

# ACCELERATING PROGRESS ON HIV TESTING AND TREATMENT FOR CHILDREN AND ADOLESCENTS THROUGH IMPROVED STRATEGIC INFORMATION

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**This policy brief highlights key elements of the 2020 WHO consolidated HIV strategic information guidelines (1) pertinent to HIV testing and treatment for children. It is designed to support country strategic information teams to choose, collect and systematically analyse the strategic information needed to strengthen programme management and monitoring of testing and treatment for children and adolescents.**

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HIV among children and adolescents presents unique features that affect how diagnosis, treatment and care is provided across the age continuum of 0–19 years. Identifying and testing infants for HIV requires different interventions than for school-aged children or adolescents. Optimal antiretroviral drug regimens may require changes as children age and grow. Models of care to retain children in treatment and ensure that they have suppressed viral loads must leverage different opportunities and address various challenges over the life-course.

Nevertheless, the capacity of country programmes to identify gaps, tailor their services to children of different age groups and monitor how well they are meeting the needs of these children has been hampered by a lack of age-disaggregated data about HIV testing, treatment and health outcomes of children and adolescents.

For example, in 2020, only 71 countries (of 120 reporting) provided numbers of children and adolescents receiving treatment disaggregated by five-year age groups, and only 29 countries (of 70 countries with publishable data) provided age-disaggregated data on viral load suppression for children and adolescents.<sup>1</sup>

The lack of pertinent data to support better programming has contributed to consistently poorer progress on testing, treatment and health outcomes among children and adolescents than among adults. Globally, a lower percentage of children living with HIV are diagnosed and initiate treatment than adults, and viral suppression is also lower (2). Adolescents also have lower reported treatment coverage, adherence to treatment and viral suppression rates than older age groups, although country reporting of adolescent-disaggregated data continues to be suboptimal (3,4). Overall, these factors contribute to the fact that children and adolescents younger than 15 years comprise about 5% of the people living with HIV globally but accounted for 14% of the people dying from AIDS-related causes in 2019.

The 2020 strategic information guidelines promote programme optimization for these especially vulnerable populations by laying out both:

- population-specific indicators (see Annex 1) reflecting services specific to the needs of children and adolescents; and
- priority population disaggregates (primarily based on age; see Annex 2) for several general population indicators.

Using these guidelines, especially the age disaggregation recommendations, and implementing routine cascade data review activities will help programme managers to identify bottlenecks in service availability, quality and uptake that affect children and adolescents differently from adults as well as barriers that



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<sup>1</sup> UNAIDS epidemiological estimates and Global AIDS Monitoring 2020

vary by age subgroups. Such information can guide their actions to implement improvements that are critically needed to reduce HIV morbidity and mortality among children and adolescents. Use of this policy brief will also strengthen countries' ability to monitor progress toward national and global targets as they pertain to children and adolescents, such as the 95–95–95 HIV Fast-Track goals and the Start Free, Stay Free, AIDS Free framework (5). The indicators highlighted are well aligned with other major global monitoring and evaluation frameworks, including UNAIDS Global AIDS Monitoring 2020, the Global Fund modular framework and PEPFAR Monitoring, Evaluation and Reporting. The specific progress of children and adolescents needs to be monitored so that data relative to this small subpopulation are not masked within the composite country picture.

### Strategic information in cascade services for children and adolescents

The cascade of care for children and adolescents living with HIV is similar to that for adults – diagnosis, linkage, enrolment, treatment and viral suppression. Thus, most of the indicators for children, adolescents and adults living with HIV are identical to those for adults except for a few population-specific indicators on vertical transmission and adolescent girls and young women (see Annex 1). Nevertheless, as a child living with HIV grows from birth to childhood to younger adolescence to older adolescence and adulthood, care and treatment needs and responses change. Age disaggregation therefore clearly needs to be strengthened and disaggregated data effectively used to improve service delivery to these groups along the care and treatment cascade (see Annex 2).

In previous guidance, indicators for the general population primarily used the <15 and 15+ years categories to distinguish between children and adults. However, disaggregation into finer age bands is now both more feasible and more

### Key steps to strengthening the use of strategic information to improve services for children and adolescents living with HIV

- When reviewing national HIV indicators for inclusion in aggregate reporting tools and health information systems:
  - › Include all relevant population-specific indicators (see Annex 1)
  - › Include all age disaggregation levels suggested in the strategic information guidelines (see Annex 2)
  - › Consider the data alignment requirements with individual-level tools and data systems, such as electronic medical records
- Reinforce the capacity of service delivery sites to accurately collect, validate and report on all indicators and age disaggregation levels
- Optimize the use of individual-level data in generating key programme indicators, such as the number of people living with HIV receiving antiretroviral therapy and total attrition from antiretroviral therapy
- Encourage health ministry–convened routine data review activities with strong components on child and adolescent cascades for use in real-time programme improvement and include disaggregated data when reporting to regional and global platforms such as the UNAIDS Global AIDS Monitoring and other partner reporting systems.

necessary, enabling better appreciation of children and adolescents as distinct populations. Throughout childhood and adolescence, finer age disaggregation can reveal gaps in HIV testing, antiretroviral therapy and viral load coverage of specific age groups and provide essential information for planning age-appropriate approaches to service delivery. In addition, finer age disaggregation enables more accurate forecasting of commodity needs and programme planning tailored to the characteristics of the people living with HIV.

Monitoring the adolescent HIV epidemic in particular can be improved if HIV data are adequately disaggregated by age and sex (6). Better reporting of five-year age-disaggregated data for adolescents will enable programme managers to adapt service delivery to

the significant differences in health-seeking behaviour, number acquiring HIV infection and health outcomes between younger adolescents (10–14 years old) and older adolescents (15–19 years old). In addition, having access to these five-year data sets is the only way to enable countries to monitor progress among all adolescents (10–19 years old).

Finer age disaggregation is now more viable in many settings because of the expansion of digital platforms for individual-level data, such as electronic medical records. Defining unique identification standards and consistent data standards between individual-level and aggregate data systems is important. Further, the reduction in the number of recommended priority indicators enables greater focus on age differences. The strong WHO recommendation to disaggregate and analyse the priority indicators by age groups among children and adolescents is consistent with guidance from UNAIDS Global AIDS Monitoring and development partners such as the Global Fund to Fight AIDS, Tuberculosis and Malaria and PEPFAR.

The proposed age categories for disaggregating HIV-related data from birth through adolescence generally fall into three levels.



Photo: WHO /Anna Kari.

- Level 1 comprises 11 age categories: 0–4<sup>2</sup>, 5–9, 10–14, 15–19, 20–24, 25–29, 30–34, 35–39, 40–44, 45–49 and 50+ years.
- Level 2 comprises seven age categories: 0–4, 5–9, 10–14, 15–19, 20–24, 25–49 and 50+ years.
- Level 3 comprises two categories: <15 and 15+ years.

The level of age disaggregation recommended for each indicator depends on both the source of the data and the expected utility of greater disaggregation in identifying patient groups that require more attention. For most indicators collected through routine facility data, the recommended age disaggregation is level 2. For select testing and linkage, antiretroviral therapy and viral load indicators, the recommended age disaggregation is level 1. Finally, several indicators of vertical transmission use more specific age bands in their definitions; for example, early infant diagnosis examines infants 0–2 months and 2–12 months old. For survey-based indicators, sample size constraints, especially for younger age groups, may limit the feasibility of more than level 3 age disaggregation. Maintaining consistency of disaggregation categories across indicators – for example, testing, linkage of new diagnoses to antiretroviral therapy, antiretroviral therapy retention and viral load suppression – is critical for effective cascade analysis.

### *Determining the numbers of children exposed to and living with HIV<sup>3</sup>*

Indicators such as early infant diagnosis (VT.2) and antiretroviral therapy coverage (AV.1) require estimates of the number of children exposed to or living with HIV in the denominator. Spectrum AIM software, which country-based teams use to generate

<sup>2</sup> Although the first category, encompassing 0–4 years of age, is used for general cascade indicators, there are specific vertical transmission indicators that use narrower age bands in their definitions to capture service delivery coverage during critical windows of care for exposed and newly diagnosed infants.

<sup>3</sup> See subsection 2.3.1 of the HIV strategic information guidelines (1) for more detail.



Photo: WHO / SEARO / Gary Hampton

estimates, incorporates data on HIV prevalence, fertility, treatment regimens provided to pregnant women, duration of breastfeeding and other country-specific data to estimate the number of children newly infected with HIV and the timing of these infections. The numbers of children living with HIV are then estimated based on the number of children receiving antiretroviral therapy and co-trimoxazole and considering competing causes of mortality. The relatively sparse directly observed data for children used in the models result in uncertainty around these estimates. Since such models as Spectrum AIM are regularly updated and refined, the specific impact of such changes, including on the estimated numbers of exposed children and children living with HIV, are documented in the methods section of UNAIDS' global AIDS report, which is published every year in July.

### *Monitoring children and adolescents across multiple sources of care*

The collection, organization, reporting and interpretation of strategic information for children and adolescents present specific challenges. For example, HIV-exposed infants and young children and adolescents may be lost to follow-up before their HIV status is determined, creating difficulty in accurately counting the number of children and adolescents living with HIV. There are also many service provision points at which children living with HIV are identified and enrolled in care – for

example, referral hospitals, antenatal care clinics, antiretroviral therapy sites, maternal and child health settings, immunization clinics and well-child clinics. Children and adolescents are often diagnosed in one facility and then referred to another facility to start care. They may be subsequently transferred to yet another site to continue treatment and other support services. Children and younger adolescents also depend on caregivers for access to health-care services, further complicating efforts to collect consistent data over time. Unique identifier codes for users, tracking mother–infant pairs and digital information systems can strengthen programmes' ability to accurately document these clients as they move within the system.

### **Selection and use of indicators**

WHO encourages national programmes and stakeholders involved in children and HIV to be forward-thinking and ambitious both in selecting indicators and in investing in their health information systems and data use. As countries with significant numbers of children living with HIV decide on their optimal list of indicators, WHO strongly recommends using the indicators in Annex 1 and the recommended age disaggregation levels set out in Annex 2 to optimally analyse and improve services. For example, trends in the volume and positivity of tests among children (TL.2) help to gauge whether children living with HIV



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have access to testing and are being diagnosed. The linkage to antiretroviral therapy and the number of people living with HIV receiving antiretroviral therapy (antiretroviral therapy coverage) indicators (TL.3 and AV.1) provide key measures of programme effectiveness in identifying, tracking and retaining children and adolescents living with HIV in care services as they progress from infancy through childhood and adolescence. If treatment and care coverage rates are low, programmes should assess HIV diagnosis strategies as well as uptake and retention in care. The trend in the percentage of eligible children newly initiating antiretroviral therapy (AV.4) can be monitored to assess progress in improving uptake and increasing the scale of treatment services.

Just as critical is establishing routine cascade data review processes (see Fig. 1.7 on key components in establishment of routine data reviews in the HIV strategic information guidelines (1)). Health ministry staff leading child and adolescent HIV programme services

should be encouraged to convene all relevant stakeholders for this purpose, such as communities and civil society, academic, implementing and donor partners etc. These representative technical groups should define the indicators and disaggregation standards as well as the analytic visualization, interpretation and operational procedures necessary to making these data reviews effective.

Reviewing vertical transmission (VT) indicators, such as early infant diagnosis coverage (VT.2) and final outcome of preventing the mother-to-child transmission of HIV, including pregnant adolescents (VT.6), is critical to monitor progress in the path to elimination and may help to identify gaps in identifying children and adolescents living with HIV and strategies for improving the early diagnosis of children at risk. Although all infants identified and confirmed HIV-positive are eligible to start antiretroviral therapy immediately, HIV-exposed (but not confirmed HIV-positive) infants need to be followed

over time until their final HIV status is determined.

Several quality-of-care indicators monitor the effectiveness of programmes addressing children and adolescents at different ages. For total attrition from antiretroviral therapy (AV.2), programmes should track children and adolescents living with HIV who were lost to follow-up and investigate why they stopped treatment. Infants, children and adolescents living with HIV may drop out of the cascade at various stages and, once lost to follow-up, experience higher mortality rates. Low rates of viral load suppression (AV.3) may indicate low levels of adherence that may be related to the person's age and require age-appropriate interventions.

### *Strategic information and quality improvement*

As described in subsection 1.3.3 of the HIV strategic information guidelines (1), quality improvement is a specific method designed to continually improve programme performance as part of a routine process. Generally, health facility teams apply it within a national quality improvement programme. It is designed to test changes in programme services, continually measure the effects of these changes and use data to address gaps and thus improve clinical performance and health outcomes over time.

Quality improvement involves measuring performance using standardized indicators, selecting quality challenges (including access and coverage), exploring their root causes, designing and implementing contextually appropriate solutions and assessing their impact using rapid, iterative tests of change. Like the general routine cascade data review activities described above, quality improvement requires

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high-quality data collection, reporting and use of indicators, typically a selected subset of the highest priority service indicators and disaggregated cascade analysis.

## Conclusion

Infants, children and adolescents may experience unique barriers to HIV testing, care services and antiretroviral therapy retention and adherence based on their age and developmental

stage. Collecting, reporting and using data with set priorities will equip programmes and stakeholders with the essential tools required to ensure the quality of, and equal access to, services throughout the care and treatment cascade and across all age groups.

## Annex 1: Population-specific indicators

Ref. no.	Short name	Short description	Age Disaggregation
Vertical transmission			
VT.1 (new)	Viral suppression at labour and delivery	% of HIV-positive pregnant women who are virally suppressed at labour and delivery	Age (<15, 15–19, 20–24, 25+)
VT.2	EID coverage	% of HIV-exposed infants who receive a virological test for HIV within 2 months (and 12 months) of birth	Age of infant (<2 months, 2–12 months)
VT.3	Infant ARV prophylaxis coverage	% of HIV-exposed infants who initiated ARV prophylaxis	NA
VT.4	ART coverage in pregnant women	% of HIV-positive pregnant women who received ART during pregnancy and/or at labour and delivery	Age (<15, 15–19, 20–24, 25+)
VT.5	ART coverage in breastfeeding mothers	% of HIV-exposed breastfeeding infants whose mothers are receiving ART at 12 (and 24) months postpartum	Age (<15, 15–19, 20–24, 25+)
VT.6	Final outcome of PMTCT	% of HIV-exposed infants whose final outcome status is known	Outcome status (HIV-positive, HIV-negative and no longer breastfeeding).
AGYW-Specific			
GW.1 (new)	AGYW HIV/SRH integration	% of AGYW seeking contraception/family planning who received an HIV test	Age (10–14, 15–19, 20–24, 25–49, 50+)
Burden/impact			
BI.4	Final MTCT rate	Estimated % of children newly infected with HIV from mother-to-child transmission among women living with HIV delivering in the past 12 months	

## Annex 2: General population indicators with recommended age disaggregation

Level 1 age disaggregation: 0–4, 5–9, 10–14, 15–19, 20–24, 25–29, 30–34, 35–39, 40–44, 45–49, 50+)

Ref. no.	Short name	Short description
TL.2 (new)	HTS testing volume and positivity	Number of HIV tests conducted (testing volume) and the % of HIV-positive results returned to people (positivity)
TL.3	Linkage to ART	% of people newly diagnosed with HIV initiated on ART
AV.1	PLHIV on ART	Number and % of people on ART among all people living with HIV at the end of the reporting period
AV.2 (new)	Total attrition from ART	Number and % of people living with HIV reported on ART at the end of the last reporting period and/or newly initiating ART during the current reporting period who were not on ART at the end of the reporting period
AV.3	PLHIV who have suppressed VL	% of PLHIV on ART (for at least 6 months) who have virological suppression
AV.4	New ART patients	Number of PLHIV who initiated ART

## Indicators with level 2 age disaggregation: 0–4, 5–9, 10–14, 15–19, 20–24, 25–49, 50+

Ref. no.	Short name	Short description
TL.1	PLHIV who know their HIV status (first 95)	Number and % of people living with HIV who know their status
TL.4	HTS index testing and partner notification	Number of people who were identified and tested using index testing services and received their results
AV.5	Late ART initiation	% of PLHIV who initiate ART with a CD4 count of <200 cells/mm <sup>3</sup>
AV.6	VL testing coverage	% of people on ART (for at least 6 months) with VL test results
AV.7 (new)	Early VL testing (at 6 months)	Number and % of PLHIV on ART who had VL monitoring at 6 months after initiation of ART
AV.8	Appropriate second VL test	% of people receiving ART with VL ≥1000 copies/mL who received a follow-up VL test within 6 months
BI.1	People living with HIV	Estimated number of people living with HIV
BI.3	New HIV infections (per 1000 population)	Estimated number of people newly infected with HIV per 1000 uninfected population
BI.5	AIDS mortality	Total number of people who have died from AIDS-related causes per 100 000 population

## Indicators with level 3 age disaggregation (or other age groups):

Ref. no.	Short name	Short description	Age Disaggregation
Testing & linkage			
AV.9	ARV toxicity Prevalence	% of ART patients with treatment-limiting toxicity	Age (<15, 15+)
TB/HIV			
TB.1	TPT initiation	Number and % of eligible PLHIV on ART who initiated TB preventive treatment	Age (<5; 5–15; 15+)
TB.2	TPT completion	% of PLHIV on ART who completed a course of TB preventive treatment among those who initiated TPT	Age (<15, 15+)
TB.3	TB diagnostic testing type	% of PLHIV with TB symptoms who receive a rapid molecular test as a first test for diagnosis of TB	Age (<15, 15+) Additional recommendation for settings with robust electronic HIS, for example, EMRs: <ul style="list-style-type: none"> <li>Disaggregation by detailed age &lt;18 month–4 years, 5–14, 15–19, 20–24, 25–49, 50+).</li> </ul>
TB.4	PLHIV with active TB disease	% of PLHIV newly initiated on ART who have active TB disease	Age (<15, 15+) Additional recommendation for settings with robust electronic HIS, for example, EMRs: <ul style="list-style-type: none"> <li>Disaggregation by detailed age (&lt;18 month–4 years, 5–14, 15–19, 20–24, 25–49, 50+).</li> </ul>
Dft.1	TB screening coverage among new ART patients	% of PLHIV newly initiated on ART who were screened for TB	Age (<15, 15+)
Dft.2	TB symptom-screened positive among new ART patients	% of PLHIV newly initiated on ART who were screened for TB symptoms and who screened positive	Age (<15, 15+)
Dft.3	TB testing among those symptom-screened positive	% of people living with HIV newly initiated on ART and screened positive for TB symptoms who then are tested for TB	Age (<15, 15+)
Dft.4	TB diagnosis among those tested for TB	% of PLHIV newly initiated on ART and tested for TB who are diagnosed with active TB disease	Age (<15, 15+)

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POLICY BRIEF

HIV STRATEGIC  
INFORMATION

