

## Children, HIV and AIDS



### KEY POINTS:

- There has been significant success in reducing the number of new HIV infections among children since 2000 but, for children living with HIV, AIDS-related illnesses are still among the leading causes of infant mortality.
- Although prevention of mother-to-child transmission programmes are generally successful when implemented, there needs to be a greater scale-up of coverage, in addition to increasing early infant diagnosis after birth and during breastfeeding.
- More needs to be done to support the prevention of HIV among vulnerable children and to address the unique antiretroviral treatment adherence challenges that affect children living with HIV.

Explore this page to find out more about [why children are at risk of HIV](#), [HIV prevention programmes](#), [early infant diagnosis](#), [barriers to testing](#), [access to antiretroviral treatment](#), [treatment and support](#) and [the future of the HIV epidemic among children](#).

Globally, the annual number of new infections among children (0-14 years) has almost halved since 2010 with a 47% reduction in new HIV cases.<sup>1</sup> Since 1995, an estimated 1.6 million new HIV infections among children have been averted due to the provision of antiretroviral medicines (ARVs) to women living with HIV during pregnancy and breastfeeding. The vast majority of these infections (1.3 million) were averted between 2010 and 2015.<sup>2</sup>

Despite this significant progress, the number of children becoming newly infected with HIV remains unacceptably high. In 2016, 24% of pregnant women living with HIV did not have access to ARVs to

prevent transmission to their infants.<sup>3</sup> In the same year, around 160,000 children became infected with HIV; this equates to 438 children a day.<sup>4</sup>

In 2015, in the 21 highest-burden countries, only 54% of children exposed to HIV were tested within the recommended two months.<sup>5</sup> In the following year, an estimated 1.8 million children were living with HIV, but just 43% had access to ARVs. Although treatment coverage has improved since 2010, when just 21% of children living with HIV were on antiretroviral treatment (ART), the current situation means that around half of the children in need do not have access.<sup>6</sup>

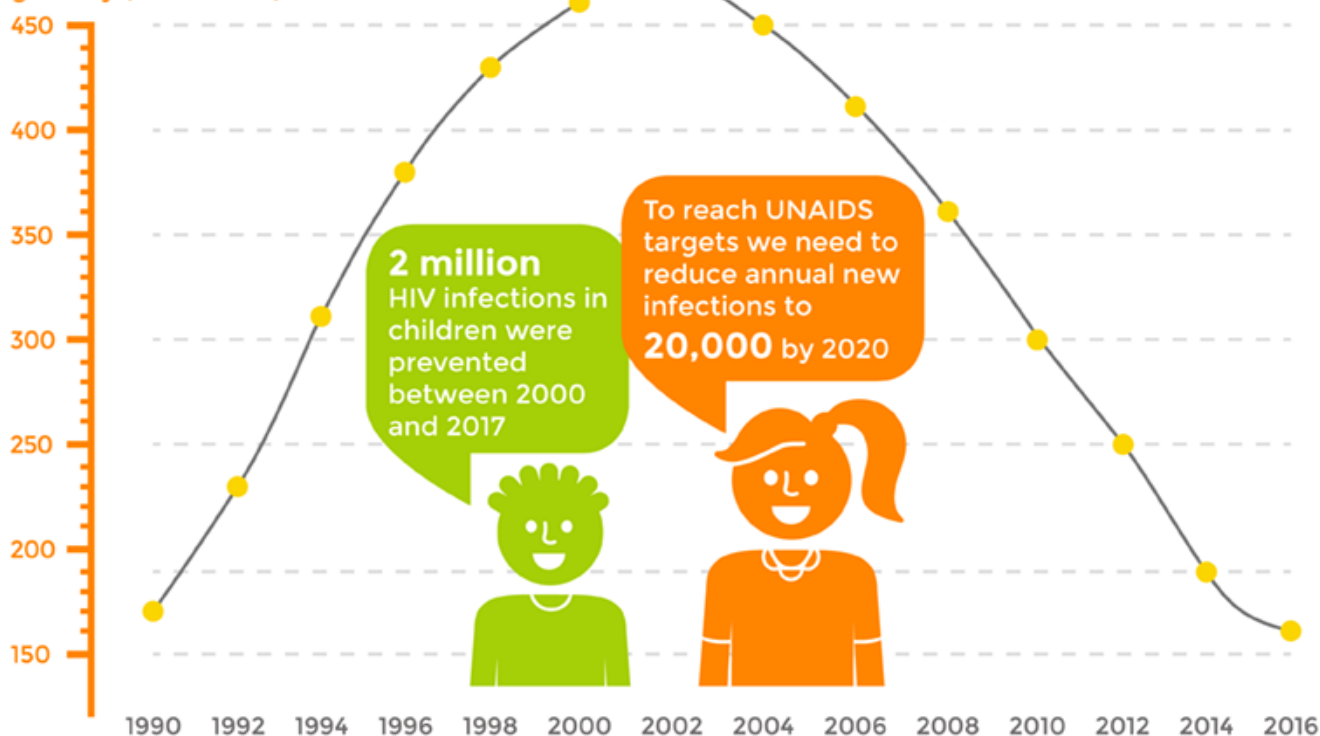
The majority of children living with HIV live in [Africa](#), where AIDS remains the leading cause of death among adolescents.<sup>7</sup> Globally, 120,000 children died due to AIDS-related illnesses in 2016. This equates to 328 deaths every day.<sup>8</sup> In fact, children aged 0–4 years living with HIV are more likely to die than any people living with HIV of any other age.<sup>9</sup> This is despite a 62% reduction in AIDS-related deaths among this age group globally, since 2000.<sup>10</sup>

In addition, millions more children are indirectly affected by the impact of the HIV epidemic on their families and communities.<sup>11</sup>

Regular HIV testing, treatment, monitoring and care for children living with HIV can enable them to live long and fulfilling lives. However, a lack of necessary investment and resources for adequate testing, paediatric ARVs and child-friendly prevention programmes mean children continue to suffer the consequences of the epidemic.

## New HIV infections in children aged 0-14 years old.

Number of new infections globally (thousands)



Source: World Bank - accessed 5th December 2017 and UNICEF analysis of UNAIDS 2017 data

# Why are children at risk of HIV?

## Mother-to-child transmission (MTCT)

The majority of children living with HIV are infected via mother-to-child transmission (MTCT), during pregnancy, childbirth or breastfeeding. This is sometimes referred to as 'vertical transmission' or 'parent-to-child-transmission'.

MTCT of HIV can be stopped, as long as expectant mothers have access to [preventing mother-to-child transmission \(PMTCT\)](#) services during pregnancy, delivery and breastfeeding.<sup>12</sup> With funding, trained staff and resources, new infections among many thousands of children could be avoided.

Breastfeeding is now responsible for the majority of MTCT.<sup>13</sup> When formula feeding is not a viable option, women can greatly reduce the risk of transmitting HIV to their child at this stage if they exclusively breastfeed and are on ART. However, in 2013 only 49% of women continued to take ARVs while breastfeeding, compared to 62% of women who took ARVs during pregnancy and delivery. This highlights the urgent need for education about the importance of continuing treatment post-birth.<sup>14</sup>

Without ART, a third of infants who acquire HIV as a result of MTCT will not reach their first birthday, and half will not reach their second birthday.<sup>15</sup>

## HIV infection in medical/healthcare settings

Although very rare today, HIV infection can occur in medical settings. For instance, through needles that have not been sterilised or through blood transfusions where infected blood is used.

It was reported in 2012 that over the past decade in Kyrgyzstan, 270 children have been infected with HIV in hospitals as a result of doctors not following universal precautions during medical procedures.<sup>16</sup>

## Orphans and vulnerable children

One of the most devastating impacts of HIV is the loss of whole generations of people in communities hardest hit by the epidemic. In this regard, it is often children who feel the greatest impact via the loss of parents or older relatives.

An 'orphan' is defined by the United Nations as a child who has 'lost one or both parents'. An estimated 13.4 million children and adolescents (0-17 years) worldwide had lost one or both parents to AIDS as of 2015. More than 80% of these children (10.9 million) live in sub-Saharan Africa.<sup>17</sup> In some countries which are badly affected by the epidemic, a large percentage of all orphaned children – for example 74% in [Zimbabwe](#), and 63% in [South Africa](#) – are orphaned due to AIDS.<sup>18</sup>

Remarkable gains have been achieved in mitigating the economic and social impact of HIV and AIDS on children and families over the past decade. Still, children orphaned by AIDS, or who are living with sick caregivers, continue to face an increased risk of physical and emotional abuse as compared with other children in sub-Saharan Africa, including other orphans. This increases these children's vulnerability to HIV.<sup>19</sup>

HIV programmes focusing on orphans and vulnerable children (sometimes referred to as OVC) are a vital strategy for reducing vulnerability to HIV in children. These programmes focus on supporting

carers of children, often older generations, keeping children in school, protecting their legal and human rights, and ensuring that their emotional needs are catered for.<sup>20</sup>

## HIV prevention programmes for children

In June 2011 UNAIDS and the United States President's Emergency Plan for AIDS Relief (PEPFAR) launched the 'Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive' [pdf] along with 22 countries, which, at the time, accounted for 90% of the global number of pregnant women living with HIV. The Global Plan galvanised global and national political will and action, resulting in some of the most impressive and significant gains in the history of the HIV response.<sup>21</sup>

The 'Start Free, Stay Free, AIDS Free' initiative, which was launched in 2016 and is led by UNAIDS and PEPFAR, aims to build on the progress achieved under the Global Plan to scale up HIV prevention, treatment, care and support services for children, adolescents and young women. The initiative aims to elevate and amplify efforts that are already accelerating progress, including the DREAMS Partnership, the Accelerating Children's HIV/AIDS Treatment (ACT) Initiative and ALL-IN.<sup>22</sup>

This approach adopts a 'lifecycle approach' to programming, which means it responds to the changing contexts that people face at different ages.<sup>23</sup>

The Start Free, Stay Free, AIDS Free initiative has three parts:

- Start Free aims to complete the job started by the Global Plan by reaching and sustaining 95% of pregnant women living with HIV with lifelong HIV treatment by 2018, and by reducing the number of newly infected children to fewer than 40,000 by 2018 and 20,000 by 2020.<sup>24</sup>
- Stay Free has the objective of ensuring that children with an HIV-free start stay HIV-free throughout their childhood. It aims to do this by intensifying the focus on reaching and empowering adolescent girls and young women and engaging men and boys.<sup>25</sup>
- AIDS Free targets the children and adolescents living with HIV who often are left behind by HIV responses. The initiative aims to provide 1.6 million children (aged 0 to 14) and 1.2 million adolescents (aged 15 to 19) living with HIV with ART by 2018.<sup>26</sup>

## Prevention of mother-to-child transmission (PMTCT)

For many countries around the world, PMTCT is their most successful and important HIV prevention priority. However, considerable gaps in coverage exist across the world.

As of June 2016, Armenia, Belarus, Cuba and Thailand had been certified by the WHO to have eliminated MTCT.<sup>27</sup> By 2015, seven countries in East and Southern Africa had greater than 90% coverage of PMTCT services. This includes South Africa, which is home to 25% of the region's pregnant women living with HIV. East and Southern Africa has achieved the largest decline in MTCT anywhere in the world, falling from 18% of infants born to mothers living with HIV in 2010 to 6% in 2015—a threefold decrease.<sup>28</sup>

The Middle East and North Africa is the region that has shown the least amount of progress, as nearly one third of women living with HIV passed the virus on to their children in 2015. The MTCT rates in Asia and the Pacific and western and central Africa were also well above the global average of 10%.<sup>29</sup>

An estimated 45% of new HIV infections among children in 2015 occurred in West and Central Africa. Although the region has seen a 31% reduction in new child (sometimes referred to as paediatric) HIV infections between 2010 and 2015 this is considerably lower than the 66% reduction in East and Southern Africa.<sup>30</sup> The situation is particularly challenging in Nigeria, which in 2015 had the second largest HIV epidemic in the world. In the same year, Nigeria had the greatest number of new HIV infections among children globally—an estimated 41,000 — roughly equivalent to the next eight countries combined.

There has only been a 21% decline in new child HIV infections in the country since 2009, compared to an average reduction of 60% among other Global Plan priority countries.<sup>31</sup>

A major contributor to the successful increase in treatment coverage for pregnant women living with HIV has been the involvement of communities. Entry to, and retention in, care have been shown to greatly improve through community engagement and support, and through community service-delivery models. Networks and support groups of women living with HIV have been particularly valuable in boosting outreach activities and PMTCT service delivery, providing counselling, supporting treatment adherence, educating women about their reproductive rights, encouraging them to seek care and HIV testing, and providing psychosocial support to women coming to terms with a new diagnosis of HIV.<sup>32</sup>

At the end of 2015, more than half of the countries in sub-Saharan Africa were using community health workers to provide and support key HIV services, including PMTCT.<sup>33</sup>

Despite this, in 2013 around 54% of pregnant women did not receive an HIV test, and were therefore unaware of their HIV status. Of those who did receive a test and were diagnosed positive, 7 out of 10 received PMTCT services. This helped avert 900,000 new HIV infections in children between 2009 and 2013.<sup>34</sup>

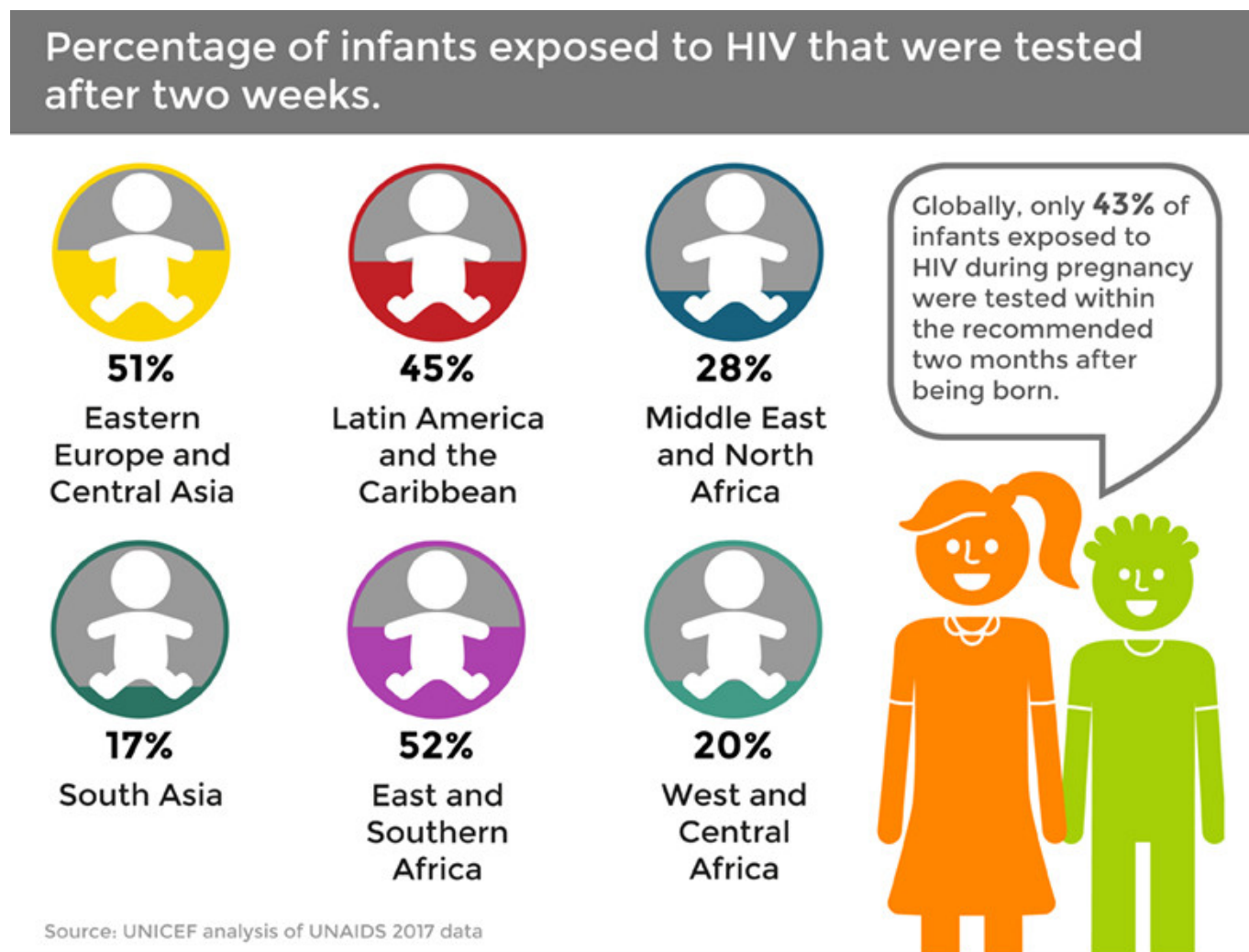
Changes to PMTCT treatment regimens over the past five years have played a major part in the impressive decline in vertical transmission rates. In 2010, the majority of pregnant women living with HIV were provided with ARVs solely to prevent onward transmission to the child they were carrying at the time. But evidence suggested that immediate and lifelong ART for pregnant women diagnosed with HIV is more effective than on-again, off-again approaches. In 2015, the World Health Organisation (WHO) recommended that all pregnant women living with HIV be provided with Option B+, which involves the immediate offer of lifelong ART—going beyond pregnancy, delivery and breastfeeding—regardless of CD4 count (which indicates the level of HIV in the body). By 2015, 91% of the 1.1 million women receiving ARVs to prevent MTCT were on lifelong ART due to the global rollout of Option B+. This greatly improved rates of viral suppression, when HIV is reduced to such a low level that onward transmission is highly unlikely, during both the breastfeeding period and afterwards for these women.<sup>35</sup>

Some gains were also made in the efforts to prevent unintended pregnancies in countries with large numbers of paediatric HIV infections, although an unmet need for family planning still persists in many countries. Between the periods of 2000–2004 and 2010–2014, unmet needs for family planning among married women declined by more than 10% in Ethiopia, Kenya, Lesotho, Malawi and Rwanda.<sup>36</sup> Among the countries with available data in sub-Saharan Africa, Zimbabwe had the lowest unmet need for family planning among married women (10%).<sup>37</sup>

However, there is still a lack of information about the use of contraception among many women in sub-Saharan Africa, specifically at the national level for women living with HIV. Some earlier studies

have suggested that women living with HIV may be more motivated to use contraception and therefore have different unmet needs than other women, but there is still a knowledge gap in this area.<sup>38</sup>

There has also been little change in the rate of new HIV infections among women.<sup>39</sup> An additional 5.2 million women of reproductive age were newly infected with HIV between 2010 and 2015, including 1.2 million in South Africa. As a result, the substantial need for PMTCT services for women of reproductive age will continue for the foreseeable future.<sup>40</sup>



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## Early infant diagnosis

When an infant has HIV the likelihood of them dying from an AIDS related illness declines by 75% if they are given ART within the first 12 weeks of life.<sup>41</sup>

As a result, the 2013 WHO treatment guidelines recommend that infants exposed to HIV be tested at the first postnatal visit—usually when they reach four to six weeks of age—or at the earliest opportunity thereafter, and that infants (and all children below the age of five) who test positive for HIV start treatment immediately.<sup>42</sup>

Despite significant investment, only 54% of children exposed to HIV received HIV testing within the first eight weeks of life in 2015 (described as 'early infant diagnosis'), although this marks a slight increase since 2014 when 51% were tested.[43](#)

Coverage of early infant diagnosis remains low in the majority of Global Plan priority countries. Only Lesotho, South Africa, eSwatini and Zimbabwe provided HIV testing to more than half the infants exposed to HIV within their first eight weeks of life in 2015.[44](#)

Infants infected in utero (in the womb) or during labour and delivery have a poor prognosis compared to infants infected during breastfeeding, and they require urgent ART to prevent early death. However, identifying those infants using the common antibody HIV test is a challenge due to the presence of maternal HIV antibodies, which may persist for as long as 18 months in a child's bloodstream.[45](#)

Some mothers do not bring their babies back for testing by the recommended six weeks, and other babies living with HIV may die within the first six weeks. In an effort to ensure that more infants living with HIV are diagnosed and initiate treatment, the South African National Department of Health launched guidelines that called for all HIV-exposed infants to be tested at birth and at 10 weeks in 2015.[46](#) South Africa's experience with at-birth testing is being watched carefully to see whether key challenges can be overcome, such as mothers not bringing their babies back for the 10-week test after their babies test negative for HIV at birth.[47](#)

HIV-negative new mothers at high-risk of HIV are also insufficiently tested while they are breastfeeding. As a result, infants are exposed unknowingly to HIV at this stage.[48](#) The shift in the timing of HIV transmission from mother to child, which has moved from pregnancy to breastfeeding, has created a new urgency for focusing on new-mother's adherence to ARVs and retaining mothers and infants in care to the end of the breastfeeding period.[49](#)

Despite this, many women living with HIV are not aware that they need to remain on treatment while breastfeeding their infants, and opportunities to reinforce the adherence messages and resupply women with ARVs are fewer once the baby is born, as women reduce their contact with the health system.[50](#) It is essential that infants are re-tested for HIV when they cease breastfeeding but again many infants do not undergo this test.[51](#)

## HIV testing for children

Access to HIV testing in children over 18 months of age remains poor in many countries, creating a bottleneck for the scale-up of treatment.[52](#)

Screening children for HIV at inpatients sites and nutrition clinics, alongside testing in the context of PMTCT programmes, provides the best opportunities for diagnosing HIV infections in children that might otherwise go undetected.[53](#)

Many HIV-positive children in low and middle-income countries remain undiagnosed. For example, one estimate from Kenya suggests that only 40% of children with HIV are diagnosed.[54](#)

## Barriers to HIV testing for infants and children

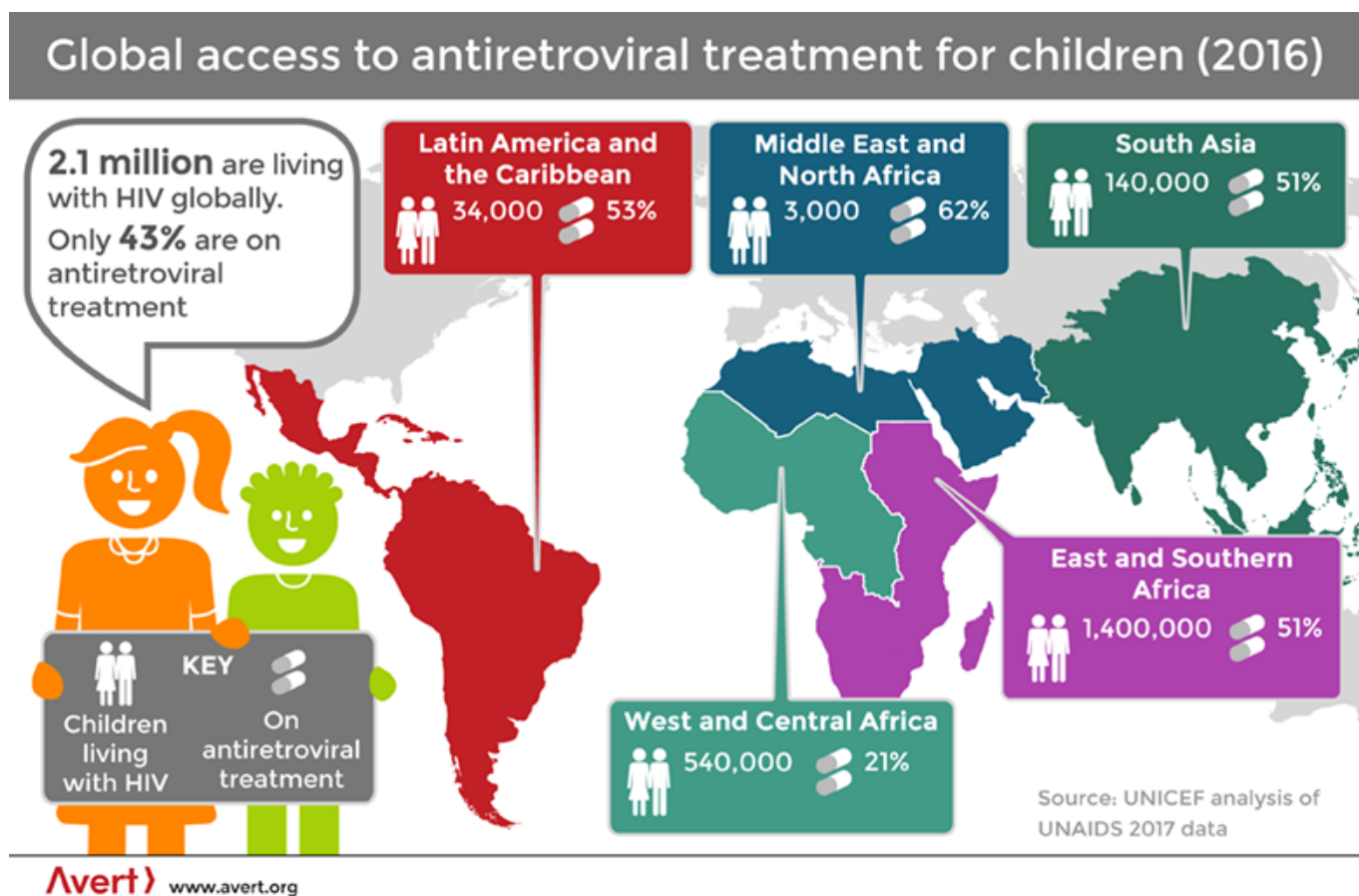
The most commonly available virological HIV tests for infants require complex laboratory instruments

and highly specialised personnel, making it difficult for caregivers in rural areas to provide consistent and timely results.<sup>55</sup>

In many rural, inaccessible areas, HIV testing is simply unavailable. Instead, healthcare professionals must use clinical diagnosis to ascertain a child's HIV-positive status. Unfortunately this results in a lot of infections going undetected.<sup>56</sup>

A number of portable point-of-care testing systems have been developed in response to this challenge. As of 2016 there were three on the market that can be run from battery packs or main electricity and are rugged enough for use in mobile laboratories. Because they are small and portable, and because they can be operated by trained non-laboratory personnel, point-of-care technologies are likely to increase access to early infant diagnosis and reduce loss to follow-up. An evaluation of the first commercially available point-of-care and near-patient testing, conducted in multiple African countries, suggests that these tests are as accurate as laboratory testing.<sup>57</sup>

Even when children and infants are tested, ineffective transport and poor communication systems may result in prolonged turnaround times between blood sample collection at clinics and the return of results. For example, a study in Zambia found that the turnaround time from sample collection to return of results to the caregiver was 92 days. This leads to higher proportions of exposed infants and children being lost to follow-up, initiating treatment very late or dying before they can start treatment. Others do not have access to appropriate paediatric formulations.<sup>58</sup>





## Access to antiretroviral treatment for children

It is vital that infants and young children who are living with HIV receive HIV treatment as early as possible, and are followed up with consistent monitoring, as they have significantly worse treatment outcomes than adults. Without treatment, half will die by their second birthday.

Given the strong evidence of benefit, WHO recommends treatment for all children and prioritises it for the youngest infants and those with compromised immune function.<sup>59</sup>

Despite this recommendation, low rates of HIV testing in infants prevent those who need it getting prompt access to HIV treatment. Children are, as a result, less likely than adults to receive treatment: only 43% were receiving treatment in 2016 compared to 54% of adults.<sup>60</sup>

### Antiretroviral treatment adherence

HIV treatments for children work. Unfortunately, there is limited range of age-appropriate antiretroviral drugs which are available in paediatric formulations – especially second- or third-line alternatives – which makes treatment even more challenging.

The palatability of drugs, for example, can be complicated as some are tricky to swallow and can taste unpleasant. In addition, the volume of medicines recommended for children under the age of three is a challenge, and some of these medicines need to be kept cool, which can be an issue in some countries. <sup>61</sup>

However, there was a major breakthrough in May 2015, when the United States Food and Drug Administration gave tentative approval for an improved paediatric formulation in the form of small oral pellets. These pellets come packaged in a capsule that is easily opened, allowing them to be sprinkled over a child's food, or, in the case of a smaller infant, placed directly into the mouth or over expressed breast milk. Previously these formulations were only available in tablet form that could not be broken or a liquid that required refrigeration and had an unpleasant taste, making it extremely difficult to administer to infants.<sup>62</sup>

Children have a different immune response to HIV compared to adults as their bodies are constantly developing, and their high rate of metabolism makes the dosing of HIV medicines particularly difficult.<sup>63</sup> As such, paediatricians treating children growing up with HIV also need to be aware of special dosage instructions.

On average, people living with HIV who live with it from childhood will have to take ARVs 20 years longer than people who acquire HIV as adults, which heightens adherence issues. As more children are growing older with HIV, the inadequacies of HIV services for older children are coming to light.<sup>64</sup>

These include the complexity of adhering to treatment for children as they become adolescents, when they may want freedom rather than strict medical regimes, coupled with a lack of age-appropriate services and confusion around ARV regimes as they transition between child and adult treatment regimes.<sup>65</sup>

### Drug resistance and treatment costs

Although the cost of initial (or 'first line') ART for children has reduced dramatically due to the availability of generic drugs, if a child develops drug resistance and needs to begin a second line of

drugs, treatment becomes far more expensive.<sup>66</sup>

In fact, HIV drug resistance (HIVDR) to the select few medications which are palatable among children is becoming an increasing concern among health practitioners with more children developing treatment resistant strains of the virus as a result of the scale up of prevention of mother-to-child transmission (PMTCT) programmes. For infants exposed to PMTCT programmes, the WHO has also estimated that there is a HIVDR prevalence of 21.6%, compared to just 8.3% among those with no treatment exposure.

In 2017, the results from a five-year-long study observing the efficacy of treatment in Zambia found that 40% of infants diagnosed with HIV in Lusaka had resistance to at least one ART drug by 2014 compared to 21.5% in 2009.<sup>67</sup>

Despite the scientific advances made in research and development for new HIV medicines for adults, the options for children lag behind significantly. In high-income countries the market for HIV medicines for children has almost disappeared as new HIV infections among children have been virtually eliminated. As a result, the incentive for companies to develop formulations for children has reduced because children living with HIV in low- and middle-income countries represent a less viable commercial market. There is an urgent need for improvement in paediatric ARVs, in particular to keep their costs low.<sup>68</sup>

## Loss to follow-up

Even where treatment is available and accessed, retention in care is frequently cited as a key issue in many countries.<sup>69</sup>

In 2014, a systematic review of 30,000 children living with HIV under the age of 10 showed that nearly 5-29% of patients were lost to follow up or had died within 12 months of starting their treatment.<sup>70</sup>

A similar study involving 13,611 children from low-income countries in Asia and Africa found that at 18 months after initiation of ART, 5.7% had died, 12.3% were lost to follow-up, and 8.6% had transferred to other clinics. Loss to follow-up was much greater in West Africa (21.8%) compared to Asia (4.1%).<sup>71</sup>

Children are more vulnerable to being lost to follow-up than adults because they rely on their parents or caregivers to gain access to healthcare services.<sup>72</sup> Some of the reasons children are lost to follow up include lack of caregiver contact information, stigma and counselling challenges, the burden on people to return for results, and weak follow-up within clinics.<sup>73</sup>

### CASE STUDY: Improving HIV care retention for infants in Uganda

In some areas of Uganda, less than 3% of infants born to women living with HIV in 2013 were retained in care after one month. With support from PEPFAR, the Ministry of Health worked with 22 health facilities to improve retention of mothers living with HIV and their babies. Mothers were interviewed to better understand their challenges. The survey showed that 80% of retention problems were caused by forgotten appointments, scheduling conflicts, lack of transport, privacy concerns and fear of disclosure to their partners.

The information was used to improve the quality of care. Peers were engaged to locate other mothers and their babies from the same community who had been lost to follow-up. By February 2014, 10 months after the baseline study, the 22 health facilities had all achieved strong gains, retaining more than 60% of mother-baby pairs.<sup>74</sup>

Many national health registries are still not properly formatted to facilitate long-term follow-up of HIV-exposed infants or mother-baby pairs. Several countries are moving to paper-based or electronic registers that capture data on HIV-exposed infants and mother-baby pairs through numerous care visits in order to prompt paediatricians to determine the final HIV status of the infant at the end of breastfeeding. Electronic health records allow for joint tracking of the mother and her infant using one tool, and enable babies to be tested and treated even when they are brought to the clinic for follow-up by someone other than the mother.<sup>75</sup>

Malawi is piloting the use of the short message service (SMS) widely available on mobile phones to send reminders to mothers who miss postnatal appointments. SMS is also being used in Kenya, South Africa, Mozambique, Zimbabwe, Rwanda and Zambia to send the results of infants' HIV tests from centralised laboratories to printers in community-level health facilities. A systematic review comparing paper-based systems and SMS systems showed that SMS printers quickened the delivery of test results by an average of 17 days.<sup>76</sup>

In Kenya, an HIV Infant Tracking System (HITSsystem), which sends computer alerts to health care and laboratory staff working on early infant diagnosis, alongside SMS alerts to mothers, increased the proportion of HIV-exposed infants retained in care nine months after birth; decreased turnaround times between sample collection, laboratory results and notification of mothers; and increased the proportion of infants living with HIV who initiate ART.<sup>77</sup>

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**Treatment and support for children living with HIV**

## HIV disclosure

Conveying the importance of HIV treatment to a young child or adolescent can be difficult. Many caregivers delay telling a child about their HIV positive status for a number of reasons. They may be anxious about stigma from the community, guilt regarding transmission, uncertainty in how to disclose, and fears of negative reactions or difficult questions from the child.<sup>78</sup>

However, it is important for a healthcare worker or carer to disclose a child's status to them, to prevent the child feeling isolated and finding out their status accidentally or in public. Evidence also suggests that children who were given reasons for needing to take medication were much more likely to have improved viral suppression, adherence and remain in treatment for longer.<sup>79</sup>

A study of a nationally implemented intervention to assist healthcare workers and caregivers with HIV disclosure to children in Namibia found that, among children who reported incorrect knowledge regarding why they take ARVs, 83% showed improved knowledge after the intervention (defined as knowledge of HIV status or adopting intervention-specific language). At enrolment, only 11% knew their status but an additional 38% reached full disclosure following the intervention. The average time to full disclosure was 2.5 years. The study found the intervention helped improve adherence to ART which improved viral suppression.<sup>80</sup>

## Psychosocial wellbeing

Many children living with HIV experience tough life events that could affect their psychosocial wellbeing, such as losing caregivers to AIDS-related illnesses, stigma, shock about their status, and not understanding the importance of adhering to treatment.

To mitigate these events, it is important to encourage children to have a positive outlook on life, which can be helped by making full use of services such as support groups.<sup>81</sup>

A 2014 study of families affected by HIV in Bangladesh found that, while children's lives are affected by any chronic condition their parents may have, when the condition is stigmatised and carries what the study describes as "social and moralistic connotations", the impact on the family is much greater in intensity and consequences. The study found that community members did not like to interact with HIV-positive people and their children due to a fear of being infected. It found peer support can be emotionally beneficial to children affected by HIV, as children - like adults - will often seek support from friends to cope with stressful situations.<sup>82</sup>

Young children listen and learn from peers and get easily motivated by each other, therefore awareness-building through peers, such as forming peer groups or youth clubs at schools, can play a key protective role in the lives of HIV-affected children. The study also recommends that children are enabled to inform the development of strategies that empower them to cope with living in families affected by HIV.<sup>83</sup>

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I have faced problems in my community previously, due to HIV. People thought that as my mother is infected with HIV, we are also infected... When I was a child people asked me, does your mother

have AIDS? Then many children did not play with me. Someone said, “Your mother has kharaprog [HIV] you also have kharaprog, don’t come to us and don’t play with our children.” Our neighbours said that our father was a kharaplok [bad person]. As he did kharapkaj [bad practices] in India so he became AIDS patient.

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- Rafik, a 15-year-old boy from Bangladesh whose mother is living with HIV and whose father died of an AIDS-related illness<sup>84</sup>

## Right to education

All children living with HIV have the right to attend school, just as any other child does. Policies need to be in place to ensure a child living with HIV at school is not subjected to [stigma and discrimination](#) or bullying, and that their status is kept confidential.<sup>85</sup>

The inclusion of sex and HIV & AIDS education for young children is vital for tackling the stigma surrounding HIV, and to teach others the facts about HIV transmission.<sup>86</sup> HIV-awareness programmes are important to encourage openness about HIV rather than silence.<sup>87</sup>

There are many ways to reach young people; including through social groups, the media, and peer outreach - not just at school.

## Family support for children living with HIV

Supporting a family holistically can be the best way to ensure a good quality of life for the child. This should include social protection schemes that provide external assistance to poorer families in areas where HIV prevalence is high. Such schemes are now seen as a valuable part of improving the lives of children affected by HIV.<sup>88</sup>

### CASE STUDY: Building the resilience of families affected by HIV in Rwanda

A 2014 study of families affected by HIV in Rwanda focused on a locally adapted, home-based intervention which aimed to improve the functioning of families and caregiver-child relationships, connect vulnerable families to available formal and informal HIV services, and promote emotional and behavioural health among HIV-affected children.<sup>89</sup>

Thirty-nine children and adolescents (aged 7- 17) from 20 different families were enrolled in the study. It found that, six months after the intervention had been carried out, caregivers reported improvements in children's behaviour, and that family connectedness, good parenting and social support were sustained and strengthened. Children’s self-esteem also improved, and symptoms of depression, anxiety and irritability declined.<sup>90</sup>

## Financial support for children living with HIV

Reduced household income combined with increased expenses (for example for treatment, transport and funerals) can push families affected by HIV into poverty, which has negative outcomes for children in terms of nutrition, health status, education and emotional support. For example, a study of monthly household income of HIV-affected families in Cambodia found income to be 47% lower than non-affected families. Similarly, in China the income of the vast majority of HIV-affected families (93%) decreased by more than 30% following diagnosis.<sup>91</sup>

Enabling a household to move away from economic vulnerability can lead children to benefit from better nutrition, the opportunity to go to school instead of work and better access to healthcare.<sup>92</sup> Evaluations of national social protection programmes have established that social protection (in particular, cash transfers) contributes to improving access to health, education and nutrition, strengthening social networks, increasing access to treatment and prevention and reducing child and adolescent vulnerability and risk-taking.<sup>93</sup>

For example, in Malawi a cash transfer programme that had specific conditions to keep girls in school reduced the school dropout rate by 35%. It also resulted in a 40% reduction in early marriages, a 30% reduction in teenage pregnancies and a 64% reduction in HIV risk within 18 months.<sup>94</sup>

The effectiveness of these interventions has seen the number of cash or income transfer programmes double in Africa between 2000 and 2012, supporting US\$10 billion worth of transfers during this period.<sup>95</sup>

## Childhood illnesses

Childhood illnesses such as mumps and chickenpox can affect all children but children living with HIV may find these illnesses are more frequent, last longer, and are not as responsive to treatment.

In 2015, around 40,000 children living with HIV died from tuberculosis (TB).<sup>96</sup> Although TB-related deaths for children living with HIV are in decline, having stood at 74,000 in 2012,<sup>97</sup> many countries only report HIV as the underlying cause of death, with TB as the contributory cause, meaning this number may be higher than is currently recorded.<sup>98</sup>

## The future of the HIV epidemic among children

Children are disproportionately affected by the HIV epidemic, and continue to be left behind in the provision of life saving treatment.

Interventions that meet the specific needs of families, driven by the experiences and recommendations of children, are needed to enable the 50% of children living with HIV who are without treatment to access it. Without this, children aged 0–4 years living with HIV will continue to be the age group most at risk of AIDS-related deaths.<sup>99</sup>

A combination of efforts are needed to prevent new HIV infections among children, ensure that their mothers remain healthy and improve the diagnosis and treatment of HIV for children. While huge gains have been made in preventing MTCT of HIV, the fact that an additional 5.2 million women of reproductive age were newly infected with HIV between 2010 and 2015 means the substantial need for PMTCT services will continue for the foreseeable future.<sup>100</sup>

Paediatric HIV diagnosis, testing and treatment needs to be scaled up to bring it in line with adult services and should be made available closer to where the children most affected live. Health workers need to be trained to provide effective HIV services for children living with HIV.[101](#)

Community support systems are invaluable and need to be strengthened to allow them to effectively support children and carers to keep them healthy and ensure that they have access to the HIV services they require.[102](#)

More medicines specifically adapted to the needs of children need to be developed, and kept at an affordable price. To achieve this requires political will and investment by industry. Government, nongovernmental organisations, research partners, health experts and civil society need to advocate strongly for the development of child-friendly fixed-dose combinations to ensure that simple and effective treatment becomes rapidly available and accessible for all children in need.[103](#)

Alongside this, there needs to be greater support for the families and communities that provide the material, social, and emotional foundation for a child's development.

*Photo credit: ©AVERT by Corrie Wingate. Photos are used for illustrative purposes. They do not imply any health status or behaviour on the part of the people in the photo.*

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Last full review:

17 May 2017

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