# Improving
# UNAIDS' paediatric and
# adolescent estimates

## BACKGROUND

This document provides paediatric HIV programme managers with an overview of how paediatric and adolescent HIV estimates are produced, what the technical challenges and gaps in the data are, how those challenges are being addressed and what paediatric HIV programme managers and monitoring officers can do to improve their national estimates of the number of children and adolescents living with HIV.

Robust estimates of the number of children and adolescents living with HIV are critical to determining HIV treatment needs and gaps among children. Estimates of the number of new child HIV infections provide evidence of the impact of prevention of mother-to-child transmission of HIV services. Those data help to plan, advocate, monitor, evaluate, strategize and allocate resources appropriately *(1)*. However, producing strategic information about the HIV epidemic among children can be challenging.

## HIV DATA SOURCES AMONG CHILDREN

In most low-resource settings, health records of diseases, including HIV, are the primary source of data, but are often incomplete. Children are either not tested for HIV or, in the event they are, the result goes unrecorded in the clinic, district or national registers. In an attempt to increase reporting, the World Health Organization (WHO) and the United States President's Emergency Plan for AIDS Relief have been promoting efforts to test children at risk during immunization visits. While this approach improves testing rates for children for as long as they are returning to clinics for immunization, it only covers the first year *(2)*. However, breastfeeding, and thus exposure to HIV, often lasts longer than one year. In addition to the women who know their HIV-positive status before their baby is born, more women will become infected with HIV during the breastfeeding period. A woman who is breastfeeding when she seroconverts has a 26% chance of transmitting the infection to her child *(3, 4)*. A child who is infected with HIV during breastfeeding is likely to remain unsymptomatic for a number of years *(5)* and thus is unlikely to be tested for HIV, reducing the chance of diagnosis and hence inclusion in the health information system.

Population-based household surveys that include HIV testing are a second potential source of data on HIV among children. However, most household surveys do not have sample sizes large enough to provide a robust measure of HIV prevalence among children. In some countries with high rates of mother-to-child transmission of HIV—either currently or in the past 15 years—it is possible to measure national-level HIV prevalence. However, the prevalence data will not be robust enough to provide a measure of HIV incidence or prevalence at the subnational level or other forms of disaggregation *(2)*. Even well-resourced, large sample size surveys, such as the Population-Based HIV Impact Assessment (PHIA) surveys conducted in high-prevalence countries, have confidence intervals that are sometimes wider than the prevalence level *(6, 7)*. Measures of HIV prevalence among children become very imprecise in countries where HIV prevalence among women is less than 5% *(2, 8)*. In addition, household surveys are not able to measure a mother-to-child transmission of HIV rate, as these surveys miss any children that will have died between birth and the survey.

The challenges that make it difficult to identify children living with HIV in health systems are the same challenges that prevent children and their parents from knowing their status and accessing life-saving antiretroviral therapy. In 2018, an estimated 54% [42–70%] of children living with HIV were on antiretroviral therapy. However, 81% [61– >95%] of pregnant women living with HIV accessed antiretroviral therapy to prevent mother-to-child transmission of HIV, indicating the considerable challenges in identifying children living with HIV.

In the absence of reliable data, programme managers and planners rely on models to estimate new HIV infections, the mother-to-child transmission of HIV rate, HIV prevalence and AIDS-related deaths among children. Models to estimate HIV incidence and prevalence among children rely on available country-specific data and make assumptions based on fertility patterns among women, HIV prevalence among pregnant women, adult survival and studies of mother-to-child transmission of HIV rates associated with different antiretroviral therapy regimens.

## PROCESS OF DEVELOPING ESTIMATES

UNAIDS and partners support countries to annually update models used to estimate the impact of HIV on their populations *(9)*. Using the updated models, country HIV estimate teams add their most recent programme and surveillance data to the models to produce annual HIV estimates. Every year the new set of estimates include revised historical estimates and estimates for the most recently completed year. The 2019 estimates cover the years 1970 to 2018. In countries where data are available, the estimates are also available by province. The models produce estimates of the number of people living with HIV, new HIV infections, births to women living with HIV and AIDS-related deaths. All of these indicators are available by five-year age group and sex.

The resulting estimates are sent to UNAIDS for review and outputs are compiled and released on UNAIDS' publicly available website (aidsinfo.unaids.org). Data published on the AIDSinfo website include indicators for children 0–14 years, adolescents 10–19 years and young people 15–24 years by sex. Antiretroviral therapy coverage is only published for the 0–14-year age group owing to challenges compiling data in countries for the narrower age groups as well as challenges in estimating the number of children living with HIV in many concentrated epidemic countries.

## REFERENCE GROUP ON PAEDIATRIC ESTIMATES

UNAIDS convenes a reference group on estimates, modelling and projections to advise on how to improve and update the models using the latest science and available data (www.epidem.org). The reference group recommendations are implemented in the AIDS Impact Module of the Spectrum computer package (www.avenirhealth.org), which countries use to develop their HIV estimates. A subgroup of the reference group addresses paediatric estimation methods and is co-convened annually with WHO. This collaboration links the models used to estimate the HIV paediatric epidemic with data for forecasting the need for antiretroviral medicines.

In October 2017, the paediatrics subgroup proposed a set of recommendations to improve child HIV estimates (the report and earlier reports can be found at www.epidem.org). The recommendations for the 2019 models are described below.

## MODEL STRUCTURE

Spectrum uses demographic data from 1970 through the current year, including age-specific fertility, mortality and international migration patterns, derived from the United Nations Population Division's World Population Prospects 2017 to produce child estimates (10). Fertility assumptions and changes over time are especially important for the accuracy of the child model. Countries can update the assumptions if they have recent census or survey data that have not yet been included in World Population Prospects data (see Figure 1 for a diagram of the model structure.) Fertility data combined with HIV prevalence among pregnant women are used to estimate the number of births to women living with HIV. Country teams enter the number of pregnant women on different antiretroviral therapy regimens and the timing of starting the specific regimen. The probability of transmission to the infant is applied based on the regimen the mother was on during pregnancy and breastfeeding. The model estimates the number of children infected during pregnancy, delivery or breastfeeding. Figure 1 shows the assumptions used to estimate the mother-to-child transmission of HIV rate, how many children are living with HIV and how many children die of AIDS-related causes.

The child model depends heavily on the data entered on the number of pregnant women on antiretroviral therapy and retention on those medicines. If those programme data double count women or include women who were not retained on antiretroviral therapy, the estimated number of women with a suppressed viral load and onward transmission will be incorrectly estimated. Data on the age at which a child starts antiretroviral therapy and how well they adhere to antiretroviral therapy also has an important impact on survival and on the estimated number of children living with HIV. A full description of the methods used to estimate children living with HIV is provided elsewhere (11).

**Figure 1. Summary of the child model in the Spectrum AIDS Impact Module**
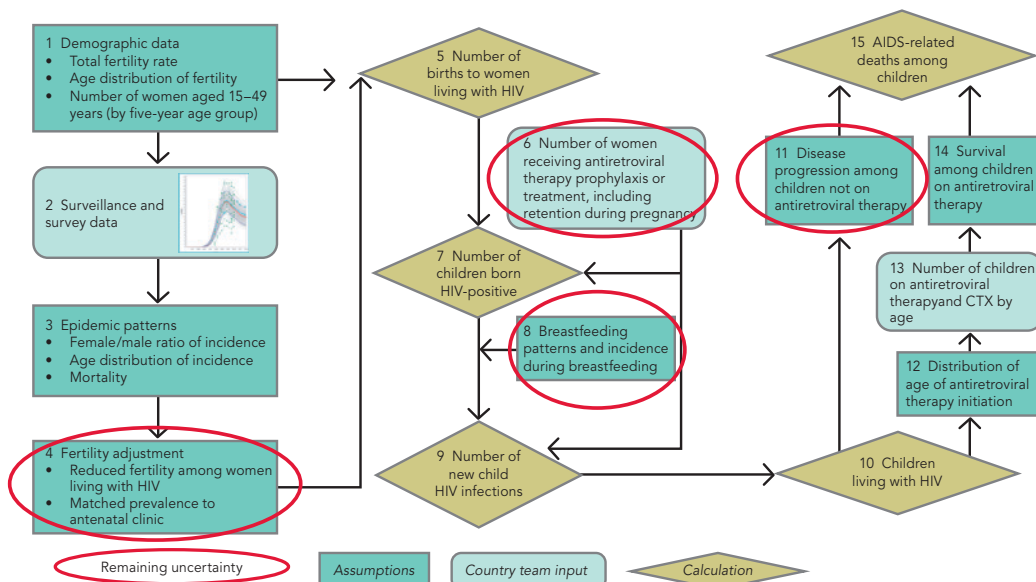
# MOST RECENT RECOMMENDATIONS

The 2018 paediatric reference group made a number of recommendations for the 2019 model.

1. Fertility among women living with HIV: the 2019 Spectrum model included updated parameters about the fertility of women living with HIV and not receiving antiretroviral therapy. The new parameters led to higher fertility among women living with HIV early in the epidemic before prevention of mother-to-child transmission of HIV services were available. In turn, this adjustment would increase historical estimates of the number of children living with HIV in the years prior to the availability of prevention of mother-to-child transmission of HIV services. At the same time, the model has started to use HIV prevalence data from routine testing among pregnant women at antenatal clinics to calibrate the estimated births to women living with HIV. This increased the estimates in some countries and decreased the values in others. There is still some work to be done to ensure the country data used for this calibration are robust.

2. Breastfeeding among women living with HIV: a new analysis of survey data collected in early 2019 found that women living with HV early in the epidemic had shorter breastfeeding duration. This was surprising, as it was assumed that women who did not know their HIV status would have similar breastfeeding patterns as women who were HIV-negative. In the 2019 estimates, a number of high-burden countries with household surveys from the early 2000s were able to make an adjustment to the estimated breastfeeding duration to capture this change. The impact of this change is a reduced number of new child HIV infections during breastfeeding over the course of the epidemic.

3. The combination of the two above changes results in very small changes in the estimates of new child HIV infections.

4. Probability of mother-to-child transmission: analysis conducted for the UNAIDS reference group on estimates, modelling and projections found very minor updates based on the latest published literature on the probability of transmitting HIV from mother to child. This had no impact on the estimates

5. Retention on treatment of pregnant women: there is still very little data available from countries on the retention of women on antiretroviral therapy during pregnancy. An analysis suggested that only 80% of women are retained on treatment at delivery. This default value is now applied to both women already on antiretroviral therapy before pregnancy and women who started antiretroviral therapy during the pregnancy. Previously, 75% of women already on antiretroviral therapy were assumed to be retained at delivery.

6. Updated age at initiation of antiretroviral therapy for children: the average age of children starting on antiretroviral therapy has changed over the years as children are diagnosed earlier. Data from the IeDEA network and the CIPHER network provide data on the average age of children starting antiretroviral therapy in multiple regions around the world. Since this age distribution changes over time, UNAIDS updates the assumptions in Spectrum as those data are made available. The most recent change found an increase in the proportion of children starting on antiretroviral therapy at under two years of age. There were also some small

adjustments to the proportion of children starting antiretroviral therapy over 10 years of age. This has a very small impact on the number of children living with HIV and AIDS-related deaths.

7. Child treatment: the previous model had assumptions that reflected increased survival among children on cotrimoxazole and antiretroviral therapy. Based on recent research, the assumptions about reduced mortality among children on cotrimoxazole and on antiretroviral therapy were removed from the model. This change resulted in a very small increase in child AIDS-related mortality.

## VALIDATION OF MODELLED ESTIMATES

A comparison of the modelled estimates of HIV prevalence among children against recent household-based surveys in seven countries in sub-Saharan Africa shows comparable results with all but one survey within the uncertainty bounds of the surveys and estimates (see Figure 2).

A number of studies have been carried out to estimate mother-to-child transmission of HIV rates and evaluate the impact of prevention of mother-to-child transmission of HIV services. Those studies have been useful for validating the estimates of transmission at six weeks after birth (12). However, owing to considerable loss to follow-up and the inability to capture transmission from women who seroconvert during breastfeeding, those studies were not useful for validation of the final transmission rate (13). A study in Zimbabwe overcame this limitation by following a random selection of mother–infant pairs regardless of the mother's initial HIV status until 18 months (14). While useful for validating the estimates, this study was limited by high levels of drop-out among the participants in the study and because children were not followed until the end of breastfeeding and thus the end of HIV exposure.

**Figure 2. HIV prevalence among children 0–14 years from the UNAIDS 2019 estimates and household surveys 2016–2018 (Spectrum estimate is for the year of the survey)**
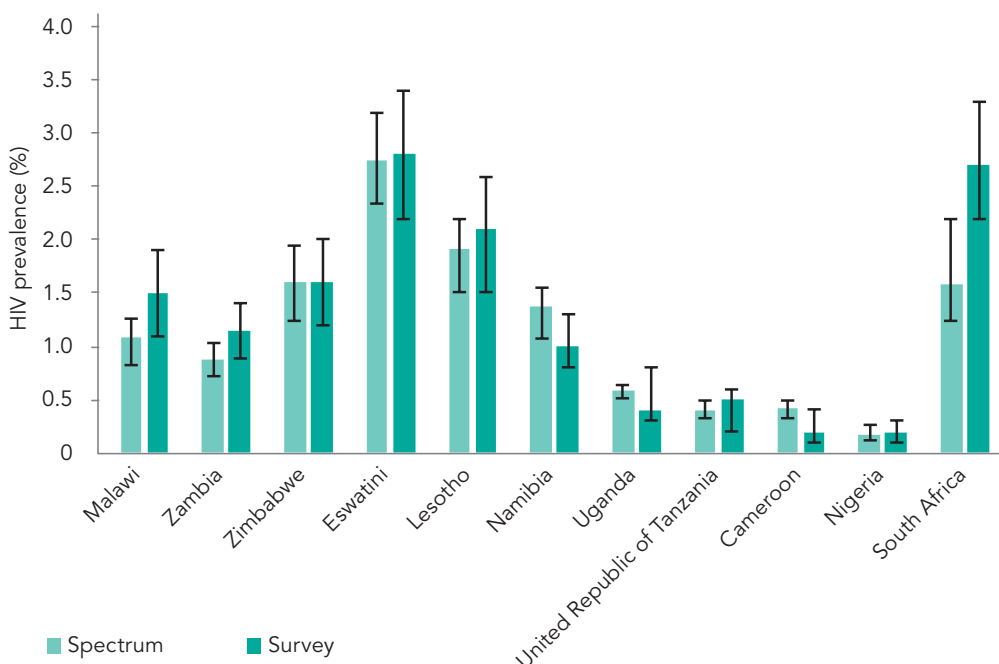
## OUTSTANDING ISSUES

Despite the recent improvements, there are still challenging areas in the child estimates.

In concentrated epidemics, fertility patterns among women living with HIV are likely to be different from the general population, making it difficult to estimate the number of births to women living with HIV. Also, some countries with concentrated epidemics selectively test pregnant women for HIV based on risk behaviours, including sex work and drug use. The HIV prevalence results from this testing strategy will not reflect prevalence in the population of all pregnant women, limiting the opportunity to estimate HIV prevalence among pregnant women.

Retention among pregnant women is an important aspect of the model. Nevertheless, there are few data on nationally representative retention among pregnant women. Ideally a measure of viral suppression at delivery would provide more accuracy in the transmission probability for women on antiretroviral therapy.

Assumptions about mortality among children not on antiretroviral therapy have been a long-standing issue with the child estimates in Spectrum. Current assumptions are based on data from high-income countries early in the HIV epidemic, before treatment was available. These data are not likely to represent low-resource settings, where the interaction of poorer nutrition and higher underlying mortality will have a different impact on survival outcomes. Child survival is also likely to improve as parental survival increases with earlier initiation of treatment and as more effective regimens are introduced *(15)*.

## HOW PROGRAMME MANAGERS CAN STRENGTHEN PROGRAMMES TO IMPROVE CHILD ESTIMATES

Programme managers should:

- Use patient or prevention of mother-to-child transmission of HIV registers that capture retention monitoring of pregnant women on treatment or use data collected at delivery in order to capture whether the woman has been retained in care and on treatment until delivery.

- Record women who are known to be living with HIV at the first visit to the antenatal clinic and whether they were already on antiretroviral therapy before the likely conception date.

- Implement unique identifier systems that avoid duplication of women counted in antenatal clinic testing and prevention of mother-to-child transmission of HIV treatment data.

- Ensure that reporting forms capture age-specific antiretroviral therapy data and share those data with the national HIV estimates team in the country to incorporate into their Spectrum files.
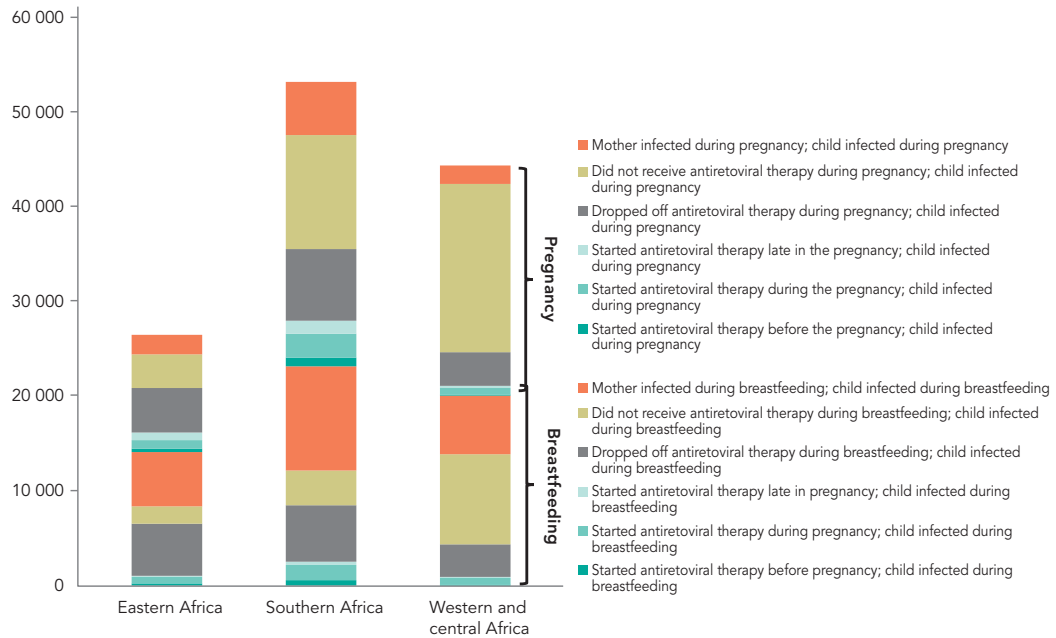
- Support efforts to produce age-specific data on treatment. In 2019, only 35 countries reported the number on antiretroviral therapy for the 10–14-year age group, while, in 2017, 84 countries reported those data.

- Work with their national HIV estimates team to review and comment on child and adolescent estimates and the data entered into the model that affect those estimates. The team should be told how the estimates will be used, so they can advise on the strengths and limitations of the estimates.

- Share any studies or research on child or adolescent HIV outcomes that can help validate and improve the models

In 2019, a new feature was added to the Spectrum software that allows countries to understand how the model estimates new child infections and the mother-to-child transmission of HIV rate. If the data entered into the model are of high quality, this tool also allows programme managers to see where they need to focus services. The tool is a stacked bar (known as the Mushavi stacked bar) that reflects the different gaps in prevention of mother-to-child transmission of HIV services that lead to child HIV infections.

Figure 3 presents the results for the Start Free, Stay Free, AIDS Free focus countries in three regions. The *y* axis shows the total number of child HIV infections and the different colours refer to the cause of the child infection. The three bars show that in eastern Africa, the number of new child HIV infections are estimated to be primarily due to pregnant and breastfeeding women not being retained on treatment (the grey portion of the bar). While in southern Africa, a large portion of new infections are due to women who seroconvert during breastfeeding (the dark orange in the bottom part of the bar). Finally, in western and central Africa, the new HIV infections are due primarily to women not on antiretroviral therapy during pregnancy and breastfeeding (the yellow part of the bar).

The results of this stacked bar are only as good as the data that are entered into the models. Countries need to have good measures of retention in care of pregnant women and reliable data on how many women are on different antiretroviral therapy regimens and when they started on those regimens. The duration of breastfeeding among women living with HIV is also important, which is usually available from household surveys. Finally, the modelled estimates of pregnant women living with HIV are also critical for the accuracy of the tool. However, even when those data are somewhat imprecise, looking at the impact of changing the impacts is useful for programme managers to understand what are the key components of mother-to-child transmission.

**Figure 3. Mushavi stacked bar displaying cause of new child infections, Start Free, Stay Free, AIDS Free focus countries by region, 2018**



Legend:
- Mother infected during pregnancy; child infected during pregnancy
- Did not receive antiretoviral therapy during pregnancy; child infected during pregnancy
- Dropped off antiretoviral therapy during pregnancy; child infected during pregnancy
- Started antiretoviral therapy late in the pregnancy; child infected during pregnancy
- Started antiretoviral therapy during the pregnancy; child infected during pregnancy
- Started antiretoviral therapy before the pregnancy; child infected during pregnancy
- Mother infected during breastfeeding; child infected during breastfeeding
- Did not receive antiretoviral therapy during breastfeeding; child infected during breastfeeding
- Dropped off antiretoviral therapy during breastfeeding; child infected during breastfeeding
- Started antiretoviral therapy late in pregnancy; child infected during breastfeeding
- Started antiretoviral therapy during pregnancy; child infected during breastfeeding
- Started antiretoviral therapy before pregnancy; child infected during breastfeeding

## USEFUL LINKS

Currently available data on child and adolescent estimates: Aidsinfo.unaids.org

Reports on the UNAIDS Reference Group for Estimates, Modeling and Projections: Epidem.org

Spectrum software and manuals: Avenirhealth.org

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