

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



## KEY POINTS

- Prevention of mother-to-child transmission (PMTCT) programmes offer a range of services for women of reproductive age living with or at risk of HIV to maintain their health and stop their infants from acquiring HIV.
- PMTCT services should be offered before conception, and throughout pregnancy, labour and breastfeeding.
- PMTCT services should include early infant diagnosis at four to six weeks after birth, testing at 18 months and/or when breastfeeding ends, and ART initiation as soon as possible for HIV-exposed infants to prevent HIV acquisition.
- Keeping women and infants in PMTCT programmes after delivery is challenging. In some countries more infant infections are now occurring during the postnatal period due to breastfeeding rather than pregnancy or labour due to the high rates of women who leave care.
- Around 1.4 million HIV infections among children were prevented between 2010 and 2018 due to PMTCT programmes.

Explore this page to find out more about [WHO guidelines for PMTCT](#), [global PMTCT targets](#), [progress in the prevention of mother-to-child-transmission](#), [barriers to the uptake of PMTCT programmes](#) and [the future of PMTCT programming](#).

HIV can be transmitted from an HIV-positive woman to her child during pregnancy, childbirth and breastfeeding. Mother-to-child transmission (MTCT), which is also known as 'vertical transmission', accounts for the vast majority of infections in [children](#) (0-14 years).

Without treatment, if a pregnant woman is living with HIV the likelihood of the virus passing from mother-to-child is 15% to 45%. However, antiretroviral treatment (ART) and other interventions can reduce this risk to below 5%.<sup>1</sup>

PMTCT programmes provide a range of services to women and infants. These include preventing HIV infections among women of reproductive age (15–49 years), preventing unwanted pregnancies among women living with HIV, and providing women living with HIV with lifelong ART to maintain their health and prevent transmission during pregnancy, labour and breastfeeding.

PMTCT programmes also support safe childbirth practices and appropriate infant feeding, as well as providing infants exposed to HIV with virological testing after birth and during the breastfeeding period, ART for prevention and effective treatment.

Around 1.4 million HIV infections among children were prevented between 2010 and 2018 due to the implementation of PMTCT services.<sup>2</sup>

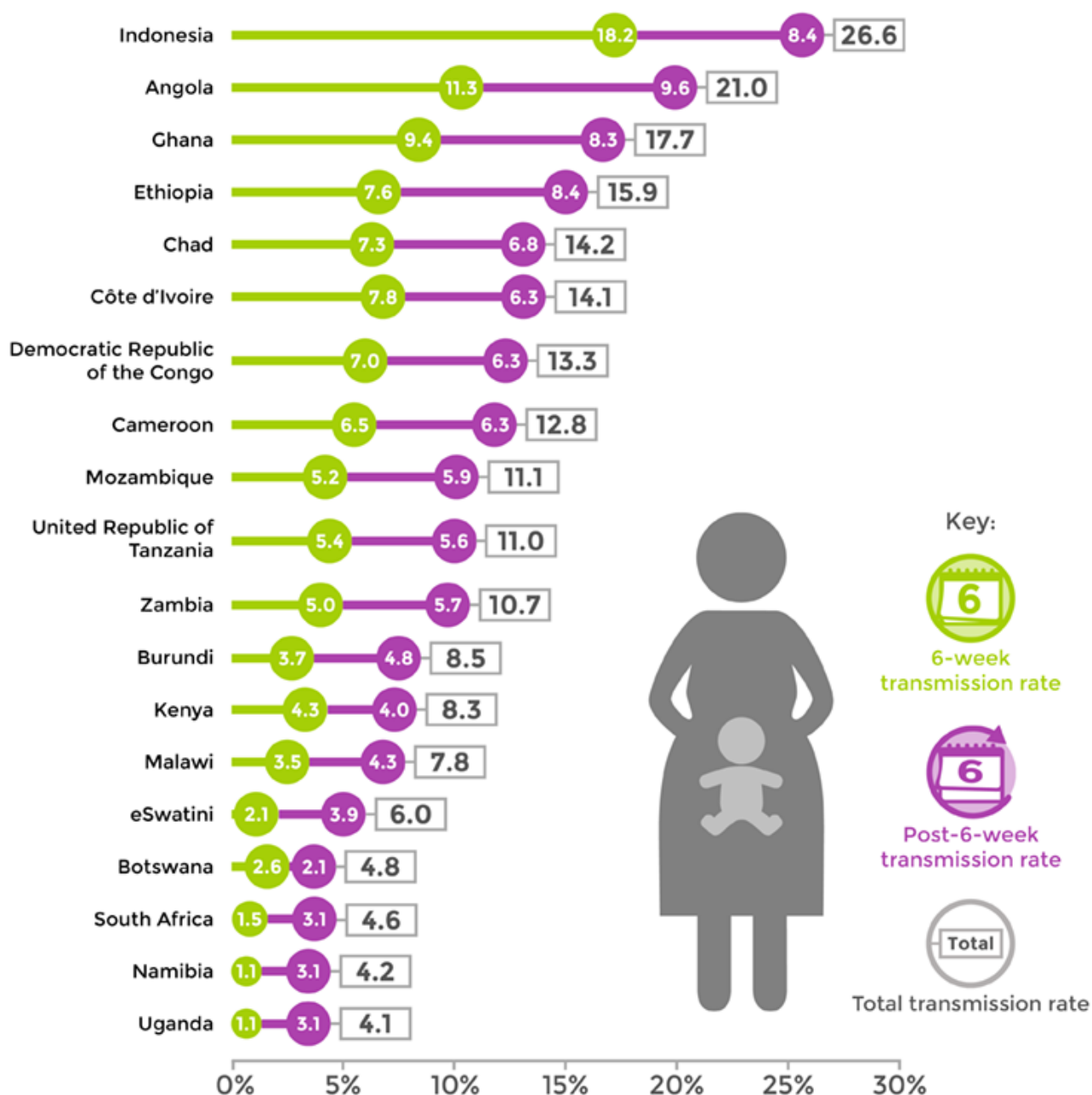
In 2017, 80% of pregnant women living with HIV were receiving ART, a significant increase from 2010 levels when only 51% had access.<sup>3</sup>

Despite this significant progress, 740,000 women of reproductive age became HIV positive in 2016. Around 73% of these women live in just 23 countries, the vast majority of which are in sub-Saharan Africa, and are classified as high-priority for PMTCT by UNAIDS.<sup>4</sup>

In 2017, just over half (52%) of the 1.8 million children living with HIV were receiving ART. Among those without access to effective treatment, 110,000 died due to AIDS-related illnesses.<sup>5</sup>

In 2017, roughly half the 180,000 children newly infected with HIV were infected during breastfeeding.<sup>6</sup> There are particular challenges in maintaining women living with HIV in care and on effective ART throughout the breastfeeding period, as well as reducing, detecting and managing new infections occurring among women while they are pregnant or breastfeeding. As a result, in some countries more infant infections are now occurring during the postnatal period rather than pregnancy or labour.<sup>7</sup>

## Six-week, post-6-week and final mother-to-child transmission rate by country, 2016



Source: UNAIDS 2017 estimates

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## World Health Organization PMTCT guidelines

The World Health Organization (WHO) promotes a comprehensive approach to PMTCT programmes which includes:

- preventing new HIV infections among women of reproductive age
- preventing unintended pregnancies among women living with HIV
- preventing HIV transmission from a woman living with HIV to her baby
- providing appropriate treatment, care and support to mothers living with HIV and their children and families.<sup>8</sup>

## Guidelines for pregnant women living with HIV

In September 2015 WHO released guidelines recommending that all pregnant women living with HIV be immediately provided with lifelong treatment, regardless of CD4 count (which indicates the level of HIV in the body). This approach is called Option B+.<sup>9</sup> By 2015, the implementation of Option B+ had resulted in 91% of the 1.1 million women receiving antiretroviral (ARV) drugs as part of PMTCT services being offered lifelong ART.<sup>10</sup>

A year later, WHO released guidelines recommending a 'treat all' approach, meaning all people diagnosed with HIV should be offered immediate treatment. This has increased the number of women of reproductive age who are receiving ART, regardless of whether they are pregnant or not.<sup>11</sup> All but two of the 23 countries deemed a priority for PMTCT by UNAIDS have moved to implement these guidelines.<sup>12</sup>

## Guidelines on infant feeding for mothers living with HIV

WHO bases its recommendations on infant feeding for mothers living with HIV on the comparative risk of infants acquiring HIV through breastfeeding with the increased risk of infants dying from illnesses such as malnutrition, diarrhoea and pneumonia, which increases if they are not breastfed.

In 2016, WHO released guidelines recommending that mothers living with HIV who are on treatment and are being fully supported to adhere to it should exclusively breastfeed their infants for the first six months of life, then introduce appropriate complementary foods while continuing to breastfeed for at least 12 months and up to 24 months or longer (similar to the general population).

When ARV drugs are not immediately available, the WHO guidelines still recommend mothers exclusively breastfeed for the first six months of an infant's life and continue, unless environmental and social circumstances are safe for, and supportive of, replacement feeding. This decision should be based on international recommendations and consideration of:

- the socioeconomic and cultural contexts of the population groups served by maternal and child health services
- the availability and quality of health services
- the local epidemiology (which diseases are common and who they affect), including HIV prevalence among pregnant women
- the main causes of under-nutrition among mothers and children, and infant and child mortality.

When ARV drugs are unlikely to be available, such as in acute emergencies, mothers living with HIV are still recommended to breastfeed their infants to increase their chances of survival.<sup>13</sup>

## Does an undetectable viral load prevent HIV transmission while breastfeeding?

People on antiretroviral treatment who maintain an undetectable viral load (which is when HIV in the body has been suppressed to such a low level that blood tests cannot detect it) are not at risk of transmitting HIV to sexual partners. This has led to the question of whether women living with HIV who are undetectable can breastfeed without fear of passing HIV to their infant.

Research on breastfeeding women living with HIV that includes viral load data is limited. What evidence does exist indicates that an undetectable viral load provides significant protection from HIV

transmission. However, there have been cases of HIV transmission among breastfeeding women with undetectable viral loads.<sup>14</sup>

Currently, most high-income countries recommend women living with HIV do not breastfeed whether they are virally suppressed or not. This is because formula feed and clean, boiled water are widely accessible. So any risks around dirty water or malnutrition have been eliminated. In low- and middle-income countries this risk is far greater, leading WHO's advice on infant feeding to differ.

## Guidelines for HIV-exposed infants

If an HIV-exposed infant is given ART within the first 12 weeks of life, they are 75% less likely to die from an AIDS-related illness.<sup>15</sup>

This is one of the reasons WHO recommends that infants born to mothers living with HIV are tested between four and six weeks old. This is often referred to as 'early infant diagnosis'.<sup>16</sup>

WHO further recommends that another HIV test is carried out at 18 months and/or when breastfeeding ends to provide the final infant diagnosis.<sup>17</sup> As proportionally more infant infections are now occurring during breastfeeding these tests are becoming increasingly important.

According to WHO guidelines, all infants who test positive for HIV should be immediately initiated on treatment. The treatment should be linked to the mother's course of ARV drugs and would vary according to the infant feeding method as follows:

- breastfeeding: the infant should receive once-daily nevirapine from birth for six weeks
- replacement feeding: the infant should receive once-daily nevirapine (or twice-daily zidovudine) from birth for four to six weeks.<sup>18</sup>

## Global prevention of mother-to-child transmission targets

UNAIDS launched *Start Free Stay Free AIDS Free* in 2017, also known as the *Super Fast-Track Framework and Action Plan*. This builds on the successes achieved under the *Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive* (Global Plan), which was released in 2011, while bringing additional focus to the HIV prevention and treatment needs of children and adolescents.

*Start Free Stay Free AIDS Free* embraces the goals adopted by UN member states in the 2016 Political Declaration on Ending AIDS. It commits to the dual elimination of mother-to-child transmission of both HIV and congenital syphilis (syphilis can result in miscarriage, stillbirth, neonatal infections and death). As PMTCT is not 100% effective, elimination of HIV is defined as reducing the final HIV transmission rate to 5% or less among breastfeeding women and to 2% or less among non-breastfeeding women by 2020.<sup>19</sup>

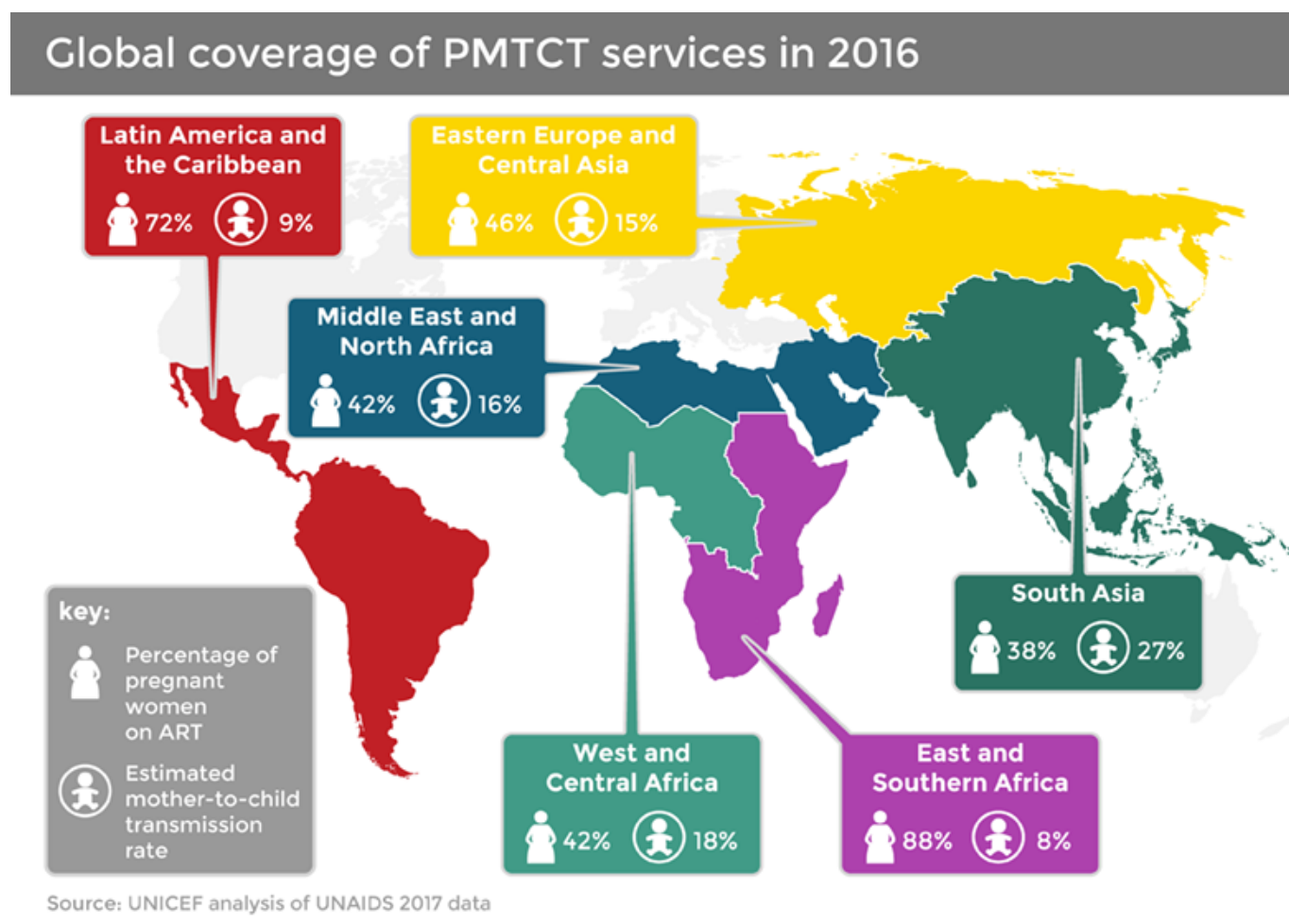
The 2017 framework is designed to accelerate action in 23 priority countries: Angola, Botswana, Burundi, Cameroon, Chad, Côte d'Ivoire, the Democratic Republic of the Congo, Ethiopia, Ghana, India, Indonesia, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Eswatini, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe.

In 2016, these countries were home to 87% of all children and adolescents living with HIV in the



world. They were also where 87% of new HIV infections among children and 81% of new HIV infections in adolescent girls and young women (10–24 years) occurred.<sup>20</sup>

Targets include reducing the number of new HIV infections among children to fewer than 40,000 by 2018 and fewer than 20,000 by 2020, reducing the number of new HIV infections among adolescents and young women (aged 10–24) to fewer than 100,000 by 2020, and providing 1.4 million children and 1 million 15-19-year-olds with HIV treatment by 2020. There is also a commitment to ensure that 95% of pregnant women living with HIV are receiving lifelong HIV treatment by 2018, a target that is unlikely to be met.<sup>21</sup>



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## Progress in prevention of mother-to-child transmission

A number of countries have now reached the elimination threshold for mother-to-child transmission of HIV and syphilis. These are Belarus, Cuba, Thailand and Malaysia, Anguilla, Antigua and Barbuda, Bermuda, Cayman Islands, Montserrat and Saint Kitts and Nevis. Armenia has eliminated vertical transmission of HIV and the Republic of Moldova has eliminated vertical transmission of syphilis.<sup>22 23</sup> Outside of these countries, progress on the key focus areas is mixed, as outlined below.

### Preventing new HIV infections among women of reproductive age

Globally, new infections among women of reproductive age decreased by just 2% between 2010 and 2015 and by 6% among adolescent and young women (15 to 24 years), an age group that is at particularly high risk of HIV. During this time, 5.2 million women of reproductive age were infected

with HIV, including 1.1 million women in South Africa alone.[24](#) [25](#)

In 2016, an additional 740,000 women of reproductive age became HIV positive, 540,000 of whom lived in 23 PMTCT priority countries.[26](#)

Evidence has revealed a cycle of HIV infection among older and younger people that may be at play in many high-prevalence settings: young women are acquiring HIV from adult men, then as these young women grow older they are transmitting HIV to adult men in their peer group, and the cycle repeats. Gender inequalities and harmful gender norms underpin this cycle. Lower access to education, lower levels of economic independence and intimate partner violence erode the ability of women to negotiate safer sex and retain control of their bodies.

Numerous HIV prevention programmes are trying to address this cycle of infection. For instance, SheConquers in South Africa began in 2016 with the aim of decreasing new HIV infections, teenage pregnancies and gender-based violence among young women and adolescent girls, to increase and retain young women and adolescent girls in school, and to increase economic opportunities for young people, particularly young women.[27](#)

Education about HIV and contraception is also crucial. Research suggests comprehensive sexuality education programmes with an explicit focus on gender rights and gender power dynamics are five times more effective than those that do not in reducing HIV and other sexually transmitted infections (STIs).[28](#)

## Preventing unintended pregnancies among women living with HIV

Family planning is one of the most important PMTCT measures. When women living with HIV are supported to plan when they do and do not have children, the number of children being born with HIV reduces. HIV positive women are also at greater risk of dying from pregnancy-related complications than women who are not living with HIV. In 2015, WHO estimated that 4,700 maternal deaths were caused indirectly by AIDS-related illnesses globally.[29](#)

Sub-Saharan Africa has the highest HIV prevalence in the world and the highest unmet need for contraception, with one in five women unable to plan or limit pregnancies.[30](#)

Studies have shown that women living with HIV have higher unmet need for family planning and reproductive health services than the general population, in part due to lack of investment in integrated family planning and HIV services. In 2014, a global survey on the sexual and reproductive health and rights (SRHR) of women living with HIV, the largest to date, led by and conducted among women living with HIV, found 60% of respondents had at least one unplanned pregnancy and that less than half had ever obtained family planning services.[31](#)

Integrating family planning services into HIV services has been one approach to making both more accessible to women and couples living with HIV, and significant progress has been made in the past decade. In 2017, a systematic review of the evidence found overall integration of family planning into HIV care and treatment programmes with modern methods including contraceptive use and knowledge among women living with HIV. However, it found the difference it made in meeting unmet need for family planning was more limited, with the level of need extremely high, even at the integrated sites.[32](#)

## Preventing HIV transmission from a woman living with HIV to her infant

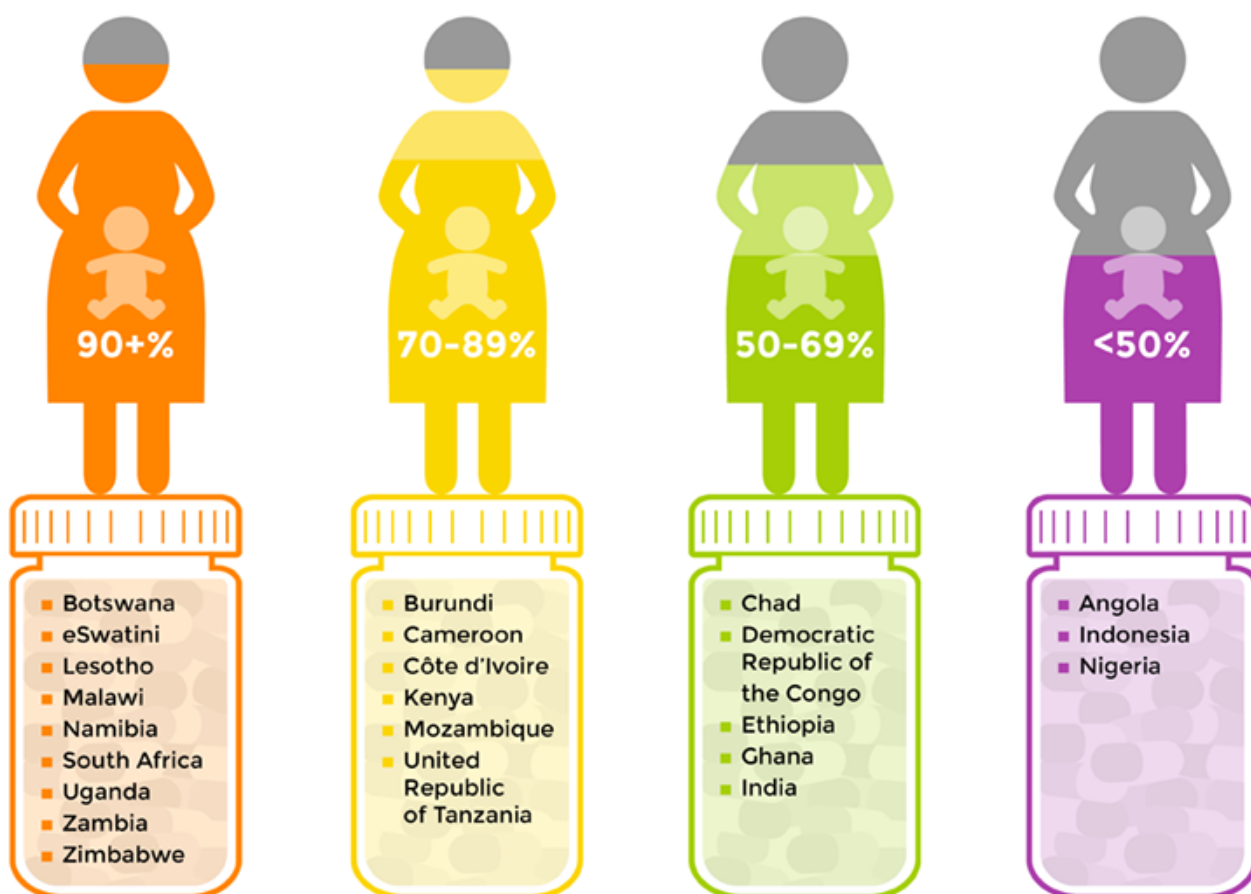
Since 2010, 1.4 million infections among children have been averted<sup>33</sup> and there has been a 48% decline in new child infections among the 23 UNAIDS' priority countries.<sup>34</sup>

However, in 2017, 180,000 children became HIV positive, the vast majority through vertical transmission.<sup>35</sup>

In the same year, 80% of pregnant women living with HIV were receiving ART.<sup>36</sup> At least nine of UNAIDS' 23 priority countries have reached or nearly reached the target of 95% of pregnant women living with HIV on lifelong ART, and another six countries appear on track to do so.<sup>37</sup>

Recent gains have been particularly impressive in eastern and southern Africa where in 2017 an estimated 93% of women living with HIV had initiated, or were already on, ART during pregnancy. As a result, the percentage of children in the region who acquired HIV from their mother declined from around 18% in 2010 to 10% in 2017.<sup>38</sup>

### % of pregnant HIV-positive women in priority countries receiving antiretroviral treatment to prevent mother-to-child transmission, 2017



Source: UNAIDS 2018 estimates

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ART coverage for pregnant women living with HIV is considerably lower in western and central Africa at 48%. In 2017, an alarming one in five children born to mothers living with HIV in the region became HIV positive during childbirth or breastfeeding.<sup>39</sup>



Because Nigeria is a densely populated country with high HIV prevalence, the lack of progress here is of particular concern for western and central Africa. Nigeria is one of four countries in the world where annual infections among children are above 10,000, the others being Mozambique, South Africa and Tanzania.<sup>40</sup>

In 2017, 35% of pregnant women in Nigeria received an HIV test, fewer than in 2015 when 42% did. Of those women diagnosed with HIV in 2017, just 30% were on ART. In the same year, 36,000 children became HIV positive, a number that has been rising since 2014. Early infant diagnosis is also extremely low at only 12%.<sup>41</sup> By comparison, in Cote d'Ivoire 92% of pregnant women received an HIV test in 2017, 70% of pregnant women diagnosed with HIV were on ART and 40% of infants received early infant diagnosis.<sup>42</sup>

Only 22% of pregnant women living with HIV received ART in the Middle East and North Africa in 2017.<sup>43</sup> In 2015, nearly one third of pregnant women living with HIV passed the virus on to their infant, making it the region that has made the least amount of progress.<sup>44</sup>

In 2017, approximately three quarters of pregnant women living with HIV in Latin America and the Caribbean received ART, while coverage was 56% in Asia and the Pacific. However, Indonesia is significantly behind the regional average, with coverage of just 13%.<sup>45</sup>

## Birth defects and dolutegravir

In May 2018, a preliminary analysis from a Botswana study of more than 10,000 pregnant women living with HIV found dolutegravir (DTG), a commonly-used ARV, may be associated with serious birth defects.

The findings came from Tsepamo, a four-year surveillance study of all babies born to women at eight clinics in Botswana to assess the frequency of neural tube defects among infants, which can cause large holes in an infant's spine or prevent the top of the skull from forming.

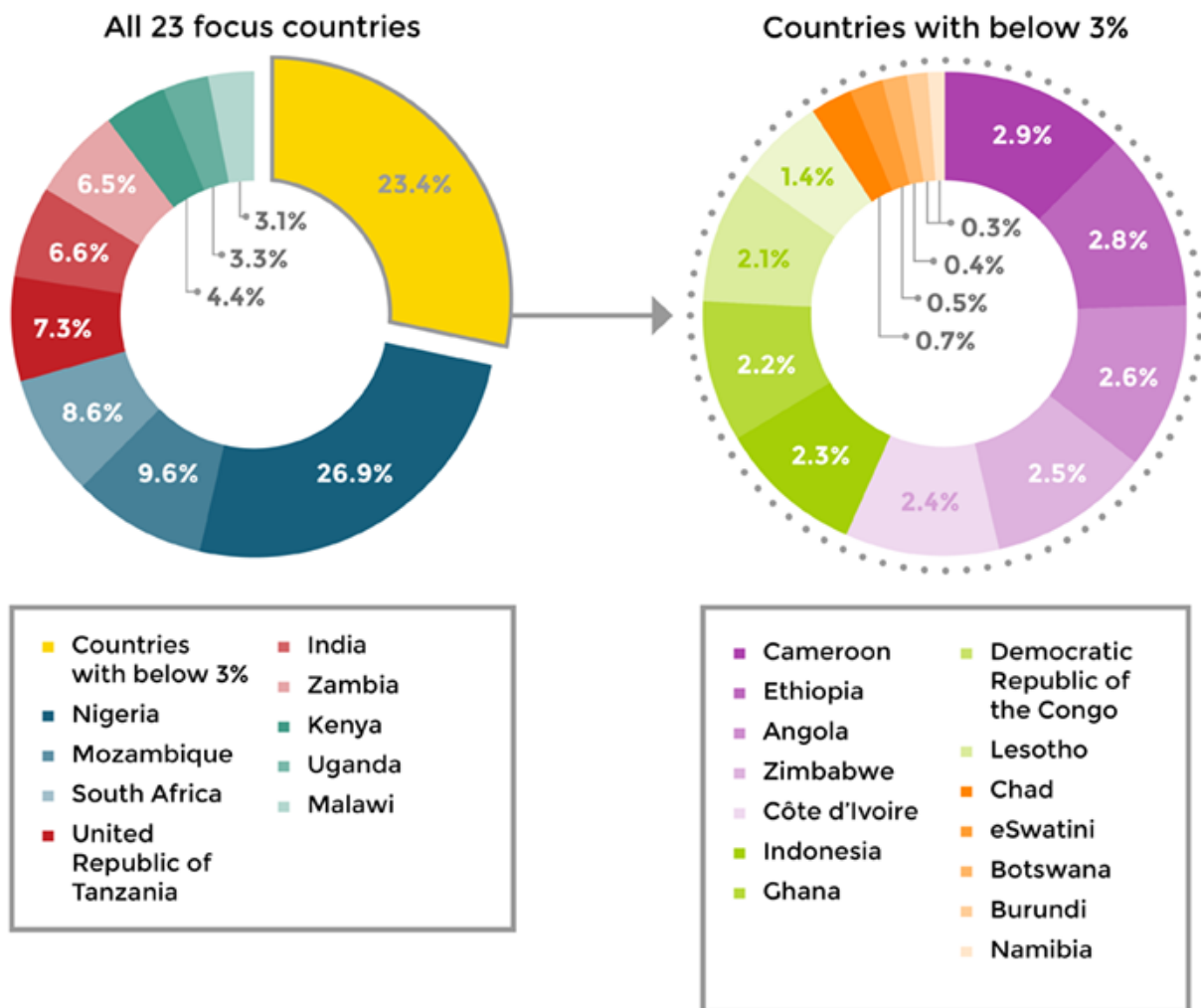
Initial data found an increase of neural tube defects among women who were taking DTG at the time of conception at a rate of 0.94%, nine times higher than other ARV drugs. This led WHO to issue an 'alert' warning about the potential danger.

In July 2018, researchers reported more data from that study which suggests the risk may be lower than first thought. WHO then released a guidance describing the Botswana data as a signal of a potential safety risk but recommend that DTG still be considered a preferred first- or second-line drug for 'everyone living with HIV over six years and weighing more than 15 kg, including adolescents and young women of childbearing potential, who are using consistent and reliable contraception.'

The Tsepamo study has now been expanded to 18 clinics, which should capture nearly 75% of all births in the country. By March 2019, data on 1,200 babies born to mothers who started DTG pre-conception will be available that will provide more evidence on the issue.<sup>46</sup>

## Providing appropriate treatment, care and support to mothers living with HIV and their children

## Distribution of children infected through mother-to-child transmission, 23 focus countries, 2016



Source: UNAIDS 2017 estimates

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### Retaining women in PMTCT programmes after they've given birth

The need to support more women to adhere to ART during breastfeeding is a growing priority for PMTCT programmes. This is because it is common for women to gradually stop taking ARV drugs after giving birth, which not only compromises their health but also puts their infant at an increased risk of acquiring HIV during breastfeeding.

In 2017, roughly half of new infections among children took place during breastfeeding, and in some countries more infant infections are now occurring during the postnatal period rather than pregnancy or labour due to the high rates of women who leave care.<sup>47</sup> A review of large studies in Kenya, South Africa, the USA and Zambia found 76% of pregnant women adhered to ART during pregnancy, but only 53% did so post-birth.<sup>48</sup>

A study from Malawi suggests that women who started treatment in the context of PMTCT services were five times more likely to be lost to follow-up compared to those who started treatment for their own health.<sup>49</sup>

Integrating ART services for mothers with maternal and child health services is a simple and highly effective way of retaining mothers in care after they have given birth. For example, a study from South Africa found the integration of postnatal HIV treatment services into maternal, neonatal and child health services markedly improved treatment outcomes. Around 77% of the mothers who were offered ART as part of maternal, neonatal and child health services achieved viral suppression, compared with 56% of the mothers who were referred to separate treatment services.<sup>50</sup>

In addition, 'mentor mothers' are playing important roles in helping retain mothers in care and supporting strong adherence to treatment, especially after they have given birth. An evaluation in nine districts of eastern and central Uganda found facilities using the mentoring model had stronger retention in HIV care and higher uptake of early infant diagnosis compared with other services. The psychosocial wellbeing of the mothers receiving mentoring support was also better.<sup>51</sup>

## Providing support for HIV exposed infants

There is emerging evidence about the negative impact on the health and development of infants who are exposed to HIV, even if they do not become HIV positive.

Some studies have found higher levels of illness, death and stunted growing among HIV exposed infants compared to those who have been born to HIV negative mothers.<sup>52</sup> The reasons behind this are not yet fully understood, and may be attributable to co-existing factors such as malnutrition, however research is growing.

## Early infant diagnosis

HIV positive infants and children who start treatment late are more likely to experience treatment failure, which underlines the need to diagnose HIV as early as possible.

In 2017, just 50% of infants who were exposed to HIV had been tested by eight weeks of age.<sup>53</sup> However, there is wide variation between countries.

South Africa and Eswatini respectively reached 80% and 78% of infants with an early infant diagnosis test, but significant gaps remain for many countries: only nine of 23 priority countries have achieved coverage rates of 50% or greater in 2016.<sup>54</sup>

Intensified efforts to identify children living with HIV are growing. Turnaround time and the actual return of test results to providers and parents are critical bottlenecks to early initiation of treatment.<sup>55</sup> Point-of-care testing has the potential of helping to overcome the problems associated with the time gap between test and result. Point-of-care technology makes it possible to test infants on-site and receive the results within hours. This means that HIV-positive infants can begin ART immediately which reduces the risk of loss to follow-up.<sup>56</sup>

Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), Unitaid and partners are delivering a four-year, US \$63 million project to expand point-of-care early infant technology in Cameroon, Côte d'Ivoire, Kenya, Lesotho, Mozambique, Rwanda, ESwatini, Zambia, and Zimbabwe. Between 2015 and 2019, EGPAF aims to test 250,000 infants and identify 14,600 infants living with HIV. It will also produce and share valuable evidence regarding the feasibility, utility, and cost of utilising this technology.<sup>57</sup>

A large, randomised study in Mozambique found infant HIV point-of-care tests significantly improved retention in care and ART initiation. The study found that, whereas all of the results gained through point-of-care testing were made available at the health facility, 19% of the results from tests gained through standard lab testing failed to be returned to the facility.

Similarly, 99.5% of point-of-care results were provided to the infant's caregiver, compared to 65% of the standard test results. In addition, only 7.2% of the results of standard care tests reached the caregiver within two months of testing, and only 47.2% within six months of testing.

The study found that infants receiving point-of-care tests were seven times more likely to start ART within two months than those receiving standard tests. While 89.7% of infants who tested positive on a point-of-care test had started treatment within two months of diagnosis, only 12.8% of those tested by the standard method had started treatment. Six months after testing, infants in the point-of-care arm of the study were still around two-and-a-half times more likely to be on treatment than those tested using standard testing methods.[58](#)

In the absence of point of care testing, other approaches are being found to be effective. These include providing HIV testing for children presenting with malnutrition or tuberculosis, HIV screening during immunisation visits, and encouraging adults living with HIV to have their children tested.[59](#)

## Providing treatment and care for HIV positive infants and children

There is an urgent need to accelerate treatment for children living with HIV across the priority countries. Globally in 2017, just over half (52%) of 1.8 million children living with HIV were receiving treatment.[60](#) This is far below the target of 1.6 million children on treatment by the end of 2018, as adopted in the 2016 Political Declaration on Ending AIDS.[61](#)

Among the 23 priority countries, in 2016, four reported treatment coverage among children of 60% or greater (Botswana, Kenya, Namibia and Eswatini). There continues to be low ART coverage among children in the western and central Africa, with six out of eight priority countries reporting treatment coverage in 2016 that was equal to or less than 25%.[62](#)

Due to a lack of treatment, 110,000 children died due to AIDS-related illnesses in 2017.[63](#)

Infants and young children who acquire HIV have a high risk of illness and death. Among those who are infected during pregnancy and/or labour, this risk is exceptionally high, with a peak between three to four months of age. Half of infants with HIV infection will die before their second birthday if they do not receive treatment.[64](#)

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## Barriers to the uptake of PMTCT programmes

As well as the scale-up of PMTCT programmes, a number of barriers need to be overcome in order to increase access to these services.

### Knowledge about HIV, MTCT and PMTCT

A number of studies have identified the link between knowledge of HIV, MTCT and PMTCT and uptake of PMTCT services. For example, research from Togo reported a 92% HIV testing uptake among participants where:

- 77% of pregnant women agreed that unprotected sex increased the risk of HIV transmission to their child
- 61% recognised that the risk of HIV transmission to their child was higher for mixed breastfeeding than for exclusive breastfeeding.<sup>65</sup>

A study of more than 10,000 women in Tanzania found that only 46% of respondents had adequate knowledge on MTCT and PMTCT. Factors associated with having adequate knowledge were experiencing at least one pregnancy, higher education levels, higher household wealth, living in an urban area, being exposed to HIV education, having taken an HIV test or knowing where to get tested for HIV. Women living with HIV were more likely to have adequate knowledge of MTCT than women who were HIV negative (56% compared to 46%).<sup>66</sup>

Conversely, other studies have associated high levels of HIV, MTCT and PMTCT knowledge with lower acceptability of PMTCT. One study from south west Nigeria recorded that, while 99.8% of pregnant women were aware of HIV and had very high knowledge of MTCT (92%) and PMTCT (91%), 71% had negative views towards PMTCT. This was due to factors such as stigma and discrimination.<sup>67</sup>

### Knowledge of HIV status

Knowledge of HIV status is vital in order for pregnant women to access the appropriate treatment and care for themselves and their infants.

The percentage of pregnant women being tested for HIV varies greatly between countries, with many of the priority 23 countries now achieving coverage of 70% and above. However, others have testing rates far behind this. For example, in the Democratic of Congo 37% of pregnant women received an HIV test in 2017, and a similar rate was seen in Nigeria at 35%. In Indonesia, less than a third of pregnant women (28%) received an HIV test.<sup>68</sup>

Pregnant adolescent girls and young women are less likely than older pregnant women to know their



HIV status before starting antenatal care.[69](#)

The traditional model for HIV testing is voluntary counselling and testing (VCT) also known as the 'opt in' method, in which people take the initiative in asking for an HIV test. Whereas, increasingly, PMTCT services are adopting an 'opt out' strategy, also known as physician or provider initiated testing and counselling (PITC), which means that women have to actively opt out or decline an HIV test after being given information and counselling about it.[70](#)

A study was carried out to determine the perception about 'opt out' HIV testing among 500 pregnant women attending the antenatal clinic at Adeoyo Maternity Hospital, Ibada in Nigeria. Almost all (97%) respondents had done an HIV test and received the results due to the 'opt out' approach.[71](#)

Slightly less than half (48%) mentioned the hospital as the first source of information about HIV. However, knowledge of HIV and PMTCT was high among the vast majority of women (95%), which the study partly attributes to the information and counselling session that all respondents had attended before testing.[72](#)

Some women in the study reported testing because they feared they would be suspected of being HIV positive should they decline. Others thought they might be denied antenatal care (ANC) if they refused testing. This brings to question the voluntariness of the 'opt out' strategy as about a fifth of the study participants felt that they were forced to have an HIV test.[73](#)

Not knowing one's HIV status acts as a barrier to PMTCT services. The point at which women are tested for HIV can also impact on their journey through PMTCT, should they test positive. For example, a study of pregnant women living with HIV from Cameroon, Cote d'Ivoire, South Africa, and Zambia found women who were diagnosed with HIV before their pregnancy were more likely to adhere to PMTCT treatment than women who tested positive during pregnancy.[74](#)

In addition, data from a number of African countries suggests women are three times more likely to acquire HIV during pregnancy and breastfeeding than at other times. Despite this elevated risk, many women are not being retested for HIV during these times, and they may be unaware of the need to take additional precautions. This is a major concern in settings with high HIV prevalence.[75](#)

## Confusion over exclusive breastfeeding

There is a certain amount of confusion about the best approach to breastfeeding for women living with HIV. This may stem from the fact that the recommended feeding approach is dependent on national or sub-national advice.

Research from [Tanzania](#) compared two hospitals that offered different infant feeding options. Hospital A promoted exclusive breastfeeding as the only infant feeding option, while hospital B followed Tanzanian PMTCT infant feeding guidelines which promote patient choice. Women in hospital A trusted the advice given and were confident in their ability to exclusively breastfeed, whereas women in hospital B expressed confusion and uncertainty about how best to feed their infants.[76](#)

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We were given the drugs to protect the baby from HIV infection but it can also happen that the baby may have already been born with

HIV and then you breastfeed him. Again if he is not found with HIV, he may have it in future. So I start to think that I should just stop breastfeeding and start formula feeding.

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- *A mother living with HIV from Lusaka, Zambia*<sup>77</sup>

## HIV stigma, discrimination and PMTCT

A body of research has highlighted how [HIV-related stigma and discrimination](#) can affect a pregnant woman's decision to enrol on PMTCT programmes and interrupt adherence to treatment and retention in care.<sup>78</sup>

It has been estimated that over 50% of vertical HIV transmissions globally can be attributed to the cumulative effect of stigma.<sup>79</sup>

A systematic review of studies on PMTCT in Cameroon, Côte d'Ivoire, Ethiopia, Kenya, Lesotho, Malawi, Rwanda, South Africa, Tanzania, Uganda, Zambia, Zimbabwe found HIV-related stigma impeded access to ARVs for mothers living with HIV.<sup>80</sup>

Similarly, research from Johannesburg, South Africa found that, while the effect of stigma on retention of women at any given stage along the cascade can be relatively small, the cumulative effect can be large.<sup>81</sup>

At the individual level, psychological difficulties following an HIV diagnosis were common among mothers and hindered ARV uptake. These included shock, denial of disease, depression or fear of handling side effects and a lifelong commitment to treatment.<sup>82</sup> Family and community-level barriers most frequently identified in the review were HIV-related stigma and fear of telling partners and family members. These factors deterred women from attending HIV/PMTCT clinics to receive ARV drugs for themselves and their infants, or from starting or continuing to take treatment. Lack of partner support was also a major hindrance, and women anticipated or experienced negative reactions from partners, including violence and separation, after sharing their HIV test results.<sup>83</sup>

A study involving 60 PMTCT outreach workers in Maharashtra, India describes stigma as the most persistent challenge facing HIV-positive pregnant and breastfeeding women. Many were fearful of telling their husbands and other family members, leading them to stop treatment because they felt unable to explain why they were on medication or might be experiencing side effects. Stigma also meant many were worried about being seen giving their baby medication in case it led to their HIV status being revealed to family members.<sup>84</sup>

A study in England partnered six 'Mentor Mothers' with six mothers, all of whom were living with HIV. Some said they had been sneered at and called 'dirty', found themselves at the centre of gossip or felt that their condition had been 'swept under the carpet', leaving them fearful of even looking at information on HIV. They strove to hide their HIV status in order to avoid the stigma they sensed within diaspora African communities.

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My immediate family... I don't want [them] to go: 'Oh, she's got this thing, she's going to die'.

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- *Participant, Mentor Mother project, 2016.*[85](#)

Trained peer support from fellow mothers proved a powerful way of addressing many of their challenges, including fears and feelings of isolation, gaps in maternity care and emotional wellbeing.

## Stigma in healthcare settings

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I know of a woman living with HIV who went to [an] antenatal [clinic and] at the point of delivery, [the doctor] went through the files and when he saw her file he said, 'This one, [I] am not touching her.' She was on the stretcher already and [was] in labour. He said, 'It's a positive case... I didn't leave my house to come and do a positive case today. I am not prepared.' The woman was left on the stretcher.

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- *A woman living with HIV from Nigeria*[86](#)

For women living with HIV, experiences of stigma, discrimination and abuse often occur when they seek maternal healthcare. This can take many forms including physical abuse, non-consented clinical care, non-confidential care, non-dignified care, abandonment or denial of care, and detention in facilities.[87](#)

The International Community of Women Living With HIV reports how pregnant women living with HIV have experienced service providers using extra gloves or bleach when dealing with them and asking women to not come close to them, touch things, and cover their mouths while talking. This discrimination and fear means that many women avoid going to hospitals and accessing PMTCT services.[88](#)

Many healthcare workers don't have the necessary skills or equipment to confidently handle delivery for an HIV-positive woman, and given the risk of accidental exposure, most nurses shy away from dealing with such patients.[89](#)

A report from the Middle East and North Africa region illustrates numerous human rights violations experienced by women living with HIV as they attempt to access healthcare, with a number of women reporting being refused treatment due to their status.

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As soon as I told [the doctor I was HIV positive], she moved away and so did the entire medical team. Within half an hour, I was moved to another hospital carrying the papers that proved I was someone living with HIV – and that made the answer from every hospital ‘no beds available’. I was physically in pain from fractures in my shoulder and thigh, and psychologically hurt by the rejection, stigma and discrimination I was facing. I had to lie to the medical team in order to get the treatment and care I needed.

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- *Sabera, a woman living with HIV in Sudan.*[90](#)

In various countries, women living with HIV report being poorly treated by doctors and nurses and being told they should not have children. Some women report being sterilised during delivery via caesarean section with healthcare providers giving PMTCT as the reason. They routinely report being asked to sign papers or verbally consent to sterilisation while in labour, or healthcare workers obtaining consent for the procedure from their husbands or fathers at this stage. Many women report being unaware they have been sterilised until they try to have another child.[91](#)

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During the caesarean and under the effects of the anaesthesia they forced her into sterilization so that she couldn't have more children. She didn't sign a consent. When she was recovering from the anaesthesia, she saw that her finger was stained with ink.

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- *A woman living with HIV from Mexico, describing another woman's experiences.*[92](#)

## Hard to reach populations

Restrictive policy environments, stigma and discrimination in healthcare settings, gender inequality and economic marginalisation undermine access to PMTCT services for women from populations most affected by HIV, such as sex workers and women who use drugs.

A study in Ukraine found pregnant women who inject drugs were more likely than other pregnant women to be diagnosed with HIV during labour and to have more advanced HIV. They also were less likely to receive ART. As a consequence, vertical transmission rates in this population were higher than in the general population.[93](#)

Young women also face major challenges accessing PMTCT services. Healthcare providers often lack the training and skills to deliver youth-friendly services and do not fully understand laws around the

age of consent. Age-restrictive laws, such as those that ban contraception under a certain age, also act as barriers to sexual and reproductive health and rights (SRHR) and HIV services.

A South African study found adolescent mothers (aged 15–19) had three times lower prevention of mother-to-child transmission uptake and triple the early mother-to-child transmission, compared with mothers aged 20 and over. Adolescents in the study were found to be having more unplanned pregnancies and were more likely to have their first ANC visit later in pregnancy.<sup>94</sup>

More age-disaggregated data on pregnant women living with HIV is needed to better understand the specific barriers facing young pregnant women.

## Country and clinic resources

In resource-poor settings, shortages of PMTCT staff, interruptions in treatment and supplies of medical equipment, as well as a shortfall in counselling services, all act as barriers to PMTCT services.

These factors often mean long waiting times for post-test counselling and many leave without getting their HIV test results.<sup>95</sup>

Poor monitoring of PMTCT services by healthcare workers also leads to poor retention in care. Research from Ethiopia reported poor follow-up rates in the PMTCT programme because healthcare facilities did not have registered information on HIV-positive mothers.<sup>96</sup>

A study on the provision of reproductive health services including PMTCT services in a primary healthcare setting in Tshwane, South Africa found patient overcrowding and long waiting times all hampered people's access to services. The factors leading to long waiting times were staff shortages and an increase in clients as people moved to the area.<sup>97</sup>

The importance of virological testing, particularly early infant diagnosis, is hampered by a lack of resources for point-of-care testing alongside a lack of knowledge among healthcare providers and mothers or caregivers. The fact that in many places HIV treatment for mothers and babies is followed up separately, rather than as a pair, presents another barrier to successful early infant diagnosis.

## Cultural beliefs and gender dynamics

In many settings, traditional gender roles and cultural beliefs mean that men often make decisions determining women's participation in HIV testing and wider SRH services.<sup>98</sup>

In 2017, 29 countries require women to obtain the consent of a spouse or partner to access SRH services.<sup>99</sup> This lack of access to comprehensive HIV and SRH services means that women are less able to look after their sexual and reproductive health and rights (SRHR) and reduce their risk of HIV infection.

Where SRHR and HIV services exist, they are primarily for married women and do not meet the specific needs of unmarried women of any age, particularly young women and adolescent girls. Gender dynamics also feed into discrimination from service providers, stemming from views around female sexuality.

In many communities in sub-Saharan Africa, pregnancy is viewed as a 'woman's affair', with a man's role primarily to provide financial support.



A Ugandan study found that, even if men saw accompanying their partner to antenatal clinics or PMTCT services as good practice, many still felt their main role was to provide financing for registration and delivery fees.<sup>100</sup>

A 2018 study among women and men in Kibera, Kenya found that health clinics were generally viewed as places for women and children, especially for antenatal and postnatal care.

Some men in the study viewed their partner's participation in PMTCT services as a threat to the control they wished to exert over her health and actions. Male partners who were aware of or suspected that they were also HIV positive, or took the steps to be tested after a female partner shared her HIV status, were more likely to allow her to enrol and fully participate in the area's PMTCT programme and be supportive of following PMTCT strategies such as medication or consistent feeding practices at home.<sup>101</sup>

## Male involvement

Greater involvement of male partners can also increase retention in PMTCT services and adherence to treatment.

Partner testing can identify whether male partners are HIV-positive and may be putting women at risk, and condom use can be promoted more strongly. Voluntary medical male circumcision (VMMC) has also been found to reduce female-to-male sexual transmission of HIV by 60%.

Fourteen countries have been prioritised for scale-up of VMMC, all of which are priority countries for Start Free Stay Free AIDS Free. Providing VMMC to 25 million additional men by 2020, with a focus on young men (aged 10-29), is also given a specific target within this framework.<sup>102</sup>

Generally, research has highlighted the beneficial impact of male involvement in programmes to prevent the mother-to-child transmission of HIV to tackle new infections among infants.<sup>103</sup>

A 2015 study of couples in Zimbabwe's Midlands province found men from couples who had previously experienced HIV testing and counselling were more likely to be involved in PMTCT. This implies that promotion at all other HTC entry points might enhance male involvement in PMTCT. Having time to visit the clinic with his partner also meant a man was more likely to be involved in PMTCT.<sup>104</sup>

Healthcare workers' friendliness towards male partners was significantly associated with male involvement in PMTCT. The study found that those men who felt needed and an important part of the pregnancy by healthcare workers when they accompanied their wives for ANC were more likely to become involved in PMTCT.<sup>105</sup>

Being afraid of knowing one's HIV status was associated with male partners being less likely to be involved in PMTCT. About 45% of the male partners interviewed in the study reported that they engaged in extra-marital affairs. The majority of these men refused to accompany their wives for PMTCT due to the fear of knowing their HIV status, which might result in stigma, discrimination, domestic violence or abandonment by their wife if positive. Three quarters of respondents also highlighted how fear of HIV test results was the main barrier to involvement in PMTCT. Men who perceived themselves at risk of HIV were therefore more likely to refuse to go for couple HIV testing and counselling. This implies the need for more HIV educational and behaviour change communication programmes for male partners in order to address issues to do with the benefits of

knowing one's HIV status.[106](#)

Inviting men to use voluntary HTC services, offering PMTCT services at sites other than ANC ones (such as bars, churches and workplaces), as well as prior knowledge of HIV and HIV testing facilities have all been identified as ways of increasing male involvement.[107](#)

## The future of PMTCT programming

Although huge strides have been made on PMTCT, a number of gaps continue to exist.

More effective counselling and preparation of women testing positive for HIV while pregnant is needed before they start ART to improve adherence levels after they have given birth. Community-based support and peer support is particularly needed to help women cope with HIV-related stigma and adhere to treatment. Some of these improvements can be achieved through further integration of HIV services and maternal and child health services.[108](#)

As some mothers living with HIV are lost to follow-up when they change healthcare providers, better data systems are also needed to enable women to be provided with appropriate services after transferring.[109](#)

The rapid expansion of point-of-care early infant diagnosis must become a key focus, particularly after the scale-up programmes now being carried out have provided the evidence-base needed for effective implementation.[110](#) Intensified efforts to identify infants and children living with HIV by integrating testing into other healthcare services, such as those for immunisation and nutrition, are also needed.[111](#)

Young pregnant women living with HIV and women from key populations are also in need of enhanced support via programmes that address the specific vulnerabilities and difficulties they face.[112](#)

Above all, the perception of reproductive health as being primarily the domain of women needs to change, and there should be more emphasis on promoting and facilitating couples testing and male involvement in PMTCT programmes in general.[113](#)

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