
Improving UNAIDS' paediatric and adolescent estimates

BACKGROUND

This document provides paediatric HIV programme managers with an overview of how paediatric and adolescent 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. These data are also used to 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 for diseases, including HIV, are the primary source of data, but are often incomplete. Children are either not tested for HIV or, in the event that they are, the result goes unrecorded in the clinic's, district's 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 of children for as long as they return to clinics for immunization, it only covers the first year (2), but breastfeeding, and thus exposure to HIV, often lasts longer than one year.

Some women will know their HIV-positive status before their baby is born, while other 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 virus to her child (3, 4). A child who is asymptomatic is unlikely to be tested for HIV, reducing the chance of diagnosis and 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 incidence or prevalence at the subnational level or other forms of disaggregation (2).

Changes from one survey to another are difficult to measure in population-based surveys because of the large confidence intervals. 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 (5, 6). Measures of prevalence among children become very imprecise in countries where HIV prevalence among women is less than 5% (2, 7).

The challenges that make it difficult to identify children living with HIV in health systems are the same challenges that prevent their parents from knowing their status and accessing life-saving antiretroviral therapy. In 2017, an estimated 52% [37–70%] of children living with HIV were receiving antiretroviral therapy.

In the absence of reliable data, programme managers and planners rely on models to estimate HIV prevalence, new HIV infections 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, adult survival and research on mother-to-child transmission of HIV rates associated with different antiretroviral therapy regimens.

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) that 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 paediatric HIV epidemic with data for forecasting the need for antiretroviral medicines.

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

PROCESS OF DEVELOPING ESTIMATES

UNAIDS and partners support countries to update the models used to estimate the impact of HIV on their populations annually (8). 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 includes revised historical estimates and estimates for the most recently completed year. The 2018 estimates cover the years 1970 through to 2017. In countries where the data are available, the estimates are also available by province. The models produce estimates of people living with HIV, new HIV infections, AIDS-related deaths and births to women living with HIV by five-year age groups 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 also includes indicators for children aged 0–14 years, adolescents aged 10–19 years and young people aged 15–24 years disaggregated 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.

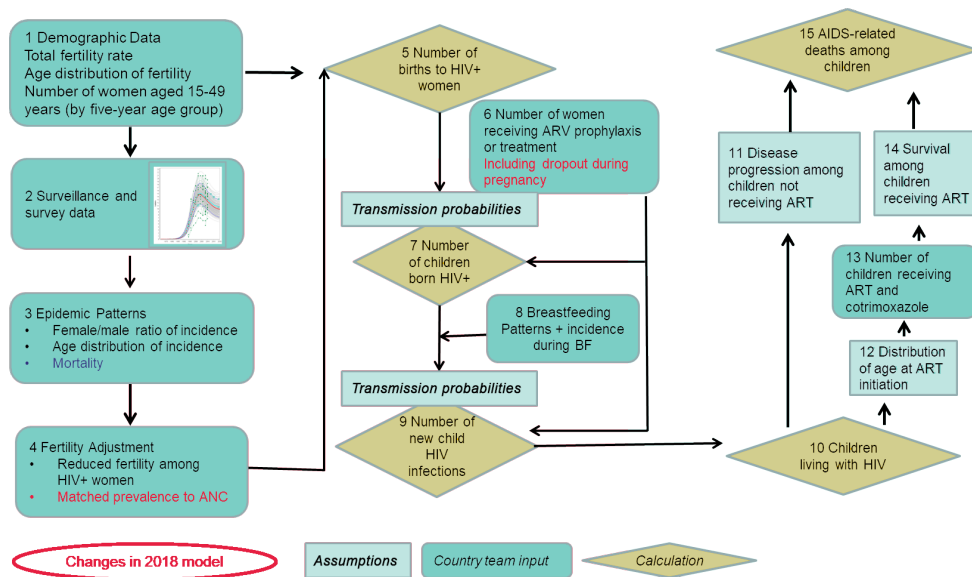
MODEL STRUCTURE

Spectrum uses demographic data from 1970 through to 2022, 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 (9). Fertility assumptions and changes over time are especially important for the accuracy of the child model. Countries can update these assumptions if they have recent census or survey data that have not yet been included in the 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. Depending on the antiretroviral therapy regimen that women receive, the transmission probability for that specific regimen is applied to determine whether a child likely to be infected during pregnancy, delivery or breastfeeding. Figure 1 shows the assumptions used to estimate how many children are living with HIV depending on when they were infected and whether they start on antiretroviral therapy.

The child model depends heavily on the data entered on the number of pregnant women accessing antiretroviral medicines and retention on those medicines. If those programme data double count women or include women who were not retained on antiretroviral medicines, the estimated number of women with a suppressed viral load and onward HIV transmission will be incorrectly estimated. Data on the age at which a child starts antiretroviral therapy and how well they adhere to it also have an important impact on survival and on the estimated number of children living with HIV.¹

¹ A full description of how Spectrum works is available at avenirhealth.org. A brief description of the child model within Spectrum is available at Mahy M, Penazzato M, Ciaranello A, Mofenson L, Yianoutsos CT, Davies MA, et al. Improving estimates of children living with HIV from the Spectrum AIDS Impact Model. *Aids*. 2017;31 Suppl 1:S13–S22.

Figure 1. Summary of the child model in the Spectrum AIDS Impact Module



MOST RECENT RECOMMENDATIONS

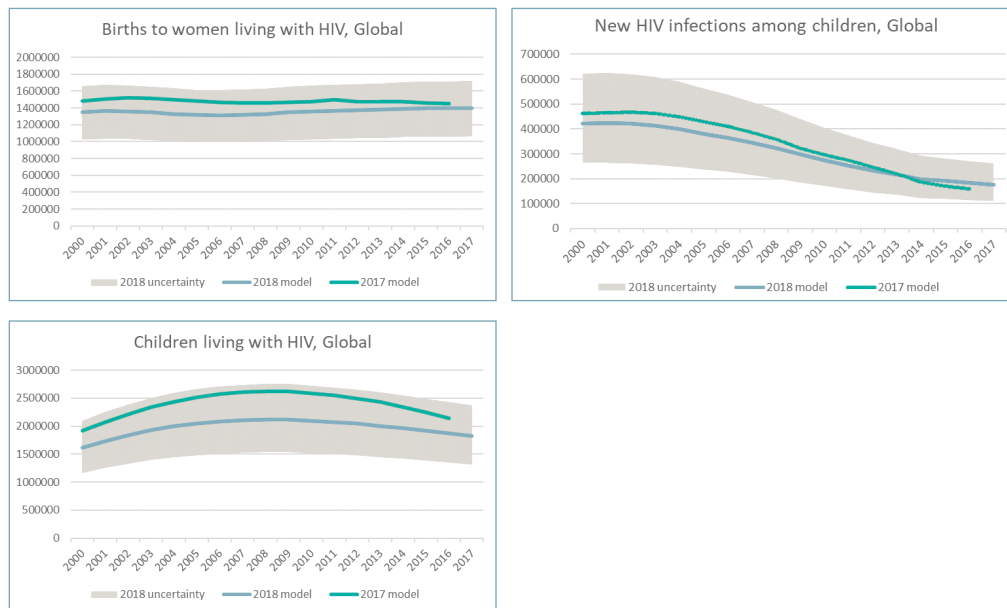
The October 2017 paediatric reference group meeting made two major recommendations for changes in the model.

1. Countries with high-quality routine antenatal clinic prevalence data should use those data to determine prevalence among pregnant women.
2. Allow countries to specify retention of pregnant women on antiretroviral medicines through delivery of the baby. This can be entered for pregnant women already on antiretroviral therapy before conception or for women just starting antiretroviral therapy based on testing during antenatal visits. Default values included in the model were based on 21 published studies on retention among pregnant women, primarily in eastern and southern Africa. Countries were strongly encouraged to update these results with available data. Previously it was assumed that all women on antiretroviral therapy or started on antiretroviral therapy would remain on antiretroviral therapy until delivery. Drop-out during breastfeeding was included in previous models.

The impact of these two model changes is evident in global trends in births to women living with HIV, new child HIV infections and the number of children living with HIV. As a result of introducing the use of routine antenatal clinic testing data to estimate prevalence among pregnant women, global estimates for 2018 compared with those from 2017 show fewer births among women living with HIV. As the reduction in births to women living with HIV cumulates over time, the historical number of children newly infected and living with HIV is lower than in the 2017 round.

By capturing imperfect retention among pregnant women, the 2018 model estimates a higher transmission rate and thus the decline in new child infections is not as rapid as was estimated in the 2017 model.

Figure 2. Comparison of the 2017 estimates and 2018 estimates for new HIV infections among children, births to women living with HIV and children living with HIV, global

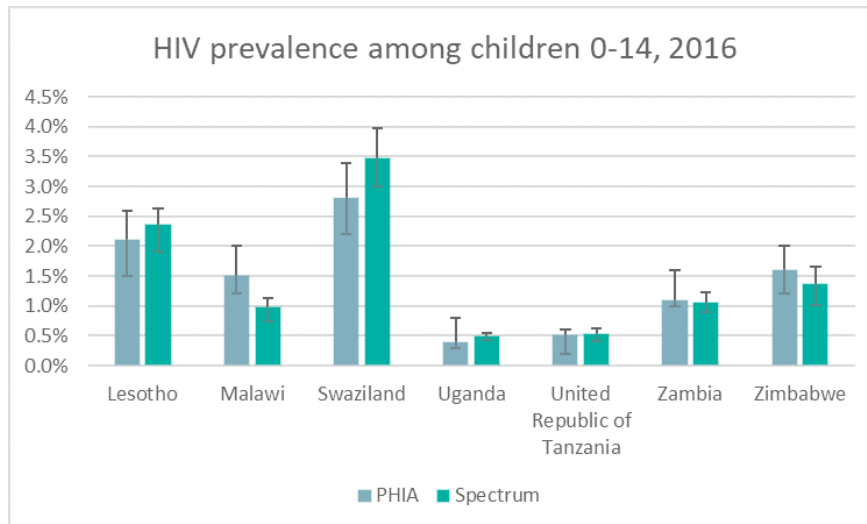


VALIDATION OF MODELLED ESTIMATES

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 3).

A number of studies have been done to estimate mother-to-child transmission of HIV rates and evaluate the impact of services for preventing mother-to-child transmission of HIV. These studies have been useful for validating the estimates of transmission at six weeks after birth (10). However, due to considerable loss to follow-up and the inability to capture transmission from women who seroconvert during breastfeeding, these studies were not useful for validation of the final transmission rate (11). A recent 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 (12). While useful for validating the estimates, this study was limited by high levels of drop-out and because the child was not followed until the end of breastfeeding and thus the end of HIV exposure.

Figure 3. HIV prevalence among children aged 0–14 years from UNAIDS estimates and Population-Based HIV Impact Assessment surveys



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.

The new approach of incorporating retention among pregnant women is an important addition to 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 accessing antiretroviral medicines.

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 (13).

HOW PROGRAMME MANAGERS CAN STRENGTHEN PROGRAMMES TO IMPROVE CHILD ESTIMATES

- Ensure that reporting forms capture age-specific antiretroviral therapy data.
- Use patient or prevention of mother-to-child transmission of HIV registers that capture retention monitoring of pregnant women on treatment.
- Record women who are known to be living with HIV at the first antenatal clinic visit and whether they are already on antiretroviral therapy.
- Implement unique identifier systems that avoid duplication of women counted in prevention of mother-to-child transmission of HIV testing and treatment data.
- Support efforts to produce age-specific data on treatment. In 2018, only 51 countries reported the number on antiretroviral therapy for the 10–14-year age group, while, in 2017, 84 countries reported those data. This large drop in the number of countries reporting disaggregated antiretroviral therapy data is likely due to changes in the reporting format of the Global AIDS Monitoring tool in 2018.
- Work with national HIV estimate teams to review and comment on child and adolescent estimates and the data entered into the model that affect those estimates. Let the teams know 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.

USEFUL LINKS

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

Reports on the UNAIDS Reference Group for Estimates, Modelling and Projections: epidem.org

Spectrum software and manuals: avenirhealth.org

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