

Monitoring the Elimination of Mother to Child Transmission (eMTCT) Program in Eastern Africa by Women Living with HIV

Report

By

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April 2016

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Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Anti-Retroviral Therapy
ARV	Anti-retroviral
CCC	Comprehensive Care Centre for HIV/AIDS
CPD	Continuous Professional Development
EID	Early Infant HIV Diagnosis
eMTCT	Elimination of Mother-to-Child Transmission of HIV
FGD	Focus Group Discussion
FP	Family Planning
GIPA	Greater Involvement of People Living with HIV and AIDS
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
IRB	Internal Review Board
ICWEA	International Community of Women Living with HIV&AIDS, Eastern Africa
IUD	Intra-uterine Device
KI	Key Informant
LWHA	Living with HIV/AIDS
MIWA	Meaningful Involvement of Women and Girls Living with HIV/AIDS
MTCT	Mother-to-Child Transmission of HIV
NGO	Non-governmental Organisation
PCTR	Polymerised Chain Reaction
PMTCT	Prevention of Mother-to-child Transmission of HIV/AIDS
RCNF	Robert Carr Network Fund
RUTF	Ready to Use Therapeutic Feeds
SRHR	Sexual and Reproductive Health Rights
SSA	Sub-Saharan Africa
STI	Sexually Transmitted Infections
UNAIDS	Joint United Nations Programme on HIV and AIDS
WHO	World Health Organisation
WLHIV	Women Living with HIV

1.0 Introduction

1.1 Background

HIV/AIDS is one of the biggest challenges in the developing world. The pandemic has hit Sub-Saharan Africa (SSA) most, with an estimated 24.7 million [23.5–26.1 million]¹ people living with HIV; nearly 71% of the global total. Uganda, Kenya and Tanzania are among the 10 top countries that account for 81% of all people living with HIV in SSA. Recent evidence suggests that HIV affects women more than men in developing countries, and women are more likely to become infected with HIV through unprotected heterosexual intercourse. In addition, millions of women are directly affected by the HIV and AIDS epidemic through mother-to-child transmission (MTCT)². For example, 58% of the total number of people living with HIV in SSA are women, and the percentage of young women aged 15-24 living with HIV is twice that of young men³. Mother-to-child transmission (MTCT) of HIV is a significant contributor to HIV transmission; in 2013, 240,000 [210,000–280,000] children were newly infected with HIV, while in 2012 the figure was higher, estimated at 260, 000. 3.3 million Children were also living with HIV⁵.

In all Eastern Africa Countries, Mother to Child transmission of HIV is the second most common mode of spread for the virus. It is virtually the only way that young children (under 2 years of age) acquire the infection and is one of the leading causes of early childhood mortality. Without any intervention, up to 40 percent of HIV positive women will transmit the infection to their children during pregnancy, labour and breastfeeding. In Uganda for example, MTCT accounts for up to 18 % of all new infections in the country, while in Kenya it accounts for 16%. Without

¹ UNAIDS (2014). Fact Sheet. Available at: http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/factsheet/2014/20140716_FactSheet_en.pdf

² MTCT of HIV occurs when an HIV-positive woman passes the virus to the baby during pregnancy, labour and delivery, or after delivery through breastfeeding. Without prophylactic treatment, approximately 15–30% of infants born to HIV-positive women will become infected with HIV during gestation and delivery, with a further 5–15% becoming infected through breastfeeding(WHO 2010)

³ Gap Report www.unaids.org/en/media/unaids/.../2014/UNAIDS_Gap_report_en.pdf

⁴ UNAIDS (2012) ' [Women Out Loud: How Women Living with HIV Will Help the World End AIDS](#)'

⁵ UNAIDS Global Report 2013 - www.unaids.org/en/media/unaids/.../201309_epi_core_en.pdf

any intervention to reduce vertical transmission⁶, about 25,000 babies are estimated to be born with HIV every year in Uganda. In Kenya, an estimated 37,000 to 42,000 infants are infected with HIV annually due to MTCT⁷. The 4th Rwanda Demographic and Health Survey (RDHS) 2010 indicates that although Rwanda has one of the lowest HIV prevalence rates amongst pregnant women in Eastern and Southern Africa – currently standing at a national average of 4.3 per cent, the MTCT rate in the capital Kigali is much higher (between 16 and 34 per cent). In 2010, Burundi had a high maternal mortality ratio (800/100,000), which may be linked to the low rates of skilled attendance at delivery (60%)⁸.

In 2009, UNAIDS (together with other partners such as the Earth Institute) called for the virtual elimination of mother-to-child transmission of HIV by 2015 and introduced the Global Plan⁹, whose overall goal is ‘to achieve virtual elimination of HIV transmission from infected mothers to their children through enhanced provision of integrated comprehensive eMTCT services¹⁰, and to reduce morbidity and mortality among the HIV-exposed infants’. This is a shift from the previous emphasis on expanding the coverage of services for preventing Mother-to-child transmission (PMTCT). The Plan focuses on reaching pregnant women living with HIV (WLHIV) and their children—from the time of pregnancy and beyond the breast feeding period. Under the plan, countries were required to develop or update their national eMTCT plans in line with the latest global policies and guidance, global elimination goals, targets and lessons learned from equity-focused bottleneck analyses.

Accordingly, the East African Governments came up with eMTCT National Plans, policy guidelines and strategic frameworks that aim to address the existing gaps related to coverage

⁶ transmission of human immunodeficiency virus (HIV) in utero, around the time of birth, and postpartum as a result of breastfeeding ([Tóth et. al. 2001](#))

⁷UNAIDS Global Report on AIDS Epidemic 2012, issuu.com/unaid/docs/20121120_unaids_global_report.

⁸ Ibid

⁹ UNAIDS (2009). The Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive. UNAIDS, Geneva.

¹⁰ This includes: prevention of new HIV infections among women of childbearing age; preventing unintended pregnancies among women living with HIV; preventing HIV transmission from a woman living with HIV to her baby and providing appropriate treatment, care and support to mothers living with HIV and their children and families (WHO 2013)

of services for eMTCT and care for HIV positive mothers and exposed children through innovative eMTCT- EID strengthening approaches. In Kenya for example, the national PMTCT programme started in 2002, and following the release of the 2010 WHO guidelines, the country adopted option A with a provision to implement option B in areas that have capacity for initiation and monitoring systems. Uganda launched the first PMTCT policy guidelines in 2002, following lessons learnt from the PMTCT pilot in 2000. These guidelines evolved in 2008 and later in 2010 with the WHO guiding principles. Uganda then released new guidelines for PMTCT¹¹, EID, ART and Infant Feeding, which the Ministry of Health has adapted to the country's setting¹². In Tanzania, the government has been revising its PMTCT guidelines since 2006, with the latest guidelines including the implementation of Option B+¹³.

Following the release of the eMTCT guidelines, the different East African governments recognized that central to the success of their plans is the active engagement and advocacy role of WLHIV to address HIV related stigma (whether enacted, anticipated, perceived community or self) that impedes access to services by WLHIV themselves. It is the WLHIV that need the services most and who demand for comprehensive MCH services. One of the guiding principles for the national elimination plans is the focus on WLHIV to ensure reliable and equitable access to eMTCT services for all women and children, including the most vulnerable.

In November and December 2013, ICWEA organized and in some countries (Uganda) participated in key eMTCT stakeholders' meetings in 4 of the 5 countries (Rwanda, Tanzania, Burundi and Uganda). The aim was to obtain updates on the progress made in the countries on implementation of eMTCT/PMTCT and to strategically position themselves to contribute

¹¹ Ministry of Health (MoH) 2012. The Uganda National Plan for Elimination of Mother to Child Transmission of HIV, 2012-2015. MoH, Republic of Uganda, Kampala.

¹² See for example Ministry of Health (MoH) 2014. National Plan for the Roll Out of the Revised Antiretroviral Therapy Guidelines for Prevention and Treatment of HIV Infection in Uganda. MOH, Republic of Uganda, Kampala.

¹³ **See Tanzania Ministry of Health and Social Welfare (MHSW) 2013.** Tanzania National Guidelines for Comprehensive Care Services for PMTCT and Keeping Mothers Alive (Option B+), **MHSW, Dar es Salaam**

meaningfully to the planning, implementation and monitoring of the eMTCT/PMTCT Program in their respective countries. At the end of the meetings, the WLHIV developed their work plans for the coming year and highlighted the importance of monitoring the implementation of the eMTCT programs in their respective countries so that by the end of the year, they would be in a position to effectively report back to eMTCT program implementing partners and key policy makers in similar stakeholder's meetings from their informed perspectives.

Given the above background, ICWEA, working in conjunction with its membership plans to implement a Project on increasing participation and accountability by WLHIV in eMTCT, with the overall goal of improving and increasing access to Sexual Reproductive Health and Rights (SRHR) and eMTCT services. This project will be implemented in the 4 East African countries of Burundi, Kenya, Tanzania and Uganda, which are heavily burdened by HIV and also face numerous challenges in eMTCT¹⁴. This study will inform the project by providing vital information on WLHIV's knowledge and understanding of eMTCT and its related policies, the quality of eMTCT/PMTCT services and programs for WLHIV, and the challenges faced by WLHIV in accessing eMTCT services in selected countries in East Africa.

1.2 The Research Problem

PMTCT/eMTCT interventions in resource poor settings can reduce the transmission of HIV to infants and also save lives and improve the well-being of WLHIV. In Eastern Africa, most countries have developed PMTCT/eMTCT guidelines as recommended by WHO and these guidelines recognize the importance of involving WLHIV so as to ensure reliable and equitable access to eMTCT services to vulnerable women and children.

Despite the development of eMTCT guidelines by the various East African governments, WLHIV continue to face several challenges in accessing eMTCT/PMTCT services, both from the demand and supply sides. Some of these challenges include: HIV-related stigma and discrimination;

¹⁴ GTZ (2007). Prevention of Mother-to-Child Transmission of HIV in Kenya, Tanzania and Uganda, GTZ, Eschborn.

unclear messages regarding ART; mandatory testing of women and immediate initiation of ART with no mechanism to support them disclose their results to their spouses; loss of HIV positive mothers from the eMTCT care and treatment programs; low involvement of males in eMTCT programmes; unfavourable legal and policy environments; negative attitude of the health care providers; limited counselling, care and support from the health care providers; coercion into family planning, and the stock out of testing kits and ART for mothers and nevirapine for their babies. Most of these challenges were also established by the International Community of Women Living with HIV in Eastern Africa (ICWEA) while implementing the Sexual reproductive health and Rights programs in 5 Eastern Africa countries including Kenya, Uganda, Tanzania, Rwanda and Burundi¹⁵.

Whereas these challenges are real, many have not been documented basing on the lived experiences of WLHIV, as WLHIV are less involved in planning, implementation, monitoring and evaluation of eMTCT programs. Incorporating the knowledge and lived experiences of WLHIV (and their spouses) in assessing the eMTCT services they receive is critical to voicing their concerns and improving service delivery. This study seeks to enhance knowledge and understanding of these gaps by **enhancing** the assessment of the quality of eMTCT/PMTCT services and programs for WLHIV by the WLHIV themselves, considering their own reflections of their needs and priorities in accessing the services. The study has also identified the most significant challenges faced by WLHIV in accessing eMTCT services, which will be used by ICWEA and its members to influence better and quality eMTCT/PMTCT services and programs for WLHIV.

¹⁵ See ICWEA (2014). HIV/AIDS and Sexual Reproductive Health Rights Project among Women Living with HIV. End of Project Report. ICWEA, Kampala; and Mugumya, F. and Asaba, R.B. (2015). 'HIV/AIDS and Sexual Reproductive Health Rights Project among Women Living with HIV'. Draft End of Project Evaluation Report. ICWEA, Kampala.

2.0 Objectives of the Project

2.1 Overall Objective

The overall objective of this study, which also forms the first phase of the project was to assess the quality of eMTCT/PMTCT services and programs for women living with HIV, taking into account the perspectives of WLHIV themselves, and their needs and priorities that would effectively address the underlying gaps hindering access to the services.

2.2 Specific Objectives

- i. To explore WLHIV's knowledge of eMTCT and eMTCT related policies, strategies and guidelines.
- ii. Examine the availability and accessibility of eMTCT/PMTCT services for women living with HIV in the designated health facilities in relation to the country policies and guidelines.
- iii. Identify the health system gaps that undermine the quality of eMTCT/PMTCT services delivered and the current barriers to WLHIV's access to eMTCT/PMTCT services
- iv. To make key recommendations to the relevant program implementers, planners and key stakeholders for eMTCT/PMTCT programs, and to the upcoming project in general, on successful strategies for improving the quality and accessibility of eMTCT / PMTCT services based on the lived experiences of WLHIV.

2. Methodology

2.1 Study Design

This study adopted a cross-sectional and exploratory qualitative research design to obtain (at a single point in time) knowledge, experiences and opinions of stakeholders (including WLHIV) about eMTCT service delivery and access to other sexual and reproductive health rights especially by HIV positive women and girls (the demand side), and from other key stakeholders at national and local levels especially eMTCT service providers (the supply side). The study largely utilised the grounded theory principle, whereby the researchers had an open mind

(Grbich, 2004¹⁶; Goulding, 2002¹⁷) in their inquiry. The voices and lived experiences of women living with HIV, and the views and perspectives of men living with HIV and eMTCT service providers were obtained and analysed in an iterative manner and in different contexts on knowledge of eMTCT and related policies and guidelines, the current quality, challenges and lessons for improving access and general friendliness of eMTCT services.

2.3 Study Sites, Study Population, Targets and Sampling

Initially this study was to be undertaken in four of the five member countries of ICWEA namely, Uganda, Kenya, Tanzania and Burundi. Due to financial and human resource constraints, political instability and ethical review complexities, Tanzania, and Burundi were left out. Thus, the present draft report is based on data from Uganda and Kenya. These countries were chosen to participate in this study because they fall among the 22 countries focused at by the 2011-2015 Global Plan for eMTCT and keeping HIV positive mothers alive. The 22 countries nearly all of which are in sub-Saharan Africa have the highest number (nearly 90%) of HIV pregnant mothers who are in need of services.

This study targeted women who are utilising eMTCT/PMTCT services, their spouses and eMTCT/PMTCT policy and programme implementers in Uganda and Kenya. The respondents for this study were purposively selected at various levels of service delivery. The identification and selection process for study participants was spearheaded by ICWEA, supported by the ICW Country Chapters. In each country, participants were supposed to be drawn from the national level, targeting the ministries of Health and relevant agencies involved in HIV/AIDS programming particularly on eMTCT/PMTCT. National Chapters of Networks of women living with HIV supported the identification and selection of such agencies. At lower levels, two local governments at the level of a district, one highly performing and the other poorly performing were selected per country, also in consultation with stakeholders. In addition, study

¹⁶ Grbich Carol (2004) *New Approaches in Social Research*. Sage Publications, Thousand Oaks. London

¹⁷ Goulding Christina (2002) *Grounded Theory: A practical Guide for Management, Business and Market Researchers*. Sage Publications, Thousand Oaks. London.

participants were designed to be drawn from active networks of women living with HIV regardless of whether they came from the selected districts/regions. This was mainly because of the need to maximize views and experiences of women in accessing eMTCT services.

As earlier indicated, two countries (Uganda and Kenya) rather than four (as earlier planned) participated in this study. Also, not all the targeted participants were reached in these two countries owing to difficulties in ethical approval of the study in Kenya; it had been assumed that ethical approval that was granted in Uganda would also apply in Kenya but this was not the case. Consequently, it was not possible to conduct key informants with service providers in Kenya. Fortunately this was not a problem in Uganda. From each of the two selected districts per country, five Focus Group Discussions (FGDs) were conducted; two of these with HIV positive women aged 31 - 49 , and the other two FGDs with young HIV positive women aged 15 -30 (see Table 1). Also, one FGD with men, who were spouses of the women accessing eMTCT services was conducted.

In Uganda, data from three Key Informant Interviews (KIIs) conducted in Kanungu and Masindi districts has so far been analysed. These include interviews with Health Workers at different public health facilities; policy implementers at the district; and one with a policy implementer at the national level. Table 1 summarises the study participants met in Uganda and Kenya and analysed so far.

Table 1. Sample Distribution of FGDs and KIIs/IDIs per Country

Uganda (Kanungu District)*	
	2 FGDs - HIV positive Women aged 31- 49
	2 FGDs - HIV positive Women aged 15 – 30 years
	1 FGDs - Men (HIV positive)
Total FGDs (Uganda)	9
	2 KII - Health Workers
	1 KII - National-Level Policy Implementer
Total KIIs (Uganda)	3
Kenya (Busia and Kakamega Districts)	

	4 FGDs - Women aged 31- 49
	4 FGDs - HIV positive Women aged 15 – 30 years
	2 FGDs – Men (HIV positive)
Total FGDs (Kenya)**	10

* The second district was Buliisa, whose data is yet to be analysed

**Owing to IRB approval difficulties, KII for Kenya were not undertaken. This gap is being filled with the review of secondary material/documents.

2.4 Methods of Data Collection

Focus Group Discussions (FGDs) and Key Informant Interviews were the main methods of data collection. These were supplemented by documents/records review at the health facilities. Data collection was done by thoroughly trained research assistants who spoke the local languages in the targeted districts. All the FGDs and in-depth interviews were tape recorded and later transcribed for analysis and report production. Supervisors not only over-saw data collection in their respective areas but also participated in conducting key informant interviews.

2.5 Data Management and Quality Control

A number of planning/preparatory activities were undertaken before data collection. These included recruitment and training of Research Assistants and Supervisors/Facilitators. Women Living with HIV were prioritised for the data collection and management processes, but with support from the Principal Investigator and her co-Investigator. Supervisors and Research Assistants were trained to understand the research objectives, the scope (including the relevant technical aspects of eMTCT, the methodology, tools and other practical aspects of interviewing and processing of qualitative data such as transcribing. The Principal Investigator and the Research Advisors provided this training and support for ICWEA to map out the final plan for research implementation as well as quality assurance.

2.6 Data Processing and Analysis

All the interviews and FGDs were audio recorded and later transcribed from the local languages directly into English. All the transcribed notes were analysed largely using the grounded theory

approach; themes and sub-themes addressing the key objectives and the research questions were generated and data grouped/coded following these categories.

2.7 Ethical Considerations

Discussions were held with relevant district officials to seek their guidance and support to undertake the study in the different in-country sites. Advice on accessibility, safety and community support to research activities in the sampled areas was sought. Verbal informed consent was sought from all the respondents/participants prior to the interviews and discussions. Study participants were assured of the confidentiality of their responses and that the information they provide was to serve purposes only specific to this study and not anything else. The interviewers also ensured that interviews and FGDs took place in socially approved settings and were conducted in consideration and honour of the community values and norms. Consent was also sought from the respondents/participants to use audio recorders and adequate explanation provided as to why they were important as well as how the recorded voices were to be used only for purposes of this study.

In the reporting of findings, individual identifications were not used so as to guarantee confidentiality in reporting responses; only second names were used. Great care was taken to minimize the potential for distress or harm to the study participants. Actions included; the careful wording of questions to ensure that they are non-judgmental; providing interviewers with a five days training, including how to respond if someone disclosed violence or requests assistance; providing all participants with information about potential sources of support; and ensuring that follow-up support could be made available if requested. Finally, this study sought ethical approval from The Aids Support Organisation (TASO) accredited Review and Ethical Committee (REC), based in Kampala, Uganda. The study has also been registered with the Uganda National Council of Science and Technology (UNCST).

2.8 Gender Considerations

This study recognizes that gender issues affect the provision and effectiveness of eMTCT services. For example, whereas eMTCT targets HIV positive women and their children, the stigma associated with HIV and access to services affects their relationships with their male spouses, sometimes leading to violence and shunning of services by women¹⁸. Patriarchal norms may also limit women and men's access to the services. Thus, the study engaged with both the WLHIV and their male spouses from its inception. Since the study constitutes the first phase of the project, men were also interviewed in FGDs, and efforts were made to explain to them the importance of their views and attitudes towards eMTCT services received by their spouses and children. The fact that the study was undertaken by WLHIV, gender relations between the WLHIV and their spouses were carefully explored further in male FGDs in a friendly and confidential atmosphere to allow both groups to reveal the key issues impacting on their access to eMTCT services, and how they can be overcome.

3.0 Findings of the Study

Introduction

This chapter explores the major findings of the study, which are presented thematically following its objectives outlined in Chapter One. As such, the following themes are covered: knowledge of eMTCT and its related policies and guidelines; the availability and accessibility of eMTCT or PMTCT services and, health system gaps that undermine the quality of services for WLHIV. These themes are discussed taking into account what WLHIV themselves say supplemented by perspectives and experiences of stakeholders consulted through key informants who included both coordinators and providers of services. A good attempt is made to provide contextual differences of between Kenya and Uganda.

¹⁸ See for example GTZ (2007). Prevention of Mother-to-Child Transmission of HIV in Kenya, Tanzania and Uganda. GTZ, Eschborn; UNAIDS (2014). Global Gap Report. UNAIDS, Geneva.

3.2 Knowledge of eMTCT and Related Policies, Strategies and Guidelines

Awareness about PMTCT or eMTCT among PLWHAs is vital in communicating information and improving access to the services¹⁹. Pregnant mothers or WLHIV's knowledge of eMTCT or PMTCT also plays a major role in limiting the spread of HIV to children, and in keeping the mothers alive²⁰. In this study, women and men living with HIV were asked to explain what they understood by eMTCT, whether they had heard about any policy or strategy or guidelines on eMTCT in their midst, how they came to learn about the policies/strategies/guidelines and whether they have ever seen copies of the same and where.

3.2.1 Understanding/Knowledge of eMTCT/PMTCT: *What is eMTCT?*

Asked to state what they understood by eMTCT, most of the WLHIV (and men) in both Uganda and Kenya thought that it was the same as PMTCT. They also thought that eMTCT was mainly about the third prong or element of PMTCT that involves providing antiretroviral medicine prophylaxis to prevent the transmission of HIV from mothers or WLHIV to their unborn or born children during pregnancy, labour/delivery and during breastfeeding. Some simply thought of eMTCT as a strategy that enables an HIV positive pregnant woman to deliver a child that is HIV negative. They noted:

eMCT means stopping children from acquiring HIV from their mothers
(FGD, Young Women, Kihiihi Health Centre IV, Kanungu District, Uganda)

I understand that PMTCT means those women who have HIV/AIDS going to the hospital to deliver there and then being given drugs that they should take in order to give birth to children who are HIV negative **(FGD, Older Men, Busia Town, Busia District, Kenya)**

¹⁹ See Pokharel, Nirmala, Mangala Shrestha and Sami Lama (2012). Awareness on HIV/AIDS and prevention of mother to child transmission of HIV/AIDS among stake holders and people living with HIV/AIDS in Dharan municipality, Sunsari, Nepal. *International Journal of Nursing and Midwifery* Vol. 4(2).

²⁰ See for example Moses AE, Chama C, Udo S (2008). Knowledge, Attitude and Practice of Ante-Natal Attendees toward Prevention of Mother to Child Transmission (PMTCT) of HIV Infection in a Tertiary Health Facility, Northeast-Nigeria. *JTWM* 8: 4455 and Tesfaye G, Tufa B, Likisa J, Alebachew M, Temesgen G (2015). Knowledge, Attitude and Practice towards PMTCT of HIV among Women Attending Ambo Hospital ANC Clinic, West Ethiopia. *J AIDS Clin Res* 6:407.

In full it [eMTCT] is preventing HIV transmission from an HIV positive mother to the child and by doing this first of all you should know your status. For my case I knew my HIV status in 2006 when I became pregnant. I followed the doctor's instructions and when I delivered I breast fed my babies exclusively. They are twins and are HIV negative. In fact that is what made me get this opportunity to advise other women on positive living so that they can also give birth to HIV negative children

(FGD, Older Women, Malaba, Busia District, Kenya)

According to my own understanding, it is when a mother is pregnant and is HIV positive and should go for ante-natal at least four times throughout her pregnancy. She should take ARV's and when it is time for delivery, she should deliver from a hospital, and then health workers continue to care for that baby. Then they do the first HIV test for the baby and after one and a half months, they do another test. Then she [the mother] should breastfeed for one year and after 8 months the mother should bring the baby back for the last test **(FGD, Men, Nyamirama Health Centre III, Kanungu District, Uganda)**

Only a few participants described eMTCT as a more comprehensive strategy aimed at not only ensuring that new infections in children are eliminated, but also keeping mothers alive through options B and B+. The following illustrate:

.....here in Busia we are heading to eMTCT not PMTCT. We are trying to eliminate not to prevent so we are fighting against the virus to eliminate it through antiretroviral therapy. So on first contact with the mother who is HIV positive, we enrol the mother on ARVs and then after we follow-up this mother in every step up to birth. We encourage this mother to deliver in the hospital, and when this mother delivers in the hospital we give nevirapine prophylaxis to prevent the baby from being infected with the virus. And when the baby is breast feeding we encourage the mother to breast exclusively up to 6 months and then after 6 months the baby will start eating other things. We take it as complementary feeding and when the baby is 9 months we take the second PCR test – the first PCR we take it at 6 weeks- and then at 18 months we take antibody test. Then we discharge this baby to the PMTCT, whether it is negative or positive and then we link the mother to the CCT for continued therapy **(FGD, Older Women, Busia, Busia District, Kenya)**

I know that [eMTCT] is when a pregnant woman goes for ANC, and she is tested for HIV. If found positive, the mother is started on ARVs for life **(FGD, Older Women, Kihiihi Health Centre IV, Kanungu District, Uganda)**

Source of eMTCT Knowledge

Asked to state how they came to know about eMTCT, most of the WLHIV/FGD participants from Uganda and Kenya mentioned health workers/personnel, such as doctors/nurses and health facilities (mainly health centres and hospitals), as shown in Table 2.

Table 2. Reported Sources of Knowledge on eMTCT by Women and Men Living with HIV

Country	
Kenya	Uganda
Hospitals	Health Centres
Doctors/health assistants/nurses	Hospitals (doctors/health assistants/nurses)
Health facilities	VHTs and health volunteers
Television programs/news	Radios/radio programmes
Programme/activity launches e.g., governor care in Kakamega district	Churches
	Friends

As shown in Table 2, the other sources of eMTCT knowledge were different in the two countries, with FGD participants from Uganda mentioning village health team members (VHTs), radio programs, friends, and churches, while those from Kenya outlined televisions and programme or activity launches such as governor care as reported from Kakamega district.

3.2.2 Knowledge of eMTCT Related Policies, Strategies and Guidelines

Whether WLHI had heard about eMTCT Policies/Strategies/Guidelines

We also asked the male and female FGD participants and key informants whether they had heard about any policy, strategy or guidelines on eMTCT/PMTCT. Most of the FGD participants in Uganda and Kenya said they had not heard of the policies/strategies or guidelines. The few that had heard of the eMTCT policies/guidelines could not clearly name them. For example none of the study participants in Uganda (including the more trained and knowledgeable key informants) mentioned the Uganda National Plan for Elimination of Mother to Child Transmission of HIV (2012-2015)²¹; the new National Plan for the Roll Out of the Revised Antiretroviral Therapy (2014)²², nor the Policy Guidelines to Increase Utilization of Services for Elimination of Mother-to-Child HIV Transmission in Uganda (2013)²³, which include Option B+, and the Integrated National Guidelines on Antiretroviral Therapy, Prevention of Mother to Child

²¹ See Ministry of Health (MoH) 2012. The Uganda National Plan for Elimination of Mother to Child Transmission of HIV, 2012-2015. MOH, Republic of Uganda, Kampala.

²² See Ministry of Health (MoH) 2014. National Plan for the Roll Out of the Revised Antiretroviral Therapy: Guidelines for Prevention and Treatment of HIV Infection in Uganda. MOH, Republic of Uganda, Kampala.

²³ MoH (2013). Policy Guidelines to Increase Utilization of Services for Elimination of Mother-to-Child HIV Transmission in Uganda. Ministry of Health, Kampala.

Transmission of HIV, Infant & Young Child Feeding (2012)²⁴. It is also worth noting that none of the women (and men) LHIV in Kenya articulated a single eMTCT/PMTCT policy, not even the then popular strategic framework for eMTCT (2012-2015)²⁵. It was therefore not surprising that the WLHIV had limited knowledge about the major provisions of the eMTCT policies/strategies/guidelines in their countries, as discussed in the next sub-section.

The FGD participants only mentioned hospitals/health facilities or health workers as their sources of information. Some FGD participants from Kenya and Uganda explained that they had seen books or other documents and charts on eMTCT in health facilities, and that the charts had pictures or drawings of HIV positive mothers breast feeding or taking ARVs among other aspects of eMTCT. For example:

Yes, they [guidelines/policies] are there in the hospital. I saw some drawings of pregnant mothers, others are written about PMTCT explaining what it means and also how to be careful when you give birth, and the drugs you will be given. **(FGD, Older Women, Busia, Busia District, Kenya)**

The study participants from Uganda mentioned other sources of knowledge on eMTCT policies/guidelines, such as local leaders, radio programmes or reading books (mentioned by WLHIV, for example Box 1) and workshops/trainings provided by the Ministry of Health and some NGOs and continuous professional development (CPD) courses, which were mainly singled out by the key informants

Box 1: Sources of Knowledge on eMTCT Policies/Strategies/Guidelines

I. From Where Did You Get Information about a policy, strategy or guidelines to prevent or eliminate Mother to Child Transmission of HIV in this community?

- R1. From health workers
 - R2. NGO's came on ground and gave us information on the policies
 - R3. Even on radio programs
 - R3. Through reading books
- (FDG, Young Women LHIV, Kihiihi HCIV, Kanungu District, Uganda)**

²⁴ See WHO (2012). Integrated National Guidelines on Antiretroviral Therapy, Prevention of Mother to Child Transmission of HIV, Infant & Young Child Feeding. Ministry of Health, Kampala.

²⁵ See MOH (2012). Towards the Elimination of Mother to Child Transmission of HIV and Keeping Mothers Alive: Strategic Framework 2012-2015.

Knowledge of Provisions of the eMTCT Policies/Strategies/Guidelines

Our findings show that WLHIV in Kenya and Uganda generally have scanty knowledge about the provisions of their eMTCT policies/strategies/guidelines, a common characteristic being their articulation of some of the rights of WLHIV (such as the right to give birth, receive ANC and ARV prophylaxis for them) and all WLHIV receiving ANC at health facilities (Table 3).

Table 3. Summary of Provisions of eMTCT Policies/Strategies/Guidelines Reported by the Study Participants

Country	
Kenya	Uganda
Rights of WLHIV (right to give birth, to be attended to in health facilities etc)	Rights of WLHIV
Family Planning (e.g., child spacing)	EID guidelines or enrolment of exposed children on ARVs*
ARV Therapy for pregnant women	ANC
WLHIV attending ANC	
Protocol on Option B+	

*Mainly mentioned by Key Informants

Table 3 further shows that the participants from Uganda, mainly key informants were more knowledgeable about some of eMTCT strategies outlined in their policies, strategies or guidelines, particularly on EID. Interviews with health workers in Uganda generally revealed that most of them were also not aware of the sexual and reproductive health rights of WLHIV.

No we have not heard of SRHR for HIV positive women. Yes we know about SRHR in general which we learnt from schools and MOH charts but we don't have them in the health unit, I know that like any other woman an HIV+VE woman have the same rights.
(Interview with Health Workers, Ruyeyo Health Centre, Uganda)

I cannot tell where I learnt them from but I have heard about them from meetings and trainings. I have been a trainer for reproductive health since 2001, but what I know; is that most H/workers don't know about women rights because they rarely talk about them
(eMTCT Coordinator Kanungu District, Uganda)

3.3 Availability and Accessibility of eMTCT/PMTCT Services for WLHIV

3.3.1 Access to ANC, eMTCT/PMTCT and Family Planning services

Antenatal care services at health facilities constitute one service line through which all the other services targeting the baby, the mother and father can be provided²⁶. In some health facilities ANC and family planning services are provided on a daily basis from Monday to Friday while in others the services depend on availability of medical supplies including drugs.

We provide services like HIV testing and counselling, Antenatal, and ART.... We have many services like Family Planning, Immunization, Health Education, CD4 count, and viral load tests; we do continuous medical education (CME) and maternity services which are open for 24 hours....Everything we do from here because we have a very well equipped laboratory and it's free of charge, PCR [Polymerase Chain Reaction], Malaria treatment, Urinalysis etc., so everything is comprehensive **(Interview with Health Workers, Kanungu HCIV, Kanungu District, Uganda)**

ANC is done every day from Monday to Friday, so it is a routine; every mother who comes here is welcomed and given all the services available like HIV testing and counselling. In case a mother tests positive, she is immediately initiated on ART because of the availability of testing kits and trained staff. **(Interview with Health workers, Kanungu HCIV Kanungu District, Uganda)**

Outreaches and Community based Services (VHTs)

The study also indicates that despite challenges, some health facilities also have arrangements for follow-up on clients who are initiated on ART and VHTs/peer educators play a key role in such circumstances.

Our system here works such that we give appointment to clients for review, and whoever fails to turn up we use our cell phone to call them and find out....We also have VHTs (Village Health Teams) whom we use to reach the mothers that have failed to turn-up on their appointment days **(Interview with Health Workers, Kanungu HCIV Kanungu District, Uganda)**

Prophylaxis for Exposed Babies and Early Infant Diagnosis

²⁶ E.g., WHO (2014) ' HIV/AIDS: Prevention of mother-to-child HIV transmission, WHO, Rome.

Prophylaxis treatment and Early Infant Diagnosis (EID) are fundamental for the care of the baby born of an HIV infected mother²⁷. The findings of this study indicate that these services are a priority for pregnant and lactating mothers, with most health facilities providing EID as early as 6 weeks, in line with the STAR SW and local policy guidelines. The test is done again 6 weeks after cessation of breast feeding (and mothers are advised to stop breast feeding at six months), and at 18 months PCR is done. Nutritional support or care is also provided, such as p75 milk, plumpy nut, ready to use therapeutic feeds (RUTF).

We do PCR at 18 months... those babies are also brought on a monthly basis by their mothers who come to be part of the baby home care package where we meet those mothers..... We also provide prophylaxis for children that are exposed as well as cancer screening because those HIV positive mothers are likely to get cancer of the cervix
(Interview with Health Workers, Kanungu HCIV, Kanungu District, Uganda)

Immediately after delivery the child is given nevirapine syrup and the mother is given ARVs and septrin and this is for all the mothers....The good thing is that we do not experience any stock-outs of drugs ...and women come back for treatment once they are started on treatment. **(Older Women's FGD, Lubao – Kakamega Rural, Kenya)**

They get a syrup, whose name I don't know well. [aaahhh....nevirapine syrup]. They used to be given milk but they no longer give. They also give formula milk up to today depending on the viral load of the mother. If the mother's viral rod is more than 1,000 and she is breast feeding they do not give. **(FGD, Older Men, Malaba, Busia District, Kenya)**

FGD participants also confirmed that babies or their mothers may be given other foods such as cooking oil, flour, and porridge (in Malaba in Kenya). In Uganda, FGD participants from Kanungu district wondered why snacks such as rice, soda and mandazi that used to be given to the mothers and their children in the past were no longer being provided. The other services and products provided to babies exposed to HIV included mosquito nets and immunization.

²⁷ See WHO and UNICEF (2007). Guidance on Global Scale-Up of the Prevention of Mother-to-Child Transmission of HIV: Towards Universal Access for Women, Infants and Young Children and Eliminating HIV and AIDS Among Children. Geneva.

3.3.2 Perspectives of WLHIV on Quality and Access to ANC, Family Planning and eMTCT Services in General

Long distances, long queues, poor male support, low staffing levels and drug stock-outs remain formidable challenges that mothers and health facilities have to 'patiently' wait to resolve. In addition, there are mothers who take too long to visit antenatal clinics as well as those who do not deliver babies in health centres. The findings of this study indicate that on average, most HIV positive pregnant mothers in communities visited in Uganda and Kenya attend their first ANC when four to five months pregnant, contrary to the recommended first trimester. These mothers continue to cause speculation that they delay because they are visiting traditional birth attendants (TBAs). It is such mothers that need to be followed up.

Some mothers come for first antenatal visit at 18 or 20 weeks although others come in the first trimester to confirm pregnancies. The number of pregnant mothers who come for ANC services reduces at the fourth visit compared to the number at first visit. The numbers of mothers who come to deliver in the health unit also reduces when compared to the number that attends ANC services. I have been here for only two months and have observed that the number reduced by one half. We are not sure if there are traditional birth attendants around who keep them there. **(Interview with Health workers, Rugyeyo Health Centre III, Kanungu District)**

Distance to and from Health Facilities, Transport Costs and Waiting Time

Distance, inadequate staffing at health facilities, and the associated waiting time continue to constrain women's effective utilization of services acting both as direct and indirect barriers to accessing/demanding for the services. A thin staff team at the health facilities in many situations according to the findings of this study has resulted into too much workload and stress for the few health workers, which is negatively affecting how health workers will talk to patients.

Services are mainly accessed at health centres which for many mothers are not only distant, but terrains such as those in Kanungu exacerbate mobility challenges for the women. In Kanungu District, participants in one of the FGDs mentioned distances ranging from 3 to 25 miles as can be seen in their response in verbatim box 2 below:

Box 2: Estimated distances covered in accessing services in Kanungu District, Uganda

I. How far from your homes are health centres where you go for Ante-Natal Care and eMTCT services?

- R1. About 25 miles;
- R2. Mine is about 10kms;
- R3. For me it's about 8miles;
- R4. About 3 miles;
- R5. About 5kms;

(FDG, Young Women LHIV, Kihiihi HCIV, Kanungu District, Uganda)

Interviews with health workers also confirm distance as a key barrier to accessing services.

On the side of clients most of them come from very far. A client from Rutenga Sub-County wakes up at 5:00 in the morning and reaches the health centre at 10:00am, spends more than 4 hours at the health unit, and reaches home in the night. And 'yes' some clients do not come back because of the delays at the health unit.

Some Health facilities have endeavoured to undertake sensitization and education outreaches to help in attracting higher uptake of services targeting mothers who are affected by distance, but these efforts are limited due to inadequate funding. **(KII interview, Health workers, Rugyeyo HCIII)**

The problem of physical accessibility especially due to distance affects both the would-be new eMTCT clients but also those already enrolled into care and their children. Peer educators and mentor mothers also lack the motivation to remain very useful gap fillers, as explained by one of the health workers commented.

There are no funds meant for the following up on lost mothers who come from the same area with the last mother are request to visit them and talk to them....The peer educators are not facilitated, apart from only one who is facilitated by STAR-South West, an NGO **(Interview with Health Workers, Kanungu HCIV, Kanungu District, Uganda)**

Long Waiting Time

Focus group discussions with women in Uganda and Kenya not only point to socio-economic [e.g. transport to health facilities, gender stereotypes and stigma etc.] constraints affecting women on the demand side of services but also the supply side.

It takes time because of few staff at the health facility....it takes like 4 hours but we don't take this as challenge so long as you have got the services. There is no discrimination and drugs are available. **(FGD, Young WLHIV, Nyamirama, Kanungu District, Uganda)**

Cost of Other Drugs and Unclear Procedures in Care

Findings from focus group discussions with WLHIV indicate that long distances and very long waiting time at health facilities among other things affect women's interest and motivation to visit the health facilities because they also value the time they would save to for engaging in other productive activities. Moreover, they also observed that not all prescriptions are provided for free, and so they also need to work to supplement on the other efforts for their care and livelihood.

You might be sick or admitted in the ward. So you are supposed to use money. Some of us are widows, we have to go and work like her she is a supplier of water if she is in bed she will not have money. So if you go to Kakamega county hospital you have to be with money because every drug prescribed you have to buy, but you lack money. We don't buy ARVs but other drugs we have to buy. **(FGD with older WLHIV, Kakamega)**

Furthermore, the findings show that the 'burden' of accessing services by the women could be exacerbated by unclear procedures and circumstances through which women in 'care' receive supplies/donations meant for them and/or their children.

Sometimes you are given food in the hospital and when you go to receive it you find that someone else already signed for the same food without your consent **(Older Women's FGD, Lubao – Kakamega Rural, Kenya)**

These findings not only point to the need for sustained efforts to make every service attractive to WLHIV but also other efforts that will be handy will be those aimed at reducing the burden of distance, such as outreaches ed. There may be challenges of stigma, but those who have already opened up will find this helpful, and more could similarly open up.

Women's Perspectives on the Quality of Family Planning services

The study findings show that Family Planning services exist in close proximity with the HIV clinics. The WLHIV (and men) in both Kenya and Uganda were able to enumerate on the variety of family planning services/methods they are advised; which include among others condoms (the most preferred due to being non-hormonal), levonorgestrel implants, depo, imlarion, pills, injectables, tubal-ligation (TL), natural methods or dual protection that combines one or more of the stipulated methods.

To me it [family planning] is very important so as to avoid unnecessary pregnancies....to me a condom is most advised because it has no side effect....condoms would be preferred a lot because other methods make women not to like sex again while you are in need of sex as married people. **(Older Men's FGD, Kakamega Town, Kenya)**

We are always advised to use dual methods of family planning; if you are using implants to prevent pregnancy, you could also use a female or male condom for protection against sexually transmitted infections such as syphilis.....and we prefer to use condoms because they are not hormonal, they do not have any side effects and you can use a male or female condom. **(Older Women's FGD, Lubao – Kakamega Rural, Kenya)**

A key informant from Uganda added:

We have a wide range of family planning methods in our facilities. We have condoms pills, implants, VDS, vasectomy, tuba ligation and others. Yes all these are given to HIV positive and HIV negative clients who need them. The most common family planning methods are depo and imlarion. Condoms are mostly for men. The most preferred methods are depo because women do not miss or forget like pills. **(District eMTCT Coordinator, Kanungu District, Uganda)**

The study findings also show that where necessary clients for family planning are referred to facilities where more advise and services can be obtained.

... for us in Chikusa we have an HIV clinic there but if you want to have family planning you have to be referred to the MCH centre in Kakamega county hospital. I have never seen family planning services being provided at Chikusa. **(Older Women's FGD, Lubao – Kakamega Rural, Kenya)**

It is important also to note that some health facilities administer family planning methods without full consent of the clients as mentioned in one of the FGDs with WLHIV.

I delivered by caesarean section and the TL was done without telling me. I was told later that TL was done on me because I was not supposed to have more children. I was told to sign without knowing what I was signing for...., so I was forced. **(Older Women's FGD, Lubao – Kakamega Rural, Kenya)**

Perspectives on the Quality of Pre and Post-Test Counselling Services

Most women living with HIV (WLHIV) that participated in interviews and Focus group discussions for this study indicated that they got to know their HIV status when they went for antenatal (ANC) care services, and as part of the routine and service and policy guidelines, were advised [required] to test for HIV. Health workers interviewed in both Kenya and Uganda have this in their service delivery framework as a known practice following global and national guidelines for eMTCT/PMTCT.

HIV testing and counselling for pregnant mothers is not optional for mothers who attend ANC... It is routine and mandatory for all the ANC clients whose status is not known.
(Health workers, Kanungu HCIV Kanungu District, Uganda)

The findings of this study generally reveal an appreciation of the quality of counselling services received when WLHIV visit ANC clinics, but also with some formidable challenges that need to be addressed especially group counselling. Some of the experiences shared by study participants on how they were handled during post-test counselling are examples on constitute some infringements on privacy and perceived lies, particularly by the counsellors in health facilities.

The services were good. The counsellor even reached an extent of [deceiving] me that she is also like me (that is, HIV positive) so that I do not fear.... **(FGD with young Women living with HIV, Kihiihi Health Centre IV, Uganda)**

The health workers interviewed indicated that primarily, mothers who are not in 'care' have to be prepared by counsellors at the health facilities for the test through pre and post-test counselling. It was found out that for the most part, the mothers are cooperative and ready to be enrolled into care after testing positive.

When the mothers come, they first receive pre-test counselling..... We have not had cases where mothers go away before receiving their HIV test results... Yes, mothers are co-operative... the mothers who do not know their HIV status and who are not in care 'must' test for HIV. **(Key Informant [Group] Interview with Health Workers, Rugyeyo HCIII, Kanungu District, Uganda)**

Group Counselling

Challenges related to staffing that does not match the number of clients has sometimes compelled health workers to undertake group rather than individual counselling except where mothers are handled as they come one by one. Both service providers and recipients seem to agree on the fact that there are weaknesses around counselling.

Counselling is normally done in general, whenever mothers come, they sit in a group, it is done by midwife who is on duty and it is a routine... We have to counsel them as a group then they go for testing when they come back from testing, you give them the post-testing counselling, then individual counselling as we are giving results **(Key Informant Interview with Health Workers, Kanungu Health Centre IV)**

They keep counselling one by one because we don't arrive on the same time. But sometime back they used to counsel in a group and even now days it is the same and if you have like some question that you want to share with the doctor, there you can see him individually and that counselling is done before and after being tested **(FGD Young Women, Nyamirama, HCII, Kanungu, Uganda)**

The mothers are not getting adequate counselling which has caused mothers to drop out stop treatment. This is mainly due to health workers being jumpy doing other services like labouring and attending to other cases at the Health units **(eMTCT Coordinator, Kanungu District, Uganda)**

Male Involvement and Support to Spouses

In focus group discussions with men, dynamics around HIV testing or how they got to know their status were found to be different from those of the WLHIV. Unlike the women, men do not easily go for ANC. As a means to motivate men to escort their spouses, health facilities still give a priority to the mothers who come with their spouses for ANC services.

Whenever they [men] escort their wives for Antenatal, we give them first priority, we attend to them first, we welcome them, we have their pressure taken, we also deworm them like everything is provided to them as the first priority then they go for HIV testing, we counsel them together, we give them results together and they are also happy. We also provide mama kits to them as part of the motivation. **(Health workers, Kanungu HCIV Kanungu District, Uganda)**

Low involvement of men is also blamed on poverty and gender roles in households. Men are believed to be on the move most of the time looking for money through sale of labour, in addition to them having naturally poor health seeking behaviours. This was confirmed by a key informant:

The main reason for low male involvement is that most families are below the poverty line and men are always on the move serving as casual labourers. Most men don't stay with their families and mostly men are known to have poor health seeking behaviours. **(eMTCT Coordinator, Kanungu District)**

In addition, the services at health centres that are understaffed tend to be less attractive to the already poorly interested men. When the mothers are many, the few nurses at the health facility cannot effectively handle individual counselling, and may resort to group counselling which is less effective in preparing the men to accept. Their being few on the ground is also further said to influence the way they speak to people due to stressful work conditions. When a male partner is not involved in the health seeking behaviour of his spouse, the men tend to be rude to them. As one key informant confirmed, health workers can lose their temper due to overworking.

Health workers' attitudes change; they have mood swings when they are over worked **(District eMTCT Coordinator, Kanungu)**

Service delivery incentives to promote male involvement such as the requirement that women who come to the health facility come in the company of their spouses be served first may be good but WLHIV whose spouses have consistently remained reluctant view this as unfair to them. The women acknowledge that involving males is difficult due to the complexities of disclosure such as patriarchal norms and the fear of the men turning violent. Here is an example from Kenya:

I don't know what we can do to increase the uptake of men, because these women may test HIV negative when we do not know the status of the man. So the baby who is inside is at a high risk of getting infected because of the unknown status and also when a woman tests HIV positive we also do not know the status of the man. However much we tell these women to go and practice safer sex, to adhere well, and yet their partner's status is not known we are doing nothing. As my colleague has said it is very difficult for the woman to tell the man that today I have gone to the health facility and I have tested positive, you will get so many blows and you will not believe yourself. **(Old Women's FGD, Malaba, Kakamega, Busia District, Kenya)**

The female FGD participants added that involving males is only possible if deliberate incentives to attract them in the same way as women are initiated at health facility level. The women for

example proposed incentives such as health talks for couples, ‘taata kits’ and financial incentives although they argued that if these are introduced they should not supplant but serve as complementary to the current maama kits.

Introducing health talks that are for both men and women, especially when a woman is escorted by her husband. It would be good for them [men] and they should be attended to first **(Young Women’s FGD, Lubao, Kakamega, Rural Kenya)**

Our husbands are not interested in escorting us to the health units; they say they are always busy. I think if Taata kits can be introduced the same way as Maama kits were introduced, men could go to health units to get them for their wives. I think if we give them some incentives like transport for every man who has escorted the woman is introduced, men can come up. **(Older WLHIV, Kihiihi HCIV, Kanungu District, Uganda)**

To elaborate more on the poor levels of interest men have towards supporting their partners, findings from FGDs with men themselves indicate that some men still want to ‘rely’ on the HIV test results of their spouses to [determine] their own HIV statuses, while others tend to remain in denial until after repeated tests have been taken (see verbatim interview in box 3). Some men fear to face the consequences of being declared HIV positive, something which makes them to become violent and to separate with their spouses. Such men have missed appropriate counselling and support which they would adequately have if they accepted to be part of the ANC service seeking activities of their spouses.

Box. 3. How men LHIV came to Know About their HIV Status

How did you come to know about your HIV status?

- R1 Me to know that I am HIV positive, it took some good time but later I started falling sick now and then but one time I told my wife to go to the hospital and my intention was to test HIV and I had wanted to test when my wife was there. So after testing the results were positive and we started drugs from then on.
- R3 Me how I came to know, I tested once, I was negative. The second time I was also negative, but I was not contented. I tested almost five times and then the sixth time that is when I tested positive.

(FGD with men, Kanyantorogo Health Centre III, Kanungu District)

Barriers and Gaps in eMTCT Health Care Systems

3.3 Barriers and Gaps in eMTCT/PMTCT Health Care Systems

The identification and elimination of barriers and gaps towards EMTCT services in resource-limited settings enables the improvement of services, reduces on vertical transmission and contributes to KMA. This study investigated the barriers or gaps by examining six technical health system services or ‘input’s: the health workforce; infrastructure such as laboratories; the supply chain, mainly supply of drugs, equipment and related logistics; FP services; MCH services including EID, and rights of WLHIV²⁸. Many of the challenges and gaps have been identified in Section 3.2. This section will only summarises them or provides more details of those that have been discussed.

3.3.1 Health Staff

As already discussed in Section 3.2, the issue of inadequate staff at health facilities was top on the list of the barriers or health system gaps in both Uganda and Kenya (Table 4). As the FGD participants themselves lamented, the shortage of health workers at health facilities leads to long delays and queues, and makes WLHIV spend long hours receiving ANC, MCH, AVT, CD4 and DNA-PCR testing services for them and their children. The long hours spent at health facilities queuing also mean that WLHIV go without meals and get fatigued in the process.

Table 4. Staffing Gaps reported by Women and Men Living with HIV in that Order

Country	
Kenya	Uganda
Few/inadequate staff	Few/inadequate staff
Rude/unfriendly	Poor attitudes towards WLHIV
They discriminate/have discriminatory attitudes	Bad tempered
Not well trained on eMTCT	Not well trained on eMTCT

²⁸ WHO and UNICEF (2007). Guidance on Global Scale-Up of the Prevention of Mother-to-Child Transmission of HIV: Towards Universal Access for Women, Infants and Young Children and Eliminating HIV and AIDS Among Children. Geneva.

Friendly or welcoming	Long and time consuming queues
Very slow when attending to WLHIV	

As shown in Table 4, some Key Informants and FGD participants reported that the health workers were not well trained on PMTCT/eMTCT, and others had limited knowledge of the rights of WLHIV or even made wrong prescriptions.

Only one of the four midwives in our health centre has ever got training on eMTCT. The rest of us have only read leaf lets and done on-job trainings **(Interview with Health Workers, Rugyeyo Health Centre, Kanungu District, Uganda)**

Another challenge we are facing as mentor mothers is that the health centre provides us with nurses some of whom have not undergone this PMTCT training. They seem not to understand the legitimate, so it has been a challenge for us. Some of our mothers who turned out to be positive for the first time were initiated on ART. So when this mother is initiated on ARVs, she is not given the right instructions especially the medication that that mother has to take say may be at night. And just because of the health worker's negative attitudes towards the mothers who are positive, this mother will not be instructed correctly on how to get the medication. Like there was a time we had a case a mother was initiated on ART for the first 2 weeks and in that 2 weeks she was taking efavirenz during day time for 2 weeks and yet it is supposed to be given at night **(FGD with Young WLHIV, Busia Town, Busia District, Kenya)**

Undeniably, the bad attitudes and discriminatory and unethical conduct of some of the health workers towards WLHIV (and some HIV positive males) is another issue of concern.

3.3.2 Health Infrastructure

The findings indicate most of the health facilities in Uganda and Kenya provide the basic infrastructure and services required for eMTCT, such as laboratory tests (CD4, HB, urinalysis and virologic HIV testing in infants or PCR) are done at the health facilities that were visited. However, the tests of some STIs such as syphilis are sometimes not available in some health centres in Uganda, particularly in Kanungu District as revealed by the health workers from Rugyeyo. In addition, some key informants (and FGD participants) from Uganda complained about the limited space or working environment under which health workers carry out their work, with some operating more than one clinic in a single space and thus infringing on patients' privacy. This was revealed by a key informant from Kanungu Health Centre IV, who admitted that sometimes their space is not enough or is 'squeezed'; and that they have to

improvise. These findings demonstrate that whereas most of the health centres can handle laboratory tests for WLHIV, they are constrained by space for other services.

3.3.3 The Supply Chain for Drugs/Equipment

Perhaps the biggest challenge affecting supplies of drugs and equipment in health facilities in Uganda and Kenya is that of stock outs (Table 5).

Table 5. Supply Chain Issues Reported by Women and Men Living with HIV and Key Informants

Country	
Kenya	Uganda
ARVs unavailable/stock outs e.g., septrin	ARVs unavailable/stock outs e.g., septrin syrups for babies
ARVs available e.g., nevirapine, septrin	Stock outs of mama kits (KIs, Rugyeyo HC)
Transportation/delivery delays to CCC	Stock outs of testing kits or reagents (KI, Kanungu HCIV and FGD Young women Kihiihi HC)
	Family planning methods e.g., mama kits unavailable (KI, eMTCT coordinator)
	ARVs available
	Expiry of drugs in stores (FGD Men Kanungu)

As shown in Table 5, FGD participants from Uganda and Kenya reported that on many occasions, ARVs (such as septrin and nevirapine) run out at health facilities. Unlike Kenya, female FGD participants and key informants from Rugyeyo and Kihiihi Health Centres in Kanungu District in Uganda testified that there were more stock outs of family planning methods such as pills, testing kits and mama kits in their health facilities.

Another challenge we have here is about the stock outs of mama kits. Maama kits here in Rugyeyo are not well stocked so mothers run to other health facilities which have them in stock **(Interview with Health Workers, Rugyeyo Health Centre, Kanungu District, Uganda)**

In Kenya, the transportation and delivery or use of supplies from CCCs remains a challenge for WLHIV, not the lack of drugs as such, as established by older women LHIV in Busia.

For me, last month I went to pick for my child drugs and I was told they [septrin] were over....I can see it is matter of transportation because we normally order drugs from the CCC to come to this MH. So when they order and in the store they are finished they tell you come tomorrow or come next week and you take but it is not that there are no drugs, they are there but they are in the stores and you have to order. There is a process of

getting those drugs from the CCC to this way. (**Older Women’s FGD, Busia, Busia District, Kenya**)

The other gaps related to supplies include some family planning methods not being available and some drugs expiring in the stores, all of which were reported by key informants and FGD participants in Kanungu district in Uganda.

3.3.4 Family Planning Services

As noted in Section 3.3 above, WLHIV are provided with a number of family planning options such as condoms, pills, levonorgestrel implants, injectables, depo, implanon and tubal ligation, and most women exercise their right by selecting the best method after considering its pros and cons. WLHIV are also advised to use dual protection, in which they combine condoms with other long-term methods. Apart from the use of tubal ligation on one woman from Lumbao in Kenya without her consent, the other challenges with FP include the side-effects of the hormonal methods, and some men refusing to condomise and telling their spouses that they are already HIV positive.

3.3.5 Maternal and Child Health Services

Maternal Delivery Services

Our findings indicate that the health facilities in Uganda and Kenya provide a number of maternal delivery services to WLHIV. The FGD participants said that health workers in Kenya and Uganda advise WLHIV to deliver from health facilities, where several precautions are undertaken to prevent transmission of HIV to babies/infants during labour and delivery. These methods include ART before delivery, avoiding or minimizing prolonged labour, minimizing vaginal examinations, avoiding ARM, avoiding unnecessary trauma and the use of aseptic techniques when disinfectants are available (see box 4).

Box. 4. Maternal Health Delivery Services Provided to WLHIV

What maternal health and delivery services do the health facilities you go to provide to HIV positive pregnant mothers?

- R1 They give us a tablet to take. After delivery, they give you syrup for the child
- R2 Health workers put too much attention on you in order to monitor you in delivery so that you don't affect your child
- R3 There is no vaginal examination
- R4 They monitor you like others but they still have that thing of your HIV status
- R5 They avoid artificial rupture of membranes to all women

FGD with Young WLHIV, Kihiihi HCIV, Kanungu District, Uganda

HIV positive pregnant mothers are also advised to carry their own mama kits and sundries such as soap, basins and jik to use after delivery. HIV positive pregnant mothers also deliver through two methods – normal delivery (or SVD) or Caesarean Section. Unluckily, most of the pregnant mothers are not given a chance to select their preferred delivery method, particularly when they are likely to develop complications. The majority deliver normally but those that experience prolonged labour are recommended or referred for caesarean section which comes at a cost, ranging between UGX 50,000-300,000 (US\$ 15-90) in Ugandan health facilities.

Early Infant Diagnosis and Support for Babies

EID procedures for children of WLHIV are fairly followed at health facilities, as discussed in Section 3.2. FGD participants and key informants from Uganda and Kenya noted that the babies exposed to HIV are also given ARVs at birth and, at a later age, nutritional supplements depending on the condition of the mother and the child. The major challenges WLHIV reported here included transport costs, delayed tests of their children due to queues and laboratory attendants being temporarily absent, no nutrition and feeding of the HIV positive mothers themselves, and inability to buy snacks or meals for them and their children while attending EID at the health facilities (as was the case in the past in parts of Kanungu district in Uganda).

3.3.6 Other Services Provided to WLHIV

FGD participants confirmed that WLHIV in Uganda and Kenya receive other pertinent services such as free cancer screening (cervical and sometimes prostrate which was reported by older men from Kakamega in Kenya, see box 5), TB screening, STI screening and materials such as mosquito nets, safe water vessels, blankets, and sanitary soap.

Box 5: Other Services Provided to WLHIV Apart from ANC, HCT, ART, FP, MHD and EID

What other kind of support do you get apart from ANC, HCT, ART, FP, MHD and EID?

- R1 *When receiving ART services, they give us a health talk. They will tell you to first go for cancer screening (for women) and there is a room there. Then they will also screen you to see if you have STDs and you are treated. There is a private hospital where they screen STIs freely and they treat them.*
- R2 *If you go to the ART clinic they will ask you, is there anything else disturbing you? Last time I was coughing but I was given the medication.*
- R3 *[On whether STI tests are free] Yes, May be if there are no drugs you are advised to go and buy.*
- R4 *[Even TB screening?] Yes, it is free, unless if you go for x-ray you pay 800 (eight hundred) and it's only in Kakamega hospital*

(FDG Older Men I HIV Kakamega Town Kakamega District)

Another key support service revealed here was that of social support groups such as ‘couple support groups’ in Kenya and small male action groups (SMAGS) in Uganda, locally known as Emanzi that literally means ‘the brave’. These groups provide the much needed counselling and support to WLHIVs and their male counterparts and enable them to adhere to ARVs.

3.3.7 Human Rights of WLHIV

According to the universal Declaration of Human Rights (UDHR) of 1948 and the Convention on elimination of all forms of discrimination against women (CEDAW) of 1979, all people should be treated equally despite their differences. WLHIV have a right to education, knowledge and access to any kind of information that they deem necessary for their positive living. They have a right of expression of what they need, a right to privacy and equality, and a right to consent about services that eMTCT service providers give them like a right to have an HIV test, receive and accept the results and go for counselling. WLHIV also have a right to know what ARVs they are given and how to adhere to them and why; a right to be educated about the different methods of family planning, its importance and how to make a choice of their own.

The rights of WLHIV were investigated in this study, and the results indicate that their rights of family planning are largely known or respected by even the health workers as demonstrated below:

We know their rights, like a right to be treated like any other mother, a right to health education. She [WLHIV] has a right of privacy, a right to information, a right to know about the drugs she is taking and why, a right not to be discriminated and yes some are protected **(Interview with Health workers, Kanungu HC, Kanungu District, Uganda)**

Obviously we allow the ladies to make their family planning choices. We teach them and they decide for themselves the method they want. This is so because the best method the mother will use is that one she chooses herself. For us we give general information then after getting informed, they choose the method they want **(Interview with Health workers, Kanungu HC, Kanungu District, Uganda)**

Mothers are allowed to choose family planning methods of their choice and all the family planning methods are the same for both HIV positive and negative mothers, **(Interview with Health Worker, Rugyeyo Health Centre, Kanungu District, Uganda)**

Most of the methods of family planning are available at the health centre, such as pills, injections, condoms, IUD and implants. Women are given a chance to choose the

method of family planning that they we want and health workers explain each method to us. The family planning options prescribed are for both women living with HIV and those who are negative **(Older Women’s FGD, Nyamirama HCIV, Kanungu District, Uganda)**.

The eMTCT guidelines also postulate that WLHIV should be given thorough counselling about disclosure issues particularly to their male spouses/husbands, as it helps a lot in adherence to ARVs. Also men who come with their wives can get a chance to test their HIV status and they get prompt treatment at the health centres without lining up. However, as demonstrated in the earlier sections, forcing women to come with their husbands or spouses infringes on their rights, as some of them do not stay with them. Indeed, and as the earlier findings of this study show, most men do not want to attend ANC with their wives or spouses and simply do not want to test for HIV, claiming that they have to work to fend for their families. For example:

Some men do support their wives but majority of them are against it. Few men in Kanungu support their wives to go for these services although we are trying but still the number is low because we are like at 25% **(Interview with Health Workers from Rugyeyo HC, Kanungu District, Uganda)**

Another aspect of rights of WLHIV that was investigated in this study was the right to choose to breast feed their babies or not, information being availed to them about infant feeding options, and counselling about the benefits and challenges for them to make informed choices. Those on exclusive breast feeding should be given Nevirapine and those who don’t breast feed go for AFASS criteria. They need nutritional advice when breast feeding or when they have stopped.

However, as demonstrated in Section 3.2 and parts of 3.3 above, there are still some capacity gaps from the supply side, especially health workers who lack adequate knowledge on eMTCT, the rights of WLHIV and administering of FP methods.

However this is evident that if the eMTCT program has to realize its goals something in this area needs to be done in order for the health workers to be aware of the rights of WLHIV to best serve them. And those who seem knowledgeable need refresher courses in order for the eMTCT goals to be realized.

4.0 Conclusions and Recommendations for Better eMTCT/PMTCT Services and Programs for WLHIV

4.1 Conclusions

4.1.1 Knowledge on eMTCT and Related Policies

This study has shown that most of the WLHIV in both Uganda and Kenya perceive eMTCT to be centred around the prong or element of providing ARV prophylaxis to prevent HIV transmission to children, that is during pregnancy, labour, delivery and breastfeeding or simply ‘delivering’ a baby who is HIV negative. This is partly due to the fact that this element has been given most attention by governments in both countries, neglecting other crucial elements of eMTCT such as the provision of care, treatment and support for mothers and their families (or keeping mothers alive) and option B+. Health workers/personnel in health centres and hospitals play a crucial role in sensitising WLHIV (and their male spouses) about eMTCT and the related policies, strategies and guidelines. WLHIV in Kenya and Uganda have scanty knowledge about the eMTCT policies/strategies/guidelines, a common characteristic being their articulation of some of the rights of WLHIV (such as the right to give birth and ARV prophylaxis for them and their children) and all WLHIV receiving ANC at health facilities. Key informants from Uganda seem to be more knowledgeable about other services provided in the policies or guidelines, particularly EID.

4.1.2 Availability and Access to ANC and Other eMTCT Services

This study has shown that most of the WLHIV receive ANC, HCT, FP, EID (including nutritional support and materials such as mosquito nets and blankets) and CME services at health facilities. WLHIV’s access to these facilities is influenced by distance, poor support by men, transport costs, treatment costs (and poverty), staff at health facilities, privacy, motivation of VHTs and peer educators/mothers or other volunteers, waiting time or queues and availability of medical supplies such as drugs and testing kits. Only a few health facilities have arrangements for

follow-up on clients who are initiated on ART, and community-based persons such as VHTs/peer educators are critical.

4.1.3 Barriers to Health Systems/eMTCT Services

There are important health systems gaps that hamper women's access to eMTCT. The issue of inadequate staff is most prominent in both Uganda and Kenya, and leads to long delays and queues at health facilities. Due to inadequate staff at the health facilities, WLHIV spend long hours receiving ANC, MCH, AVT, CD4 and DNA-PCR testing services for them and their children, many times going without meals and getting fatigued in the process. The discriminatory attitudes and unethical conduct of some of the health workers towards WLHIV (and some HIV positive males), and their limited capacity to deliver eMTCT services is also a crucial gap that requires attention. Most of the health facilities in Uganda and Kenya provide the basic infrastructure and services required for eMTCT. For example, laboratory tests such as CD4, HB, and virologic HIV testing in infants are done at the health facilities that were visited in both countries, with the exception of certain STIs such as syphilis whose tests are sometimes not available in some health centres in Uganda, particularly in Kanungu District.

With regard to the supply chain, whereas stock outs of crucial supplies such as ARVs for both WLHIV and their children are common in health facilities in both countries, there are more stock outs of mama kits, testing kits and family planning methods in health facilities in Uganda. In Kenya, transportation and delivery of supplies from CCCs is still a problem. WLHIV receive a range of free family planning services at health facilities in both countries. The commonest family planning options provided include condoms, pills, levonorgestrel implants, injectables and tubal ligation, and most women select the best method after considering its pros and cons. WLHIV are also advised to use dual protection, which involves combining condoms with any of the other long-term methods such as levonorgestrel implants.

The health facilities also provide a number of MCH services to WLHIV. Health workers in Kenya and Uganda advise WLHIV to deliver from health facilities and several precautions are undertaken to prevent transmission of HIV to babies/infants during labour and delivery, such as

avoiding or minimizing prolonged labour, minimizing vaginal examinations, avoiding ARM, avoiding unnecessary trauma and the use of aseptic techniques when disinfectants are available. HIV positive pregnant mothers are also advised to carry their own mama kits and sundries such as soap, basins and jik to use after delivery. Unfortunately, most of the HIV positive pregnant mothers do not have the liberty to select their preferred delivery method. The majority deliver normally or through SVD, but those that experience prolonged labour are recommended or referred for caesarean section which comes at a cost, ranging between US\$ 15-90 in Ugandan health facilities for example. EID procedures for children of WLHIV are fairly followed at health facilities, as most of them first test the infants at the age of 6 weeks, and then at 8-9 months for the second tests. The babies exposed to HIV are also given septrin or nevirapine syrup at birth and, at a later age, nutritional supplements such as RUTF, plumpy nut and clamp soya. A neglected issue here is the nutrition and feeding of the HIV positive mothers themselves, many of whom miss meals or do not enjoy a balanced diet due to limited income. HIV positive mothers also contend with hunger while at health facilities, which comes as a result of spending long hours receiving ANC, HCT, ARP, EID and other services.

4.2 Recommendations for Accelerating eMTCT Services

This assessment of the quality of eMTCT/PMTCT services and programs in Kenya and Uganda has revealed a number of gaps and challenges that are based on the lived experiences of WLHIV. Addressing these gaps, or improving the SRHR and eMTCT services of WLHIV in East Africa requires a number of interventions which include but are not limited to the following:

- There is a need to sensitive WLHIV about eMTCT, particularly emphasizing the other neglected three elements or prongs of preventing HIV among reproductive-age women, family planning and care, treatment and support for mothers and their families, and of course option B+, a relatively new strategy in East Africa. WLHIV also need to be educated on the relevant eMTCT policies, guidelines and strategies in their countries with emphasis on their rights so that they are able to demand for adequate eMTCT services and also hold office bearers or health workers accountable.

- Another important intervention required is the use of effective strategies that can reduce the stigmatization and discrimination of WLHIV (and to some extent that of their male counterparts) by communities and health workers, an issue that was commonly singled out in Kenya and Uganda. WLHIV (and health workers and communities) should be educated on how to overcome the individual, social, intersecting and manifesting forms of stigma, and how stigma impedes HIV prevention and eMTCT services in general.
- eMTCT services should be made more available and accessible to WLHIV and their spouses through community outreach or house-to-house programmes. This can reduce pressure on the already inadequate eMTCT infrastructure at health facilities, and also the long and costly distances that WLHIV (and HIV positive men) have to travel to reach these facilities.
- WLHIV need to be supported to advocate for the improvement of staffing, infrastructure and availability of drugs and testing kits at health facilities. This advocacy should for example focus on increasing the medical staff (doctors, nurses and laboratory technicians) at the health facilities; separation or ‘departmentalisation’ of ANC, ART and MCH services for privacy and convenience of WLHIV; and prompt and adequate delivery of ARVs (including paediatric ARVs) and testing kits at health facilities to minimise stock outs.
- Related to the issue of staffing is the need to facilitate, motivate and train VHTs, peer or mentor mothers, peer educators and perhaps WLHIV themselves so that they continue to support WLHIV to access eMTCT services. These individuals play an active role in counselling WLHIV and encouraging them to enrol for ART and MCH services but face numerous challenges such as transport. The training should address neglected issues in eMTCT such as FP and male involvement.
- The issue of male involvement in eMTCT needs to be addressed in more innovative ways as it significantly affects WLHIV’s access to eMTCT. HIV positive men should be targeted

and sensitized (by WLHIV, peer mothers, mentor mothers, VHTs and health personnel) about the benefits of their involvement in ANC, ART and EID, and the consequences of their non-involvement such as difficulties in disclosure, family breakdowns and domestic violence. New and 'attractive' approaches such as rewards, prompt services for couples that attend eMTCT and 'Taata kits' may also need to be explored here.

- WLHIV also need to be empowered economically so as to strengthen their access to eMTCT services and also improve on their ability to meet their livelihoods and other needs such as child education. For example, supporting WLHIV to start income-generating activities of their choice will enable them to travel to health facilities, improve on their (and their children's) nutrition or diet and also minimise on the side effects of ARV medication such as body weakness and dizziness.

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