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

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.