

PREVENTION OF MOTHER-TO-CHILD TRANSMISSION

TECHNICAL UPDATE



**IMPLEMENTING THE 'TREAT ALL' APPROACH AMONG
PREGNANT AND BREASTFEEDING**

WOMEN LIVING WITH HIV IN THE WHO AFRICAN REGION

Lessons from a workshop on "Gathering knowledge and best practices from Option B+: the path to 'Treat All'" held from 23 to 26 August 2016 in Victoria Falls, Zimbabwe

CONTENTS

PREVENTION OF MOTHER-TO-CHILD TRANSMISSION.....	1
EXECUTIVE SUMMARY.....	3
ABBREVIATIONS AND ACRONYMS	4
ACKNOWLEDGEMENT	5
BACKGROUND.....	6
KEY OPERATIONAL UPDATE	8
1. HIV TESTING IN PMTCT	8
1.1 Repeat HIV testing to verify positives.....	8
1.3 Partner testing.....	12
2. TREATMENT INITIATION.....	15
2.1 Ensuring readiness to initiate lifelong ART in PMTCT services.....	15
2.2 Preparing health care workers to initiate clients on ART	15
2.3 Community engagement.....	15
3. RETENTION AND TRANSITION BETWEEN SERVICES.....	16
3.1 Preventing loss to follow-up before and after delivery	16
3.2 Preventing loss to follow-up.....	18
3.3 Early identification of defaulters among pregnant and breastfeeding women	20
3.4 Tracking defaulters along the continuum	20
ANNEXES.....	22
1. Readiness assessment for treatment initiation in pregnancy and breastfeeding	22
2. Preparation for treatment initiation in pregnancy and breastfeeding	22
REFERENCES.....	23

EXECUTIVE SUMMARY

In the context of AFRO Transformation Agenda which aims at meeting health's needs and expectations of people in Africa Region, quality of care is a key performance indicator in the implementation of Reproductive, maternal, new-born, child and adolescent programs. However, quality of care can be compromised during the scaling up phase of health programs or initiatives.

The Prevention of Mother-To-Child Transmission (PMTCT) program has made tremendous progress in scaling up ART in pregnant women living with HIV, building on the 2011-2015 Global Plan towards the elimination of new infections among children by 2015 and keeping their mothers alive. ART coverage in PMTCT moved from 36% in 2009 to 77% in 2015, which has resulted in 1.6 million new infections in children averted globally. Important lessons were learnt in the process that have informed the rollout of "Treat All", as recommended by the 2016 WHO Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection.

WHO, UNICEF and other partners of the interagency task team the elimination of MTCT (IATT) convened a large country-led workshop in August 2016 on 'Gathering knowledge and best practices from B+ to Treat All.' The meeting brought together 20 countryⁱ teams from across the Africa Region. Based on operational considerations for scaling up and enhancing quality of care in the 20 participating countries, key messages and best practices emerging from field have been summarised in this technical update to guide program managers and stakeholders in quality PMTCT intervention. They are grouped under the following three key themes:

- i) **Repeating HIV testing to verify positives and retesting HIV-negative women** are key component of quality PMTCT intervention towards elimination of mother-to-child transmission. Dual testing HIV/Syphilis should be prioritized in the first trimester of pregnancy. Countries must have clear policies and SOPs for repeating testing before initiation of ART and retesting negatives in the third trimester of pregnancy, at delivery, and at specific points, at least twice or thrice during breastfeeding since incident HIV infections have been noted and associated with a higher MTCT risk.
- ii) **Ensuring readiness to initiate lifelong ART in PMTCT services is essential.** Treatment preparedness packages should be defined in advance and implemented for higher retention and better mother and infant outcomes. The challenge of striking a balance between the convenience, simplicity and rapidity of same-day initiation and the importance of giving enough time for patients to be ready to initiate treatment was noted.
- iii) **Retention and transition between services to address loss to follow-up (LTFU).** The focus should shift from tracking women already lost to preventing defaulters. Best strategies include decentralization, integration, reduction of stigma within health facilities, improvement of client preparation prior to ART initiation and transition from antenatal care as well as use of appointment booking diaries and improving and strengthening community engagement.

ⁱ Angola, Botswana, Burundi, Cameroon, Chad, Côte d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Swaziland, United Republic of Tanzania, Uganda, Zambia and Zimbabwe.

ABBREVIATIONS AND ACRONYMS

ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral (drug)
AZT	Azidothymidine (also known as zidovudine)
FDC	Fixed-dose combination
HIV	Human immunodeficiency virus
IATT	Interagency task team
LTFU	Lost to follow-up
MCH	Maternal and child health
MNCH	Maternal, New born and child health
MTCT	Mother-to-child transmission (of HIV)
NVP	Nevirapine
PBW	Pregnant and breastfeeding women
PCR	Polymerase chain reaction
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission (of HIV)
PNC	Postnatal care
PrEP	Pre-exposure prophylaxis
RDT	Rapid diagnostic test
RMNCAH	Reproductive, Maternal, New born, children and Adolescent Health
SMS	Short Message Service
SOP	Standard operating procedure
TBA	Traditional birth attendant
TDF	Tenofovir Disoproxil Fumarate
VL	Viral load
WHO	World Health Organization

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BACKGROUND

In 2013, the World Health Organization (WHO) released the “Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection”. These guidelines recommended that all pregnant and breastfeeding women (PBW) initiate lifelong triple antiretroviral therapy (ART) regardless of clinical or immunological criteria and continue lifelong ART in all (Option B+) or discontinue treatment at the end of mother-to-child transmission of HIV (MTCT) risk, except among those “eligible” (Option B).

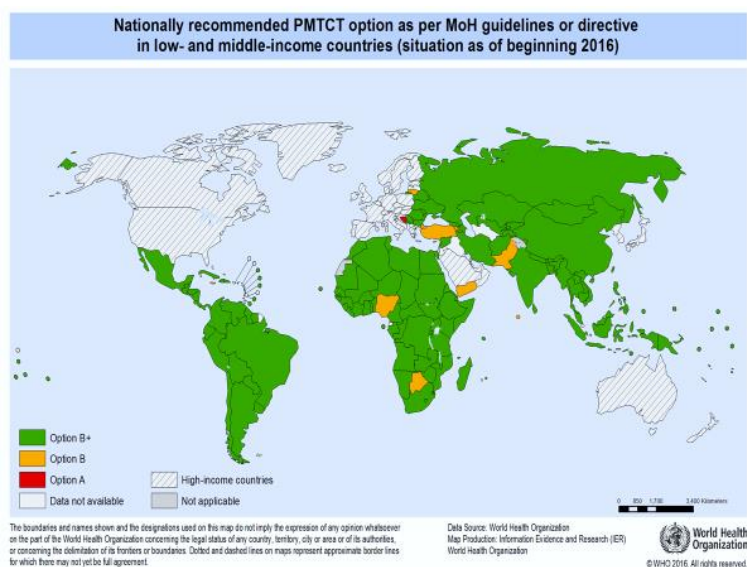
Option B+ was recommended over other options because of its four potential health benefits: (i) improvement of the mother’s health by early initiation of antiretroviral therapy; (ii) prevention of horizontal transmission to sexual partners; (iii) decreased risk of developing drug resistance caused by stopping and re-starting antiretroviral drugs (ARVs) with subsequent pregnancies; and (iv) decreasing the risk of mother-to-child transmission (MTCT) in future pregnancies by ensuring that the woman is on ART at the time of conception.

Operational and programmatic factors were critical considerations in the B+ recommendation. Removing clinical and immunological eligibility criteria of Option A and using a single regimen that could be provided as a once-daily fixed-dose combination (FDC), enabled task shifting of ART services from physicians to maternal, newborn and child health (MNCH) nurses. Task shifting also allowed for decentralization of services to lower level/primary health facilities which, in turn, expanded access to HIV testing and treatment.

The B+ recommendation was a major paradigm shift for prevention of mother-to-child transmission (PMTCT) programmes. It emphasized the advantages of one simplified approach for all, rather than multiple options based on clinical eligibility. For the first time, emphasis shifted from primarily protection of infants from HIV infection to include mothers’ health.

The revised 2015 Guidelines on “When to Start ART” took the next step to a “TREAT ALL” approach (test and offer ART to all people living with HIV, regardless of CD4 or clinical stage). Most of the 21 priority African countries¹ in the “Global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive” began implementing Option B+ between 2013 and 2014, and were all rolling out B+ at national level, leading to a remarkable increase in the number of pregnant and breastfeeding women (PBW) initiated on ART. Figure 1 shows the distribution of Option B+ in low-middle-income countries in 2016.

Figure 1: Distribution of PMTCT Options worldwide, 2016



The roll-out of B+ provided important lessons for ART scale-up. Different countries implemented the policy in different ways; in the process, they identified their own context-specific barriers to implementation three key challenges have been consistently identified:

- How to accurately identify HIV-positive PBW and test the partners of HIV-negative women to identify women in discordant relationships who are at risk of acquiring HIV during pregnancy and in the postpartum period;
- How to start ART in newly-identified PBW; how to strike a balance between ensuring readiness to initiate lifelong ART and the need to start treatment as soon as possible;
- How to retain PBW on ART throughout the risk period for vertical transmission and as they transition from MNCH settings to ART clinics for ongoing treatment and care.

WHO is supporting Member States in the WHO African Region to strengthen their health systems by adopting an integrated approach and community involvement to improve the quality of care and to scale up priority programmes.

This technical update summarizes consensus on best practices and knowledge that emerged from the workshop, based on operational considerations for scaling up and enhancing quality of care in the prevention of mother-to-child transmission with a view to eliminating new HIV infections in children in the African Region.

KEY OPERATIONAL UPDATE

1. HIV TESTING IN PMTCT

The objective of HIV testing is to accurately identify HIV-positive pregnant and breastfeeding women, while partner testing enables the identification of women at risk of acquiring HIV during pregnancy and breastfeeding.

The 2016 WHO recommendations on testing for all PLHIV and pregnant women are the following:

- National programmes should retest all persons newly diagnosed with HIV with a second specimen using the same testing algorithm and a second operator before they enrol in care and initiate ART; .
- In high prevalence settings:
 - Provider-initiated testing and counselling (PITC) should be considered as a routine component of the package of care in all antenatal, childbirth, postpartum and paediatric care settings. Where breastfeeding is the norm, lactating mothers who are HIV-negative should be retested periodically throughout the breastfeeding period;
 - All HIV-negative pregnant women should be retested in the third trimester, during labour and/or after childbirth because of the high risk of acquiring HIV during pregnancy;
- In antenatal care settings, couples and partners should be offered HIV testing services with support for mutual disclosure.

1.1 Repeat HIV testing to verify positives

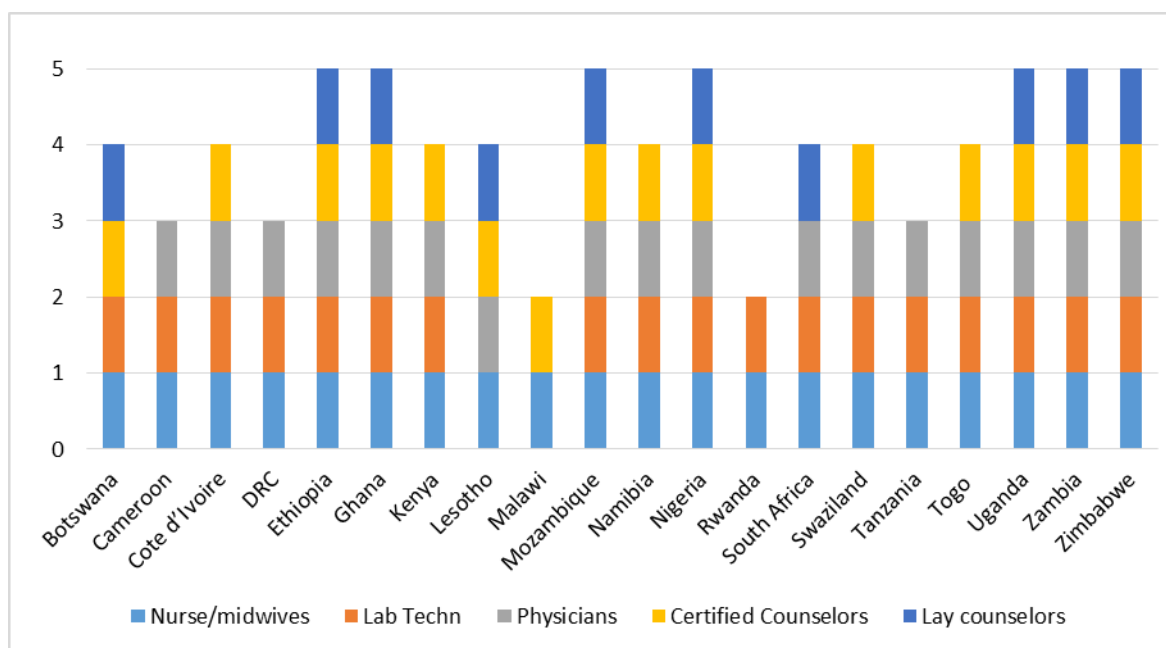
HIV testing is now routinely conducted using rapid diagnostic tests at the point of care. Often, the testing services providers are not only laboratory staff but also other health care workers such as physicians, nurses, midwives and nurse assistants; in some countries, there have trained lay providers. Countries have begun using the dual rapid test for HIV/syphilis in various settings. A reactive test result for HIV should not be considered as definitive and should be followed by an additional HIV test prior to starting lifelong ART according to the national algorithm. For pregnant women with a reactive syphilis result, an immediate treatment should be considered.

Figure 2 presents the findings of the pre-workshop survey on the different cadres that conduct HIV testing in the 20 sub-Saharan African countries. In 10 out of the 20, HIV testing is also provided by lay counsellors.

The pre-workshop survey also revealed that only 12 out of the 20 countries had an established quality assurance mechanism for HIV testing, even though several studies and documentations have highlighted the risk of misdiagnosis in field settings.

It was also noted that only 5 out of the 20 countries (Botswana, Kenya, Lesotho, Malawi, and Rwanda) had included the recommendation for '**Repeat testing to verify positives**' in their national policy. Five other countries (Ethiopia, Namibia, Swaziland, Uganda, and Zambia) were planning to start '**Repeat testing to verify positives**' in 2017.

Figure 2: Cadres that provide HIV testing by country: results from the pre-workshop survey



Data are limited on how consistently this policy is applied in practice. In survey responses, some countries noted that despite national guidelines, repeat testing for verification of positives was not always done; and when it was done, it was sometimes after ART initiation (Kenya, Malawi, and Botswana). It is, therefore, imperative for providers to be trained on the process of repeat testing to verify positives and to ensure that all patients with a new positive result are retested before they initiate ART. Retesting refers to testing of a new specimen for each newly diagnosed individual, conducted by a different provider if possible, using the same testing algorithm, prior to initiation of ART.

Four main concerns raised by countries regarding operationalization of **'Repeat testing to verify positives'** include: (a) implementation in health facilities with only one provider; (b) distrust of HIV testing services if communities and patients perceive them as unreliable; (c) delay of ART initiation because of repeat testing to verify positives; and (d) management of discordant results

(a) Implementation in health facilities with only one provider

Many health facilities, particularly those in rural areas, do not have more than one health care provider. Since misdiagnosis is, in part, due to provider performance, it is always preferable that, if possible, a different provider repeats the testing algorithm on a new sample. However, **where no other providers are available, it is better for repeat testing to be conducted by the same provider, rather than not being done at all**. At the same time, it is important for programmes to ensure that supervisory visits and quality assurance mechanisms are in place in all health facilities across the country. Programmes should also analyse data to identify patterns of discordance between test results. This may enable identification of health facilities with greater variability in their results and help determine whether such facilities should benefit from specific interventions to address provider workloads or additional capacity needs.

(b) *Confusion and distrust of HIV testing services if communities and patients perceive them as unreliable.*

The reasons for repeat testing to verify HIV-positive status need to be clearly explained to clients. It is important to emphasize (i) that the primary reason for repeat testing to verify positives is ***not because the testing service is unreliable per se, but because double checking HIV status prior to starting lifelong ART is good clinical practice.*** Clients should be informed of the entire testing process; this should start at the pre-test counselling session.

Therefore, there is a need for efforts to improve community literacy on the topic which should start before implementation of the strategy. Improved community literacy raises awareness and the benefit for the client and minimizes negative consequences.

(c) *Delay of ART initiation because of repeat testing to verify positives*

Countries noted that repeat testing should not be a reason to delay initiation of treatment; repeat testing should not be done at a different time from the first test but rather as soon as the first positive result is obtained. This ensures that clients receive a definitive result timely.

(d) *Management of discordant results*

Where discordant results are obtained (an initial test gives a positive result but a repeat test for verification shows a negative result), three following key considerations:

- WHO recommends that clients (or their specimens) should be referred to a higher-level facility for additional testing;
- Urgent follow-up should be considered, especially for PBW, in order to have a definitive result;
- Health facilities with higher rates of discrepancy should be prioritized for supervision, capacity building and quality assurance.

Key messages:

- Repeat testing should be done as soon as the first positive result is obtained so as to ensure that clients receive a definitive result timely. This also applies for dual testing HIV/Syphilis
- Repeat testing to verify positives should be conducted by a different provider; where no other providers are available, it is better for the repeat test to be conducted by the same provider, rather than not being done at all.
- In the case of discordant results, the clients (or their specimens) should be referred to a higher-level facility for additional testing; urgent follow-up should be considered for PBW.
- Supervisory visits should be paid to all health facilities in the country and quality control mechanisms should be available in those facilities.
- Efforts to improve community literacy should start before implementation of a repeat testing strategy.
- Forecasts for rapid diagnostic test (RDT) kits should include additional requirements for implementation of verification of positives, partner testing and retesting of HIV-negative PBW.
- The consistent use of a register for stock control at all facilities is crucial.

1. 2 Retesting HIV-negative women

Retesting of women for the prevention of mother-to-child transmission of HIV to identify those who may seroconvert in pregnancy or during the breastfeeding period *has been recommended by WHO.*

Incident HIV acquired during pregnancy or breastfeeding is associated with a higher risk of MTCT and the risk of incident HIV infection during pregnancy, birth and breastfeeding in some settings is very high.² Therefore, testing pregnant women only at the first antenatal visit may result in missed identification of acute infection during the risk period for vertical transmission. Most of the countries (19 out of 20) reported that retesting HIV-negative women in pregnancy and during breastfeeding was included in national policy, although programmes adopted different time points for retesting (Table 1).

Table 1: Time points for retesting HIV-negative pregnant women, August 2016

Country	Every 3 month	3rd trim.	At delivery	During BF
Botswana	√			
Cameroon	√			
Mozambique	√			
Swaziland	Every 8 weeks.			
South Africa	√			
Zambia	√			
Lesotho		√	√	√
Namibia		√	√	√
Uganda		√	√	√
Zimbabwe		√	√	√
Kenya		√	√	6 weeks, every 6 mo
Cote d'Ivoire		√	√	
Nigeria		√	√	
Tanzania		√	√	
Ethiopia		√		
Ghana		√		
Malawi			√	
Rwanda			√	
Togo			√	
DRC	Not recommended in the national policy			

Only a few countries monitored implementation of the retesting policy (Table 2). Reasons cited for missed opportunities for retesting by health workers included heavy workloads, lack of time, lack of testing supplies, and forgetting to retest.

Table 2: Proportion of HIV-negative pregnant and breastfeeding women retested for HIV, August 2016

Country	Every 3 months	3rd trim.	At delivery	During BF
Botswana		42%	6%	73%
Cameroon	15%			
Cote d'Ivoire		15%		
Ghana		98%		
Malawi		91%	97%	
Mozambique			14%	
Namibia		40%		5%
Rwanda			100%	
South Africa	60%			
Swaziland			13%	42%
Tanzania		17%	7%	
Uganda		19%	6%	7%

Although all programmes recognized the importance of retesting of HIV-negative PBW, concerns arose on feasibility and frequency of the testing, particularly in the postnatal period:

- (a) *Human resources.* Services for PBW are delivered in primary care settings and almost entirely by nurses, making it imperative for policies to be simple to implement;
- (b) *Testing resources.* Even in countries with a high HIV burden, the majority of women attending antenatal and postnatal clinics will be HIV-negative. This implies a large volume of retests, especially if retesting is performed every three months as recommended in some countries, and if national practice is for women to breastfeed for two years or longer;
- (c) *Priorities for retesting.* As a minimum, retesting in pregnancy should be considered for the third trimester and at delivery.
- (d) *Testing during the postpartum period.* Frequency of testing in breastfeeding women should include at least two or three points, depending on country context. This requires regular follow-up of HIV-negative women in the postnatal period. Since countries have defined schedules and good coverage for infant immunization, testing schedules for HIV-negative breastfeeding women could be aligned with immunization schedules.
- (e) *Recording of results.* For implementation purposes, it is crucial that results and dates of tests be recorded on the woman's (or child's) card. This can be challenging for confidentiality but is necessary for identifying the women who need retesting. Results may be coded to minimize the risk of inadvertent disclosure of HIV testing results.

Key messages

- National policies on frequency of retesting for HIV-negative PBW should be simple.
- More frequent testing should be offered in settings of higher HIV prevalence and higher HIV incidence, and to individuals and groups at higher risk.
- The minimum standard for retesting of negatives should include retesting in the third trimester of pregnancy up to and including delivery, and at least two or three points during breastfeeding.
- Testing for HIV-negative breastfeeding women could be aligned with the immunization schedule and retesting should be offered within family planning services.
- To identify women who need retesting, results should be systematically recorded so that details of previous HIV-negative test results are documented on the mother's health card and can easily be reviewed by the provider to ensure that retesting opportunities have not been missed.

1.3 Partner testing

Testing male partners within an RMNCAH setting can have clear benefits since it leads to identification of HIV-infected male partners of both HIV-positive and HIV-negative women. For HIV-negative PBW, the identification of HIV-positive male partners allows for interventions to prevent sexual transmission to the women while protecting both the mother and the baby. Such interventions include the use of pre-exposure prophylaxis (PrEP) for HIV-negative women³ and ART for their HIV-positive partners. However, male partner testing is not always implemented and sometimes is only implemented for male partners of HIV-positive women. A total of 15 out of 20 countries provided data on male partner testing, with coverage that varied

between less than 5% and 84% (median 20%). Two countries (Lesotho and Uganda) reported that male partner testing was only offered to male partners of HIV-positive women (Table 3).

Table 3: Proportion of male partners of pregnant women tested at ANC, August 2016

Country	Botswana	Cameroon	DRC	Ethiopia	Kenya	Lesotho	Malawi	Mozambique	Namibia	Rwanda	Swaziland	Tanzania	Togo	Uganda	Zambia
Male partner testing	19%	5%	14%	20%	6%	6% partners of HIV +PW	30%	36%	45%	84%	36%	54%	3%	28% partners of HIV+ PW	50%

Health facilities often lack the conditions to support the presence or participation of partners at antenatal clinics. Furthermore, strategies to encourage male partner testing, such as giving priority to women who attend services with their partners, have in some cases, resulted in delays for unaccompanied women. These clear challenges for implementation should not hamper expansion of male testing and male involvement. More efforts are needed to expand testing for all male partners of PBW, regardless of the women's HIV status. In addition, where there may be multiple partners, testing should not only focus on the primary or 'formal' partner but should be extended to all male sexual partners. This implies that health care workers:

- (a) should be non-judgemental and should not indulge in stigmatization;
- (b) need to be trained to improve their skills in couple counselling and to help women disclose their HIV status to their partners.

Testing should be offered at different times, and in settings that are more conducive to men such as after work (e.g., Saturdays or late afternoons) and during home visits; self-testing should also be envisaged. Testing can also be conducted in settings that are commonly frequented by men. While such a strategy could increase testing in men, it may not always lead to partner testing since, in most cases, it is not possible to establish a link with partners.

Community literacy: To increase demand for male-partner testing, community leaders and male champions should be encouraged and used to promote messages. Whatever the strategy implemented to improve male-partner testing, it is important to guarantee the safety of the woman and to avoid coercion. Several countries offer incentives to women who attend antenatal clinics with their partners (mostly by letting health workers see them first). However, this may have unintended negative consequences, such as delaying services for women who do not have partners. These women may also lack access to resources and support because they do not have regular partners. Seeing such women last may, in fact, make it less likely that they will return for care.

Management of commodities is often a challenge in the implementation of all these testing strategies. Forecasting for test kits should include additional requirements for partner testing, verification of positives and retesting of HIV-negative women during pregnancy and breastfeeding. Countries should also use commodity registers regularly for stock control in all health facilities.

Key messages

- All male partners of PBW should be tested regardless of the women's HIV status.
- Testing should be extended to all male sexual partners of PBW, not just the 'primary' partner.
- Health care workers should be trained in couple counselling and in helping women disclose their HIV status to their partners.
- Testing could be offered at different times and in settings that are more conducive to men (e.g., after work, during home visits, etc.).
- Community involvement should be expanded to increase demand for male-partner testing inside and outside the health facility.
- Ensuring women's safety and avoiding coercion and unintended negative consequences for women is crucial and should be guaranteed.

2. TREATMENT INITIATION

2.1 Ensuring readiness to initiate lifelong ART in PMTCT services

With the roll-out of B+, and now the ‘Treat-All’ recommendation, barriers to rapid initiation of ART have been removed. In many national programmes, this has translated to “same-day start”, wherein pregnant women are tested in the ANC setting and, if found to be HIV-positive, are immediately started on ART. In 18 out of the 20 sub-Saharan African countries that responded to the pre-workshop survey, same-day ART initiation for PBW is recommended by national policy.

The issue is therefore not so much about ‘when to start’ but rather ‘how to start’ and how to prepare the client appropriately. In light of the relative urgency of starting ART during pregnancy, especially where women present late, an elaborate protocol should be developed by each country that includes intensified pre-treatment education is required. Given the importance of starting ART without delay to minimize the risk of mother-to-child transmission, a treatment preparedness package should be defined in advance and should be implemented for each case in a rapid and timely manner.

It is especially important that national programmes that are implementing a ‘Treat-All’ policy should develop and field-test protocols for rapid assessment and preparation for ART in newly-diagnosed clients (see the annexes).

2.2 Preparing health care workers to initiate clients on ART

Health care workers need to improve their skills for comprehensive service delivery, including the ability to provide quality counselling for treatment preparedness. Training should not only focus on ARV use and the monitoring of side effects; it should also address the feelings, attitudes and perceptions of health care workers. Some of them may be affected by client results and may need support themselves. Health facilities are also often a place of stigmatization, in large part demonstrated by the behaviour and attitudes of health care workers towards their clients.

2.3 Community engagement

In many countries, option B+ was rolled out without adequate engagement of the community; this partially explains the low acceptance rate in some settings. The views of community and religious leaders have tremendous impact on women’s decisions and behaviours about their health. Strategies to improve community literacy and awareness should be implemented in all countries. Substantial body of literature has documented the positive impact of community and/or peer support interventions on Prevention of Mother to Child Transmission service delivery including in improving retention in care. Countries should strengthen programs that

increase linkages between facilities and peer supports, find innovative strategies to increase male involvement around PMTCT and expand the role of community health workers to maximise available opportunities for providing health care interventions.

Key messages

- A **readiness assessment tool** could be used during pre-treatment initiation sessions to identify women who are ready for same-day initiation and those who may need intensified counselling and support for decision.
 - The tool should consider the gestational age at presentation, the woman's reaction to the diagnosis, whether she had previously been tested, family context, and her ability to return when needed for preparation visits.
- National programmes should develop a **treatment preparedness package** for women who are not ready to start on the same day of testing.
 - Patient preparedness should not only be the responsibility of the nurses; all available staff, including doctors, counsellors, and peer supporters, should also be involved.
 - PLHIV networks, community support groups and key community members should be involved in providing additional counselling and adherence or retention support.
 - Health care workers need to improve their skills in quality counselling and in pre-treatment preparedness.
- Strategies to improve community literacy should be implemented in all countries.

3. RETENTION AND TRANSITION BETWEEN SERVICES

3.1 Preventing loss to follow-up before and after delivery

Retention in care and adherence to ART is a major challenge for most programmes and patients.

Studies have shown that retention is lower among women initiated on ART during pregnancy and breastfeeding compared to other adults. Among pregnant women starting on ART, those started within Option B+ are healthy and have lower retention than women who were initiated based on clinical or immunological criteria.⁴ Most of the losses among PBW occurred early after initiation. This is because women started on lifelong ART as a result of Option B+ have a higher risk of never returning for a second visit, compared to those started because of advancing clinical or immunological disease. This phenomenon should thus be considered as 'failure to start ART' rather than 'loss to follow-up'.

Only 7 out of the 20 countries reported national data on retention rates among PBW on B+. Relatively few countries have a monitoring system that is capable of disaggregating retention data for PBW among the general adult population. Overall, between 20% and 45% of PBW were lost to follow-up 12 months after ART initiation (Table 4).

Table 4: Proportion of loss to follow-up (LTFU) among pregnant women 12 and 24 months after ART initiation, August 2016

Country	DRC	Ghana	Kenya	Malawi	Mozambique	Tanzania	Uganda
% LTFU 12 mo.	45%	20%	25%	24%	34%	40%	31%
% LTFU 24 mo.		36%	30%	28%	48%		36%

Factors leading to a higher risk of being lost to follow-up after childbirth include the following:

- (a) fragmentation of service delivery with follow-up visits required at different times and in different locations for the mother and her newborn;
- (b) the misconception that if all is well with the newborn, there is no longer a need to remain in care or to take medication;
- (c) general challenges of the early postpartum period, including maternal recovery and infant feeding.

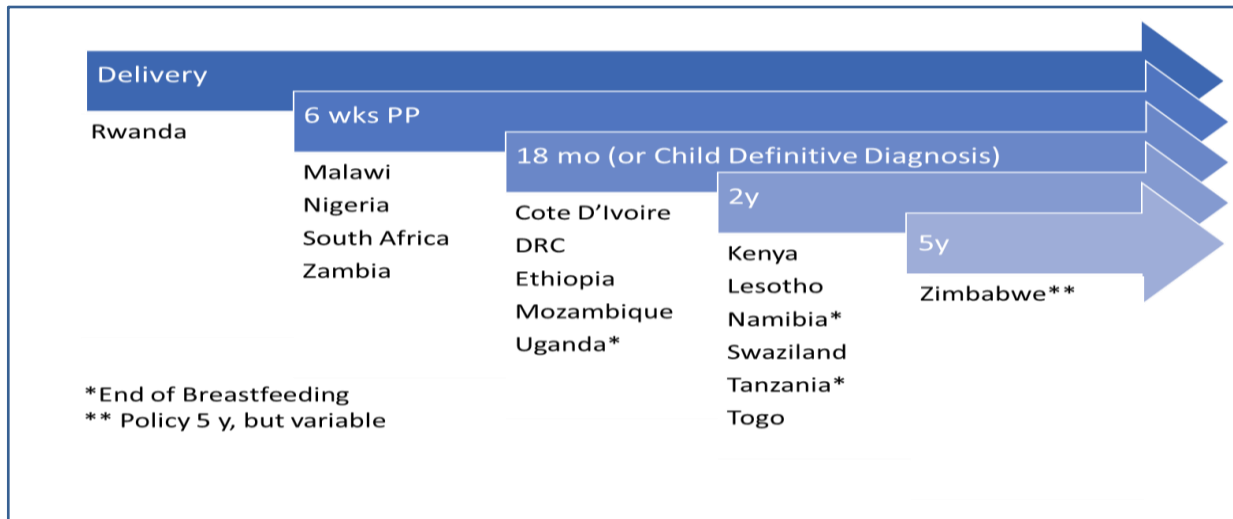
In addition, the transition from antenatal to postnatal services and from MCH-based ART services to ART clinics for the general population are specific points on the care continuum at which women may become lost to follow-up. Figure 3 shows how the timing of when PBW on ART transition from MCH to ART clinics varies across 17 countries in sub-Saharan Africa. In two countries (Botswana and Ghana),ⁱⁱ pregnant women with HIV are referred to and followed up at the ART clinic from the time they are initially diagnosed. In the other countries, transition occurs at different time points. In some countries this happens after childbirth or after the six weeks of postpartum visits. Many countries reported that policies actually vary from site to site and are determined by the caseload of health care workers. The majority of countries transfer women once the baby has had a definitive diagnosis.

If the baby is diagnosed HIV-positive, this transfer can take place as early as two months after childbirth. However, if the baby is HIV-negative, transition occurs once a final HIV-negative diagnosis is obtained after cessation of breastfeeding.

In many programmes, tracking of clients who have missed appointments only begins when that client has been formally identified as 'lost to follow-up' (LTFU). In most countries, this is three months after the last documented ARV refill, which is often quite late for the purposes of the PMTCT programme. It should be noted that throughout pregnancy and breastfeeding, there is a daily risk of mother-to-child transmission; a long lapse between ARV refills inevitably results in a periodic rebound of the viral load. In order to achieve optimal maternal health as well as success in prevention of MTCT, it is essential to achieve and maintain viral suppression.

Figure 3: Transition times from MCH to ART clinics for adult PBW in 17 countries, August 2016

ⁱⁱ Since the workshop, Ghana has changed this approach and PW currently receive their ART at ANC



It is, therefore, important to retain women in care and to ensure that they never fail to collect ARV refills in a timely manner. For PMTCT programmes to succeed, the focus should shift from *tracking* women lost to follow-up to *preventing* loss to follow-up (LTFU). This can only be achieved by strengthening interventions to prevent defaulting from treatment and by early identification and tracking of women who fail to return for even a single ARV refill.

3.2 Preventing loss to follow-up

Interventions for preventing defaulters can be divided into two main groups: health facility interventions and community-focused interventions.

Actions at the health facility:

This subsection is gathering knowledge and experiences around decentralisation, integration, stigma reduction and client literacy to prevent loss to follow-up.

- (a) *Decentralization of services.* Bringing health services closer to the client could reduce direct costs (such as transportation) and indirect ones (such as loss of earnings associated with time spent travelling to the health facility);
- (b) *Integration.* Consolidation of multiple services (e.g., pregnancy care, HIV care, counselling, pick-up of ARVs, collection of blood samples, newborn and child care) into one single visit in one place could reduce the number of visits required and the time spent at the facility. This may also serve to reduce stigma, since all clients will be seen in the same clinic and will receive all services together. To be effective, this type of service integration needs to be carefully planned for, in terms of physical space, human resources (including data clerks needed to register clients), client burden for individual health workers, patient flow and monitoring and evaluation requirements. The use of integrated registers and eHealth technologies may help to reduce the time a provider spends on recording and reporting, thus freeing up time for clinical care;

- (c) *Reduction of stigma within health facilities.* Structures and processes that highlight the fact that some clients have HIV should be removed. For example, special pharmacy windows reserved for ARV pick-ups should be closed and special forms for HIV-associated laboratory tests should be discontinued. In other cases, health care workers can enhance stigma by the way they behave, for example, when they segregate PMTCT clients in waiting rooms or designate certain days as 'special PMTCT days'. Educating health care workers on stigmatization and its effects, and on legal requirements to protect patient confidentiality and rights could lead to a reduction in the manifestation of such behaviour. Furthermore, accountability systems that address stigma and improve the quality of services can be instituted, for instance by installing suggestion boxes in health centres, conducting periodic interviews with clients, enhancing community feedback to health facilities, and identifying and recognizing best-performing health care workers based on client satisfaction;
- (d) *Availability of ARV.* Local stock-outs of commodities, particularly (but not only) in rural areas are unfortunately quite commonly reported (in 8 out of 20 countries). Indeed, when missed visits for ARV refills are recorded, it is quite often not because the patient did not report for pick-up but because the medicines were actually not available;
- (e) *Improvement of client literacy prior to ART initiation.* Preparation of clients prior to ART initiation is critical and has been discussed above. In addition to this, client education should be continued during treatment. This requires health care worker training and support as discussed in the section above; or could be done through initiatives such as 'expert clients', etc.
- (f) *Prevention of losses during the transition from antenatal care to postnatal care.* Most of losses during this transition can be prevented by using two approaches:
- adequately preparing for the transition beginning with the first antenatal visit and strengthening appropriate messages at childbirth and thereabouts;
 - scheduling mother and baby postnatal follow-up visits to coincide with the immunization schedule;
- (g) *Prevention of loss from maternal and child health clinics to adult ART or chronic disease clinics.* Two successful experiences to preventing losses are to be considered:
- (i) prioritizing the scale-up of ART services for all patients so that the whole family can be attended to in the same facility; mobile clinics can be temporarily deployed to provide ART care in peripheral facilities where ART services are not yet available;
 - (ii) considering the option of maintaining women within MCH for an extended period (e.g., to the end of breastfeeding, or up to two years after childbirth); this can be prioritized in low-volume health facilities where ART services exist only within MCH, and where transition usually occurs early in the postpartum period (i.e., at childbirth or at 6 weeks).

Community engagement and peer support

The follow-up of PBW after ART initiation should be strengthened by pairing each woman with a peer counsellor/expert client or community health worker that can perform home visits. Family support groups can be established to enhance psychosocial support.

Communication is one innovative approach that can be employed to improve treatment literacy. Interventions should include mass communication campaigns, videos within and outside health facilities (mobile cinemas in rural areas), and social networks, particularly targeting adolescents.

Among good practices to strengthen the links between health facilities and the community, Stakeholders consider:

- (i) Community health workers escort women who deliver at health facilities to their homes after childbirth to strengthen such links. This was for example done by 'Safe motherhood action groups' in Zambia;
- (ii) Well-known opinion leaders in the community (e.g. chiefs, traditional birth attendants, etc.) could help to ensure that the women go back to the health facility after childbirth. This strategy could be inclusive of all women, regardless of their HIV status (and could be linked with vaccination coverage or postnatal visits).

3.3 Early identification of defaulters among pregnant and breastfeeding women

Improving awareness among health care workers and in the health system about retention in care is certainly a first step towards improving retention. This could include awareness about use of enhanced indicators such as are employed for early retention. Implementation of monitoring systems that facilitate data collection for these indicators would also be helpful and should be promoted and supported.

The monitoring and evaluation system does not always include the means to facilitate follow-up of mother and baby all through the continuum of care: in only 13 of the 20 countries, the unique identifier for pregnant women is linked to the one in the ART register. Furthermore, only in five of these health facilities, the unique identifier of the mother is linked to that of her exposed baby.

Moreover, longitudinal registers for mother follow-up (or follow-up of mother and baby) have only been implemented in nine countries. More widespread use of such registers could lead to easier and early identification of defaulters and should be promoted.

3.4 Tracking defaulters along the continuum

Several strategies have been implemented that are aimed at tracking clients lost to follow-up. They include:

- (a) Use of SMS reminders as preventive measures (to remind clients of appointments a few days before they occur) or for tracing (SMS messages sent to defaulters). In some countries, this service is subsidized by telephone companies;
- (b) Employment of community health workers, mentor mothers, or other groups to conduct home visits and track back defaulters.

Combining tracking of defaulters from HIV services with tracking of defaulters from other services should be considered as it is a more cost-effective and less stigmatizing approach.

Key messages

- Decentralization and integration of services are key to improving attendance and relieving the burden on patients.
- Stigma is still a huge challenge within and outside health facilities; countries should eliminate structures that identify patients as HIV-infected; strategies to reduce stigma triggered by the behaviour of health care workers should be pursued; community involvement is crucial if stigma is to be reduced in all settings.
- Merging follow-up of the mother and the infant together would be crucial to improving their follow-up and should help minimize loss to follow-up.
- Community engagement is a key factor not only for increasing awareness but also for ensuring support to HIV-positive pregnant and breastfeeding women and their families.
- Early identification of defaulters is essential, particularly in PMTCT programmes. Countries should consider adopting such mechanisms as unique identifiers, longitudinal registers, and booking diaries in their efforts to identify defaulters.
- Several approaches can be used to trace back persons lost to follow-up; integration of tracking efforts with those of other services should also be considered as a means of improving effectiveness and sustainability.

ANNEXES

1. Readiness assessment for treatment initiation in pregnancy and breastfeeding

A rapid readiness assessment tool could be used during post-test counselling or in the pre-treatment initiation session to determine a woman's level of readiness for lifelong ART.

The tool could help health care workers to identify women who are ready for same-day initiation and those who may need more support and counselling. These are some of the factors to consider:

- (a) *Gestational age*: Women identified positive in the first trimester of pregnancy with are not ready to start can be given time for intensified counselling. However women arriving late in pregnancy or those identified during childbirth need to start urgently;
- (b) *Reaction of the woman to the diagnosis*. Observed level of shock, denial or depression may lead to delay the ART initiation and intensify counselling and support involving peers.
- (c) *Previous diagnosis*. Has the woman been previously diagnosed? Did she know her HIV status prior to the current HIV test? For women already prepared, the initiation should not delay
- (d) *The family context*:
 - (i) Presence of a stable relationship, willingness of the woman to disclose to her partner, presence of other support within the family or the community: those women have a better ability to cope with the diagnosis and a higher probability of retention once initiated;
 - (ii) Existence of an abusive relationship, need to maintain secrecy with the partner or others in the family, absence of support groups in the same community, a higher level of stigmatization within the family or community would suggest women at high risk of being lost to follow-up, pregnant adolescents and young women: such clients may need better preparation and delay prior to starting them on ART;
- (e) *Practical aspects*. Practical aspects such as distance to the clinic and ability to return for preparation visits when needed should also be considered and support provided accordingly.

2. Preparation for treatment initiation in pregnancy and breastfeeding

- (a) *Preparation package for women*. For better readiness to start treatment on the same day of testing, national programmes should develop a preparation package for women. For women who are not ready, close support should be provided;
- (b) *Non-prescriptive counselling requirements*. Enhanced preparation should not be over-prescriptive in counselling requirements; the duration of preparation should be considered on a case-by-case basis;
- (c) *Human resources*. Preparation of patients should not be the sole responsibility of the nurse. If other members of the clinic team are to be involved, good communication within the team is essential;

- (d) *Linkages with the community.* A mapping of PLHIV networks in the catchment areas of the facility will help to identify opportunities for linkages with community support groups or with key community members who can provide additional counselling and adherence or retention support;
- (e) *Family and partner involvement.* Partner involvement should be part of the preparation and should always be with the consent of the woman. Women may need practical support to be empowered to disclose;
- (f) *Emphasis on benefits for mother and infant health.* Every woman wants a healthy baby and the pleasure of being able to raise it by herself; it should be emphasized that she herself needs to be healthy for this to happen. ART is a lifelong regimen; it does not stop with the baby's birth or after the baby has been definitively diagnosed; long term retention is, therefore, essential.

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