the virus, with quality of life?”]

**Nutritional support 28/143 (19.6%)**

10-12, Female, India: “...nutritional support”
10-12, Female, India: “Free ...nutrition”
10-12, Female, India: “... nutrition support ...”
10-12, Female, India: “lack of nutrition support in the ...”
10-12, Female, India: “To provide free education and increase community care centre for children”
10-12, Male, India: “Nutrition support”
10-12, Male, India: “Free ... nutrition ...”
13-14, Female, India: “... free nutrition...”
13-14, Female, India: “Provision for free...nutrition support”
13-14, Female, India: “... free nutrition support”
13-14, Female, India: “.. nutrition...”
13-14, Male, India: “Free nutrition for healthy life of the PLHIV”
13-14, Male, India: “Required nutrional support...”
15-16, Male, India: “...Free nutrition...”
15-16, Male, India: “Nutrition support”
15-16, Male, India: “... free nutrition...”
15-16, Male, India: “Good nutrition support...”
17-18, Male, India: “...free nutrition...”
17-18, Male, India: “Good nutrition support needed.”
19-20, Female, India: “Provision for free ... nutrition...”
19-20, Female, India: “Provision for nutrition support....”
19-20, Female, India: “Nutritional support for staying healthy”
19-20, Male, India: “Provision for free ... nutrition support.”
21-22, Female, NR: “Free ...provision for nutrition support...”
21-22, Male, India: “what about me and my sister who is born with HIV? ... no good food”
21-22, Male, India: “Provision for free ... nutrition support for the PLHIVs”
23-24, Male, India: “Free nutrition support...”
23-24, Male, India: “Availability of free ... nutrition support”

**Free (general) education, access to educational materials 24/143 (16.8%)**

10-12, Female, India: “Free education ...”
10-12, Female, India: “Education...”
10-12, Female, India: “... free education ...”
10-12, Female, India: “To provide free education and increase community care centre for children”
10-12, Male, India: “Free education...”
13-14, Female, India: “Provision for free education...”
13-14, Female, India: “Free education system”
13-14, Female, India: “Provison for free education...”
13-14, Female, India: “Free education...”
13-14, Female, India: “... education...”
15-16, Female, NR: “Provision for free educations”
15-16, Male, India: “Free education...”
15-16, Male, India: “Free education...”
15-16, Male, India: “lack of proper education, education support and scholarships for PLHIV”
17-18, Female, India: “Free education”
17-18, Male, India: “Free education...”
19-20, Female, India: “… free education system from the government.”
19-20, Female, India: “Provision for free education support...”
19-20, Male, India: “Provision for free education...”
21-22, Female, NR: “Free education...”
21-22, Male, India: “what about me and my sister who is born with HIV? no education...”
21-22, Male, India: “Provision for free education... for the PLHIVs”
23-24, Male, India: “… free education...”
23-24, Male, India: “Availability of free education...”

VCT/HCT/VCCT  2/143 (1.4%)
10-12, Female, Malawi: “promote htc for those who have not tested”
23-24, Male, Jamaica: “Put some from of legislation in place that help to guide the volunteer counsel confidential testing (VCTT) to assist in the youth development and recommendation.”

Work and skills  5/143 (3.5%)
19-20, Male, Malawi: “give us young people what we need care and jobs or parts time jobs”
23-24, Female, India: “Vocational trainings and items as a part of income generation for PLHIV”
23-24, Female, Senegal: “Trouver des stratégies pour l’insertion des jeunes séropositives dans l’emploi et améliorer leurs conditions de vie. ” ["I think it is important to find strategies of integration of young people living with HIV on the job market and improve their conditions of life.”
23-24, Male, Uganda: “yeah you people create for us technical schools such that even young people can do some thing. some of us we want to improve on our talent.””
23-24, Other (bisexual), Philippines: “Job opportunities with people who has HIV”

Cure, vaccine  4/143 (2.8%)
15-16, Female, Kazakhstan: “Я хочу спросить: Долго ли ещё осталось ждать вакцину от СПИДа...” [“I want to ask: How long will still have to wait for a vaccine against AIDS...”]
19-20, Male, Mexico: “¿Qué tan probable es que encuentren una cura?” [“How likely is that a cure is found?”]
21-22, Female, Thailand: “จากที่ได้ฟังเพื่อนๆของฉันบอกว่ามีการพัฒนาการฉีดวัคซีน” [“Want a treatment developed to cure for HIV infection”]
23-24, Male, Mexico: “Que todos deseamos que pronto apareciera una cura, aunque parece que los esfuerzos en investigación están dedicados a encontrar una vacuna y a quienes estamos infectados simplemente nos alargan la vida con los ARV.” [“We all wish that a cure is found quickly. However, it seems researchers are more concerned in finding a vaccine and let us, the patients, simply living with ART.”]

Research  1/143 (0.7%)
23-24, Male, Mexico: “¿Ustedes han contemplado la participación de JVVIH en el desarrollo de estas actividades y cómo van a involucrarnos después de la publicación de los resultados?” [Did you involved young people living with HIV in the development of these activities and how will they be involved after the publication of the results?]

Orphans  1/143 (0.7%)
13-14, Female, Cameroon: “je suis orphelin et je suis mal”

Surveys and forms  2/143 (1.4%)
17-18, Male, Malawi: “well i would only say that you just need to make more survey for more young people understand the importantance learning more about HIV”
17-18, Male, Namibia: “yeah, i woul like you guys to reduce any questions about HIV (status) on application forms and what not......”
HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV

ANNEX 11 (b): Values and preferences: ALHIV care, treatment, and attitudes – literature review

Care and treatment values, preferences, and attitudes of adolescents living with HIV:

a review of qualitative literature

Introduction

Globally, over two million adolescents aged 10–19, and five million young people aged 15–24 are living with HIV. Many factors contribute to this high prevalence: from low levels testing and linkage to care and prevention, to poor retention in care and adherence to antiretroviral treatment (ART) in this population. By increasing adolescent-focused treatment and care services, adolescents and young people (10–24 years) will be more likely to be better engaged in care and treatment, thus reducing morbidity and mortality in this greatly underserved population.

Adolescents living with HIV (ALHIV) have been infected with HIV through one of two pathways: through vertical transmission (from mother to child via pregnancy or breastfeeding) or through horizontal transmission (from either sexual or non-sexual methods, e.g. injecting drug use, exposure to infected blood, medical procedures).

For these guidelines, two other reviews were conducted to examine the availability of HIV testing and counselling services for adolescents and services providing HIV care and treatment for ALHIV. These reviews have indicated significant barriers and facilitators to improving the provision of and access to health care and HIV services for ALHIV; however, few of the included studies included the perceptions, values, and preferences of the adolescents themselves.

This systematic review was conducted to look specifically at published literature on research conducted directly with ALHIV aimed at gaining their experiences with, perceptions of, and/or desires to access various types of HIV services. The review was limited to literature published in the last five years, and was conducted using PubMed (including MEDLINE), Google Scholar, and Google. The search method employed combinations of terms for adolescents, HIV, care, service, and values and preferences. Of the 42 qualified studies, 74% were descriptive (31), while only 19% (8) were quasi-experimental and 7% (3) were RCTs. Forty per cent (17) of the studies were conducted in middle or low-income countries, while 60% (25) of the studies were conducted in high-income countries (although a majority of these were in rural or low-income areas or examined significantly underserved populations).

The results from this review will inform the development of World Health Organization (WHO) guidelines on the provision of health and HIV care to adolescents living with HIV.

Within this literature review, the following questions were explored:

- What are adolescent perceptions of and attitudes toward health-care and HIV service delivery?
- What do adolescents perceive and value in adolescent-focused models or interventions recently developed and/or studied?
• What do adolescents perceive and value as facilitators to disclosure, adopting preventative behaviours (secondary prevention), accessing care, adhering to ART, being retained in care, and successfully transitioning from paediatric and/or adolescent HIV care services to adult HIV care services?
• What do adolescents perceive as barriers to disclosure, adopting preventative behaviours (secondary prevention), accessing care, adhering to ART, being retained in care, and successfully transitioning from paediatric and/or adolescent HIV care services to adult HIV care services?

Methods
A systematic review of literature published in the last five years was conducted using PubMed (including MEDLINE), Google Scholar, and Google. The search method employed combinations of terms for adolescents, HIV, care, service, and values and preferences (Table 1).

Table 1. PubMed search filters and results

<table>
<thead>
<tr>
<th>Search terms and filters</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>(((&quot;hiv&quot;[MeSH Terms] OR &quot;hiv&quot;[All Fields]) OR (&quot;human&quot;[MeSH Terms] OR &quot;immunodeficiency&quot;[All Fields] AND &quot;virus&quot;[All Fields]) OR &quot;human immunodeficiency virus&quot;[All Fields]) AND (((&quot;adolescent&quot;[MeSH Terms] OR &quot;adolescent&quot;[All Fields]) OR (&quot;adolescent&quot;[MeSH Terms] OR &quot;adolescent&quot;[All Fields] OR &quot;adolescents&quot;[All Fields]) OR (&quot;adolescent&quot;[MeSH Terms] OR &quot;adolescent&quot;[All Fields] OR &quot;youth&quot;[All Fields]) OR (young[All Fields] AND (&quot;persons&quot;[MeSH Terms] OR &quot;persons&quot;[All Fields] OR &quot;people&quot;[All Fields]))) AND ((care[All Fields] OR services[All Fields]) OR service[All Fields]) AND (((values[All Fields] OR preferences[All Fields]) OR (&quot;perception&quot;[MeSH Terms] OR &quot;perception&quot;[All Fields] OR &quot;perceptions&quot;[All Fields]) OR opinions[All Fields]) OR (&quot;attitude&quot;[MeSH Terms] OR &quot;attitude&quot;[All Fields] OR &quot;attitudes&quot;[All Fields]) AND (&quot;2008/03/02&quot;[PDat] : &quot;2013/02/28&quot;[PDat]))</td>
<td></td>
</tr>
<tr>
<td>1090</td>
<td></td>
</tr>
</tbody>
</table>

Inclusion criteria
Studies were considered eligible for inclusion based on the following criteria:
1. Studies may include randomized controlled trials, observational studies, case reports, expert opinion pieces
2. Unpublished studies and studies published in non-English language journals
3. Studies must include discussion or reports of youth between the ages of 10-24 years
4. Studies considered eligible for inclusion must pertain to one of the following topics:
   • Description, comparison, or evaluation of a study aimed at gaining the health-care values, preferences, attitudes, or perceptions of adolescents living with HIV
   • Perceived and actual barriers to adopting preventative behaviours
   • Perceived and actual barriers to accessing HIV and health care and retention in care
   • Perceived and actual barriers to adherence to ART
   • Perceived and actual barriers to successful transition from paediatric and/or adolescent services to adult services
   • Perceived and actual facilitators to adopting preventative behaviours
   • Perceived and actual facilitators to accessing HIV and health care and retention in care
   • Perceived and actual facilitators to adherence to ART
   • Perceived and actual facilitators to successful transition from paediatric and/or adolescent services to adult services
5. Published and unpublished articles or reports entered into the databases between February 2008 and February 2013 were included in the review. No other limitations were used.

Data Extraction

Data from the articles were extracted and organized into a table by study design, methods used, sample size and population factors, the inclusion of comparison or additional groups (if relevant), location(s) of the study, topics addressed, and main conclusions or outcomes. The studies were ranked according to their study design type and quality of evidence using the same four-point scale (with four representing the highest quality) as other systematic reviews: 4 = randomized controlled trials (RCTs); 3 = quasi-experimental, involving a comparison group; 2 = descriptive, with no comparison group; 1 = reviews, case studies, or grey literature.

Results

The literature search retrieved 1090 references. Of these 1090 references, 938 were excluded following title and abstract review. Of the remaining 152, a further 110 were excluded based on retrieval of the full paper and based on the previously mentioned inclusion criteria. Forty-two references remained eligible and were included in the review (figure 1).

Figure 1. Inclusion flow diagram

Description of Included Studies

As the purpose of this review was to examine adolescent values, preferences, and perceptions, it is not surprising that the 74% of studies were descriptive (31), while only 19% (8) were quasi-experimental and 7% (3) were RCTs. Only 40% (17) of the studies were conducted in middle or low-income countries, while 60% (25) of the studies were conducted in high-income countries (although a majority of these were in rural or low-income areas or examined significantly underserved populations).
Table 2. Countries and regions represented in the studies*

<table>
<thead>
<tr>
<th>Countries and regions represented</th>
<th>No. of studies per country or region</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>17</td>
</tr>
<tr>
<td>Botswana</td>
<td>1</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>1</td>
</tr>
<tr>
<td>Kenya</td>
<td>1</td>
</tr>
<tr>
<td>Malawi</td>
<td>1</td>
</tr>
<tr>
<td>South Africa</td>
<td>5</td>
</tr>
<tr>
<td>Tanzania</td>
<td>3</td>
</tr>
<tr>
<td>Uganda</td>
<td>4</td>
</tr>
<tr>
<td>Zambia</td>
<td>1</td>
</tr>
<tr>
<td>Americas</td>
<td>19</td>
</tr>
<tr>
<td>USA (&amp; Puerto Rico)</td>
<td>19</td>
</tr>
<tr>
<td>Asia</td>
<td>3</td>
</tr>
<tr>
<td>Australia</td>
<td>1</td>
</tr>
<tr>
<td>China</td>
<td>2</td>
</tr>
<tr>
<td>Europe</td>
<td>6</td>
</tr>
<tr>
<td>Romania</td>
<td>1</td>
</tr>
<tr>
<td>Switzerland</td>
<td>2</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>3</td>
</tr>
</tbody>
</table>

* The total numbers do not correspond to the total number of articles; some references were multi-country studies.

Key findings

Within the literature review, five key areas were identified:

Confidentiality and disclosure. For ALHIV privacy and confidentiality are major concerns in the provision of care. Adolescents are particularly sensitive to the stigma associated with HIV, and it is important for providers to offer a safe environment that ensures the privacy of young patients or clients and confidentiality of their discussions, decisions, test results, and treatment. The literature discussed disclosure in three ways: disclosure of parent or guardian’s serostatus to the adolescent, disclosure of the adolescent’s status by the parent or guardian, or disclosure of the adolescent to others. Major facilitators to the latter included the recognition by health-care providers that disclosure is a gradual process that should be based on the adolescent’s development and readiness to reveal their HIV status to others, and that this process requires a wide range of support – from providers, caregivers, peers, and the community – and skills development to increase self-confidence, self-efficacy, and empowerment. The major barriers to disclosure were fear of unintended or unwanted disclosure by teachers, parents, or friends, or because of inadequate privacy in clinics or pharmacies; and fear of negative reactions from family, friends, and the community.

Table 3. Confidentiality and disclosure

<table>
<thead>
<tr>
<th>Confidentiality and Disclosure</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERCEIVED / ACTUAL FACILITATORS</td>
</tr>
</tbody>
</table>

- Strategies and support for disclosure to friends, family, partners (33, 32)
- Disclosure as a process, not a one-time event (33, 20)
- Disclosure to some, not all (20)
- ‘The health-care team should systematically address the issue of disclosure with the adolescent and his family (or foster parents), the aim being to balance the right of the adolescent and that of the adolescent’s family to maintain privacy against the concerns of sexual partners, as well as the adolescent’s interest in divulging HIV status to relatives, school staff, and friends.’ (30)
- Programming areas: (27)
  - providing immediate post-diagnosis support (27)
  - stigma reduction (within the child’s “circles of care”) (27)
  - capacity building (of the caregivers and children to meet their own PSS needs) (27)
| Knowledge | Disclosure strategies (33)  
|           | o To adolescent  
|           | o By adolescent  
|           | Understanding the meaning of disclosure (33)  
|           | Knowledge of HIV (32)  
|           | Disclosure as an adherence strategy (28)  
| Caregivers (parent, guardian, etc.) | Passive disclosure: 'the decision to disclose was most often taken by the parents/foster parents who would frequently make the disclosure themselves or advise their children how to do so (e.g., to school staff)' (30)  
|           | Suggested gradual, partial disclosure based on child's readiness (27)  
|           | Tell the truth (27)  
| Psycho-emotional factors | Trust (33, 19, 17)  
|           | Autonomy / power (33)  
|           | Construction of identity (32)  
|           | Relationship with HIV (32)  
|           | Motivational readiness (31)  
|           | Self-efficacy (31)  
|           | Group and individual counselling and support help ALHIV fend off internalized stigma (27)  
|           | Grief support (27)  
|           | Psychosocial support (PSS) for disclosure (27)  
|           | Positive views of life: strong family relationships, support from family/caregivers, strong friendships, clinic as positive support, participating in activities (including school) (24)  
|           | Positive views of the future: normal lives, having families (24)  
|           | Self-esteem/self-worth/self-confidence (20)  
|           | Developing disclosure skills (20, 16)  
| Social / Sexuality and relationships | Active disclosure: 'refers to the adolescent's decision to reveal his or her condition directly (e.g., to friends, or sexual partners).'  
|           | Psychosocial support (PSS) for disclosure, stigma, and grief (27)  
|           | Families (18, 7)  
|           | Support groups (18)  
|           | Peer support (16, 8, 7)  
| PERCEIVED / ACTUAL BARRIERS | Non-compliance often connected with fear of disclosure (36, 4)  
| Therapeutic | Lack of communication and impersonal interactions with health-care providers regarding disclosure (32)  
| Structural / facility-based / programming | Lack of privacy at clinics - particularly if parents are required to accompany them (18)  
|           | Weak health systems, negative health-care providers' attitudes, poor evaluation of adolescents' abilities to receive and process information (18)  
| Knowledge | No understanding of the meaning of HIV serostatus disclosure (33)  
|           | Conflicting ideas about ART and the restriction it places on their lives (32)  
|           | Knowledge of HIV (32)  
|           | Lack of knowledge in the general public may lead to inappropriate reactions (30)  
|           | Myths and misconceptions (18, 13)  
|           | Lack of tailored messages (18)  
|           | Lack of communication directly with adolescent (18)  
|           | Information from friends is wrong (18)  
| Caregivers (parent, guardian, etc.) | HIV-positive mothers 'were more insistent on not disclosing even if the adolescent wanted to' (30)  
|           | Teachers who do not treat the disclosure as privileged information (30)  
|           | Mother's afraid to disclose their own status to their HIV-infected children (fear that their child would hate them, not sure of the reaction (29)  
|           | Family disclosure to child (often not related to the child's capabilities, e.g. personal reasons, or to protect the child from stigma) (27)  
| Psycho-emotional factors | Trust (19)  
|           | Fear of negative repercussions / reactions from disclosure (40, 30)  
|           | Fear of unintended/unwanted disclosure (8)  
|           | Indecision because of difficulty accepting their infection and do not feel like 'normal' adolescents (30)  
|           | How much to disclose (33)  
|           | Support versus vulnerability (33)  
|           | Relationship with HIV (32)  
|
- Construction of identity (32)
- Depression (31, 21)
- Fear of rejection, discrimination (30, 19)
- Seropositivity is a very personal and intimate (30)
- Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30)
- Age-specific disclosure issues: (30)
  - younger adolescents - attitudes toward disclosure mostly related to attitudes of the parents, particularly the mother. (30)
  - older adolescents - ‘engaged in their search for autonomy, tended to decide independently what to say and to whom’. (30)
- Suggested gradual, partial disclosure based on child’s readiness (27)
- Stressors (26)
- Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse) (24)
- Stigma and emotions related to disclosure (difficulty keeping it a secret, fear of a negative reaction to disclosure of status), (23):
  - Trust issues related to disclosure (barrier: trusting the person they disclose to, unsure how to handle disclosure even to someone they trust) (23)
  - Reasons for disclosing (desiring a closer relationship with someone, warn others of the risk) (23)
  - Lack of self-esteem/self-worth/self-confidence (20)
  - Emotional abuse as a result of disclosure (20)
- Reasons for disclosing (desiring a closer relationship with someone, warn others of the risk) (23)
- Lack of self-esteem/self-worth/self-confidence (20)
- Emotional abuse as a result of disclosure (20)

**Social / sexuality and relationships**

- Fear of stigma and discrimination (33, 30, 18, 3)
- Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30)
- Protecting loved one from distressing information (33)
- Telling partners (33)
- Rejection and lack of support (family, friends, significant others) (20)
- Lack of age-appropriate disclosure (18)
- Non-disclosure from parents (18)
- Poor or no social networks (18)

### Accessing care

Access to care—broadly defined to include not only physical access to treatment and care, but also financial and social support—is important for AHLIV. Those adolescents studied wanted not only universal access to care, but also care designed specifically for their needs and provided in a youth-friendly atmosphere. Positive trusting relationships with and between parents or guardians and health-care providers, and the availability of counselling and support were the primary facilitators of adolescents accessing care. Provider and community stigma, as well as inadequate or misinformation about HIV were found to be major barriers to utilization of available services.

**Table 4. Accessing care**

<table>
<thead>
<tr>
<th>Accessing Care</th>
<th>PERCEIVED / ACTUAL FACILITATORS</th>
</tr>
</thead>
</table>
| **Protective behaviours** | - Rejecting difference, portraying positivity and health, HIV is a small part of life (19)  
| | - Protective behaviours used to deal with stigma: (35)  
| | - I seek treatment earlier for common conditions (I visit the clinic every time I am sick (seek treatment earlier for minor conditions)) (35)  
| | - I don’t allow myself to get sick (even get flu injections) (35) |
| **Therapeutic** | - ART extends lives and provides opportunities for PLHIV to actively engage in a range of activities (family and community) (13) |
| **Structural / facility-based / programming** | - Measures implemented by clinics to help with transportation (40)  
| | - Support from family and day-care centres/orphanages (40)  
| | - Improved training and simple measures employed at clinics (40)  
| | - Communication with clients/patients (39)  
| | - Programmes attempted to address stigma in social environments, such as communities and schools (27)  
| | - Confidentiality/privacy (26)  
| | - the importance of conducting treatment readiness (26)  
| | - HIV services (18)  
| | - Supportive health-care professionals (7) |
| **Knowledge** | - Inclusion of normalizing statements before asking for sensitive information (content includes: dose timing, disclosure, stigma, and food insecurity) (37) |
• Defining and understanding terms: ‘missing a dose’, ‘having a side effect’; understanding the difference between ‘occasionally’ and ‘almost never’ (37)
• Knowledge of HIV (32)

**Caregivers (parent, guardian, etc.)**

• Seeing children’s health improve on treatment (40)
• Well-educated caregiver (3)
• Good relationship between caregiver and health-care provider (3)

**Psycho-emotional factors**

• Trust in physicians (17)
• Trust in health-care system (17)
• Attitudes about HIV medication (17)
• better public knowledge about HIV would facilitate uptake (40)
• Construction of identity (32)
• Relationship with HIV (32)
• Motivational readiness (31)
• Self-efficacy (31, 21, 17, 16, 11, 9)
• Self-esteem (27, 23, 20)
• Peer support (27)
• Group and individual counselling and support help ALHIV fend off internalized stigma (27)
• Grief support (27)
• Reordering priorities (focusing on the positive), infusing ordinary events with positive meaning, relying on their spirituality to help them adjust to their HIV diagnosis (26)
• Positive views of life: strong family relationships, support from family/caregivers, strong friendships, clinic as positive support, participating in activities (including school) (24)
• Positive views of the future: normal lives, having families (24)
• Self-esteem/self-worth/self-confidence (20)
• Empowerment (learning to support, accept, and value themselves; decision-making skills; role models) (20)

**Social / Sexuality and relationships**

• Psychosocial support (PSS) for disclosure, stigma, and grief (27)
• Self-efficacy (21, 11, 9)
• Peer support (16, 8, 7)

**Technology**

• Communication with clients/patients: (39)
  o cell phones (39)
  o text messaging (39)
• +CLICK (web-based intervention) animated educational tool to be used to increase knowledge (25)

**PERCEIVED / ACTUAL BARRIERS**

**Protective behaviours**

• Protective behaviours used to deal with stigma: (35)
  o keep silent about HIV status (pretend I haven’t been tested, only my family and support group know, people never say when they are divorced or beaten) (35)

**Therapeutic**

• Fear of re-infection or ‘superinfection’ (15)
• Condom negotiation (some reported 60-70% of sexual acts were unprotected) with multiple barriers to safe sex (lack of communication, lack of access to condoms, lack of education about STIs, ‘getting caught up in the moment’, partners not caring - e.g. there’s medication for it, so why use a condom?) (20)

**Structural / facility-based / programming**

• Long queues (40)
• Negative staff attitudes (inapproachability, rudeness, patient-blaming) (40)
• Missed testing opportunities at health-care facilities (providers do not routinely suggest testing despite symptoms presented) (40)
• provider difficulties with paediatric counselling (40)
• Venesection (more training needed for providers) (40)
• Weekly visits too challenging, monthly better (39)
• Providers had to offer flexible scheduling (39)
• Lack of communication and impersonal interactions with health-care providers (32)
• Lack of privacy at clinics - particularly if parents are required to accompany them (18)
• Lack of adolescent care or youth-friendly services (15)
• Public clinic nurses generate much of the stigma (nurses tell the adolescents they are not supposed to have children because they have HIV and are dying) (15)
• Pregnant women are primary beneficiaries, pregnant adolescents more likely to go to ANC where they will get better treatment (12, 11)
• Distance to clinic (11)

**Knowledge**

• Misperceptions about HIV and ART (ART will make you sicker, diagnosis will make the illness proceed faster) (40)
• Difficulty describing specific drug information (37)
• Conflicting ideas about ART and the restriction it places on their lives (32)
• Myths and misconceptions (18, 13)
• Lack of tailored messages (18)
• Lack of communication directly with adolescent (18)
• Information from friends is wrong (18)
• Conspiracy beliefs (17)
Caregivers (parent, guardian, etc.)
- Lack of money for: (40)
  - transportation
  - food
  - treatments for opportunistic infections;
- Poor access to welfare grants (40)
- Lack of coordination amongst multiple caregivers (40)
- Maternal guilt (40)

Psycho-emotional factors
- Construction of identity (32)
- Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30)
- Stressors (26)
- Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse) (24)
- Lack of self-esteem/self-worth/self-confidence (20)

Social / sexuality and relationships
- Stigma (41, 34, 33, 30, 3)
  - perceived public stigma against PLWHA (41)
  - perceived public stigma against children affected by HIV (41)
  - person stigma (41)
  - enacted stigma (41)
  - hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30)
- Disorganized social environments (36)
- Adolescent sexuality (36)
- Rejection and lack of support (family, friends, significant others) (20)
- Poor or no social networks (18)
- Lack of adolescent care or youth-friendly services (15)
- Poverty (11)

Adherence to ART. High adherence to ART by ALHIV was linked to adequate psychological adjustment, effective coping mechanisms, and discussion about and adoption of explicit medication routines. ALHIV identified both positive and negative factors as facilitators to adherence to ART: positive – e.g. free or low-cost medications, an electronic reminder, family and peer support, self-esteem and empowerment skills building and support; and negative – e.g. taking medication regularly so ‘people won’t know I’m sick’, fear of consequences, and fear of re-infection or superinfection. Depression, regimen fatigue, weak health-care systems, lack of youth-friendly services or privacy, and incorrect or misinformation were articulated as the primary barriers to adherence to ART for ALHIV.

Table 5. Adherence to ART

<table>
<thead>
<tr>
<th>PERCEIVED / ACTUAL FACILITATORS</th>
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<tbody>
<tr>
<td>Protective behaviours</td>
</tr>
<tr>
<td>- Protective behaviours used to deal with stigma: (35)</td>
</tr>
<tr>
<td>- adherence to ARTs (take medication (regularly) so people won’t know I’m sick) (35)</td>
</tr>
<tr>
<td>- Rejecting difference, portraying positivity and health, HIV is a small part of life (19)</td>
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<tr>
<td>- Fear of consequences (2)</td>
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<tr>
<td>Therapeutic</td>
</tr>
<tr>
<td>- Attitudes toward the disease: cost kept one adherent (29)</td>
</tr>
<tr>
<td>- Availability of ART (18)</td>
</tr>
<tr>
<td>- Fear of re-infection or ‘superinfection’ (15)</td>
</tr>
<tr>
<td>- ART extends lives (13, 12)</td>
</tr>
<tr>
<td>- ART provides opportunities for PLHIV to actively engage in a range of activities (family and community) (13, 12)</td>
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<tr>
<td>- Presence of a wall/mobile alarm (3)</td>
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<tr>
<td>Structural / facility-based / programming</td>
</tr>
<tr>
<td>- Adherence support (32)</td>
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<tr>
<td>- The setting and organisation of health-care teams should allow for ongoing discussions with HIV-positive adolescents that focus on their perceptions of their disease, how they cope with it and their treatment, and how they could improve their adherence (29)</td>
</tr>
<tr>
<td>- Evolving strategies for adherence, adherence partnerships, reliance on professionals for adherence support (28)</td>
</tr>
<tr>
<td>- Contextual factors (28)</td>
</tr>
<tr>
<td>- Programmes attempted to address stigma in social environments, such as communities and schools (27)</td>
</tr>
<tr>
<td>- Disclosure as an adherence strategy (28)</td>
</tr>
<tr>
<td>- confidentiality/privacy (26)</td>
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<tr>
<td>- The importance of conducting treatment readiness (26)</td>
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<tr>
<td><strong>Peer educators and support (18, 11)</strong></td>
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<tr>
<td>----------------------------------------</td>
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<tr>
<td><strong>Services that encourage empowerment (18)</strong></td>
</tr>
<tr>
<td><strong>ART clinic set-ups (3)</strong></td>
</tr>
<tr>
<td><strong>Knowledge</strong></td>
</tr>
<tr>
<td><strong>Beliefs and expectations about HIV (28)</strong></td>
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<tr>
<td><strong>Tailored information (18)</strong></td>
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<tr>
<td><strong>Caregivers (parent, guardian, etc.)</strong></td>
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<tr>
<td><strong>Families (18)</strong></td>
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<tr>
<td><strong>Good relationship between caregiver and health-care provider (3)</strong></td>
</tr>
<tr>
<td><strong>Psycho-emotional factors</strong></td>
</tr>
<tr>
<td><strong>Attitudes about HIV medication (17)</strong></td>
</tr>
<tr>
<td><strong>Self-esteem (27, 23, 20)</strong></td>
</tr>
<tr>
<td><strong>Self-efficacy (31, 21, 17, 16, 11, 9)</strong></td>
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<tr>
<td><strong>Effective coping strategies or mechanisms (29, 26)</strong></td>
</tr>
<tr>
<td><strong>Grief support (27)</strong></td>
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<tr>
<td><strong>Adaptive goal processes (26)</strong></td>
</tr>
<tr>
<td><strong>Positive views of the future: normal lives, having families (24)</strong></td>
</tr>
<tr>
<td><strong>Empowerment (learning to support, accept, and value themselves; decision-making skills; role models) (20)</strong></td>
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<tr>
<td><strong>Social networks (18)</strong></td>
</tr>
<tr>
<td><strong>Peers support (16, 8, 7)</strong></td>
</tr>
<tr>
<td><strong>Technology</strong></td>
</tr>
<tr>
<td><strong>Younger patients depended on their parents to remind them, older patients had different strategies to remind them (a little box I keep with me, first thing I do when I wake up, alarm clocks or cell phones, post-it notes on mirrors.) (29)</strong></td>
</tr>
<tr>
<td><strong>Media (18)</strong></td>
</tr>
<tr>
<td><strong>Cellphone reminders</strong></td>
</tr>
<tr>
<td><strong>Web-based training programme</strong></td>
</tr>
<tr>
<td><strong>Perceived / Actual Barriers</strong></td>
</tr>
<tr>
<td><strong>Therapeutic</strong></td>
</tr>
<tr>
<td><strong>Arvs rationed, adolescents low in priority (11)</strong></td>
</tr>
<tr>
<td><strong>Inadequate food supply (to take with medication) (11, 10)</strong></td>
</tr>
<tr>
<td><strong>Fears of adverse side effects / drug toxicity (10, 4, 1)</strong></td>
</tr>
<tr>
<td><strong>Regimen fatigue (10, 4)</strong></td>
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<tr>
<td><strong>Difficult med routine / too many pills (10, 4, 3)</strong></td>
</tr>
<tr>
<td><strong>Drug / alcohol use (10)</strong></td>
</tr>
<tr>
<td><strong>Perceived / Actual Barriers</strong></td>
</tr>
<tr>
<td><strong>Protective behaviours</strong></td>
</tr>
<tr>
<td><strong>Poor adherence to medication regimens (36)</strong></td>
</tr>
<tr>
<td><strong>ARVs rationed, adolescents low in priority (11)</strong></td>
</tr>
<tr>
<td><strong>Existence of mandatory guardian presence in the process of youth accessing HAART (11)</strong></td>
</tr>
<tr>
<td><strong>Regimen fatigue (10, 4)</strong></td>
</tr>
<tr>
<td><strong>Difficult med routine / too many pills (10, 4, 3)</strong></td>
</tr>
</tbody>
</table>
- Ran out of pills (10)
- Too busy, schedule interfered (10, 4)
- Forgot (10, 4)
- Concerns about fake drugs on the market (1)
- Fear of withdrawal of donor support (1)
- Child refused, felt sick, felt good (4)

### Structural / facility-based / programming
- Lack of communication and impersonal interactions with health-care providers (32)
- Lack of privacy at clinics - particularly if parents are required to accompany them (18)
- Weak health systems, negative health-care providers' attitudes, poor evaluation of adolescents' abilities to receive and process information (18)
- Lack of adolescent care or youth-friendly services (Public clinic nurses generate much of the stigma (nurses tell the adolescents they are not supposed to have children because they have HIV and are dying) (15)
- Pregnant women are primary beneficiaries, pregnant adolescents more likely to go to ANC where they will get better treatment (12, 11)
- Staff misassessing the youth’s stage (11)
- Distance to clinic (11)
- Existence of mandatory guardian presence in the process of youth accessing HAART (11)

### Knowledge
- Conflicting ideas about ART and the restriction it places on their lives (32)
- Attitudes toward the disease: while understood to be part of their disease, many did not perceive medicine taking as part of their routine (29)
- Adherence is fluid (both definition and practice) (28)
- Myths and misconceptions (18, 13)
- Lack of tailored messages (18)
- Lack of communication directly with adolescent (18)
- Information from friends is wrong (18)
- Conspiracy beliefs (17)
- Access to ART limited to wealthy, famous, or socially or politically connected (12)
- Having sex on ART makes you weak (12)
- Beliefs that exchange blood transfusion can replace 'dirty' blood (HIV infected) with 'clean' blood (uninfected) (12)
- Inaccurate beliefs about treatment (3)

### Caregivers (parent, guardian, etc.)
- Multiple caregivers (4)
- Frequent and situational challenges to adherence (caregivers being away, running out of medication, child sleeping, difficulty keeping to dosage schedules during the summer months) (28)
- Roles of caregiver / lack of autonomy for adolescent (4)
- Absence of a private place to take medication when neighbours/relatives visit (3)

### Psycho-emotional factors
- Emotional struggles / depression (34, 31, 21, 4)
- Attitudes toward the disease: while understood to be part of their disease, many did not perceive medicine taking as part of their routine (29)
- Opposition to the medication-taking as children grow older (28)
- Stressors (26)
- Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse) (24)
- Lack of self-esteem/self-worth/self-confidence (20)
- Child's age (4)

### Social / sexuality and relationships
- Stigma (41, 34, 33, 30, 3)
  - perceived public stigma against PLWHA (41)
  - perceived public stigma against children affected by HIV (41)
  - person stigma (41)
  - enacted stigma (41)
  - hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30)
  - rejection and lack of support (family, friends, significant others) (20)
- Poor or no social networks (18)
- Lack of adolescent care or youth-friendly services (15)
- Poverty (11)

### Technology
- Less adherent adolescents were less explicit about their strategies: 'it comes naturally [no need for electronic reminders], I just tell myself that I shouldn’t miss it' (29)

**Retention in care.** All health-care facilities or delivery sites should be safe spaces where adolescents can freely express their emotions and concerns, and where providers demonstrate patience, understanding, acceptance and knowledge about the choices and services available to the adolescent. For ALHIV, health-care providers’ attitudes were either significant facilitators or barriers to retention in care. Also
important was the strength of the relationship between the health-care provider and adolescent (and parent or guardian depending on the age and readiness of the adolescent). Like the other key findings, an ALHIV’s level of self-esteem and feeling of empowerment to make decisions improved retention, as did supportive family or family-like environments and peer support. Similarly, barriers to retention in care included the lack of youth-focused services and privacy, poor communication with health-care providers, misinformation, and anxiety or depression.

Table 6. Retention in care

<table>
<thead>
<tr>
<th>Retention in Care</th>
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<tbody>
<tr>
<td><strong>PERCEIVED / ACTUAL FACILITATORS</strong></td>
</tr>
</tbody>
</table>
| **Protective behaviours** | ● Protective behaviours used to deal with stigma: (35)  
  ○ seek treatment earlier for common conditions (I visit the clinic every time I am sick (seek treatment earlier for minor conditions) (35)  
  ○ Rejecting difference, portraying positivity and health, HIV is a small part of life (19)  
  ○ Fear of consequences (2) |
| **Therapeutic** | ● Fear of re-infection or ‘superinfection’ (15)  
  ● Simpler med routine |
| **Structural / facility-based / programming** | ● Programmes attempted to address stigma in social environments, such as communities and schools (27)  
  ○ Confidentiality/privacy (26)  
  ○ The importance of conducting treatment readiness (26)  
  ○ Peer educators and support (18, 11)  
  ○ Supportive health-care professionals (7) |
| **Knowledge** | ● Knowledge of HIV (32) |
| **Caregivers (parent, guardian, etc.)** | ● Well-educated caregiver (3)  
  ● Good relationship between caregiver and health-care provider (3) |
| **Psycho-emotional factors** | ● Trust in physicians (17)  
  ● Trust in health-care system (17)  
  ● Relationship with HIV (32)  
  ● Motivational readiness (31)  
  ● Self-efficacy (31, 21, 17, 16, 11, 9)  
  ● Self-esteem (27, 23, 20)  
  ● Peer support (27)  
  ● Coping strategies (29, 26, 20)  
  ● Group and individual counselling and support help ALHIV fend off internalized stigma (27)  
  ● Grief support (27)  
  ● Adaptive goal processes (26)  
  ● Reordering priorities (focusing on the positive), infusing ordinary events with positive meaning, relying on their spirituality to help them adjust to their HIV diagnosis (26)  
  ● Positive views of life: strong family relationships, support from family/caregivers, strong friendships, clinic as positive support, participating in activities (including school) (24)  
  ● Positive views of the future: normal lives, having families (24)  
  ● Self-esteem/self-worth/self-confidence (20)  
  ● Empowerment (learning to support, accept, and value themselves; decision-making skills; role models) (20) |
| **Social / Sexuality and relationships** | ● Family-centred support (21, 7)  
  ● Group homes (rather than orphanages) fostered better mental health and ‘family’ atmosphere, reducing issues of isolation and community-based discrimination/stigmatization (42)  
  ● Psychosocial support (PSS) for disclosure, stigma, and grief (27)  
  ● Peer support (16, 8, 7)  
  ● Sustained motivation (11) |
| **PERCEIVED / ACTUAL BARRIERS** |
| **Therapeutic** | ● Complex medical routine (10, 4, 3)  
  ● Drug / alcohol use (10)  
  ● Regimen fatigue (10)  
  ● Severity of illness (10) |
| **Structural / facility-based / programming** | ● Lack of communication and impersonal interactions with health-care providers (32)  
  ● Lack of privacy at clinics - particularly if parents are required to accompany them (18)  
  ● Lack of adolescent care or youth-friendly services (15)  
  ● Distance to clinic (11)  
  ● Transportation (3) |
| **Knowledge** | ● Conflicting ideas about ART and the restriction it places on their lives (32)  
  ● Myths and misconceptions (18, 13) |
<table>
<thead>
<tr>
<th>Caregivers (parent, guardian, etc.)</th>
<th>Low household income (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of tailored messages (18)</td>
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<tr>
<td>Lack of communication directly with adolescent (18)</td>
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<tr>
<td>Information from friends is wrong (18)</td>
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<tr>
<td>Inaccurate beliefs about treatment (3)</td>
<td></td>
</tr>
<tr>
<td>Psycho-emotional factors</td>
<td>Mental health issues / anxiety / depression (34, 31, 21, 4)</td>
</tr>
<tr>
<td>Stressors (26)</td>
<td></td>
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<tr>
<td>Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse (24)</td>
<td></td>
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<tr>
<td>Lack of self-esteem/self-worth/self-confidence (20)</td>
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</tr>
<tr>
<td>Social / sexuality and relationships</td>
<td>Stigma (41, 34, 33, 30, 3)</td>
</tr>
<tr>
<td>o perceived public stigma against PLWHA (41)</td>
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<tr>
<td>o person stigma (41)</td>
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<tr>
<td>o enacted stigma (41)</td>
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<tr>
<td>o Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30)</td>
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<tr>
<td>o Rejection and lack of support (family, friends, significant others) (20)</td>
<td></td>
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<tr>
<td>o Lack of adolescent care or youth-friendly services (15)</td>
<td></td>
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<tr>
<td>o Poverty (11)</td>
<td></td>
</tr>
<tr>
<td>Technology</td>
<td>Less adherent adolescents were less explicit about their strategies: 'it comes naturally [no need for electronic reminders], I just tell myself that I shouldn’t miss it’ (29)</td>
</tr>
</tbody>
</table>

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

Table 7. Successful transition to adult services

<table>
<thead>
<tr>
<th>Successful Transition to Adult Services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PERCEIVED / ACTUAL FACILITATORS</strong></td>
</tr>
<tr>
<td><strong>Protective behaviours</strong></td>
</tr>
<tr>
<td><strong>Therapeutic</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Structural / facility-based / programming</strong></td>
</tr>
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</tbody>
</table>
- Addressing grief (as a process) (27)
- Promoting peer support (through forums for interaction and peer support) (27)
- Programmes attempted to address stigma in social environments, such as communities and schools (27)
- Suggested gradual, partial disclosure based on child’s readiness (27)
- Confidentiality/privacy (26)
- The importance of conducting treatment readiness (26)
- Making process that changes over time and is influenced by developmental factors and societal attitudes towards HIV (19)
- Peer educators and support (18, 11, 5)
- Services that encourage empowerment (18)
- Youth friendly services (5)
- Games in waiting room (5)
- Morning or evening appointments (5)
- Staff trained to know how to talk with and listen to young people (5)
- Condoms available (5)

**Knowledge**
- Open communication between paediatric and adult clinical staff about transition (14)
- Access to information (14, 5)
- Knowledge of HIV (32)
- Tailored information (18)
- Sexual health information (5)
- Reproductive health information (5)

**Caregivers (parent, guardian, etc.)**
- Suggested gradual, partial disclosure based on child’s readiness (27)
- Tell the truth (27)
- Gradual developmental approach, that best suits the individual (14)

**Psycho-emotional factors**
- Preparation for adulthood (14)
- Control and responsibility (14)
- Gain independence and formulate self-identity (38, 5)
- Age-appropriate interests (38)
- Strengthening peer and romantic relationships (38)
- Defining future role in life and feeling understood (38)
- Dealing with immorality (38)
- Establish a sense of control over diagnosis/treatment - including relinquishing control when ready (regarding end of life decisions) (38)
- Construction of identity (32)
- Motivational readiness (31)
- Self-efficacy (31, 21, 17, 16, 11, 9, 5)
- Self-esteem (27, 23, 20)
- Peer support (27)
- Coping strategies (29, 26, 20)
  - Focusing on the positivity (many mentioned that faith/religion helped keep them positive) (26)
  - Reordering priorities (focusing on the positive), infusing ordinary events with positive meaning, relying on their spirituality to help them adjust to their HIV diagnosis (26)
- Group and individual counselling and support help ALHIV fend off internalized stigma (27)
- Grief support (27)
- Seeking and being provided with support (especially peer support) (26)
- Adaptive goal processes (26)
- Positive views of life: strong family relationships, support from family/caregivers, strong friendships, clinic as positive support, participating in activities (including school) (24)
- Positive views of the future: normal lives, having families (24)
- Self-esteem/self-worth/self-confidence (20)
- Empowerment (learning to support, accept, and value themselves; decision-making skills; role models) (20, 5)
- Making process that changes over time and is influenced by developmental factors and societal attitudes towards HIV (19)
- Conflict/anger management, skill learning and education (16)
- Acknowledging both independence and the need for support (readiness to play a bigger part in their own health care; support included practical help such as getting transportation to the events) (8)

**Social / Sexuality and relationships**
- Psychosocial support (PS) for disclosure, stigma, and grief (27)
- Family-centred support (21)
- Self-efficacy for sexual discussion (21)
- Making process that changes over time and is influenced by developmental factors and societal attitudes towards HIV (19)
- Peer support (16, 8, 7)

**PERCEIVED / ACTUAL BARRIERS**

**Therapeutic**
- Condom negotiation (some reported 60-70% of sexual acts were unprotected) with multiple barriers to safe sex (lack of communication, lack of access to condoms, lack of education about STIs, ‘getting caught up in the moment’, partners not caring - e.g. there’s medication for it, so why use a condom?) (20)
| Structural / facility-based / programming | • Lack of communication and impersonal interactions with health-care providers (32, 14)  
• Lack of privacy at clinics - particularly if parents are required to accompany them (18)  
• Weak health systems, negative health-care providers’ attitudes, poor evaluation of adolescents’ abilities to receive and process information (18)  
• Public clinic nurses generate much of the stigma (nurses tell the adolescents they are not supposed to have children because they have HIV and are dying) (15)  
• Lack of adolescent care or youth-friendly services (15)  
• Staff misassessing the youth’s stage (11) |
| Knowledge | • Perceptions of the disease from different developmental perspectives: under 16 years - had a ‘concrete vision’ of their disease, but were unable to explain what it mean and why (e.g., CD4 count, parents call them little soldiers, HIV is a virus, not sure how long I will live) (29)  
• Myths and misconceptions (18, 13)  
• Lack of tailored messages (18)  
• Lack of communication directly with adolescent (18)  
• Information from friends is wrong (18) |
| Caregivers (parent, guardian, etc.) | • Family disclosure to child (often not related to the child’s capabilities, e.g. personal reasons, or to protect the child from stigma) (27)  
• Guardians mentioned the loss of the relationship with the paediatric provider (14) |
| Psycho-emotional factors | • Loss of the relationship with the paediatric provider (14)  
• Mental health issues / anxiety / depression (34, 31, 21)  
• Families’ negative perceptions of and experiences with stigma of HIV disease (which undermined the desire to meet new providers) (36)  
• Perceived and actual lack of autonomy (paediatric providers feared that staff in adult clinics would demand a level of independence that adolescents did not have) (36)  
• Difficulty letting go of relationships (adolescents, guardians, and providers described a familial relationship and expressed anxiety about terminating their relationships.) (36)  
• Non-compliance often connected with fear of disclosure (36)  
• Construction of identity (32)  
• Children are unable to process their grief and get closure (27)  
• Suggested gradual, partial disclosure based on child’s readiness (27)  
• Stressors (26)  
• Negative aspects of life: HIV physically and emotionally painful, affected social interactions, isolation from others, keeping status a secret (fears of stigma), family violence, poverty, crime and drugs, verbal and physical abuse) (24)  
• Lack of self-esteem/self-worth/self-confidence (20)  
• Transition through adolescence (4) |
| Social / sexuality and relationships | • Stigma (41, 34, 33, 30, 3)  
  o perceived public stigma against PLWHA (41)  
  o perceived public stigma against children affected by HIV (41)  
  o person stigma (41)  
  o enacted stigma (41)  
• Hiding the disease was perpetuating the stigmatization that makes their lives more difficult (30)  
• Culture prohibits the discussion of death and grief with children (27)  
• Rejection and lack of support (family, friends, significant others) (20)  
• Lack of age-appropriate disclosure (18)  
• Non-disclosure from parents (18)  
• Poor or no social networks (18)  
• Lack of adolescent care or youth-friendly services (15) |

**Limitations**

At present, there are few studies, especially clinical trials, focused on adolescent populations. This is in no small part due to the legal and ethical issues related to the minimum age of consent to HTC and medical care and treatment as defined by each country.

This literature review was limited to articles published in the last five years available through PubMed, Google Scholar, and Google. While the search did not exclude articles published in other languages, the search engines did not return relevant non-English-language options. By including other search engines or databases, additional publications may have been found.
Conclusions

Primary concerns of adolescents are: universal access to care and medication; transition to and continuity of care; opportunities to participate in and be responsible for their own health-care decisions; access to provider, family, and peer support; access to informational materials about HIV, sex, and reproductive health; support for disclosure; and safe, youth-friendly, adolescent specific facilities and services.

The systematic literature review of research on the care and treatment values, preferences, and attitudes of adolescents living with HIV highlights that adolescents need to be engaged in their HIV care and treatment and have access to adolescent-specific or youth-friendly facilities and services.

Governments and organizations need to provide adolescent-friendly and adolescent-focused services that emphasize the development of responsibilities aimed at self-care. At the same time, governments must identify and address barriers to acceptable and effective provision of services to adolescents, including the training of service providers to better communicate with this unique and underserved population.
References


36. Vijayan T et al. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care*, 2009; 21:1222-1229.


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

ANNEX 13: Adolescent ARV service delivery: a review of the literature

Introduction

A significant portion of the globe’s HIV prevalence consists of adolescents, defined as the age group of 10-19 years, according to the World Health Organization. In 2010, the total worldwide number of young people between the ages of 15-24 living with HIV was 5.0 million, with eastern and southern Africa containing 2.6 million; 42% of new HIV infections among adults in the same year occurred in this age range.2

Adolescents may acquire HIV “vertically” through mother-to-child transmission (including breastfeeding); in this case, diagnosis may have been missed due to loss to follow up or else due to poor PMTCT (prevention of mother-to-child transmission) programs. Acquisition may also occur “horizontally”—either sexually or non-sexually, including intravenous drug use or medical transmission (figure 1).

---

Figure 1. Routes of entry into care

[Diagram showing routes of entry into care, including vertical transmission, PMTCT access and no access, sexual transmission (early sex, sexual abuse, MSM, sex work), non-sexual transmission (nosocomial, traditional practices, IDU), and diagnosis (EID, 18 month diagnosis, opportunistic diagnosis, child/adolescent positive status, prevention, retention).]
Globally, the number of children ages 0-14 receiving antiretroviral therapy (ART) in 2011 was 562,000; coverage was estimated to be 28% [25-32%]. Estimated coverage among adults was 57% [53-60%] worldwide and 54% [50-60%] within low- and middle-income countries, where 7 million [6.4-7.3 million] people eligible for antiretroviral (ARV) treatment are not receiving it. Figure 2 below reflects eligibility versus coverage in these countries (2011), as depicted by UNAIDS.

Figure 2.

The area in the larger circle represents the number of people eligible for antiretroviral therapy. The shaded circle and percentage represent coverage in 2011.

By increasing ARV coverage and adherence among adolescents, HIV morbidity and mortality may be reduced. Despite the large number of adolescents with HIV, however, research tailored to this particular age group is very limited, and yet the particular needs of this population differ from those of younger children and adults. The development of WHO guidelines on adolescent HIV service delivery addresses a crucial gap in the current treatment efforts. The guideline development is most effectively supported by a systematic review aiming to explore the following questions:

- What are the current antiretroviral service delivery models for adolescents?
- What are adolescents’ attitudes towards service delivery?
- What are the existing barriers to entering and remaining in ARV care? What are the existing barriers to adhering to ARV treatment?
- What factors facilitate ARV care entry and retention? What factors facilitate adherence to ARV treatment?
Methods

A systematic review of published literature was conducted using PubMed (including MEDLINE), EMBASE (Excerpta Medica), the Cochrane systematic reviews, New York Academy of Grey Literature, and OpenSIGLE; the search method employed combinations of terms for adolescents, HIV, care, and services.

Search terms

<table>
<thead>
<tr>
<th>Search</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search ([&quot;2002/10/01&quot;[Date - Entrez] : &quot;2012/10/06&quot;[Date - Entrez]]) AND (HIV AND (care OR service OR services) AND (adolescents OR young people OR youth))</td>
</tr>
</tbody>
</table>

Inclusion Criteria

Studies were considered eligible for inclusion based on the following criteria:

1. Studies may include randomized controlled trials, observational studies, case reports, expert opinion pieces.
2. Unpublished studies and studies published in non-English languages journals were considered for inclusion.
3. Studies must include discussion or reports of youth between the ages of 10-24 years old.
4. Studies considered eligible for inclusion must pertain to one of the following topics:
   - Description, comparison or evaluation of existing ART service models
   - Evaluation of outcome measures and the impact of various ART care approaches
   - Adolescent attitudes towards ART care services
   - Barriers to ART care entry and retention; characteristics associated with low care entry and retention
   - Barriers to ART adherence; characteristics associated with poor adherence
   - Facilitators to ART care entry and retention; characteristics associated with high care entry and retention
   - Facilitators to ART adherence; characteristics associated with good adherence
5. Articles published or unpublished reports prepared and entered into the databases between October 2002 and October 2012 were included in the review. No other limitations were used.
Data Extraction

Article data was extracted and organized into a table by topic, study design, income level, population factors (including sample size), intervention (if applicable), comparator (if applicable), outcome measures (including available p-values and odds ratios), main conclusions, article limitations, and studies were ranked. The ranking of studies rated the quality of the evidence on a scale of 1-4 (4 representing highest quality) by study design: 4 = RCTs; 3 = quasi-experimental, involving a comparison group; 2 = descriptive, no comparison group; 1 = reviews, case studies, grey literature.

Results

The literature search retrieved 6459 references. Of these 6459 references, 6303 were excluded following title and abstract review. Of the remaining 156, a further 103 were excluded based on retrieval of the full paper and based on inclusion criteria. 53 references remained eligible and were included in the review (figure 3).

Figure 3. Inclusion flow diagram
Description of Included Studies
Table 1 presents the frequencies of study characteristics found in references included in the review. The majority of studies were descriptive (55%), and only two out of the 53 studies included were randomized controlled trials. 83% (44) of the studies were conducted in high income countries while 2% (one study) were conducted in middle income countries and 15% (8 studies) in low income countries. Topics containing zero studies in either middle or low income countries were “Attitudes to services” and “Barriers to care entry & retention”; these topics also contained the least amount of studies overall (one and six, respectively).

Table 1. Frequencies of Study Characteristics

<table>
<thead>
<tr>
<th>TOPIC</th>
<th>REFERENCES</th>
<th>RANDOMIZED CONTROLLED TRIALS</th>
<th>QUASI-EXPERIMENTAL</th>
<th>DESCRIPTIVE STUDIES</th>
<th>REVIEWS, CASES, GREY LIT</th>
<th>INCOME LEVEL</th>
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<td>1</td>
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<td>Service Models</td>
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<td>0</td>
<td>4</td>
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<td>5</td>
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<td>Attitudes to Services</td>
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<td>0</td>
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<td>Barriers to Care Entry &amp; Retention</td>
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<td>0</td>
<td>0</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Barriers to ART Adherence</td>
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<td>3</td>
<td>13</td>
<td>5</td>
<td>17</td>
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<tr>
<td>Facilitators to Care</td>
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<td>4</td>
<td>6</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Facilitators to ART Adherence</td>
<td>14</td>
<td>1</td>
<td>5</td>
<td>7</td>
<td>1</td>
<td>11</td>
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<tr>
<td>TOTAL*</td>
<td>53</td>
<td>2</td>
<td>12</td>
<td>29</td>
<td>12</td>
<td>44</td>
</tr>
</tbody>
</table>

*(rounded % estimate of all references included)*

*The total numbers do not correspond to the sum of the above figures; some references could be categorized under more than one topic.*
Models of ARV Treatment Services

Several different model types were either described or mentioned in the findings, any of which may or may not have included the additional use of support services: outreach, mental health, case management (figure 4). Only those studies provided description of model types with or without support services are discussed in this review and included in the study characteristics figures.

Figure 4. Models of ARV Treatment Services

**Youth-specific**

Woods describes a youth-oriented collaborative care network of 2116 12-24 year olds in Boston.² The program, called “Boston HAPPENS,” utilizes a range of care approaches all catered to youth. Three primary agencies are identified: 1) multiservice outreach agencies which included street outreach, walk-in care, mobile vans and services providing basic food/clothing/shelter needs; 2) multidisciplinary, community-based health centers providing a variety of health care services (HIV, reproductive, mental health and substance abuse services in addition to support services such as outreach, youth development programs, and case management); and 3) hospitals offering youth both medical and mental health care, including adolescent clinics, HIV case management and specialty care. The program was designed to provide accessible, multidisciplinary, integrative and “client-focused” care to youth.
An outpatient adolescent HIV clinic in Kampala, managed by the Baylor-Uganda Children’s Foundation, had been a development from a needs assessment at the pediatric infectious disease clinic at Mulago Hospital, according to Kumar. The clinic cares for more than 800 HIV-positive youth (ages 12-24) mostly infected through vertical transmission. Psychosocial support also accompanies the sexual and reproductive health services offered. The same author also identified another youth-oriented HIV program called “HEAT” (Health and Education Alternatives for Teens), located in New York. The program offers support services along with comprehensive medical care for HIV-infected and at-risk 13-24 year olds.

“The Special Adolescent Clinic” (SAC) is university-based in the USA and consists of HIV-positive youth between the ages of 14-25 years, most of whom are African American or Hispanic and who had acquired HIV sexually. A “one-stop shopping” multidisciplinary approach is used, combining various medical and psychosocial services together in the same location.

“The Adolescent, Women and Children” (AWAC) treatment programs young people with HIV, also based in the USA, are designed to minimize adolescent barriers to effective care; they also employ a multidisciplinary approach addressing medical, nutritional, substance use, mental and social health needs. An additional case management system helped to facilitate the efforts to overcome adolescent barriers to care.

*Family-oriented*

A nonprofit organization called “Caring for Haitian Orphans with AIDS” demonstrates a family-oriented care model in Haiti for orphans with AIDS, ages 5-16. HIV-positive women are hired to be live-in caretakers for the children in a small house located in a “regular neighborhood” that provides a sense of community. CHO AIDS also attends to nutrition, safe water, social, psychological and educational needs of children in addition to monthly medical checkups and ARV medications.

*Multidisciplinary*

Most of the models already identified had also incorporated multidisciplinary approaches which have already been described above.

UNICEF supports a hospital in Rwanda (“Rwinkwavu”) where 570 children are part of the pediatric HIV program; in addition to ARV medication, patients visit monthly peer support clubs and receive education, thereby simultaneously addressing social and educational needs.

*Support Services*

Support services, including outreach and the use of case management, were common adjuncts to many of the models previously discussed.

Woods elaborates in a different article on the outreach component of the Boston HAPPENS program, where 56% of participants had received outreach services as their first contact (including street and telephone outreach).
Adolescent Attitudes towards ARV Care Services

Only one article was identified in this search pertaining to adolescent attitudes towards ARV care services. Seven 16-22 year olds were interviewed in the UK regarding their experiences in transitioning from pediatric to adult HIV care services. The transition was perceived to be “easy” by four out of the seven subjects; three may have possibly delayed their transition due to concerns regarding coordination of HIV and hemophiliac care and also due to fear of the adult environment. Those with had not been very involved in their own care decisions experienced more positive feelings towards transition; those who had been more involved and had developed more pediatric staff attachment expressed more sad feelings about transition and sense of relational loss.

Barriers to Care Entry and Retention

Possible adolescent barriers to ARV care entry and retention include the following (table 2):

- **Therapeutic**
  - Complex medical routine
  - Drug / alcohol use

- **Structural**
  - Transportation
  - Housing / food, clothing
  - Have children
  - No insurance

- **Psycho-Emotional**
  - Mental health, depression, anxiety
  - Denial of diagnosis
  - Patient autonomy level

- **Social**
  - Fear of adult patients
  - Stigma
  - Difficulty legging go of pediatric caregiver
Table 2. Barriers to Care Entry & Retention (page 1 of 2)

<table>
<thead>
<tr>
<th>Therapeutic</th>
<th>Author</th>
<th>Study Type ±</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complex medical routine</td>
<td>Gilliam¹²</td>
<td>2</td>
<td>13-25 yrs discussed, [N = 19 clinic workers]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Drug / alcohol use</td>
<td>Martinez¹³</td>
<td>2</td>
<td>15-24 yrs, [N = 107]</td>
<td>USA</td>
<td>14% (N=19) perceived need for drug/alcohol Rx</td>
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</table>

<table>
<thead>
<tr>
<th>Structural</th>
<th>Author</th>
<th>Study Type ±</th>
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<th>Country</th>
<th>Quantitative Outcome</th>
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<tbody>
<tr>
<td>Transportation</td>
<td>Martinez¹³</td>
<td>(see above)</td>
<td>15-24 yrs, [N = 107]</td>
<td>USA</td>
<td>40.2% (N=43) perceived need for transportation</td>
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<table>
<thead>
<tr>
<th>Housing / food, clothing</th>
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<th>Study Type ±</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
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<tbody>
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<td>Housing / food, clothing</td>
<td>Minniear¹⁴</td>
<td>2</td>
<td>13-21 yrs, [N = 202]</td>
<td>USA</td>
<td>46.7% (N=50) perceived need for housing</td>
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<tr>
<td>Housing / food, clothing</td>
<td>Minniear¹⁴</td>
<td>(see above)</td>
<td></td>
<td>USA</td>
<td>Delayed entry into HIV care associated with unstable residence: RR: 1.5*</td>
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<table>
<thead>
<tr>
<th>Have children</th>
<th>Author</th>
<th>Study Type ±</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
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<tbody>
<tr>
<td>Have children</td>
<td>Minniear¹⁴</td>
<td>(see above)</td>
<td></td>
<td>USA</td>
<td>More likely to fail to remain in HIV care (controlled for sex): RR: 1.8*</td>
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<table>
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<tr>
<th>No insurance</th>
<th>Author</th>
<th>Study Type ±</th>
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<th>Quantitative Outcome</th>
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<tr>
<td>No insurance</td>
<td>Minniear¹⁴</td>
<td>(see above)</td>
<td></td>
<td>USA</td>
<td>More likely to fail to remain in HIV care (despite access to free care): RR: 2.8*</td>
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<tr>
<th>Psycho-Emotional</th>
<th>Author</th>
<th>Study Type ±</th>
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<tr>
<td>Mental health, depression, anxiety</td>
<td>Gilliam¹²</td>
<td>2</td>
<td>13-25 yrs discussed, [N = 19 clinic workers]</td>
<td>USA</td>
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<tr>
<td>Mental health, depression, anxiety</td>
<td>Martinez¹³</td>
<td>2</td>
<td>15-24 yrs, [N = 107]</td>
<td>USA</td>
<td>44.9% (n=48) perceived mental health needs</td>
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<th>Denial of diagnosis</th>
<th>Author</th>
<th>Study Type ±</th>
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<th>Country</th>
<th>Quantitative Outcome</th>
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<td>Denial of diagnosis</td>
<td>Martinez¹³, Johnson¹⁵</td>
<td>(see above)</td>
<td></td>
<td>USA</td>
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<thead>
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<th>Patient autonomy level</th>
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<th>Study Type ±</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
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<tr>
<td>Patient autonomy level</td>
<td>Andiman¹⁶</td>
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<td>Patient autonomy level</td>
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<td>12-24 yrs, [N = 18]</td>
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Table 2 cont. Barriers to Care Entry & Retention *(page 2 of 2)*

<table>
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<th>Study Type ±</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of adult patients</td>
<td>Gilliam¹²</td>
<td>2</td>
<td>13-25 yrs discussed, [N = 19 clinic workers]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Stigma</td>
<td>Gilliam¹²</td>
<td>(see above)</td>
<td></td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Vijayan¹⁷</td>
<td>2</td>
<td>12-24 yrs, [N = 18]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Difficulty letting go of pediatric caregiver</td>
<td>Vijayan¹⁷</td>
<td>(see above)</td>
<td></td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Andiman¹⁶</td>
<td>1</td>
<td>13-24 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Gilliam¹²</td>
<td>2</td>
<td>13-25 yrs discussed, [N = 19 clinic workers]</td>
<td>USA</td>
<td>NA</td>
</tr>
</tbody>
</table>

± 4=Randomized Control Trial, 3=Quasi-Experimental, 2=Descriptional, 1=Review / grey literature
* p<0.05
NA=Not applicable
Barriers to ART Adherence

Possible adolescent barriers to ART adherence include the following (table 3):

**Therapeutic**
- Difficult med routine / too many pills
- Adverse side effects
- Regimen fatigue
- Drug / alcohol use

**Structural**
- Schedule / daily routine complications
- Unstable home
- Full-time job
- Don’t carry an extra dose of ARV meds
- Was taught how to take meds by a health worker
- Too few pediatric HIV care practitioners
- Consent

**Knowledge**
- Poor understanding of dosage importance

**Psycho-Emotional**
- Psychological struggles, depression
- Reminder of disease
- Denial
- Feel / appear well
- Forgot
- Not concerned about ART
- Persistent belief that “HIV is God’s punishment”
- Refused
- Self-destructive coping mechanism

**Social**
- Low trust of healthcare provider
- Stigma
Table 3. Barriers to ART Adherence (page 1 of 3)

<table>
<thead>
<tr>
<th>Author</th>
<th>Study Type</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Therapeutic</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Difficult med routine / too many pills</strong></td>
<td>Chandwani</td>
<td>3</td>
<td>13-18 yrs, [N = 104]</td>
<td>USA</td>
</tr>
<tr>
<td></td>
<td>Belzer</td>
<td>2</td>
<td>13-24 yrs, [N = 31]</td>
<td>USA</td>
</tr>
<tr>
<td><strong>Adverse side effects</strong></td>
<td>Belzer</td>
<td>2</td>
<td>13-24 yrs, [N = 31]</td>
<td>USA</td>
</tr>
<tr>
<td></td>
<td>Macdonell</td>
<td>2</td>
<td>16-24 yrs, [N = 186]</td>
<td>USA</td>
</tr>
<tr>
<td></td>
<td>Murphy</td>
<td>2</td>
<td>12-19 yrs, [N = 159]</td>
<td>USA</td>
</tr>
<tr>
<td></td>
<td>Andiman</td>
<td>1</td>
<td>13-24 yrs, [N = NA]</td>
<td>USA</td>
</tr>
<tr>
<td><strong>Regimen fatigue</strong></td>
<td>Merzel</td>
<td>2</td>
<td>10-16 yrs (subjects of discussion), [N = 30 caregivers]</td>
<td>USA</td>
</tr>
<tr>
<td><strong>Drug / alcohol use</strong></td>
<td>Dietz</td>
<td>2</td>
<td>13-24 yrs, [N = 178]</td>
<td>USA</td>
</tr>
<tr>
<td></td>
<td>Macdonell</td>
<td>2</td>
<td>16-24 yrs, [N = 186]</td>
<td>USA</td>
</tr>
<tr>
<td><strong>Structural</strong></td>
<td>Belzer</td>
<td>2</td>
<td>13-24 yrs, [N = 31]</td>
<td>USA</td>
</tr>
<tr>
<td></td>
<td>Macdonell</td>
<td>2</td>
<td>16-24 yrs, [N = 186]</td>
<td>USA</td>
</tr>
<tr>
<td></td>
<td>Murphy</td>
<td>2</td>
<td>12-19 yrs, [N = 159]</td>
<td>USA</td>
</tr>
<tr>
<td></td>
<td>Andiman</td>
<td>1</td>
<td>13-24 yrs, [N = NA]</td>
<td>USA</td>
</tr>
<tr>
<td><strong>Unstable home</strong></td>
<td>Andiman</td>
<td>1</td>
<td>13-24 yrs, [N = NA]</td>
<td>USA</td>
</tr>
<tr>
<td><strong>Full-time job</strong></td>
<td>Song</td>
<td>3</td>
<td>13-24 yrs, [N = 208]</td>
<td>USA</td>
</tr>
<tr>
<td><strong>Don’t carry extra dose</strong></td>
<td>Filho</td>
<td>2</td>
<td>10-19 yrs, [N = 101]</td>
<td>Brazil</td>
</tr>
<tr>
<td><strong>Was taught how to take meds by health worker</strong></td>
<td>Filho</td>
<td>(see above)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Too few pediatric HIV care practitioners</strong></td>
<td>American Acad of Pediatrics</td>
<td>1</td>
<td>0-18 yrs, [N = NA]</td>
<td>USA (refers to developing countries)</td>
</tr>
<tr>
<td><strong>Consent</strong></td>
<td>Binagwaho</td>
<td>1</td>
<td>10-19 yrs, [N = NA]</td>
<td>Rwanda</td>
</tr>
<tr>
<td></td>
<td>Strode</td>
<td>1</td>
<td>0-18 yrs, [N = NA]</td>
<td>So. Africa</td>
</tr>
<tr>
<td></td>
<td>Ho</td>
<td>1</td>
<td>15-29 yrs, [N = NA]</td>
<td>USA</td>
</tr>
</tbody>
</table>
Table 3 cont. Barriers to ART Adherence (page 2 of 3)

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Author</th>
<th>Study Type*</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor understanding of dosage importance</td>
<td>Abadia-Barrero(^{30})</td>
<td>2</td>
<td>1-15 yrs, [N = 50]</td>
<td>Brazil</td>
<td>NA</td>
</tr>
<tr>
<td>Psycho-Emotional</td>
<td>Andiman(^{16})</td>
<td>1</td>
<td>13-24 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Psychological struggles, depression</td>
<td>Murphy(^{31})</td>
<td>2</td>
<td>13-18 yrs, [N = 161]</td>
<td>USA</td>
<td>Depressed subjects less likely to identify &amp; take all of meds: OR: 0.2 (p&lt;0.001)</td>
</tr>
<tr>
<td></td>
<td>Murphy(^{21})</td>
<td>2</td>
<td>12-19 yrs, [N = 159]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Belzer(^{19})</td>
<td>2</td>
<td>13-24 yrs, [N = 31]</td>
<td>USA</td>
<td>15% reported as reason for missing meds</td>
</tr>
<tr>
<td>Reminder of disease</td>
<td>Belzer(^{19})</td>
<td>(see above)</td>
<td>13-24 yrs, [N = 31]</td>
<td>USA</td>
<td>32% reported as reason for missing meds</td>
</tr>
<tr>
<td>Denial</td>
<td>Andiman(^{16})</td>
<td>1</td>
<td>13-24 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Feel / appear well</td>
<td>Abadia-Barrero(^{30})</td>
<td>2</td>
<td>1-15 yrs, [N = 50]</td>
<td>Brazil</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Vijayan(^{17})</td>
<td>2</td>
<td>12-24 yrs, [N = 18]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Buchanan(^{32})</td>
<td>2</td>
<td>8-18 yrs, [N = 120]</td>
<td>USA</td>
<td>49% of 12-18 year olds reported “forget” as a barrier</td>
</tr>
<tr>
<td></td>
<td>Belzer(^{19})</td>
<td>2</td>
<td>13-24 yrs, [N = 31]</td>
<td>USA</td>
<td>22% reported as reason for missing meds</td>
</tr>
<tr>
<td></td>
<td>Chandwani(^{18})</td>
<td>3</td>
<td>13-18 yrs, [N = 104]</td>
<td>USA</td>
<td>Associated with missing doses: AOR: 2.53*</td>
</tr>
<tr>
<td></td>
<td>Macdonell(^{20})</td>
<td>2</td>
<td>16-24 yrs, [N = 186]</td>
<td>USA</td>
<td>“Situational temptation score”: 2.45 out of 5</td>
</tr>
<tr>
<td></td>
<td>Trocme(^{33})</td>
<td>2</td>
<td>13+ yr adols, [N = 29]</td>
<td>France</td>
<td>23/29 interviewed reported either forgetting or refusing</td>
</tr>
<tr>
<td>Not concerned about ART</td>
<td>Filho(^{33})</td>
<td>2</td>
<td>10-19 yrs, [N = 101]</td>
<td>Brazil</td>
<td>Associated with non-adherence: OR 3.47*</td>
</tr>
<tr>
<td>Persistent belief that HIV is God’s punishment</td>
<td>Lyon(^{34})</td>
<td>3</td>
<td>14-21 yrs, [N = 38]</td>
<td>USA</td>
<td>Assoc’d with worse adherence*</td>
</tr>
<tr>
<td>Refused</td>
<td>Merzel(^{22})</td>
<td>2</td>
<td>10-16 yrs (subjects of discussion), [N = 30 caregivers]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Trocme(^{33})</td>
<td>2</td>
<td>13+ yr adols, [N = 29]</td>
<td>France</td>
<td>9/29 interviewed reported refusing</td>
</tr>
<tr>
<td></td>
<td>Andiman(^{16})</td>
<td>1</td>
<td>13-24 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Self-destructive coping</td>
<td>Song(^{34})</td>
<td>3</td>
<td>13-24 yrs, [N = 208]</td>
<td>USA</td>
<td>Inversely assoc’d with attending intervention sessions: b=-3.22 (p&lt;0.01)</td>
</tr>
</tbody>
</table>
Table 3 cont. Barriers to ART Adherence *(page 3 of 3)*

<table>
<thead>
<tr>
<th>Social</th>
<th>Author</th>
<th>Study Type*</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low trust of healthcare provider</td>
<td>Andiman16</td>
<td>1</td>
<td>13-24 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Belzer18</td>
<td>2</td>
<td>13-24 yrs, [N = 31]</td>
<td>USA</td>
<td>NA 18% reported as reason for missing meds</td>
</tr>
<tr>
<td></td>
<td>Rao35</td>
<td>2</td>
<td>17-25 yrs, [N = 25]</td>
<td>USA</td>
<td>NA 50% reported skipping doses for fear of status disclosure among family or friends</td>
</tr>
<tr>
<td>Stigma</td>
<td>Vijayan17</td>
<td>2</td>
<td>12-24 yrs, [N = 18]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Martinez**36</td>
<td>2</td>
<td>15-24 yrs, [N = 178 females]</td>
<td>USA</td>
<td>Insignificant predictor</td>
</tr>
</tbody>
</table>

*4=Randomized Control Trial, 3=Quasi-Experimental, 2=Descriptional, 1=Review / grey literature
*p<0.05
**Stigma was found to NOT be a barrier to ART adherence
NA=Not applicable
Facilitators to Care Entry and Retention

Possible adolescent facilitators to ARV treatment care include the following (table 4):

**Model Characteristics**
- Treatment sites should *NOT* be HIV-specific
- Youth-specific
- Multidisciplinary / comprehensive
- Support services (outreach, case management)
- Variety of care sites
- Continuous

**Linkage to care**
- HIV test provider links youth to care
- Coordinator assists with pediatric-to-adult HIV care transition
- Pediatric case manager follows up after pediatric-to-adult HIV care transition

**Knowledge**
- Disclosure of HIV status to adolescent

**Social**
- Family-centered
- Peer support
- Relationship-building with healthcare workers
- Diversity-sensitive staff
- Youth independence is nurtured by staff
Table 4. Facilitators to Care Entry & Retention (page 1 of 2)

<table>
<thead>
<tr>
<th>Author</th>
<th>Study Type ±</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Model Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment sites should NOT be HIV-specific</td>
<td>Martinez¹³</td>
<td>15-24 yrs, [N = 107]</td>
<td>USA</td>
<td>90% of youth-focused management group were retained in care at 3 mos &amp; 70% at 6 mos; care attendance increased 7%→73% *</td>
</tr>
<tr>
<td>Youth-specific</td>
<td>Wohl³⁷</td>
<td>18-24 yrs, [N = 61] (Latino &amp; Afr-Amer MSM)</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Johnson¹⁵</td>
<td>13-18 yrs, [N = NA]</td>
<td>USA</td>
<td>Adequate visit constancy improved 31% →57% after specifying services to youth (with case managers)*</td>
</tr>
<tr>
<td></td>
<td>Davila³⁸</td>
<td>13-23 yrs, [N = 174]</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gilliam¹²</td>
<td>13-25 yrs, [N = 19 clinic workers who discussed youth]</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(see above)</td>
<td></td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Johnson¹⁵</td>
<td>13-18 yrs, [N = NA]</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Major-Wilson⁴</td>
<td>Adolescents, [N = NA]</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Palmer³⁹</td>
<td>Adolescents, [N = NA]</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Woods⁴</td>
<td>12-24 yrs, [N =2116]</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Woods¹⁰</td>
<td>12-24 yrs, [N = 2116]</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Woods¹⁰</td>
<td>Adolescents, [N = NA]</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chandwani¹¹</td>
<td>13-21 yrs, [N = 2116]</td>
<td>USA</td>
<td>83.3% of multimodal behavioral intervention group attended ≥ half the sessions (p=0.5)</td>
</tr>
<tr>
<td>Multidisciplinary / comprehensive</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support services (outreach, case management)</td>
<td>Davila³⁸</td>
<td>13-23 yrs, [N = 174]</td>
<td>USA</td>
<td>Visit constancy improved 31% → 57% after specifying services to youth with case managers</td>
</tr>
<tr>
<td></td>
<td>Gilliam¹²</td>
<td>13-25 yrs discussed, [N = 19 clinic workers]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Hightow-Weidman⁴²</td>
<td>17-24 yrs, [N = 81] (Black MSM)</td>
<td>USA</td>
<td>63% of support services intervention retained in care at 3 yrs; OR 2.58 for clinic attendance*</td>
</tr>
<tr>
<td></td>
<td>Wohl³⁷</td>
<td>18-24 yrs, [N = 61] (Latino &amp; Afr-Amer MSM)</td>
<td>USA</td>
<td>90% of a youth-focused case management group were retained in care at 3 mos &amp; 70% at 6 mos; care attendance increased 7%→73% * Longer retention with ≥2 outreach contacts or case management at ≥3 visits</td>
</tr>
<tr>
<td></td>
<td>Harris¹³</td>
<td>12-24 yrs, [N = 1426]</td>
<td>USA</td>
<td></td>
</tr>
</tbody>
</table>
## Table 4 cont.  Facilitators to Care Entry & Retention (page 2 of 2)

<table>
<thead>
<tr>
<th>Model Characteristics continued</th>
<th>Author</th>
<th>Study Type*</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variety of care sites</td>
<td>Woods⁴</td>
<td>2</td>
<td>12-24 yrs, [N = 2116]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Woods¹⁰</td>
<td>2</td>
<td>12-24 yrs, [N = 2116]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Continuous</td>
<td>Woods⁴</td>
<td>2</td>
<td>12-24 yrs, [N = 2116]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Woods¹⁰</td>
<td>2</td>
<td>12-24 yrs, [N = 2116]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Johnson¹⁵</td>
<td>1</td>
<td>13-18 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Linkage to Care</td>
<td>Hightow-Weidman⁴⁴</td>
<td>2</td>
<td>13-24 yrs, [N = 334 males]</td>
<td>USA</td>
<td>Earlier linkage associations: test provider refers to care*; calls to make appointment (p&lt;0.01)</td>
</tr>
<tr>
<td>HIV test provider links to care</td>
<td>Jeanjacques⁵⁵</td>
<td>1</td>
<td>12-24 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Johnson¹⁵</td>
<td>1</td>
<td>13-18 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Woods⁴</td>
<td>2</td>
<td>12-24 yrs, [N = 2116]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Woods¹⁰</td>
<td>1</td>
<td>Adolescents, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Transition coordinator assists with ped-to-adult HIV care</td>
<td>Kumar¹⁶</td>
<td>1</td>
<td>10-24 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Gilliam¹²</td>
<td>2</td>
<td>13-25 yrs discussed, [N = 19 clinic workers]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Pediatric case manager F/U after ped-to-adult care transition</td>
<td>Gilliam¹²</td>
<td>(see above)</td>
<td></td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>Knowledge</td>
<td>Arrive¹⁷</td>
<td>3</td>
<td>10-21 yrs, [N = 6501]</td>
<td>Cote d’Ivoire, Mali, Senegal</td>
<td>Associated with higher care retention: aHR: 0.23 (p&lt;0.0001)</td>
</tr>
<tr>
<td>Social</td>
<td>Palmer³⁹</td>
<td>1</td>
<td>Adolescents, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Peer support</td>
<td>Hightow-Weidman⁴²</td>
<td>3</td>
<td>17-24 yrs, [N = 81] (Black MSM)</td>
<td>USA</td>
<td>63% of support services intervention including peer support retained in care at 3 yrs; OR 2.58 for clinic attendance*</td>
</tr>
<tr>
<td></td>
<td>Johnson¹⁵</td>
<td>(see above)</td>
<td>13-18 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Relationship-building with healthcare workers</td>
<td>Johnson¹⁵</td>
<td>(see above)</td>
<td></td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Woods¹⁰</td>
<td>1</td>
<td>Adolescents, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Martinez¹³</td>
<td>2</td>
<td>15-24 yrs, [N = 107]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Diversity-sensitive staff</td>
<td>Gilliam¹²</td>
<td>2</td>
<td>13-25 yrs discussed, [N = 19 clinic workers]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Independence nurtured</td>
<td>Kumar⁴⁶</td>
<td>1</td>
<td>10-24 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
</tbody>
</table>

* 4=Randomized Control Trial, 3=Quasi-Experimental, 2=Descriptive, 1=Review / grey literature
* p<0.05
NA=Not applicable
Facilitators to ART Adherence

Possible adolescent facilitators to ART adherence include the following (table 5):

**Therapeutic**
- Simpler med routine / lower viral load

**Model Characteristics**
- Family-centered, community-based
- Directly-observed therapy

**Technology**
- Cell phone reminders
- Web-based training program

**Knowledge**
- Disclosure of HIV status to adolescent
- Open communication / education in a supportive context
- Health literacy

**Psycho-Emotional**
- Adjustment
- Effective coping mechanisms

**Social**
- Family support
- Peer support
- Specific med-taking strategies discussed with youth
Table 5. Facilitators to ART Adherence (page 1 of 2)

<table>
<thead>
<tr>
<th>Author</th>
<th>Study Type ±</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Therapeutic</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Machado⁴⁸</td>
<td>2</td>
<td>10-19 yrs, [N = 96]</td>
<td>Brazil</td>
<td>Sig. difference in good adherence between monotherapy (56%) &amp; double drug therapy (21%) patients*</td>
</tr>
<tr>
<td><strong>Model Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letourneau⁴⁹</td>
<td>4</td>
<td>9-17 yrs, [N = 34]</td>
<td>USA</td>
<td>Sig. adherence increase after intervention: OR 1.24*</td>
</tr>
<tr>
<td>Gaur⁵⁰</td>
<td>3</td>
<td>16-25 yrs, [N = 20]</td>
<td>USA</td>
<td>Self-reported adherence over study period: &gt;93% in all 6 “DOT successes” until week 16; only 3 sustained adherence off DOT until wk 24</td>
</tr>
<tr>
<td><strong>Technology</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dowshen⁵¹</td>
<td>3</td>
<td>14-29 yrs, [N = 25]</td>
<td>USA</td>
<td>Sig. increase in mean visual analog scale scores: 74.7 (week 0) → 93.3 (week 12)* → 93.1 (week 24)* Total med doses missed out of 5 pt.s: Post 4 wks: 1 Post 8 wks: 4 Post 12 wks: 6</td>
</tr>
<tr>
<td><strong>Web-based training program</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shegog⁵³</td>
<td>3</td>
<td>14-22 yrs, [N = 10]</td>
<td>USA</td>
<td>Sig. self-efficacy increases for taking meds right time every day; taking meds correctly even if travelling or busy at work, school, or at a party; and getting family &amp; friends’ help in remembering*</td>
</tr>
<tr>
<td><strong>Knowledge</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Merzel²²</td>
<td>2</td>
<td>10-16 yrs, [N = 30 caregivers]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td>Andiman¹⁶</td>
<td>1</td>
<td>13-24 yrs, [N = NA]</td>
<td>USA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Open communication / education in support house</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abadia-Barrero¹⁰</td>
<td>2</td>
<td>1-15 yrs, [N = 50]</td>
<td>Brazil</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Health literacy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Murphy**²⁵⁴</td>
<td>2</td>
<td>16-24 yrs, [N = 186]</td>
<td>USA</td>
<td>Insignif. association</td>
</tr>
</tbody>
</table>

* Replication of results is included for reference and clarity.
Table 5 cont. Facilitators to ART Adherence (page 2 of 2)

<table>
<thead>
<tr>
<th>Author</th>
<th>Study Type ±</th>
<th>Age, Sample Size [N]</th>
<th>Country</th>
<th>Quantitative Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Psycho-Emotional</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Adjustment</strong></td>
<td>Michaud$^{54}$</td>
<td>2</td>
<td>13-20 yrs (N=29, \text{ including } 22 \text{ females})</td>
<td>Switzerland</td>
</tr>
<tr>
<td></td>
<td>Michaud$^{54}$</td>
<td>2</td>
<td>13-20 yrs (N=29, \text{ including } 22 \text{ females})</td>
<td>Switzerland</td>
</tr>
<tr>
<td></td>
<td>Song$^{24}$</td>
<td>3</td>
<td>13-24 yrs, (N=208)</td>
<td>USA</td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family support</strong></td>
<td>Davey$^{55}$</td>
<td>2</td>
<td>14-24 yrs, (N=50)</td>
<td>USA</td>
</tr>
<tr>
<td></td>
<td>Hodgson$^{56}$</td>
<td>2</td>
<td>10-19 yrs, (N=170) (\text{includes 59 informants not in age bracket})</td>
<td>Zambia</td>
</tr>
<tr>
<td><strong>Peer support</strong></td>
<td>Hodgson$^{56}$ (see above)</td>
<td></td>
<td></td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>Merzel$^{22}$</td>
<td>2</td>
<td>10-16 yrs, (N=30 \text{ caregivers})</td>
<td>USA</td>
</tr>
<tr>
<td><strong>Specific med-taking strategies discussed with youth</strong></td>
<td>Michaud$^{54}$</td>
<td>2</td>
<td>13-20 yrs (N=29, \text{ including } 22 \text{ females})</td>
<td>Switzerland</td>
</tr>
</tbody>
</table>

± 4=Randomized Control Trial, 3=Quasi-Experimental, 2=Descriptional, 1=Review / grey literature
* p<0.05
**Health literacy NOT a facilitator to ART
NA=Not applicable
**Discussion**
Although there is urgent need to increase ARV coverage among the adolescent population, there is relatively little published literature to guide how this goal should be achieved in a way that is acceptable and effective. There are some significant findings, however, which emerge out of the findings in this review.

Documentation of current model types was very limited. Most current documentation pertains to youth-specific care, multidisciplinary care, and the addition of support services. There were no studies eligible for this review which documented links to other services such as TB, IDU, and antenatal clinics; links to reproductive health services did, however, make themselves evident in a couple of findings. Data related to adolescent attitudes towards care was even more scant, as this review only uncovered one such study.

General categories of barriers to care entry and retention included: therapeutic, structural, psychoemotional, and social; barriers to ART adherence fell within the same general categories with the addition of a “knowledge” category. General categories of facilitators to care included: model characteristics, linkage to care, knowledge, and social; facilitators to ART included the same categories, apart from the linkage category, and also included “therapeutic,” “technology,” and “psycho-emotional categories.

**Limitations**
As the quality and aims of studies were variable and limited to our inclusion criteria, some inherent challenges in synthesizing and interpreting the data subjected this review to several limitations. While 53 references were identified for the inclusion in this review, only two of these studies were randomized controlled trials, which increased the difficulty in systematically comparing and summarizing data which hold differing degrees of quality of evidence; quasi-experimental studies were additionally limited at 12 studies total. Furthermore, there is a limited number of studies focusing on the particular age range of 10-19 years; some information pertaining to this age range may have been missed in this review since those studies which are also inclusive of much younger or older age ranges without age segregation data were excluded from this analysis. And although a systematic method was used for reference inclusion and data extraction, selection bias is also a possible limitation in this review due to the inevitable element of subjective judgment. Finally, publication bias may have affected data collected and conclusions drawn in this review.

Nonetheless, the strength of the evidence used in this review has been qualified according to several elements such as study design, location, sample size, and statistical significance. Evidence may be substantially devoid of support from randomized control trials, however where the evidence shows consistency and strength of associations is where the general trends reported may be relied upon. The review methodology is transparent and repeatable, and resources other than peer-reviewed publications were also included in the review (i.e., regional databases, grey literature, newspapers, and speeches).

**Conclusion**
This review offers an overview of the current literature on adolescent ARV service delivery. This overview primarily supports the elimination of barriers and the promotion of facilitators to ARV care entry and retention as well as ARV adherence; by doing so, adolescent ARV coverage may be increased, thereby reducing adolescent HIV morbidity and mortality.
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17 Vijayan T, Benin AL, Wagner K, Romano S, Andiman WA. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. AIDS Care. 2009 Oct; 21 (10) :1222-9.


39 Palmer A. "I don't want to grow up" Transitioning HIV-infected adolescents to adult care. HIV Clin. 2007 Fall; 19 (4) :1-3.


Harris SK, Samples CL, Keenan PM, Fox DJ, Melchiono MW, Woods ER, Boston HAPPENS Program. Outreach, mental health, and case management services: can they help to retain HIV-positive and at-risk youth and young adults in care?. Matern Child Health J. 2003 Dec; 7 (4) :205-18.


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

ANNEX 15: Adolescent consent to testing: a review of current policies and issues in sub-Saharan Africa

ADOLESCENT CONSENT TO HIV TESTING: A REVIEW OF CURRENT POLICIES AND ISSUES IN SUB-SAHARAN AFRICA

Kathleen Fox, Jane Ferguson, Wale Ajose, Jerome Singh, Elizabeth Marum, Rachel Baggaley

Over the past decade, the annual number of new HIV infections and HIV-related deaths has been declining steadily in most regions of the world, primarily due to significant scale-up in prevention and treatment. Approximately 2.5 million people became newly infected in 2011—a 20% reduction from 2001 (1). Even in sub-Saharan Africa, the number of newly infected people has decreased in 23 of the 49 countries in the region (1). Despite this progress, sub-Saharan Africa still accounted for 71% of newly infected adults and children and 69% of people living with HIV in the world in 2011 (1). While there has also been decreasing incidence of HIV infection in adolescents in many countries—linked to clear trends toward safer behaviours and practices, including increased condom use and reduction in the number of sexual partners—adolescents remain particularly vulnerable to the infection, and HIV continues to be a prominent cause of death in this segment of the population (1). In many countries, incidence rates of HIV in adolescents and young people (15–24) remain unacceptably high, and adolescents still account disproportionately for over 41% of new HIV infection in the 15–49 age group (2).

Globally, over two million adolescents aged 10–19, and five million adolescents and young people aged 15–24 are living with HIV; and, it is estimated to be the sixth and eighth leading cause of death among people aged 10–14 and 15–19, respectively, the overwhelming majority in sub-Saharan Africa (2,3). In stark contrast to the 3.8 million (76%) adolescents and young people (15–24) estimated to be living with HIV in sub-Saharan Africa in 2009, only 320,000 were reported to be infected with HIV in South Asia; 180,000 in East Asia and the Pacific; 250,000 in Latin America and the Caribbean; 81,000 in Central and Eastern Europe and Central Asia; and 94,000 in the Middle East and North Africa (4). Within this young population there are significant sex differences in prevalence—young women from sub-Saharan Africa accounted for about 71% of the HIV prevalence in that region for adolescents and young people living with HIV ages 15 to 24 in 2009 (2,4).

In generalized epidemics, many adolescents living with HIV acquired the infection perinatally because either their mothers were not enrolled in prevention of mother-to-child transmission (PMTCT) interventions or as infants they were not diagnosed postnatally (5,6). Some mature into adolescence as ‘slow progressors’ unaware of their HIV status, many of whom develop chronic clinical and developmental problems that would have benefitted significantly from early diagnoses and initiation of antiretroviral therapy (ART).

Survey data collected from 2005 to 2010 in sub-Saharan Africa indicates that only 10% of young women and 15% of young men (15–24 years) were aware of their HIV status, suggesting that the epidemic within this population is potentially largely undiagnosed and, consequently, not linked with care or treatment (2). As many factors contribute to the low level of testing within this population—from the
fear of discovering they are HIV positive to the barriers to services created by national age of consent laws and social norms influencing service providers attitudes and behaviours —it is not surprising that adolescents from key affected populations (sex workers, men who have sex with men, and people who inject drugs) and vulnerable populations (e.g. incarcerated youth, young women) are likely to have even less access to HIV testing and counselling or care and treatment than the general adolescent population. Additionally, if a parent or guardian is reluctant to give their adolescent consent to get an HIV test and the adolescent is under the nationally specified age of consent, the adolescent may remain undiagnosed and, if HIV positive, be deprived of appropriate care and treatment.

**Adolescents and Risk**

The main mode of HIV transmission among adolescents, who were not perinatally infected, is unprotected heterosexual sex; however, adolescents are also exposed through injecting drug use, sex work, and non-consensual and homosexual sex (4). In countries with concentrated epidemics, exposure through drug use is often coupled with other high-risk behaviours, such as transactional sex—a major driver of HIV transmission. The criminalization of ‘illicit’ activities (e.g. drug use, transactional sex, men having sex with men) in many countries intensifies exclusion from prevention and treatment services, including HIV testing and counselling (HTC) (7). If the goals of universal access are to be achieved, prevention and treatment programs will have to reach these most-at-risk populations. Early sexual debut, low condom use, and a host of other risk-taking behaviours, combined with biological vulnerability (in adolescent girls), all contribute to the risk of HIV transmission. A wide range of factors influence the adoption of risk behaviours: the availability and access to alcohol and illicit substances, peer pressure, curiosity, and thrill-seeking behaviours sometimes lead to experimentation with drugs, alcohol, and sexuality. Similarly, structural issues such as poverty, unemployment, illegal status, conflict, and marginalization exacerbate adolescents’ connections with their families and society, and contribute to engagement in risk behaviours for HIV transmission.

The risk of HIV infection is significantly higher for adolescent girls than for adolescent boys. Globally, just over one in ten adolescent girls are sexually active before the age of 15, and in sub-Saharan Africa, young women account for 54% of all adolescents living with HIV worldwide (2). Studies have reported a strong correlation between early age of sexual debut and increased risk of HIV (2,8). Similarly, in cultures where adolescent marriages are allowed, or even encouraged, adolescent girls often find themselves powerless to make informed decisions, related to sexual behaviour, putting them at risk of HIV transmission (3,9). Adolescent girls are also subject to sexual violence and rape, both inside and outside of marriage, further exacerbating their risk of HIV infection. In many settings, adolescent boys aged 15–19 years are more likely to engage in high-risk sex than girls of the same age, and knowledge of HIV status could be important in supporting safer sex choices and uptake of HIV prevention interventions, including male circumcision. Thus, increased investment in interventions that prioritize programs focused on increasing knowledge and prevention of HIV transmission and greater access to services—including HTC for adolescents, is critical to accelerating current HIV prevention efforts.

**HTC and Adolescents**

The proportion of adolescents who have correct and comprehensive knowledge about and have been tested for HIV remains inadequate. In 2010, an estimated 34% of adolescents possessed comprehensive HIV knowledge, far from the UNGASS global target of 95%, set in 2001, (10). Based on ten population-based surveys conducted between 2007 and 2009, the median percentage of people with HIV who know their status is estimated below 40%, and the lack of awareness of HIV status is especially high for adolescents (11). Within southern Africa, gender appears to play a significant role in knowing one’s HIV status. Adolescent girls, who have significantly higher prevalence rates than adolescent boys, are more
likely to know they are infected than adolescent boys in the region, primarily because adolescent girls more frequently access health services, e.g. family planning and antenatal care, where HTC is often routinely offered \((10)\). However, although adolescent girls are now more likely to know where to get an HIV test than they were ten years ago, HIV testing rates still remain relatively low in many countries, in particular, those in sub-Saharan Africa \((3)\).

**Informed Consent and Adolescence**

To best understand the issues and challenges regarding informed consent and adolescence, it is useful to know how these terms are defined and what key issues might influence the development of national laws or policies.

Consent is defined as the agreement, expressed either verbally or in writing, to a proposed action or situation. For purposes of medical intervention or research, consent given by a subject for a procedure, course of treatment, or any other health intervention to be performed, must be informed. The subject should receive information about the intervention and must indicate that they understand the possible risks and/or benefits of participation; and, if consent is given, that it has been done so voluntarily without any feeling of coercion. Therefore, informed consent must be given by someone who has the competence to understand the elements of the intervention and the consequences of making the choice to receive the intervention.

Adolescence is typically defined as beginning with the onset of puberty and ending at the age of majority, the latter being the age at which one is recognized as an adult with its attendant responsibilities and rights. WHO defines adolescence inclusively as the period between 10 and 19 years of age in order to capture the range of developmental changes occurring during this time and to correspond with national information systems often aggregated in 5 year age bands. However, the demarcation of this life stage is dependent on the physical, mental, and cognitive maturation of an individual, as well as a range of social, cultural, and legal factors articulated by one’s community, culture, or country. The Convention on the Rights of the Child, a universally agreed upon set of non-negotiable standards and obligations, defines a child as every human being under the age of 18 years \((12,13)\). Many countries include exceptions in their legislation allowing for an adolescent in a specific group or situation to be considered a ‘mature minor’ (to have attained majority earlier than general adolescent population) \((12,13)\). However, UNICEF points out that regardless of national laws, many children under 18 years are engaged in ‘adult’ activities, such as labour, marriage, and childbearing \((14)\). Intertwined in many national policies are legal definitions of adolescence, including legal age of sexual debut, marriage, consumption of alcohol, as well as age of consent to medical treatment or HIV testing. In most countries and in most guidelines that discuss HTC, there is a tension between the desire to protect and the recognition that all adolescents, particularly older adolescents \((15\text{-}19)\), need to be able to take increasing responsibility for their lives including health-care decisions \((15)\).

The central issue in the debate over minor rights to health interventions is finding the balance between the parental responsibilities toward the adolescent, the immaturity and vulnerability of adolescent children, and his or her right to be emancipated from the decision of the parent. As a result, a patchwork of laws has been produced, making it difficult to make any overriding statements about minor and parental rights in regard to medical treatment. This highlights the acknowledged conflict between the rights of the adolescent—under the Convention on the Rights of the Child—and that of the parent or guardian who understands themself to have the legal right to make medical decisions for his or her child \((12,13)\). For adolescents, limiting the right of consent to HIV testing to parents or guardians, has serious potential implications. Studies have shown that requiring parental consent to HTC services might in fact reduce adolescent access because of perceived negative reactions from parents/guardians.
or health-care providers and the fear of HIV-related stigma (16,17). It has also been documented that adolescents may opt not to seek care because they want to avoid telling their parents about their health problems and sexual activity (18). A survey of a nationally representative sample of adolescents in the US found that 35% avoided health care so they would not have to tell their parents about their health issues, and that girls were more likely to avoid health care in order to prevent their parents’ discovery of their daughter’s high-risk behaviour (18). In another US study, a substantial increase in uptake of HTC services was observed after the removal of parental consent to HIV testing requirements in New Jersey state law (19).

Age restrictions also pose a barrier to adolescents accessing HTC services. A review analysing the HTC experiences of adolescents in over ten countries found that restrictions placing the conventional or widely accepted legal age of consent at 18 years of age prevented access to HIV testing where minors were sexually active and at risk of HIV infection (20). Another barrier to HTC services is the ambiguity and/or inconsistency in national policies on consent issues. In many countries, consent to HIV testing is either not specified or is ill defined in national policies. This may be due to the sensitivity or complexity of the issue, or to the lack of available evidence to inform decision-making. Regardless, it is common to see country policies be silent, vague, or contradictory on these issues (19). When policies are unclear or not well understood, and guidance is limited or vague, it follows that health providers may be reluctant to provide HIV testing services. This paper reviews policy issues concerning consent to HTC for adolescents, and the potential of those policies to limit or prevent adolescent access to HTC and other HIV prevention and care services.

**REVIEW OF COUNTRY POLICIES ON HTC CONSENT IN SUB-SAHARAN AFRICA**

A review of available national policies, legislation, and guidelines on HIV/AIDS, including voluntary counselling and testing (VCT) and provider-initiated testing and counselling (PITC), was conducted in 2011 and 2012. We searched the World Health Organization Library Information System (WHOLIS), Institutional Repository for Information Sharing (IRIS), Google Scholar, individual country Ministry of Health websites, and knowledge-base repositories of various organizations and institutions, including: International Labour Organization (ILO), AIDSTAR ONE (USAID), United Nations Population Fund (UNFPA), and International Planned Parenthood Federation (IPPF).

For the purpose of this review, no eligibility criteria were defined and all national policies, legislation, and guidelines making reference to adolescent or minor age of consent were included for consideration. Each document was assessed for its content on consent to HIV testing, age criteria for self-consent, and exceptions for HIV testing below the age of consent for the general population or a stipulated subpopulation. We developed a data extraction tool to capture the following information: country, legal age for consensual sexual relations or age of majority (if the former was unavailable), existence of an HTC law or policy, date of the law or policy, existence of an age of consent criteria within that law or policy, specific age of consent (with parental consent), specific age of consent (without parental consent), and exceptions for the stated age of consent to HIV testing (such as demonstrated maturity, at-risk behaviour, symptomatic, pregnant, married, young parent, head of household, abandoned children, street children, injecting drug users, commercial sex workers, or young men who have sex with men).

We also reviewed available literature on age of consent to sexual relationships with the aim of comparing it against the age of consent to HTC services. We combined a thorough scoping search with the review of existing work done by the US Department of State, United Nations Development Programme (UNDP), AVERT, as well as national documents accessed through the International Labour
Organization (ILO) and individual country websites, to arrive at our final list. Two reviewers independently analysed the findings of the scoping search for errors and disparities, and legislation or technical guidance written in languages other than English were translated.

RESULTS

Legal Adolescent Age of Consent to Access HTC in Sub-Saharan Africa

Of the 49 sub-Saharan African countries, national publications (policies, legislation, and guidelines) on HIV/AIDS were available for review from 41 countries. Of these, one country (Mauritania) had a law addressing HTC but did not mention minors or provide any detail regarding access to HTC, and seven countries limited self-consent to non-minors but did not define the term ‘minor’ within that particular HIV law or policy. Of the remaining 33 countries that provided either a clearly defined age-based or other specific criteria at which adolescents (or minors) could consent to HIV testing:

- 14 stipulate that only persons 18 years of age and above could give consent to HTC without parental guidance.
- 14 stipulate a legal age of consent to HIV testing allowing adolescents under the age of 18 years to assent to HIV testing without the additional consent of a parent or guardian. In three of those countries—Lesotho, South Africa, and Uganda—adolescents are able to consent to HTC services as early as 12 years of age.
- 5 countries did not specify an age limit, but used other criteria—demonstrated maturity, of reproductive age, married, pregnant, or engaged in HIV-risk behaviour—to enable access to HTC.

Table 1: Legal age of consent laws and policies in sub-Saharan Africa

<table>
<thead>
<tr>
<th>National laws and policies reviewed (n=49)</th>
<th>No. of countries (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Law or policy existing for HTC, age of consent clearly defined (including no age limit)</td>
<td>33 (67.3%)</td>
</tr>
<tr>
<td>Law or policy existing for HTC, but no age of consent specified*</td>
<td>7 (14.3%)</td>
</tr>
<tr>
<td>Total number of countries with laws or policies discussing age of consent to HTC (see below)</td>
<td>40 (81.6%)</td>
</tr>
<tr>
<td>Law or policy existing for HTC, but no mention of ‘adolescent’ or ‘minor’ [Mauritania]</td>
<td>1 (2.1%)</td>
</tr>
<tr>
<td>No law or policy for HTC [Chad, The Comoros, Equatorial Guinea, Eritrea, Gabon, The Gambia, São Tomé and Principe, South Sudan]</td>
<td>8 (16.3%)</td>
</tr>
<tr>
<td>Total number of countries either without HTC laws or policies, or have policies but do not mention adolescents or minors</td>
<td>9 (18.4%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>National age of consent to HTC (n=40)</th>
<th>No. of countries (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of minor not defined [Angola, Benin, Burundi, Guinea-Bissau, Madagascar, Mali, Togo]</td>
<td>7 (17.5%)</td>
</tr>
<tr>
<td>No age limit – all or most adolescents eligible** [Botswana, Cape Verde, Kenya, Mauritius, Somalia (Somaliland)]</td>
<td>5 (12.5%)</td>
</tr>
<tr>
<td>12 years [Lesotho, South Africa, Uganda]</td>
<td>3 (7.5%)</td>
</tr>
<tr>
<td>13 years [Malawi]</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td>14 years [Liberia]</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td>15 years [Ethiopia, Rwanda, Senegal]</td>
<td>3 (7.5%)</td>
</tr>
<tr>
<td>16 years [The Congo, Mozambique, Namibia, Swaziland, Zambia, Zimbabwe]</td>
<td>6 (15.0%)</td>
</tr>
<tr>
<td>18 years [Burkina Faso, Cameroon, The Central African Republic, Côte d’Ivoire, the Democratic Republic of the Congo, Djibouti, Ghana, Guinea, Niger, Nigeria, Seychelles, Sierra Leone, Sudan, United Republic of Tanzania]</td>
<td>14 (35.0%)</td>
</tr>
</tbody>
</table>
We also assessed national publications for ‘exceptions’ to providing HTC to adolescents, under the stated age of consent, without the requirement of parental consent. A total of 20 countries had exceptions in their national laws, policies, and/or guidance indicating ‘mature behaviour’, ‘symptomatic adolescents’, pregnant or married adolescents, young parents, at-risk adolescents, young heads of household, abandoned children, young commercial sex workers, street children, and emancipated minors. Of those countries, nine provided clauses for married girls to consent without parental consent, and ten gave health-care providers the right to decide whether the adolescent is mature enough to understand the HTC process and potential results and therefore is able to consent to HIV testing independently. Only three national policies discussed the right of young commercial sex workers to consent to HTC services without parental consent.

### Table 2: Exceptions for testing below legal age of consent to HTC in sub-Saharan Africa

<table>
<thead>
<tr>
<th>Exceptions for testing below stated legal age of consent (n=20 countries)</th>
<th>No. of countries</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Shows maturity and understanding of the process and potential results (health-care provider discretion)</strong></td>
<td>10</td>
</tr>
<tr>
<td>Cameroon (18 years)(^{51,52}), The Central African Republic (18 years)(^{53}), Nigeria (18 years)(^{54,55}), Côte d’Ivoire (18 years, but exception is limited to 15 years, 14 years and under can receive counselling only without parental consent)(^{56}), Djibouti (18 years, but exception is limited to 15 years, 14 years and under can receive counselling only without parental consent)(^{56}), Ghana (18 years, but exception is limited to 15 years, unless the adolescent is considered a ‘mature minor’)(^{56}), Swaziland (16 years)(^{56,57}), South Africa (12 years)(^{58,60}), Uganda (12 years)(^{61,62}), Madagascar (age of ‘minor’ not defined)(^{39})</td>
<td></td>
</tr>
<tr>
<td><strong>At risk of contracting HIV (e.g. sexually active)</strong></td>
<td>7</td>
</tr>
<tr>
<td>Sierra Leone (18 years)(^{63}), The United Republic of Tanzania (18 years)(^{64,67}), Zambia (16 years)(^{68}), Ethiopia (15 years)(^{69}), Liberia (14 years)(^{70}), Malawi (13 years)(^{71}), Kenya (no age limit)(^{29,33})</td>
<td></td>
</tr>
<tr>
<td><strong>Symptomatic</strong></td>
<td>3</td>
</tr>
<tr>
<td>Swaziland (16 years)(^{66,67}), Liberia (14 years)(^{39}), Kenya (no age limit)(^{29,33})</td>
<td></td>
</tr>
<tr>
<td><strong>Pregnant</strong></td>
<td>9</td>
</tr>
<tr>
<td>Sierra Leone (18 years)(^{63}), Zambia (16 years)(^{68}), Zimbabwe (16 years)(^{68}), Ethiopia (15 years)(^{69}), Liberia (14 years)(^{70}), Malawi (13 years)(^{71}), Lesotho (12 years)(^{29,33}), Botswana (no age limit)(^{29,33}), Kenya (no age limit)(^{29,33})</td>
<td></td>
</tr>
<tr>
<td><strong>Parent (adolescent is already a parent)</strong></td>
<td>6</td>
</tr>
<tr>
<td>Sierra Leone (18 years)(^{63}), The United Republic of Tanzania (18 years)(^{64,67}), Swaziland (16 years)(^{66,67}), Zambia (16 years)(^{68}), Zimbabwe (16 years)(^{68}), Kenya (no age limit)(^{29,33})</td>
<td></td>
</tr>
<tr>
<td><strong>Head of household</strong></td>
<td>4</td>
</tr>
<tr>
<td>Swaziland (16 years)(^{66,67}), Zambia (16 years)(^{48,69}), Ethiopia (15 years)(^{69}), Liberia (14 years)(^{70})</td>
<td></td>
</tr>
<tr>
<td><strong>Married</strong></td>
<td>9</td>
</tr>
<tr>
<td>Sierra Leone (18 years)(^{63}), The United Republic of Tanzania (18 years)(^{64,67}), Swaziland (16 years)(^{66,67}), Zambia (16 years)(^{68}), Zimbabwe (16 years)(^{68}), Ethiopia (15 years)(^{69}), Liberia (14 years)(^{70}), Malawi (13 years)(^{71}), Kenya (no age limit)(^{29,33})</td>
<td></td>
</tr>
<tr>
<td><strong>Commercial sex workers</strong></td>
<td>3</td>
</tr>
<tr>
<td>Zambia (16 years)(^{68}), Ethiopia (15 years)(^{69}), Liberia (14 years)(^{70})</td>
<td></td>
</tr>
<tr>
<td><strong>Street children</strong></td>
<td>2</td>
</tr>
<tr>
<td>Ethiopia (15 years)(^{69}), Liberia (14 years)(^{69})</td>
<td></td>
</tr>
<tr>
<td><strong>Emancipated minor</strong></td>
<td>1</td>
</tr>
<tr>
<td>Madagascar (age of ‘minor’ not defined)(^{39})</td>
<td></td>
</tr>
</tbody>
</table>

### Age of Consent to Sexual Activity Compared to Age of Consent to HTC

Where information was available, the comparison between the age of consent to HTC to the age of consent to sexual activity revealed some inconsistencies in national policies. In most countries, the age at which a person can give their own consent to an HIV test was the same as the age of consent to sexual activity. However, a total of 20 countries had exceptions in their national laws, policies, and/or guidance indicating ‘mature behaviour’, ‘symptomatic adolescents’, pregnant or married adolescents, young parents, at-risk adolescents, young heads of household, abandoned children, young commercial sex workers, street children, and emancipated minors. Of those countries, nine provided clauses for married girls to consent without parental consent, and ten gave health-care providers the right to decide whether the adolescent is mature enough to understand the HTC process and potential results and therefore is able to consent to HIV testing independently. Only three national policies discussed the right of young commercial sex workers to consent to HTC services without parental consent.
sexual activity or lower. However, in three countries—The Democratic Republic of the Congo, Guinea, and Seychelles—the age of consent to sex relations is lower than that for accessing HTC services.

Table 3: Age of consent to sexual activity versus age of consent to HTC

<table>
<thead>
<tr>
<th>Country</th>
<th>Age of consent to sexual activity</th>
<th>Age of consent to HTC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angola</td>
<td>16(^{16})</td>
<td>MND(^{17})</td>
</tr>
<tr>
<td>Benin</td>
<td>18(^{18})</td>
<td>MND(^{17})</td>
</tr>
<tr>
<td>Botswana</td>
<td>16(^{16})</td>
<td>NA-Maturity(^{5,30,31})</td>
</tr>
<tr>
<td>Burkina Faso</td>
<td>18(^{18})</td>
<td>18(^{18})</td>
</tr>
<tr>
<td>Burundi</td>
<td>18(^{18,19})</td>
<td>MND(^{17})</td>
</tr>
<tr>
<td>Cameroon</td>
<td>18(^{20})</td>
<td>marriage(^{18})</td>
</tr>
<tr>
<td>Cape Verde</td>
<td>Unknown</td>
<td>NA-Maturity, MND(^{17})</td>
</tr>
<tr>
<td>Central African Republic (the)</td>
<td>18(^{18})</td>
<td>18(^{18})</td>
</tr>
<tr>
<td>Chad</td>
<td>14(^{18})</td>
<td>NI</td>
</tr>
<tr>
<td>Comoros (the)</td>
<td>13(^{18,19})</td>
<td>NI</td>
</tr>
<tr>
<td>Congo (the)</td>
<td>18(^{20})</td>
<td>16(^{18})</td>
</tr>
<tr>
<td>Côte d’Ivoire</td>
<td>18(^{20,24,25})</td>
<td>18(^{15}) (if mature enough, then 15(^{25}))</td>
</tr>
<tr>
<td>Democratic Republic of the Congo (the)</td>
<td>14(F), 18(M)(^{26})</td>
<td>18(^{15})</td>
</tr>
<tr>
<td>Djibouti</td>
<td>18(^{27})</td>
<td>18(^{15}) (if mature enough, then 15(^{25}))</td>
</tr>
<tr>
<td>Equatorial Guinea</td>
<td>18(^{28})</td>
<td>NI</td>
</tr>
<tr>
<td>Eritrea</td>
<td>18(^{28})</td>
<td>NI</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>18(^{28})</td>
<td>15(^{18})</td>
</tr>
<tr>
<td>Gabon (the)</td>
<td>15(F), 18(M)(^{26})</td>
<td>NI</td>
</tr>
<tr>
<td>Ghana</td>
<td>16(^{29})</td>
<td>18(^{17}) (if mature enough, then 15(^{25}))</td>
</tr>
<tr>
<td>Guinea</td>
<td>15(^{29})</td>
<td>18(^{18})</td>
</tr>
<tr>
<td>Guinea-Bissau</td>
<td>16(^{30})</td>
<td>MND(^{17})</td>
</tr>
<tr>
<td>Kenya</td>
<td>18(^{31,32}) majority</td>
<td>NA-Risk(^{26,33})</td>
</tr>
<tr>
<td>Lesotho</td>
<td>18(^{34})</td>
<td>12(^{33})</td>
</tr>
<tr>
<td>Liberia</td>
<td>18(^{35})</td>
<td>14(^{36})</td>
</tr>
<tr>
<td>Madagascar</td>
<td>18(^{37})</td>
<td>marriage(^{36})</td>
</tr>
<tr>
<td>Malawi</td>
<td>16(^{38})</td>
<td>13(^{38})</td>
</tr>
<tr>
<td>Mali</td>
<td>18(^{39})</td>
<td>MND(^{37})</td>
</tr>
<tr>
<td>Mauritania</td>
<td>16(^{40})</td>
<td>18(^{18}) marriage(^{41})</td>
</tr>
<tr>
<td>Mauritania</td>
<td>16(^{40})</td>
<td>MND(^{37})</td>
</tr>
<tr>
<td>Mozambique</td>
<td>18(^{18})</td>
<td>16(^{18})</td>
</tr>
<tr>
<td>Namibia</td>
<td>16(^{42})</td>
<td>16(^{18})</td>
</tr>
<tr>
<td>Niger (the)</td>
<td>18(^{43})</td>
<td>18(^{18})</td>
</tr>
<tr>
<td>Nigeria</td>
<td>18(^{44})</td>
<td>18(^{18})</td>
</tr>
<tr>
<td>Rwanda</td>
<td>18(^{45,46})</td>
<td>15(^{51})</td>
</tr>
<tr>
<td>São Tomé and Príncipe</td>
<td>12(^{47})</td>
<td>NI</td>
</tr>
<tr>
<td>Senegal</td>
<td>16(^{48,49})</td>
<td>15(^{52,54})</td>
</tr>
<tr>
<td>Seychelles</td>
<td>15(^{50})</td>
<td>18(^{31})</td>
</tr>
<tr>
<td>Sierra Leone</td>
<td>18(^{51})</td>
<td>18(^{44})</td>
</tr>
<tr>
<td>Somalia</td>
<td>NL(^{52})</td>
<td>NA-Reproductive age(^{53})</td>
</tr>
<tr>
<td>South Africa</td>
<td>16(^{46}) (with another minor)</td>
<td>12(^{47,48,49,50})</td>
</tr>
<tr>
<td>South Sudan</td>
<td>NL(^{53})</td>
<td>NI</td>
</tr>
<tr>
<td>Sudan</td>
<td>18(^{54})</td>
<td>accountability(^{46,55})</td>
</tr>
<tr>
<td>Swaziland</td>
<td>16(^{56})</td>
<td>16(^{56})</td>
</tr>
<tr>
<td>Togo</td>
<td>16(^{57})</td>
<td>MND(^{17})</td>
</tr>
<tr>
<td>Uganda</td>
<td>18(^{58,59,60})</td>
<td>12(^{47})</td>
</tr>
<tr>
<td>United Republic of Tanzania (the)</td>
<td>18(^{61,62})</td>
<td>18(^{63,64})</td>
</tr>
<tr>
<td>Zambia</td>
<td>16(^{65})</td>
<td>16(^{66})</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>16(^{57,65})</td>
<td>16(^{57})</td>
</tr>
</tbody>
</table>

MND Minor not defined
NA No age set in law
NI No information
NL No age of consent law
NM No mention of minors
DISCUSSION

Of the 41 national policies assessed, our review found 33 national policies with age-based or other specific criteria for consenting to HTC. The remaining national policies did not clearly stipulate or define an age of consent to HTC. Ideally, the purpose of these policies is to guide decision making for adolescents, their parents or guardians, and health providers. However, when national HTC consent policies are non-existent, ambiguous, or restrictive in nature, barriers are created for both adolescents seeking services and health providers delivering services. As a result, adolescents are constrained by either parental consent requirements defined by national policies or the reliance on health providers to assess their ‘capacity or eligibility to consent’ or make medical decisions for them. These same policies, or lack thereof, have the potential to restrict the capacity of the health providers to make critical medical decisions because they fear a negative response or even legal action from parents or guardians. The resulting effect is that at-risk adolescents voluntarily presenting for HTC without parental consent are likely to be turned away by health providers. This review also reveals inconsistencies in some national policies which could result in at-risk adolescents being overlooked. For example, in Seychelles and Guinea the legal age of consent for sexual activity is 15 years and yet the legal age of consent for HTC is 18 years – this means that adolescents gain the legal right to consent to an HIV test three years after they are legally allowed to become sexually active (58,63,68,69). Scaling up HTC services for adolescents requires an understanding of the laws and policies that govern issues of consent, confidentiality, and competence (the mental and emotional capacity to understand the HIV testing process and the potential implications of the results); however, this can only be achieved by having clear, realistic, and explicit laws and policies in place.

Although the ages of consent to HTC vary widely across the 33 national policies reported, 14 (42.4%) set the age of consent at 18 years. For many years, the political and legal argument for maintaining the age of 18 years for consenting to HTC has been centred on the notion that adolescents are vulnerable, immature, and incapable of making critical decisions about their own health. More recently, the aim of national legislation, using 18 years as the age of consent, has been to align with the Convention on the Rights of the Child and be a protective measure for adolescents. And yet, especially with regard to sexual health matters, this notion seems to be steadily overshadowed by the apparent and growing consensus that adolescents are physiologically maturing at a much faster rate than they did a century ago (3). In the last century, Europe has witnessed a steady decline in the age of menarche, one of the key indicators of sexual maturity, from 17 to 13 years (74). Similar findings have been reported among girls in South Africa, where the age of menarche decreased from 14.9 to 13.1 years between 1956 and 2004 (75). At present, there is no international consensus on the age of consent to HIV testing, and very limited data to support consent to testing at a particular age. Even though countries like Lesotho, South Africa, and Uganda have lowered their age of consent to HTC, and countries like Botswana, Cape Verde, Kenya, Mauritius, and Somalia (Somaliland) have eliminated an age limit, asking instead for other specific criteria, to date none of these countries have formally documented the impact of these policies on service uptake or analysed beneficial or adverse consequences following this lowering of age for self-consent to HIV testing. Further research on the impact of these policy changes would be useful to help inform decision making on issues related to HTC and adolescents.

HIV prevention strategies must target people at a much younger age for many reasons, including the ever-growing burden of HIV among adolescents and the HIV risk-taking behaviour prevalent within this sub-population—especially among vulnerable adolescents and adolescents from key populations. Scaling up access to HTC services requires that we first expand the decision-making rights of the adolescent by increasing the legal autonomy they have to consent to HTC services. Policies are needed to support adolescents’ right to informed consent to HTC and treatment without the requirement of a parent or guardian’s consent, particularly where the need to obtain parental consent is a barrier to
access to and uptake of these services. Some adolescents have unsupportive or abusive parents or guardians, and have legitimate concerns about not discussing HIV testing with them. Studies have shown that the potential for a negative reaction from a parent or guardian is an important reason why adolescents avoid HIV testing even when they feel they have been at risk of infection, and why requiring parental consent can be a barrier to adolescents initially seek HIV testing (19, 76, 77, 78). Negative parental reactions could stem from any number of issues including: the fear that testing the adolescent could inadvertently disclose the parent’s own HIV status, the guilt or embarrassment that their child was infected through vertical transmission, or a concern that testing their adolescent might lead others to assume the parent has HIV. However, most parents are caring, supportive, and wish to act in the best interests of their child, and as such, HTC counsellors and providers should encourage adolescents to involve their parent or guardian before or during the HIV testing process, especially if the adolescent tests positive and needs helps to access and manage initial treatment and ongoing care.

While parental involvement has its clear benefits and place in HTC, adolescents should also have the option to provide their own consent to take an HIV test, with the caveat that, when possible, the counsellor should encourage and support adolescents to disclose to someone close and supportive like a parent or family member. According to a two-staged study conducted in Zambia among adolescents between the ages of 16 and 19 years who attended HTC, and subsequently tested, qualitative in-depth interviews of 40 adolescents revealed that they were 6 times more likely to plan to get tested if they discussed this decision with a family member. Of the 550 respondents later surveyed, those who did not believe their family members would be upset if they got tested were 5.5 times more likely to present for an HIV test than adolescents who believed their families would be upset (16). For those adolescents without supportive immediate family members, referrals to peer support groups could be a helpful alternative. It makes sense, then, to make sure messages on supporting youth to access HIV counselling, testing, and care should be directed to adolescents, their parents or guardians, and the communities in which they live.

Article 5 of the Convention on the Rights of the Child acknowledges that even before the age of 18, adolescents develop ‘evolving capacities’ which put them in a position to exercise their own rights (12, 13). Some countries have incorporated this concept into their HTC consent laws and/or policies by giving special permission to certain types of adolescents to request an HIV test without parental consent. Our review revealed that 20 countries in sub-Saharan Africa had exceptions in their consent laws for people below their nationally specified age of consent. Of those countries, ten required health-care providers to determine whether the adolescent was mature enough to understand the HTC process and the potential implications of the results, and nine made exceptions for pregnant and/or married adolescents. Only seven made exceptions for sexually active adolescents, three countries provided exceptions for adolescents who were either symptomatic or young sex workers, and only two provided exceptions for street children. These findings raise a seldom asked, but potentially transformational question at the national policy level: What happens to adolescents younger than the nationally specified age of consent (over half of which are defined as 16 or 18 years of age) who are not eligible for HTC because exceptions are not provided in the national policy, and do not want their parents or guardians to know that they are sexually active? The harsh reality is that this group of people will very likely not get tested, thus raising concerns about universal coverage targets. It is critical that the gaps must be addressed in order for those targets to be met.

To this end, national authorities should consider facilitating HTC access to adolescents. In settings that do not have explicit laws or policies that govern age eligibility criteria for HCT, and in settings that have set 16 or 18 years of age as the minimum age of autonomous consent for HTC access, authorities should consider setting the minimum age of consent for HTC to 12 or 14 years of age.
Authorities should also consider HTC holistically. In some settings, existing laws and policies on a range of issues related to HTC may require amendment and harmonisation to facilitate adolescent linkage to care. This includes laws and policies on access to condoms, treatment autonomy, pharmaceutical supply of ARVs, HIV prevention interventions such as pre-exposure prophylaxis (PrEP), and medical male circumcision.

It is worth considering some of the inherent limitations of this review. First, the review was limited to 41, rather than 49 sub-Saharan African countries due to the inaccessibility of national documents. Second, we could only review documents available electronically, and therefore may have missed key documents only available in hard copy. Last, it is possible that some countries mentioned in this review as not having an age of consent to HTC might actually have one, but that policy is addressed in other national documents.

CONCLUSION

Despite the limitations of our research, it is clear that in the interest of public health, and as a matter of urgency, national health authorities should improve access to HIV testing and counselling for adolescents by removing legal barriers. In so doing, more adolescents will be able to gain knowledge of their status, access care and prevention, and, hopefully, reduce the risk of acquisition or onward risk of transmission. Policies on age of consent to HTC should be reviewed and harmonized to allow greater access to adolescents without the restriction or requirement of gaining a parent or guardian’s consent. It is important to learn from the experiences of countries that have lowered the age of consent to seek HTC to 12 years, or allow HTC at any age; and if outcomes are beneficial in supporting greater access to HTC for adolescents without precipitating negative consequences, as anecdotal evidence suggests, countries should consider reviewing their consent policies accordingly. In countries where policies are ambiguous or non-existent, age of consent to HTC policies must be clarified or created in order to give adolescents clear access to HTC, care, and treatment, and minimise confusion for health providers that, more often than not, results in decisions to take no action. National recommendations must be clear, simple, and widely disseminated. This will ensure that more opportunities are taken to engage adolescents in protecting themselves and prevent further transmission of HIV.

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

ANNEX 16: Implementation plan

Operational plan to disseminate, support and monitor implementation of Guidelines for HIV Testing and Counselling for Adolescents and Treatment and Care for Adolescents Living with HIV

1. Objectives
To integrate activities based on Guidelines for HTC for Adolescents and Treatment and Care for ALHIV recommendations in national HIV/AIDS plans and in proposals to the GFATM (e.g. National Strategy Application (NSA) and other donor agencies, and to promote implementation through work with other international and UN agencies offering technical assistance to countries for adaption, implementation, monitoring and evaluation of their HIV/AIDS activities.

2. Strategic components
Through work with WHO regional and country offices, Ministries of Health, UNAIDS, UNESCO, UNFPA, UNICEF, PEPFAR and others for:
1. Advocacy
2. Regional and country promotion
3. Support to partner agencies and organizations in developing country adaptations, and for planning and implementation including development of training tools
4. Monitoring and evaluation

3. Activities

3.1 Advocacy

○ Objective:
  ▪ To raise awareness within WHO at all levels and in all regions through key international, regional and national partners (e.g. civil society, foundations, donors), governments and national programmes about the new Guidelines for HTC for Adolescents and Treatment and Care for ALHIV.

○ Content of advocacy:
  ▪ Process: evidence-based and conducted with partners
  ▪ Overview of adolescents and HIV guidelines objectives and content
  ▪ Emphasis in Good Practice Recommendations; 1) Human Rights and inclusive environments 2) Non-discrimination in health care settings and medical ethics
  ▪ Reference/linking to previous regional work
  ▪ Brief description of implementation

○ Activities and products:
  ▪ Launching event (to be coordinated with key events at which Ministries of Health are likely to be present and with UN and other partners)
Guidelines and executive summary launched on WHO website with links to other UN websites, and CDC and USAID websites, etc.
Briefing to RO, UNAIDS and cosponsors (teleconference)
Press release
Policy brief summarizing the guidelines for NGOs and community organizations
PowerPoint slide set

3.2 Regional and country promotion and planning
In conjunction with UNESCO, UNFPA and UNICEF

- **Objectives:**
  - To brief countries about the Guidelines for HTC for Adolescents and Treatment and Care for ALHIV
  - To establish country-specific targets for HTC and treatment and care services for adolescents (e.g. as part of PMTC programmes and linked to SRH and TB/HIV activities)
  - To draft priority key activities to be included in national plans and proposals to GFATM

- **Activities and products:**
  - Mailing list as per guidelines dissemination
  - Regional workshops (coordinated by UNESCO, UNFPA, UNICEF and others with support from WHO)
  - Support drafting of proposals, including M&E, covering activities related to HTC and treatment and care for adolescents, to be included in national plans and GFATM proposals
  - National targets

3.3 Support to partner agencies and organizations in developing country adaptations, and for planning and implementation including development of training tools

- **Objectives:**
  - To brief WHO staff in regions and countries
  - To work with UN partner organizations and other agencies on regional adaption, implementation and development of training tools

- **Activities and products:**
  - Briefing of regional and country WHO staff
  - Support for country adaption (lead by UNESCO, UNICEF, UNFPA and others)
  - Support for country implementation (lead by UNESCO, UNICEF, UNFPA and others)
  - Support for training material development (lead by UNESCO, UNICEF, UNFPA)
  - Incorporation of adolescent issues in health workforce training materials and counselling materials, adolescent health and sexual and reproductive health guidelines

3.4 Monitoring, Evaluation and Research

- **Objectives**
  - Include adolescent issues in WHO implementation science agenda. Present at and include in discussions of adolescent HTC and treatment programme issues at the WHO implementation science summit in November 2013.
Activities and products:
- Adolescent HIV implementation science agenda developed and shared with a wide range of partners

3.5 Time frame

Advocacy: August – December 2013
Regional promotion and planning: July 2013-March 2014
Support for technical assistance: January 2014-December 2015
Monitoring and evaluation: July 2016-December 2016
HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV

ANNEX 17: Expert meeting – participant list

Expert meeting for the development of guidelines on adolescents and HIV
29 – 31 October 2012
Harare, Zimbabwe

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