Policy Brief

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# Overcoming Shortcoming in Monitoring Retention in Option B+

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## Summary

*The retention in care is a serious pointer of achievement for the Prevention of Mother to Child Transmission(PMTCT) care program. The level of retention of women under PMTCT care program at the different time points of the cascade of the elimination of mother to child transmission (EMTCT) cascade is critical to treatment outcomes. The current methods of measuring retention in care, at health facility level are reported to under-estimate overall retention since several women self-transfer to other facilities without being accounted for. Individual health facility retention is used in care assessment and no attention is paid to transfers.*

*This policy memo provides information on the alternative courses of action that may be taken to mitigate this issue of retention in care, clearly stating the pros and cons of each course of action. It also gives a recommendation for the best course of action that should be taken.*

1. *An addendum should be developed for the PMTCT registers, that is dedicated to assessing missed appointments at health facilities, and this can be reported on in the monthly HMIS 105 report - Short term implementation*
2. *Together with the AIDS development partners, the Ministry of Health should embark on establishment of a unified patient registration database that will be able to track and identify women as they move across health facilities. This has been implemented by the Uganda Peoples' defense forces (UPDF). - Medium term implementation*

## Background

Globally, 1.6 million HIV infections in children have averted due to PMTCT. Option B+ is recommended by WHO as the approach to PMTCT. It recommends lifelong anti-retroviral therapy (ART), and it involves initiation of ART on the same day of diagnosis. This approach is believed to support the goal of eliminating the AIDS epidemic by 2030. After initiation, monthly ARV dispensing visits are managed by clinic staff and at 18 months, women are transferred to chronic care clinic where they see out the rest of their life of ART. In Uganda, PMTCT implementation started in October 2012. The level of retention of women under PMTCT program at the different time points across the elimination of mother to child transmission cascade from enrolment into care, to final transfer back to the chronic care clinic at 18 months not clearly known. Poor retention in care is one of the leading causes of virologic failure, increase of risk of drug resistant virus, and increase in the risk of mother to child transmission (MTCT). Additionally, the methods of measuring retention at health facility level was found to under-estimate retention since several women self-transfer to other facilities and are not tracked, leading to many women wrongly classified as loss to follow up (LTFU), yet they are still in care but at another health facility. This movement across health facilities also creates duplicate registration of the same women, and this over-estimates program performance in terms of coverage. Health facility levels of LTFU up under Option B+ for HIV infected pregnant and breastfeeding women after a follow up period of 25 months were as high as 53.7%. However, a big proportion (33%) of these women considered LTFU had self-transferred to another facility, and had their registration had been duplicated in the different health facilities.

Currently, records for women are kept in individual files and each woman is given an ART number in series. Each health facility allocates numbers to women without considering if she is registered in another health facility or not, and there is no way of finding out if that is the case, unless the woman discloses. There is a need to establish a national system of ensuring that all women who are registered in care are followed up effectively, without duplication of registrations in other health facilities as this may affect program performance.

## Issues

Retention in care is a serious pointer of achievement for the Prevention of Mother to Child Transmission (PMTCT) care program. The lack of identity cards, has led to high duplication of registration of women in the PMTCT care program at health system and facility level. These duplications lead to overall overestimation of program performance and coverage at district and national level. There is a need for establishment of a system wide patient registration database to ensure

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tracking of women as they move across health facilities, and reduce duplicate registrations, and give accurate estimates of performance especially as the country moves towards greater coverage and elimination of HIV/AIDS by 2030. Proper estimation of performance of the PMTCT program will help un-mask the true gap that must be bridged to truly eliminate mother to child transmission (MTCT), and provide a mechanism for reliable monitoring of the scaled-up plans. This problem may also be affecting other similar chronic care management programs that are prone to self-referral.

Findings from a recent study indicated that loss to follow up (LTFU) at health facility level after a follow up period of 25 months is high at 53.7% (Kiwanuka *et al.*, 2017). However, a big proportion (33%) of these women considered as LTFU have often simply self-transferred to another facility, and their registration had been duplicated in the different health facilities. The implication of the self-transfer of women to other health facilities and program performance is inaccurate estimation of program coverage, numbers of women registered in care, and active in care. This gap is most likely bigger, its real magnitude masked by the failure to recognize these duplicate registrations across all health facilities in the country.

This will in turn improve assessment of program performance so that the true gap can be bridged since the country seeks to eliminate MTCT. Data on all previous attendances at other health facilities need to be accessible. These data needs to be linked through a database with unique identifiers.

### *What position(s) have others taken on these issues?*

a. In Nigeria, all pregnant women enrolling in the PMTCT program are given a unique patient identifier that allows for linkage of records throughout the care cascade. This identifier is separate from the patient ID given to individuals enrolled in the adult ART program. The adult ART ID is maintained throughout a patient's lifetime of ART care, whereas the PMTCT ID is relevant only during the patient's pregnancy and infant follow-up and a new PMTCT ID number is assigned with each subsequent pregnancy. The infant identifier is linked to the mother's identifier, to aid in follow-up and tracking. For mothers that were simultaneously enrolled in the adult ART program, PMTCT IDs were used to link to adult ART database systems to abstract additional data (E Rawizza et al., 2015).

b. In South Africa, the South African National Department of Health (NDOH) has recognized that MTCT rates, including post–natal transmission, can no longer be calculated from routine National Health System data without the introduction of unique patient identifiers. And the NDOH has communicated that unique patient identifiers will likely be implemented in all public sector facilities in the 2016/17 financial year (Sherman et al., 2017). By introducing unique patient identifiers and consolidating clinical information within the laboratory information system (LIS), a more efficient method of monitoring the effectiveness of the national PMTCT program using routine laboratory data are envisaged. It is believed that this will not only preclude unnecessary duplication of data capturing within the DHIS but also reliably inform eMTCT targets.

c. The Haitian Ministry of Health and partners operate a case-based, national HIV/AIDS surveillance system (HASS), using Electronic Medical Records (EMR) to identify duplicate records (Delcher et al., 2016).

d. The UPDF has reported success in establishment of an online registration database.

## Options

### *What are the plausible courses of action, along with the pros and cons of each?*

| Course of action | Pros | Cons |
|---|---|---|
| 1. The MoH should develop an addendum for the Option B+ and ART registers, that is dedicated to assessing missed appointments at health facilities daily, and this can be reported on in the monthly HMIS 105 report<br><br>Time Horizon: Short term implementation (1 year- by end of 2018) | ✓ Ensures monitoring of women regularly<br>✓ There is a ready health workforce for implementation of this action<br>✓ It easy, and economically feasible. An online system also has challenges of reliability and coverage, with concerns of not being able to reach all corners of Uganda, due to poor infrastructure, especially in remote areas. This therefore favors the use of paper based system.<br>✓ Can easily be rolled out countrywide. | ✓ Extra workload for health workers |
| 2. Work with HIV development partners to initiate establishment of an online patient registration database.<br><br>Explore the use of Laboratory Information System (LIS) at CPHL which could prove less costly. Clear advantages of using LIS data are that it allows for near real–time monitoring of early MTCT and EID coverage and comes at very little additional cost.<br><br>Time Horizon: Medium term implementation (2-3 years- 2019) | ✓ Enhanced availability of health information in an electronic format is strategic for industry-wide efforts to improve the quality and reduce the cost of health care Improved program monitoring<br>✓ One purpose of electronic medical records (EMRs) is to increase the accessibility and sharing of health records among authorized individuals.<br>✓ Establishment of this database can provide a backbone for other program monitoring such as NCDs, NTDs, and diseases targeted for elimination/eradication | ✓ May stigmatize women- ethical hindrance<br>✓ Expensive and there may be reluctance of the government to invest<br>✓ Perspectives of key players such as politicians need to be addressed |

### *What are the approximate financial costs of each option?*

To create an addendum on HMIS data collection tools would not cost the government a lot of money and several reports and data collection tools have been amended from time to time.

In establishment of the online patient registration database, the costs would be mainly system installation and maintenance, since all health centers that provide ART in Uganda have been supported by HIV implementation partners to have facility based Open Medical Records system (Open MRS). The task would be having this system online and providing all new and existing unique identifiers to use that can be tracked across health facilities, and districts. No evaluation of this task has been carried out yet.

### *What are the political risks and potential opposition that might result from choosing an option?*

a. Laws pertaining to the disclosure of health information: Privacy of personal health information is a concern for many PLWHA. Fears of breaches in confidentiality and resulting HIV stigma can result in individuals not accessing or adhering to care and treatment (Ford et al., 2012)

b. Media may misinterpret it and report it as mandatory registration for HIV/AIDS patients. It may also facilitate the proposed bill to criminalize HIV transmission, because this data may be used to identify the culprits. This may ultimately lead to resistance from the public.

c. Lack of willingness of HIV implementing partners, with different sources of funding to share information with others.

## Recommendation

1. By the end of 2018, the Ministry of Health an addendum should be developed for the Option B+ and ART registers, that is dedicated to assessing missed appointments at health facilities, and this should be reported on in the monthly HMIS 105 report

2. By December 2019, the Ministry of Health should operationalize the online patient registration database with unique identifiers to ensure monitoring of performance through elimination of duplicate registrations. The legal and social issues related to this need should also be clearly highlighted and addressed before implementation.

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**SPEED Brief**

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