

## Missed opportunities to enrol women testing HIV-positive in antenatal and delivery services into long-term HIV care and treatment

### Introduction

Prevention of Mother to Child Transmission of HIV (PMTCT) programmes have been scaled up substantially in recent years. In 2009, it was estimated that 50% of pregnant women in East and Southern Africa were tested for HIV, up from 15% in 2005. In South Africa, Zambia and Botswana more than 90% of pregnant women were tested for HIV. However, testing is only the first step in a cascade of essential PMTCT interventions. Women identified as HIV-positive through these programmes need to be assessed for their eligibility for lifelong highly-active antiretroviral therapy (HAART). Women who do not yet require lifelong HAART should be given antiretrovirals (ARVs) for themselves and their baby as prophylaxis to prevent mother-to-child transmission, and should be given advice on infant feeding options. They also need to be linked into adult care and treatment programmes, so they can access treatment when their HIV illness has progressed.

Women who need lifelong HAART should be linked to HIV care and treatment services urgently; wherever possible they should be started on HAART during pregnancy. Giving pregnant women access to lifelong HAART is important for several reasons:

- for their own health
- to help improve the survival of mothers, which also will improve the chances of survival of their children
- where indicated, maternal HAART will further reduce the risk of transmission of HIV to their baby, compared to prophylactic antiretrovirals

However, the opportunity to get women identified as HIV-positive through testing in PMTCT services on to long-term HAART is often missed. This policy brief explores the extent of the problem, the barriers to making the most of the opportunity provided by PMTCT programmes, and discusses potential ways of overcoming these barriers. It draws primarily on evidence from quantitative and qualitative research conducted by the Evidence for Action Programme in Kenya and Tanzania.

### Background

In 2001 the United Nations General Assembly set a target for 80% of pregnant women and their children to have access to essential HIV prevention, treatment and care by 2010 to reduce the proportion of infants infected by

HIV by 50%. The focus now is on eliminating vertical transmission.

PMTCT involves counselling and testing of pregnant women; ART prophylaxis for the mother during pregnancy, labour and delivery, and the post-partum period; and ART prophylaxis for mother or infant for a variable amount of time, depending on whether the mother is breastfeeding and which of the two WHO-recommended options is being used. The WHO guidelines state that pregnant women should be assessed for eligibility to start HAART, and given this if eligible.

PMTCT activities take place in a number of different parts of the health service, including antenatal clinics (ANC), labour and delivery services, maternal and child health services, and HIV services.

### Key Points

- \* Prevention of Mother to Child Transmission (PMTCT) programmes offer an excellent opportunity to give HIV-positive pregnant women access to long-term HIV care and treatment for their own health
- \* Referral systems are failing many HIV-positive women, and the opportunity for them to receive HIV treatment for their own health and survival is being missed far too often
- \* These missed opportunities can be reduced through:
  - Ensuring the health of the woman becomes part of the responsibility of PMTCT services through effective linkages between maternal and child health and HIV treatment services, rather than only focusing on the health of her infant
  - Simplifying patient pathways to HIV treatment
  - Improved communication between pregnant women diagnosed with HIV and health workers, including additional and better counselling concerning the importance of on-going care
  - Improved monitoring of steps in care for women identified as HIV-positive in PMTCT programmes, through records systems that are designed to allow women to be tracked wherever they attend within the health facility (antenatal clinic, maternity ward, HIV care and treatment clinic, etc)

**Table 1: Percentage of HIV-positive women eligible for lifelong ART who were initiated on lifelong ART**

Country	%	Source
Botswana	37%	Chen, J.Y, et al., JAIDS, 2010. 54(1): pp.102-6
Kenya	38%	Otieno, P.A., et al. AIDS Care Psychological & Socio Medical Aspects of AIDS/HIV, 2010. 22(6): pp.729-736
Malawi	78%	Weigel, R.H., et al. XVII International AIDS Conference 2008
South Africa	51% 72%	Stinson, K., et al., TMIH, 2010. 15(7): pp.825-32 Kranzer, K., et al., PLoS ONE, 2010. 5(11): p.e13801
Zambia	14% 33% 46% 73%	Killam, W.P., et al., AIDS, 2010. 24(1): pp.85-91 Killam, W.P., et al., AIDS, 2010. 24(1): pp.85-91 Chi, B.H.M.D., et al., JAIDS, 2007. 45(1): pp125-127 Mandala, J, et al., BMC Public Health, 2009. 9: p.314

Source: Ferguson L., 2011, personal correspondence

### Missed opportunities

According to WHO figures, more than 70% of pregnant women in sub-Saharan Africa attended ANC at least once during pregnancy in 2009. This is a major opportunity to prevent mother-to-child transmission of HIV, and enable women to access HIV treatment for their own health. WHO figures show that in 2009, only 35% of pregnant women were estimated to have been tested for HIV, and 54% of HIV-positive pregnant women received ART prophylaxis or HAART in sub-Saharan Africa. Even fewer HIV-positive women were assessed for their need for lifelong HAART, and were then initiated on to HAART for their own health.

The extent to which this opportunity is being missed varies considerably between countries. A review of 9 studies in mostly research settings in sub-Saharan Africa found that the proportion of women identified as HIV-positive at PMTCT services who then went on to register with the HIV clinic ranged from 35% to 74%. Of those who were assessed for their need for lifelong ART for their own health, 14-31% needed it according to the relevant national guidelines. Table 1 shows the proportion of these women who then initiated treatment.

Drawing on data from questionnaires administered four months after delivery to women who were diagnosed with HIV in PMTCT services in Mwanza, Tanzania, Figure 1 shows the cascade

of women who tested HIV-positive in PMTCT services to accessing ART for their own health. Only 10 of the 18 women (56%) who were tested and found to be HIV-positive and who were then also found to be eligible for treatment, actually received HAART within four months of delivery.

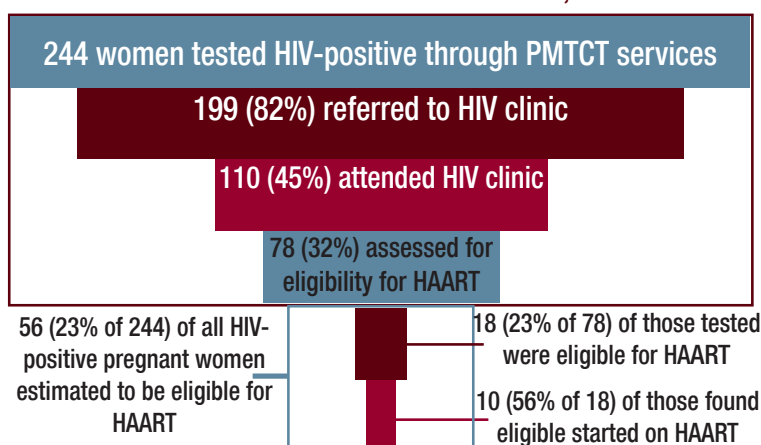
who tested HIV-positive in PMTCT services in Gilgil sub-district hospital, Kenya to accessing ART for their own health within six months of diagnosis. Only 11 of the 21 women (52%) who were tested and found to be HIV-positive and who were then also found to be eligible for treatment, actually received HAART within four months of delivery. Assuming a similar proportion of women who were not eligibility for HAART were eligible, then only 11 out of 95 HAART-eligible women (12%) received HAART within four months of delivery.

As these two diagrams show, women are being lost at all stages of the process: being referred to the HIV service, registering at the HIV service, being assessed for their need for lifelong ART, and then actually starting ART. HIV programmes expend considerably energy and resources encouraging people to access HIV testing and counselling, yet women in these studies were already using the health system,

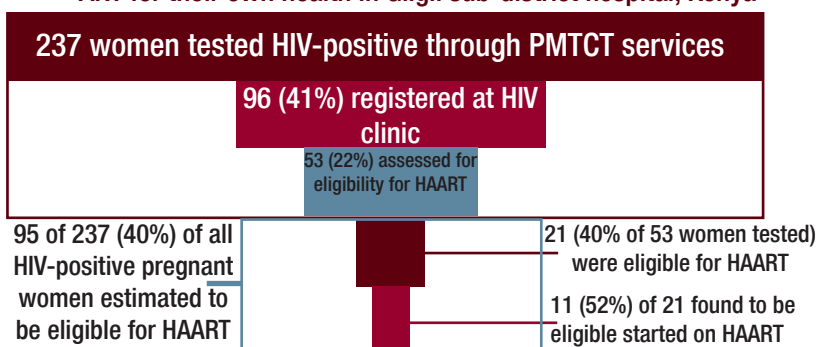
delivery. If one assumes that a similar proportion of the women who were not assessed for HAART eligibility were eligible, then only 10 of 56 HAART-eligible women (18%) received HAART within four months of delivery.

Figure 2 shows the cascade for women

**Figure 1: Cascade of women who tested HIV-positive in PMTCT services accessing ART for their own health in Mwanza, Tanzania**



**Figure 2: Cascade of women who tested HIV-positive in PMTCT services accessing ART for their own health in Gilgil sub-district hospital, Kenya**



and had already tested positive for HIV. These are important opportunities to get women on to treatment that are frequently being missed.

## Why these opportunities are being missed

### Referral systems are failing pregnant women

Interviews with health workers in both Kenya and Tanzania found that not all of them understood the guidelines that state that women should be referred to HIV services as soon as possible after testing positive, meaning that they were delaying making appropriate referrals. Some ANC health workers also reported that there was sometimes confusion over which service (ANC, maternity ward or HIV clinic) should assess women's need for lifelong HAART, meaning women fall into the gaps between the services. In Tanzania they also reported that there was a lack of coordination between ANC and HIV services, which resulted in women not attending the HIV clinic, either because they are not referred or because the HIV clinics send women back because they think the ANC clinics provide the necessary services.

### Patient pathways into HIV care are too complex

Pregnant women who test positive for HIV often have to attend a separate clinic for HIV services in addition to their standard ANC, delivery and post-delivery services. Accessing ART often involves multiple visits to the HIV clinic for a CD4 test, to receive the results, and for adherence counselling, before treatment is started. All these visits have significant costs to women in terms of transport and time, and often it is very difficult to get time off work or away from the home to make all these separate clinic visits, especially if she has not yet disclosed her HIV status to her husband, family or employer.

### Poor monitoring of patients

ANC services are not used to managing the chronic care of patients, and their records systems are not designed for tracking patients over time. Routine

monitoring records do not include unique patient identifiers. In the Kenyan study, it was found that every time a woman attended an ANC she was entered separately into the ANC register. So, if she attended the ANC twice, it appeared in the register as if two separate women had received ARV prophylaxis. This leads to overestimation, both of the number of women attending PMTCT services and the proportion of those women receiving PMTCT prophylaxis. Also there is often little or no sharing of monitoring data across separate services. This means that ANC staff are often unaware of whether women they refer on for HIV care then actually register with an HIV clinic.

### Personal factors

Women may also face personal barriers to accessing HIV treatment. Women identified as HIV-positive through PMTCT services often appear healthy, so they may not understand the importance of registering with the HIV clinic, or may even deny their status. Lack of disclosure to others, often driven by fears of stigma and discrimination, may leave women feeling socially isolated. As previously mentioned, the time required and cost of travelling to clinics may also be a barrier to accessing ART for themselves.

### Societal factors

HIV-related stigma, and the fear of stigma, may also be a significant barrier to women accessing HIV services.

### Quality of care

Low quality of care, especially the quality of interaction with health workers, can be important barriers to accessing services. Staff shortages or poor counselling training or supportive supervision can contribute to inadequate counselling at the time of HIV testing, which is particularly critical in the context of provider-initiated HIV counselling and testing.

## Grasping the opportunities

Efforts are needed to tackle these problems in order to reduce the number of women who miss out on accessing

ART for their own health. Simplifying patient pathways into HIV care from ANC services is essential. This may be through reducing the number of visits that women need to make before they start ART, or arranging appointments so women can visit both clinics on the same day to reduce the number of trips they need to make. Point-of-care CD4 tests to assess the need for lifelong ART without requiring return visits to the clinic are currently being developed and validated. When available for routine use, this will reduce the number of clinic visits pregnant women need to make, especially if this was carried out in ANC services.

Integrating the initiation of lifelong ART into the ANC services has been piloted in several settings, including Kenya, South Africa and Zambia. In Zambia the pilot study found that where ANC services enrolled patients into HIV care and initiated them on lifelong HAART, it doubled the number of eligible women who accessed ART. This strategy was acceptable and feasible as well as effective. It helped women to overcome some of the physical, economic and attitudinal barriers to receiving HAART. This approach has also had similar positive results in Kenya, doubling enrolment of eligible pregnant women on to HAART.

Improving record keeping could help to reduce the number of women who fall through the gaps between different services. At the minimum this would involve giving each woman a unique facility-wide patient number, and keeping track of who has been referred and who has taken up the referral. This could be facilitated by computerised records. This approach is starting to be used in Kenya. WHO recommend that programmes report on the percentage of HIV-positive pregnant women who were assessed for ART eligibility. Extending this reporting to include the proportion of eligible pregnant women who are on ART for their own health may help to increase the focus on women's health, rather than viewing women's HIV infection solely as a risk for their child.



## Conclusions & Recommendations

### Conclusions

PMTCT programmes offer an excellent opportunity for pregnant women who need lifelong ART for their own health and survival to access treatment. However, this opportunity is often being missed. Efforts are needed to simplify patient pathways to HIV treatment, and improve communication between different services. Integration of ART eligibility assessment and initiation into ANC services could be a promising strategy to make it easier for women to access the treatment they need. Another option would be to assess whether giving all HIV-positive women HAART if they are pregnant, irrespective of CD4 count, in order to simplify procedures.

### Recommendations

- PMTCT programmes need to prioritise the mother's own health, as well as that of her child.
- ANC and HIV services should assess at which points on the patient pathway women are being lost, and simplify their routes into HIV treatment and care
- Health services should introduce unique patient identifiers to enable women to be tracked over time and across departments in order to monitor who is accessing the services they need
- It is important to explore the feasibility, cost-effectiveness and acceptability of integrating HIV treatment into ANC services

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### Recommended Readings

Ferguson L, Grant A, Ong'ech J, Kielmann K, Watson-Jones D, Ross D, 2010: Linking women who test HIV positive in maternity services to HIV care and treatment services in Kenya: Missed Opportunities. Presentation at XVIII International AIDS Conference, <http://www.evidence4action.org/images/stories/documents/missedopportunities.pdf>

WHO 2010: PMTCT Strategic Vision 2010-2015: Preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals, Geneva

Strasser S, 2010: No Missed Opportunities: Providing ART in MCH, Presentation at Satellite Session of World AIDS Conference 2010, Vienna, Elizabeth Glaser Pediatric AIDS Foundation <http://>

[www.ped aids.org/Press-Room/Events/2010/IAS-2010-MCH\\_HIV-Integration-Satellite-Session/5--S-Strasser-Providing-ART-in-MCH-FINAL](http://www.ped aids.org/Press-Room/Events/2010/IAS-2010-MCH_HIV-Integration-Satellite-Session/5--S-Strasser-Providing-ART-in-MCH-FINAL)

WHO 2009: Antiretroviral drugs for treating pregnant women and preventing HIV infections in infants: recommendations for a public health approach, Geneva

WHO 2010: Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector. Geneva

Balira, R, 2011: Implementation of Prevention of Mother to Child Transmission of HIV and Maternal Syphilis Screening and Treatment programs in Mwanza Region, Tanzania: Uptake and Challenges. PhD thesis, available from LSHTM library.



### About Evidence for Action

Evidence for Action is an international research consortium with partners in India, Malawi, Uganda, UK and Zambia, examining issues surrounding HIV treatment and care systems.

The research is organised in four key themes:

1. What "package" of HIV treatment and care services should be provided in different settings?
2. What delivery systems should be used in different contexts?
3. How best should HIV treatment and care be integrated into existing health and social systems?
4. How can new knowledge related to the first three questions be rapidly translated into improved policy and programming?

### Partners:

International HIV/AIDS Alliance, UK  
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