Eliminating Mother-to-Child Transmission of HIV in Uganda by 2015: What will it take?

Knowledge Synthesis Working Paper No. 1

Prepared by: The Uganda HIV/AIDS Knowledge Management and Communications Capacity (KMCC) Initiative

Final Draft - 24 November 2012
Foreword

To be completed by MoH and UAC.
# Table of Contents

**FOREWORD** .................................................................................................................................................. 2

**TABLE OF CONTENTS** .................................................................................................................................. 3

**ACRONYMS** ..................................................................................................................................................... 5

**EXECUTIVE SUMMARY** ................................................................................................................................. 5

**EXECUTIVE SUMMARY** ................................................................................................................................. 8

**PART 1: EMTCT GLOBALLY- THE STRATEGIC CONTEXT** ............................................................................ 12

1.1. **A DECADE OF RENEWED GLOBAL COMMITMENTS TO EMTCT** ...................................................... 12
1.2. **EMTCT AS AN OPPORTUNITY FOR THE ATTAINMENT OF MDG TARGETS** ........................................ 14
1.3. **BACKGROUND AND RATIONALE OF THIS WORKING PAPER** .......................................................... 14

**PART 2: EMTCT IN THE UGANDAN CONTEXT** ........................................................................................ 16

2.1. **TRENDS IN THE HIV EPIDEMIC IN UGANDA** .................................................................................. 16
2.2. **IMPACT OF UNCHANGED GENDER RELATIONS ON HIV/AIDS AND HEALTH PROGRAMMES** ............... 18
2.3. **DESCRIPTION OF SYSTEMS AND STRUCTURAL ARRANGEMENTS FOR EMTCT DELIVERY** .................. 19
2.4. **NATIONAL COMMITMENTS TO EMTCT** ......................................................................................... 20
2.5. **EMTCT IN UGANDA: FROM CLINICAL TRIALS TO PILOTS AND PROGRAMME SCALE UP** ....................... 21
   *From clinical trials to action research to PMTCT programmes* ........................................................................ 21
   *The expansion of EMTCT programmes in Uganda* ....................................................................................... 21
2.6. **ADOPTING THE 2010 WHO GUIDELINES: PROGRAMME TRANSITION FROM PMTCT TO EMTCT** .......... 22
2.7. **DECISION TO MOVE TO OPTION B+: THE 2012 NATIONAL POLICY GUIDANCE** .............................. 24
2.8. **STATUS ON EMTCT IN UGANDA** .................................................................................................. 25
   *Prong 1: The primary prevention of HIV transmission to women of reproductive age* ............................. 25
   *Prong 2: The prevention of unwanted pregnancies among HIV positive women* ................................. 25
   *Prong 3: Preventing vertical transmission from a woman living with HIV to her infant* ......................... 26
   *Prong 4: Integration into ARV services* ..................................................................................................... 27
2.9. **COMPARISON OF PROGRESS WITH OTHER LOW-MID INCOME COUNTRIES** ............................... 28
   *Prong 1: The primary prevention of HIV infection among women of reproductive age* ....................... 28
   *Prong 2: Preventing unwanted pregnancy among women living with HIV* .......................................... 29
   *Prong 3: Preventing vertical transmission from a woman living with HIV to her infant* ......................... 30
   *Prong 4: Providing appropriate support, care & treatment to mothers living with HIV and their families* 32

**PART 3: ANALYSIS OF KNOWLEDGE TO IMPROVE EMTCT COVERAGE AND RETENTION IN UGANDA AND OTHER LMICS** .................................................................................. 33

3.1. **THINKING AND INVESTING STRATEGICALLY FOR EMTCT** ................................................................ 33
3.2. **OVERVIEW OF OBSTACLES AND SOLUTIONS TO INCREASED EMTCT COVERAGE AND RETENTION** .... 33

   *The importance of systems and structures* ............................................................................................... 36
   *Improving systems and structures* ........................................................................................................... 38
3.4. **FINANCIAL RESOURCES INVESTED** ................................................................................................... 41
3.5. **LOGISTICS AND SUPPLIES MANAGEMENT** ..................................................................................... 41
   *The supplies system* ................................................................................................................................. 41
   *Impacts of stock outs / shortage – supplies and staff* ........................................................................... 42
3.6. **HUMAN RESOURCES FOR HEALTH** .................................................................................................... 43
   *The importance of HRH* ............................................................................................................................ 43
   *The impact of poor HRH* .......................................................................................................................... 44
   *Improving HRH* ....................................................................................................................................... 44
3.7. **GENDER SENSITIVE COMMUNITY ENGAGEMENT AND COMMUNICATION** ................................. 47
The importance of communities .................................................................................................................. 47
The need for gender sensitive HIV/AIDS IEC around EMTCT ................................................................. 48
Meaningful involvement of PLWHIV - family planning as a choice .......................................................... 51
3.8. MALE INVOLVEMENT AND FAMILY CENTRED EMTCT PROGRAMMES ...................................... 52
The importance of involving men in EMTCT ............................................................................................. 52
Family centred EMTCT approaches .......................................................................................................... 56
3.9. THE NEED FOR ACCESSIBLE EMTCT SERVICES ........................................................................... 57
3.10. THE EMTCT ARV/ART CARE AND TREATMENT CASCADE ......................................................... 58
Option A, B or B+: Choice of ARV/ART for mother and baby .................................................................... 58
The benefits of the game changing strategy to EMTCT Option B+: ....................................................... 59
Adherence to the ARV/ART care and treatment regimens ..................................................................... 59
Postnatal EMTCT follow up of the mother and baby pair-retention ....................................................... 60
Links between EMTCT and ART programmes ......................................................................................... 62

PART 4: CONCLUSION- IMPLICATIONS FOR UGANDA ............................................................................. 64
4.1. POLICY AND NATIONAL LEVEL IMPLICATIONS .............................................................................. 64
4.2. FACILITY AND COMMUNITY LEVEL IMPLICATIONS .................................................................... 66
4.3. AREAS NEEDING FURTHER RESEARCH AND LEARNING ............................................................. 68
4.4. DATA AND KNOWLEDGE MANAGEMENT ..................................................................................... 68
4.5. POTENTIAL FUTURE SUPPORT TO EMTCT FROM THE KMCC INITIATIVE .................................... 69

ANNEX 1: REFERENCES ............................................................................................................................... 70

ANNEX 2: CONTRIBUTORS TO THIS WORKING PAPER ........................................................................ 75
List of persons and institutions consulted at district and national level ..................................................... 75
The writing team ........................................................................................................................................... 78

ANNEX 3: A SELECTION OF GOOD PRACTICES CONTRIBUTING THE EMTCT IN UGANDA .............. 80
PRONG 1: PRIMARY PREVENTION OF HIV INFECTION AMONG WOMEN OF Childbearing Age .......... 80
PRONG 2: PREVENTING UNINTENDED PREGNANCIES AMONG WOMEN LIVING WITH HIV ............. 80
PRONG 3: PREVENTING HIV TRANSMISSION FROM A WOMAN LIVING WITH HIV TO HER INFANT .......... 81
PRONG 4: PROVIDING APPROPRIATE TREATMENT, CARE AND SUPPORT TO MOTHERS LIVING WITH HIV AND THEIR CHILDREN AND FAMILIES ................................................................. 82
Acronyms

AED Academy for Educational Development
AIDS Acquired Immune-Deficiency Syndrome
ACORD Agency for Coordination of Research and Development
ADPs AIDS Development Partners
ANC Ante-Natal Care
ANECCA African Network for Care of Children Affected by AIDS
ART Anti-retroviral Therapy
ARVs Antiretroviral Drugs
AZT Zidovudine
BOCAIP Botswana Christian AIDS Intervention
CBVs Community-Based Volunteers
CD4 cells T Lymphocyte cells with CD4 marker molecule
CME Continuous Medical Education
CSOs Civil Society Organisations
d4T Stavudine
DANIDA Danish Development Assistance Programmes
DHO District Health Officer
DISH Delivery of Improved Service for Health (USAID funded)
DOTS Directly Observed Therapy, short course
EGPAF Elizabeth Glaser Pediatric AIDS Foundation
EID Early Infant Diagnosis
EMTCT Virtual Elimination of Mother-to-Child Transmission of HIV
FP Family Planning
FSW Female Sex Worker
GBV Gender Based Violence
GCWA Global Coalition of Women against AIDS
GIPA/MIPA Greater and Meaningful Involvement of People Living with HIV
GoU Government of Uganda
GTZ German Agency for International Development
HAART Highly Active Antiretroviral Therapy
HC Health Center
HIV Human Immunodeficiency Virus
HCT HIV Counselling and Testing
HMIS Health Management Information System
HRH Human Resources for Health
HTC HIV Testing and Counselling
IATT Inter-Agency Task Team on EMTCT
IAC International AIDS Conference
ICPT-G Interpersonal psychosocial support group
IEC Information Education and Communication
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>IRIN</td>
<td>Integrated Rural Information Network</td>
</tr>
<tr>
<td>KMCC</td>
<td>Knowledge Management and Communication Capacity Initiative</td>
</tr>
<tr>
<td>LMIC</td>
<td>Low and Middle Income Countries</td>
</tr>
<tr>
<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
</tr>
<tr>
<td>MARPs</td>
<td>Most at Risk Populations</td>
</tr>
<tr>
<td>MDGs</td>
<td>Millennium Development Goals</td>
</tr>
<tr>
<td>MAAIF</td>
<td>Ministry of Agriculture Animal Industries and Fisheries</td>
</tr>
<tr>
<td>MVAP</td>
<td>Market Vendors AIDS Programme</td>
</tr>
<tr>
<td>MOGLSD</td>
<td>Ministry of Gender, Labour and Social Development</td>
</tr>
<tr>
<td>MOFPD</td>
<td>Ministry of Finance Planning and Development</td>
</tr>
<tr>
<td>MOIA</td>
<td>Ministry of Internal Affairs</td>
</tr>
<tr>
<td>MOES</td>
<td>Ministry of Education and Sports</td>
</tr>
<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>MOLG</td>
<td>Ministry of Local Government</td>
</tr>
<tr>
<td>MOT</td>
<td>Modes of Transmission Study</td>
</tr>
<tr>
<td>MSH</td>
<td>Management Services for Health</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
</tr>
<tr>
<td>MTCT</td>
<td>Mother-to-Child Transmission</td>
</tr>
<tr>
<td>MTR</td>
<td>Mid-Term Review</td>
</tr>
<tr>
<td>MRC/UVRI</td>
<td>Medical Research Council/Uganda Virus Research Institute</td>
</tr>
<tr>
<td>MUJHU</td>
<td>Makerere University - John Hopkins University AIDS Research Projects</td>
</tr>
<tr>
<td>MUUWRP</td>
<td>Makerere University Walter Reed Project</td>
</tr>
<tr>
<td>NACA</td>
<td>National AIDS Coordinating Agency</td>
</tr>
<tr>
<td>NDP</td>
<td>National Development Plan</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
</tr>
<tr>
<td>NMS</td>
<td>National Medical Stores</td>
</tr>
<tr>
<td>NVP</td>
<td>Nevirapine</td>
</tr>
<tr>
<td>NNRTIs</td>
<td>Non-Nucleoside Reverse Transcriptase Inhibitors</td>
</tr>
<tr>
<td>NSAs</td>
<td>Network Support Agents</td>
</tr>
<tr>
<td>PACE/PSI</td>
<td>Population Services International- Ugandan chapter</td>
</tr>
<tr>
<td>PCR</td>
<td>Polymerase Chain Reaction</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother-to-Child Transmission of HIV</td>
</tr>
<tr>
<td>PREFA</td>
<td>Protecting Families against HIV/AIDS</td>
</tr>
<tr>
<td>PRB</td>
<td>Population Reference Bureau</td>
</tr>
<tr>
<td>PNC</td>
<td>Post Natal Care</td>
</tr>
<tr>
<td>PMMP</td>
<td>Performance and Measurement Plan</td>
</tr>
<tr>
<td>SdNVP</td>
<td>Single Dose Nevirapine</td>
</tr>
<tr>
<td>SGBV</td>
<td>Sexual and Gender Based Violence</td>
</tr>
<tr>
<td>SCM</td>
<td>Systems Chain Management</td>
</tr>
<tr>
<td>SRH</td>
<td>Sexual and Reproductive Health</td>
</tr>
<tr>
<td>STAR</td>
<td>Societies Tackling AIDS through Rights</td>
</tr>
<tr>
<td>STAR-EC</td>
<td>Strengthening TB and HIV/AIDS Responses in East Central Uganda</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>SURE</td>
<td>Securing Ugandan’s Rights to Essential Medicines</td>
</tr>
<tr>
<td>SWs</td>
<td>Sex Workers</td>
</tr>
<tr>
<td>TASO</td>
<td>The AIDS Support Organisation</td>
</tr>
<tr>
<td>THETA</td>
<td>Traditional and Modern Health Practitioners Together Against AIDS</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>TBA</td>
<td>Traditional Birth Attendants</td>
</tr>
<tr>
<td>TCMP</td>
<td>Traditional and Contemporary Medicine Practitioners</td>
</tr>
<tr>
<td>UAC</td>
<td>Uganda AIDS Commission</td>
</tr>
<tr>
<td>UAIS</td>
<td>Uganda AIDS Indicator Survey</td>
</tr>
<tr>
<td>UDHS</td>
<td>Uganda Demographic and Health Survey</td>
</tr>
<tr>
<td>UKAID/DFID</td>
<td>United Kingdom Department for International Development</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>The Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>UNGASS</td>
<td>United Nations General Assembly Special Session on HIV/AIDS</td>
</tr>
<tr>
<td>UPE</td>
<td>Universal Primary Education</td>
</tr>
<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counseling and Testing</td>
</tr>
<tr>
<td>VHTs</td>
<td>Village Health Teams</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>
Executive Summary

We are living in a decade of renewed global commitments to ending the vertical transmission of HIV. The world is now more than ever united in the drive to “welcome an HIV free generation”. Evidence demonstrates that with concerted efforts and strategic investment, there is the opportunity to see a global reduction of 50% in HIV incidence in women of reproductive age, in line with global targets. A reduction to ‘zero’ in the unmet need for family planning among HIV-positive women, a reduction to less than 5% in the risk of mother-to-child transmission of HIV, and access to antiretroviral therapy (ART) for 90% of eligible HIV-positive women, are also deemed achievable. However, the virtual Elimination of Mother-to-Child Transmission (EMTCT) faces substantial challenges in low and middle income countries (LMICs) like Uganda. Key stakeholders including - the Ministry of Health (MoH), the Uganda AIDS Commission (UAC), the Ministry of Local Government, the Ministry of Finance, other key ministries, parliamentarians, AIDS development partners, civil society and faith based organisations, the private sector and communities of people living with HIV (PLWHIV) - need to come together to achieve these ambitious targets.

This working paper has been produced by the HIV/AIDS Knowledge Management and Communication Capacity (KMCC) Initiative, in consultation with various partners, to synthesise EMTCT knowledge with the aim of informing better policy and programming decisions in Uganda. The KMCC Initiative has received initial funding from the UK Department of International Development as part of the support to the National HIV Prevention Strategy of the Government of Uganda (GoU). The synthesis in this report is in line with the four-pronged framework to EMTCT set out by the World Health Organisation (WHO). There is particular in-depth analysis of prong 3 as this where most knowledge is documented, but an effective EMTCT response requires a balanced approach. GoU has recently adopted Option B+ as the national policy for the biomedical health system response to EMTCT and there is growing evidence that option B+, whilst requiring more resource, offers significant benefits. However, it is recognised that this by itself is unlikely to achieve virtual EMTCT and there is a need to also consider the other three prongs covering primary prevention (prong 1), family planning (prong 2) and sustained family centred care for the HIV exposed infant and mother (prong 4) to allow an integrated approach to reduce vertical transmission.

The working paper provides an analysis of key EMTCT related indicators of the HIV epidemic comparing Uganda with other LMICs. We note that in the early 2000s Uganda was ahead of most LMICs with many success stories and model programmes. However in recent years a number of EMTCT performance indicators for Uganda have lagged behind other LMICs. For example Zambia tests 95% of expectant women for HIV (compared to 64% in Uganda) and Namibia has near universal access to ARVs for pregnant mothers (compared to an estimated 53% in Uganda).

Attaining EMTCT targets in Uganda by 2015 requires increased funding to the response from both the Government and international agencies, investment in health systems strengthening, and investment in gender sensitive, family centred community engagement. There is a need for strong
multi-sectoral coordination from the UAC, solid MOH/UAC relations and strong central-local government working relationships to forge effective relationships with implementing partners and to foster buy-in, ownership and accountability arrangements within the health system. There is a need for clear communication of the priority EMTCT messages which will focus on each major part of the health system, a national campaign on EMTCT and EMTCT champions at the local and national level. Thought is needed on how to lever technology more effectively, such as the use of mobile phones to get health messages to parents, midwives and others.

There is an urgent need for increased government and donor budget allocation to support Option B+ roll-out. Option B+ offers lifelong ART, lowers lifetime transmission rate, leads to less risk of resistance, enables safer breast-feeding and provides continuity of treatment throughout childbearing years. Option B+ makes breastfeeding safe, which is important for LMICs where very few mothers have any other feeding option and importantly, helps to keep more mothers alive. Although Option B+ is simpler than previous regimes it is not necessarily an easy fix and the cumulative costs of medicines under this option are more than three times as high as either Option A or Option B by year 4. It is therefore important to explore ways of delivering Option B+ more efficiently and effectively and to not lose sight of the other prongs of the WHO framework for EMTCT.

The strengthening of health systems necessitates addressing human resource numbers, retention, motivation and training. To attain EMTCT, and some of the Millennium Development Goals, Uganda must in time close the gap on the estimated national shortage of 2,000 midwives. In the shorter term, more thought is needed on how to incentivise the performance of health workers and heath units, linking benefits (monetary and non-monetary) to the achievement of agreed EMTCT targets at the local level. There is a need to establish and/or ensure the implementation of robust ethical and regulatory standards for health professionals to improve biomedical practices. The provision of technical assistance and mentorship as in-service capacity building related to Option B+ for health workers is also important.

It is important to explore task shifting like using lay counsellors or mentor mothers to conduct EMTCT counselling to improve adherence to regimens and to incorporate non-health workers into the EMTCT process to address staff shortages. There is scope for supporting off-duty staff to provide additional coverage for health facilities; for example, to implement better training, certification and retention of community health workers and other informal providers of EMTCT services. Where resources allow it would be beneficial to create better financial incentives for staff, for instance by increasing salaries or providing bonuses to those working in underserved communities or rural regions.

Strengthening stock, supplies, and logistics management will require multi-tasking of health teams so that the administering of drugs is not dependent on the availability of staff with the required skills. There is a need to ensure mothers are tested for CD4 counts sooner and for both mothers and babies to be tested for HIV as early as possible in order to strengthen infant diagnosis. It is also important to develop quicker reporting of the results of HIV tests to allow same day reports. There is
a need to ensure greater clarity of the best balance of central ‘pushing’ of medical supplies and local ‘pulling’ of supplies and to investigate the scope for more private sector involvement and partnerships in the provision of drugs and contract management.

There is a strong requirement to streamline the overall EMTCT monitoring and evaluation system focusing on interpretation and management decision making around the most important headline indicators. A strong M&E system will make it easier to identify where the most-at-risk mothers are living, which stages in the EMTCT process require most attention, and where the most successful programmes are.

Communities play a vital role in reducing vertical transmission of HIV and keeping women and mothers alive. Improving community engagement and social mobilisation around EMTCT requires careful consideration of how decisions to access EMTCT services are made, especially with reference to gender relations within the family. There is a need to ensure messages are communicated in local languages, where appropriate, and through the most effective channels, engaging traditional and religious leaders in community sensitisation and mobilisation to attract more pregnant women to be tested and to reduce stigma. Utilising innovative community mobilisation models such as the Network Model implemented by the HIV/AIDS Alliance in Uganda, involving communities and networks of PLWHIV in the planning and service delivery, and monitoring of national targets for EMTCT can have a great impact.

Particular focus is needed to effectively communicate on the subject of access to family planning services among HIV positive women, as part of prong 2 of the WHO EMTCT framework. Uganda has one of the highest birth rates in LMICs and one of the lowest rates of access to contraception suggesting that prong 2-related support has the potential for good results. Strategies can include reproductive health education in schools, programmes for out-of-school youths and early married girls and social marketing of condoms. It is important that EMTCT campaigns at community level consider the use of mass and entertainment media to disseminate messages. For example, by making use of telephone hotlines to provide anonymous counselling, peer educators in the community or workplace and care at multipurpose youth centres.

International experience in Rwanda, Botswana and elsewhere suggests that the effective involvement of male partners and fathers is crucial for effective EMTCT. Some examples on what it takes to increase male involvement and developing family centred approaches to EMTCT include: developing community outreach and communication programmes which target families not just mothers; encouraging male peers to act as champions for change among other men and investigating ways of increasing male attendance at health facility visits.

Improving access to antenatal care (ANC) services is vital for moving towards virtual EMTCT. Access to antenatal clinics as an entry to the health system can be improved through investigating ways of providing services at more local health facilities (health centre level II or within communities themselves on an outreach basis). There is need to improve systems and processes so that women require fewer visits to health facilities, to reduce the barriers which stop women and family
members from accessing services in the first place, and to implement whole family approaches which target both men and women and enable women to attend ANC and other related services. There is a need for all women to attend ANC at least 4 times during pregnancy (which is not happening at the moment), and a need for pregnant women who are HIV+ to enrol and adhere to HIV treatment with the support of the father and other community members. Mothers need a safe environment in which to give birth. It is also important to provide good postnatal care (PNC) for mothers and babies, an area which is sometimes overlooked. Postnatal care is a significant issue as 50% of vertical transmission occurs after birth this is due to poor adherence to infant feeding guidelines and a high rate of non-attendance.

There is a need to integrate EMTCT with family planning, sexual reproductive health, antenatal care and other health structures to create greater synergies for better performance. At present these services are often fragmented and hard for mothers to access.

The analysis presented in this working paper has built on knowledge from Uganda and other parts of the world, setting out what it will take to ensure ending the vertical transmission of HIV. We invite you to be a part of the movement to support efforts moving forward and together we can make virtual EMTCT a reality in Uganda by 2015.
Part 1: EMTCT Globally- The Strategic Context

1.1. A decade of renewed global commitments to EMTCT

We live in a time of renewed global commitment to ending the vertical transmission of HIV, also referred to as the Virtual Elimination of Mother-to-Child Transmission of HIV (EMTCT). The world is now more than ever united in the drive to end HIV transmission and to welcome a HIV free generation; this is becoming a more realistic target due to the advances in treatment, coverage, and more effective regimens. Recent UNAIDS reports demonstrate that through working together the global community has made great progress in responding to the HIV epidemic and more people than ever are receiving treatment, care and support. Years of investment in multi-strategies of HIV prevention are delivering dramatic results while science is offering new hope (UNAIDS, 2012). Today, the world has a real opportunity to eliminate new HIV infections in children by 2015.

The virtual EMTCT of HIV means that fewer than 5% of babies born to HIV-positive pregnant mothers contract the virus (IATT, 2012a). Recent studies demonstrate the global EMTCT status; about 330,000 [280,000–380,000] children were newly infected with HIV in 2011, almost half the number that was infected in 2003 (UNAIDS 2012a, UNAIDS & Obeid 2012). In addition, 95% of HIV infection in children is a result of mother-to-child transmission (MTCT), and this transmission occurs in 30-40% of HIV-positive pregnant women. Transmission can occur during pregnancy, labour or breastfeeding (UNAIDS 2010, ANECCA 2011 and UNAIDS & Obeid 2012). Without treatment it is estimated that half of the HIV infected children will die before their second birthday, contributing to high infant and childhood mortality rates. Access to comprehensive HIV services reduces the risk of transmission to below 5% in communities that practice breastfeeding, and to 2% in the communities that do not practice breastfeeding (WHO, 2010). The global UNAIDS EMTCT targets set to be achieved by 2015 include:

- reducing HIV incidence in women of reproductive age by 50%;
- reducing the unmet need for family planning among HIV-positive women to zero;
- reducing the risk of MTCT of HIV to less than 5%; and
- providing antiretroviral therapy (ART) for 90% of eligible HIV-positive women.

Source: UNAIDS 2011, Simonds 2012

World leaders addressing HIV/AIDS stakeholders at the July 2012 International AIDS Conference reiterated the commitments to EMTCT. Similar commitments have been made at the regional level, by the African Union and by many other local and international forums. Presented below are quotes from key world leaders on EMTCT:

- “Now is the time to take even more bold action, inspired by true global solidarity to achieve an AIDS-free world”
  UN Secretary General Ban Ki Moon
“Africa is committed to demonstrating its leadership to sustain progress and to making the vision of an AIDS-free generation a reality”
Chairperson of the Africa Union (UNAIDS, 2012).

This unprecedented global alignment of science, experience, and political support brings hope that the world will soon see negligible incidence of HIV among new-borns, creating a new generation free of HIV infection (UNAIDS 2012, Simonds 2012). Reaching the 2015 targets will reduce the number of new HIV infections among children by 90% and reduce the number of AIDS-related maternal deaths by 50% (UNAIDS, 2011). To ensure that global commitments are followed through several plans, frameworks, guidelines and commitments have been designed by leading world agencies to support the attainment of the Millennium Development Goal (MDG) targets for EMTCT by 2015.

Key documents related to international commitments to EMTCT include:

- AIDS at 30, Nations at Cross Roads (Sidibe, 2011);
- Countdown to Zero: The global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, 2011-2015 (UNAIDS, 2011);
- Together we will end AIDS (UNAIDS, 2012);
- It takes a Village: ending mother-to-child HIV transmission. A partnership uniting the millennium villages project and UNAIDS (UNAIDS, 2010);
- Preventing HIV and unintended pregnancies: strategic framework 2011–2015 (IATT, 2012a);
- Prevention of mother-to-child transmission of HIV (PMTCT) strategic vision 2010–2015: preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals (WHO, 2010);
- Rapid advice: use of antiretroviral drugs for treating pregnant women and preventing HIV infection in infants, November 2009 (WHO, 2010).

The list above demonstrates that there is an extensive and growing list of published research, guidelines and framework documents which continue to be developed as part of a global commitment to EMTCT. However, achieving the EMTCT vision will require a continued investment in a wide range of essential activities including: optimising interventions; maximising coverage and retention; strengthening health systems; engaging communities; assuring adequate human resources; implementing favourable policies; promoting leadership and coordination; mobilising adequate financial resources; developing research and innovation; and conducting surveillance and measurement (Simonds, 2012). This working paper explores knowledge on these issues, and others, in some depth.

It is important to note that despite a high-level leadership drive every day thousands of people are newly infected with HIV. Many are in the most-at-risk populations and the under-served communities. These groups require a greater level of support, information, and access to prevention services, such as condoms. Far too many people that get infected, especially women and youth, do not have the power to negotiate safer sex (UAC, 2008).
This working paper reasons that despite the global commitments for EMTCT the challenges are still enormous and complex. Low and middle income country (LMIC) programmes, including Uganda, are still catching up in adopting the most effective PMTCT regimes (Esiru 2012, MoH Malawi 2012); for example half of HIV-positive pregnant women are not on ARVs, and more than 1,000 infants globally are infected with HIV each day (Simonds 2012). This paper takes a global outlook on the EMTCT response and makes comparisons to that in Ugandan from a learning and knowledge management perspective. It will compare evidence on Ugandan EMTCT progress with other LMICs, analyse barriers and obstacles, and explore strategies to address the challenges to meeting the EMTCT targets. Finally, this working paper discusses key global, regional and local lessons learnt at policy, implementation, community and individual level with the aim of developing a ‘best practice’. This will contribute to the delivery of parts of the Ugandan National Development Plan (NDP) and will also be informative to other LMICs striving for EMTCT.

1.2. EMTCT as an opportunity for the attainment of MDG targets

The elimination of mother-to-child transmission of HIV also contributes directly to 4 of the 8 Millennium Development Goals (MDGs), and indirectly to all MDGs (UNAIDS and Millenium Villages, 2010). We elaborate on the MDGs that will be positively impacted on by the attainment of EMTCT, below:

**MDG 3:** Promote gender equality and empower women—EMTCT offers a channel to address gender equality issues, including ending gender-based violence, supporting women’s reproductive rights, increasing access to information and sexual and reproductive health services and engaging male partners (UNAIDS Millenium Villages, 2010);

**MDG 4:** Reduce child mortality—EMTCT reduces the number of infants infected with HIV, provides treatment and offers care and support for uninfected as well as infected children born to mothers living with HIV. Indirectly, EMTCT improves maternal health and ensures safer feeding practices (UNAIDS Millenium Villages, 2010);

**MDG 5:** Improve maternal health—EMTCT provides primary prevention of HIV and family planning for women of childbearing age and ensures care, treatment and support for mothers living with HIV (UNAIDS Millenium Villages, 2010);

**MDG 6:** Combat HIV/AIDS, malaria and other diseases—EMTCT prevents the spread of HIV through primary prevention in women of childbearing age, averting vertical transmission and treating both mothers and infants living with HIV (UNAIDS Millenium Villages 2010, Simonds 2012).

1.3. Background and rationale of this working paper

Acknowledging the importance of the attainment of EMTCT targets and driven by the urgency, this working paper has been produced by the Uganda HIV/AIDS Knowledge Management and Communications Capacity (KMCC) Initiative. The KMCC Initiative works in consultation and
partnership with the Uganda AIDS Commission (UAC), Ministry of Health (MoH), and district level actors, implementing partners, civil society organisations (CSOs), representatives from communities of people living with HIV (PLWHIV), academia and AIDS development partners in Uganda. A consortium of partners - led by Delta Partnership and working with the Uganda HIV/AIDS Alliance, Scriptoria Communications, the Mildmay Centre (Uganda), the Uganda Virus Research Institute/Medical Research Council - are currently managing the KMCC Initiative, supported by funding by the Government of the United Kingdom, Department for International Development (DFID).

This working paper represents a systematic synthesis and analysis of data, published and unpublished literature covering research, programme reports, stories from the field, guidelines and other documentation on EMTCT / PMTCT. The purpose of this synthesis is to present a wide range of knowledge in practical, meaningful and informative ways. The synthesis will cover behavioural, structural, bio-medical and socio economic evidence and lessons learnt, with the overall aim to inform policy makers, activists and programmers on what it will take to achieve EMTCT of HIV in Uganda by 2015. This working paper will be consulted upon further and later be used to generate products such as targeted policy briefs, key messages, media packs, newspaper pull-outs and district-level EMTCT information packs that can be used by a broad variety of audiences including: individuals and families; communities of people living with HIV (PLWHIV); implementing partners; policy makers; research bodies; the media; and parliamentarians and activists. Products will be carefully designed in collaboration with others to make sure that messages are communicated to relevant audiences in the most effective ways. Related to this working paper is a growing online catalogue (www.kmcc.org.ug) comprising of more than 200 articles on EMTCT and related RSS feeds to various online published journals. This working paper has been compiled through a thorough desk review of literature and an inclusive and participatory process of consultations with key HIV/AIDS stakeholders in both the public and non-public sector at the national and at district levels in Uganda. Care has been taken to make sure, as far as possible, that this working paper is based on a factual and balanced synthesis of knowledge which will be helpful to the Uganda National HIV/AIDS response.
Part 2: EMTCT in the Ugandan Context

2.1. Trends in the HIV epidemic in Uganda

In Uganda the national average adult HIV prevalence fell from a high of 18.5% in 1992 to about 5% in 2000. This was due to several key factors, including strong political leadership, an open approach to combating the epidemic and a strong multi-sectoral, decentralised and community response (UAC, 2011a). However, the 2004/05 sero behavioural study put the prevalence at 6.4% (Macro, 2006), and the Uganda AIDS Indicator Survey (UAIS 2011, MoH 2012) reported an increase in prevalence to 7.3% in 2011. This general increase in HIV prevalence demonstrates indisputably that HIV/AIDS remain significant health and development problems for Uganda (MoH, 2012).

Box 1: Trends in HIV Prevalence in Uganda

<table>
<thead>
<tr>
<th>Category</th>
<th>2004-05 UAIS</th>
<th>2011 UAIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total 15-49</td>
<td>6.4</td>
<td>7.3</td>
</tr>
<tr>
<td>Women 15-49</td>
<td>7.5</td>
<td>8.3</td>
</tr>
<tr>
<td>Men 15-49</td>
<td>5.0</td>
<td>6.1</td>
</tr>
</tbody>
</table>

Source: Ministry of Health 2012, Uganda AIDS Indicator Survey Press Release

HIV prevalence is higher among women (8.3%) than men (6.1%). Moreover, the prevalence increases with age until it peaks at age 35-39 for women (12%) and at age 40-44 for men (11%). 4% of young adults at age 15-24 are living with HIV. Women in urban areas have a higher HIV prevalence than those in rural areas (11% vs. 8%). The prevalence is highest among widowed women (32.4%) and lowest among women who had never been married (3.9%). Additionally, the HIV prevalence varies by region, from a low of 4.1% in mid-eastern region to 10.6% in central region.
Box 2: HIV prevalence by region, 15-49 years olds

![HIV Prevalence by Region](image)

Source: MoH 2012, Uganda AIDS Indicator Survey Press Release

Positively over the past 6 to 7 years there has been a tremendous increase in HIV counselling and testing (HCT) in Uganda. The proportion of women aged 15-49 who have been tested for HIV and received their results has increased fivefold, from 13% in 2004-05 to 66% in 2011. The increase in HCT uptake among men has been somewhat more modest, from 11% in 2004-05 to 45% in 2011. Additionally, the UAIS has indicated that 72% of pregnant women were tested for HIV and received results as part of their antenatal care (Health, June 2012). The UAIS recommends the continued need for individual behaviour change and the scale-up of evidence-based prevention interventions such as PMTCT services.

The UAIS report indicates that comprehensive knowledge of HIV/AIDS is at 33.8% for women in age group 15-49 and 41.1% for men in the same group. Women who know that HIV can be transmitted by breastfeeding and that the risk of MTCT can be reduced by the mother taking specific drugs during pregnancy is 65.2%, while only 55.7% of men know this. The National Strategic Plan (NSP) and Performance Measurement and Management Plan (PMMP) define the most-at-risk Populations (MARPS) of the HIV/AIDS epidemic as female sex workers (FSW), fishing communities, uniformed services, internally displaced persons (IDPs), mobile populations and migrant workers as well as persons living with disability (PWD).
2.2. Impact of unchanged gender relations on HIV/AIDS and health programmes

In Uganda and other sub-Saharan African countries women and girls constitute the bigger proportion of people living with HIV/AIDS (52%) when compared to men and boys (UNAIDS & GCWA, 2006), as rates of female infection continue to rise so does the risk to the attainment of EMTCT. Research has shown that women are 4-5 times more at risk of contracting HIV than men and 55% of new infections occur among women (UNAIDS, 2002). This is attributed to a combination of biological and social factors and the traditional deep-rooted gender inequalities including gender-based violence (GBV). A UN Integrated Regional Information Network report in 2006 reported that GBV rates in Ethiopia, Kenya, Uganda and other countries in the region were ‘exceedingly high’. Nine out of ten girls and women in the region reported to have been subjected to GBV. Just as GBV can lead to HIV transmission, AIDS can lead to gender based violence. In settings of domestic violence and other forms of GBV, women and girls are disempowered to negotiate for the safer-sex options of abstinence, partner faithfulness or condom use. Violated women and girls are less likely to access EMTCT facilities and other HIV treatment and care services including HIV testing. Research has shown that those subjected to GBV are more likely to be exposed to risky sexual practices including non-protected multiple partner relations (UNAIDS & GCWA, 2006). Gender inequalities and widespread GBV in the region, coupled with the lack of access to AIDS treatment, care and support services, worsen HIV transmission risks (Kivumbi et al., 2006).

With a focus on the MDG 3 target, several international and Ugandan initiatives are working to improve maternal and reproductive health targets, especially HIV. In addition implementers and policy makers are increasingly recognising the central role of gender relations, norms, and roles in HIV/AIDS and health inequalities (Population Reference Bureau, 2011). Inequitable and differential gender norms, or the social expectations and practices of male and female roles and behaviours are related to power and control over health care. Women are the main care givers within the family yet they are often unable to make household decisions such as whether to access health care, to use family planning and to decide on parenting practices. GBV prevalence remains high in many places. For example in Northern Uganda where among young women (aged 15-19) more than half (63%) have experienced GBV by a husband or partner, and 17% of women who have been pregnant have experienced physical violence during pregnancy. In Uganda, like many other sub-Saharan African countries, women represent more than half of those living with HIV. In Uganda 60% of PLWHIV are women and a staggering 75% of HIV-positive 15-25 year olds are women. Addressing gender roles and related power dynamics is necessary to ensure equitable HIV/AIDS health service expansion, particularly in EMTCT programmes. Later in this working paper we present evidence and knowledge on gender inequality in relation to barriers to EMTCT, including challenges of disclosure of status to partners, male involvement, and access to services and adherence to prescribed medicine.
2.3. **Description of systems and structural arrangements for EMTCT delivery**

Public health and HIV/AIDS programmes in Uganda fall under two major statutory bodies, the MoH and the UAC. The UAC was established in 1992 by an Act of Parliament and is the supra-sectoral agency responsible for overseeing, planning and coordinating the multi-sectoral National HIV/AIDS response. Within the National HIV/AIDS response MoH takes technical leadership, guides and coordinates the implementation of behavioural, structural and all bio-medical interventions, including the PMTCT/EMTCT programme. EMTCT presents an opportunity and a challenge to effectively integrate the national health investment plans, national HIV strategic plans (including the prevention strategies) within the broader National Development Plan and the integration of HIV/AIDS within wider health systems.

The national health system in Uganda comprises all public health facilities under the MoH, health services of the Ministries of Defence, Internal Affairs (police and prisons) and Ministry of Local Government (MOLG) (MoH Uganda, 2010). Structurally, the Uganda public health systems are decentralised and implemented through 112 district councils. Additionally there is a number of private for-profit companies, not-for-profit organisations, faith based providers, and traditional and complementary medicine practitioners (TCMPs). Within this decentralised system MoH sets policies, norms and standards, and leads on sector planning, resource mobilisation and coordination, whilst districts and health sub-districts (HSDs) lead the delivery and management of local health services. The role of district health offices (DHOs) is to plan, budget, and implement health policies and plans. HSDs do the same for the lower health centre levels and oversee health activities – both public and private - within their catchment area. Public-private partnerships remain weak in Uganda as a whole though close to 50% of health service providers in Uganda are private sector (MoH Uganda 2010, Management Sciences Health & Save the Children, 2012).

Overall Uganda faces poor coverage and access to health services. Only about 50% of all public and private health facilities offer comprehensive HIV/AIDS care services. The overall PMTCT facility coverage (hospitals, health centre levels III and IV) has increased from 77% in June 2009 to 90% by the end of June 2010 although the extent of PMTCT services can differ greatly. Access to ARVs by HIV-infected pregnant women and their new-borns remains below 60%; this is far from the 80% universal access targets (Kivumbi 2011, UAC 2011). The integration of HIV/AIDS, EMTCT, maternal, new-born and child health (MNCH) and other reproductive health and family planning services remains poor. Additionally, the average distance for a Ugandan to access a government run health facility is 7.7 km and to access a non-government facility is 6.2 km. Access in urban areas is somewhat better than in rural areas, however, over 80% of Uganda is rural and underserved (MoFEPD, 2007). Moreover, the Uganda HIV/AIDS system response is predominantly donor dependant. The 2011 UAC mid-term review has estimated an annual share of the GoU in the total HIV/AIDS funding to have grown from just 5% in 2007/08 to 9% in 2008/09 and 11% in 2009/10 (UAC, 2011a). Without the donor/partner support most of the available services would inevitably collapse.
2.4. National commitments to EMTCT

Recently Uganda has seen renewed commitment to strengthening the HIV/AIDS response. Between the years 2010 and 2011 several policy guidelines have been developed to strengthen the national response and to increase the country’s chance of realising the UAC vision of 'a population free of HIV and its negative impacts'. The most relevant policies and guidelines include:

Table 1: National policies and guidelines

<table>
<thead>
<tr>
<th>National Policies developed</th>
<th>Policies/Guidelines reviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Second National Health Policy, 2010</td>
<td>HIV Counselling and Testing Policy, 2011</td>
</tr>
<tr>
<td>National HIV/AIDS Policy, 2011</td>
<td>Infant and Young Feeding Policy, 2011</td>
</tr>
<tr>
<td>Public Private Partnership for Health Policy, 2010</td>
<td>Integrated PMTCT, ART, IYF Guidelines, 2012</td>
</tr>
<tr>
<td>HIV/AIDS Workplace Policy, 2010</td>
<td></td>
</tr>
<tr>
<td>Nutrition Policy - policy on infant and young child feeding, 2010</td>
<td></td>
</tr>
<tr>
<td>Care and Treatment policy, revised 2011</td>
<td></td>
</tr>
<tr>
<td>Uganda Antiretroviral Treatment Policy, 2011</td>
<td></td>
</tr>
<tr>
<td>Home Based Care Policy, 2011</td>
<td></td>
</tr>
<tr>
<td>HIV/AIDS Policy for the Roads Sub-Sector, 2010</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Bills initiated /processed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marriage and Divorce Bill, 2010</td>
</tr>
<tr>
<td>HIV Prevention and AIDS Control Bill 2010</td>
</tr>
</tbody>
</table>

HIV/AIDS related Sector Plans developed

| Health Sector HIV/AIDS Strategic Plan 2010/11-2014/15 |
| Sector HIV Prevention Strategic Plans 2010/11-2014/15: MOES, MOPS, MOGLSD, MAAIF, MOWT, MOIA (Prisons) |
| National Health Laboratory Services Strategic Plan 2010-2015 |
| National Condom Strategy, 2011 |
| Scale-up Plan for Prevention of MTCT of HIV and Care of Exposed Infants 2010-2015 |

Broader National Plans

| National HIV/AIDS Strategic Plan 2011/12-2014/15 |
| National Prevention Strategic Plan 2010/11-2014/15 |
| Health Sector Strategic and Investment Plan 2010/11-2015/16 |

Source: National Policies and Guidelines, 2010-2012 Adapted from (UAC, April, 2012)

The (UAC, 2011) adopts the World Health Organisation (WHO) 4 pronged approach to EMTCT and the global EMTCT targets.

**Prong 1:** Prevention of HIV among women of reproductive age within reproductive health services, such as antenatal, postpartum, and postnatal care, and within other health and HIV service delivery points, including community structures.

**Prong 2:** Provide appropriate counselling and support, as well as contraceptives, to women living with HIV to meet their unmet needs for family planning and spacing of births, and to optimise health outcomes for these women and their children.
**Prong 3:** For pregnant women living with HIV, ensure HIV testing and counselling and access to the antiretroviral drugs needed to prevent HIV infection from being passed on to their babies during pregnancy, delivery, and breastfeeding.

**Prong 4:** HIV care, treatment, and support for women, children living with HIV, and their families (UNAIDS 2011, WHO 2010, Simonds RJ. 2012).

Additionally, the NPS identifies the need for educational and behaviour change communication efforts that stress the importance of (i) creation for parent-to-child transmission prevention services; (ii) PMTCT as a family responsibility, emphasising women and men’s role in PMTCT; (iii) family planning and (iv) couple counselling and testing with risk reduction counselling and the promotion of post-delivery risk reduction for infants born to HIV positive mothers through modified breast feeding practices (UAC, 2011). Linked to the NPS is the National Plan for Elimination of MTCT: 2012 – 2015, that makes clear the EMTCT goals and targets for the reduction of HIV morbidity and mortality among HIV-positive women and HIV-exposed and HIV-infected infants. This means that at the policy level the direction is set and commitments are documented.

### 2.5. EMTCT in Uganda: from clinical trials to pilots and programme scale up

**From clinical trials to action research to PMTCT programmes**

In 1994 a US clinical trial demonstrated that zidovudine (AZT) prophylaxis could reduce mother-to-child transmission of HIV by about 70% (transmission was 25% without AZT compared to 8% with AZT) (UNAIDS, 2011). Although this immediately became the standard care given in developed countries, it was not implemented in resource limited settings such as Uganda because it was unaffordable. The AZT regimen for one mother cost about USD 1,000 at that time (Barigye, H. 2012b, Barigye, H. 2012a).

A more feasible PMTCT regimen came out of a Ugandan trial in 1997, which found that a single dose of nevirapine (NVP) given to the mother at the onset of labour and also to the new-born within 72 hours of birth reduced mother-to child transmission by 50% compared to a short course of AZT (UNAIDS, 2011). The single dose NVP regimen cost about USD 4. This became the recommended regimen for PMTCT but use of AZT from 36 weeks of gestation, in labour and post-partum was also recommended (Barigye, H. 2012b).

**The expansion of EMTCT programmes in Uganda**

In the year 2000 a pilot PMTCT programme using single dose NVP was started in Mulago, Nsambya, Mengo, Arua and Lacor hospitals. In the guidelines ‘replacement feeding’ was recommended for mothers living with HIV. Single dose NVP tablet and syrup for the mother during, and the baby after, delivery was scaled up to more health facilities beyond the pilot sites in 2001-2005. The major concern with this regimen was the development of resistance. A single mutation in the genetic structure of the virus confers resistance not only to NVP but also cross resistance to other Non-
Nucleoside Reverse Transcriptase Inhibitors (NNRTIs). NNRTIs form an essential component of the first line regimens in resource limited countries. Resistance therefore limits future NNRTI based therapies for the babies who get infected and mothers exposed to single dose NVP when they become eligible for antiretroviral therapy (ART) for their own health. As antiretroviral drugs (ARVs) got cheaper the cost-effectiveness of NVP diminished because NVP was also less efficacious in prevention of vertical transmission than combination therapies (Barigye, H. 2012a).

The national PMTCT guidelines were therefore revised in 2006 and a more efficacious regimen recommended. In these guidelines pregnant women living with HIV were offered AZT from 28 weeks of gestation, or AZT and 3TC (lamivudine) from 32 weeks of gestation and a single dose NVP during labour. Infants on the other hand received single dose NVP within 72 hours of birth and AZT suspension for 7 days. ART was recommended if the mother had CD4 <350 or WHO clinical stage III and IV. The guidelines for exclusive breast feeding message also changed and was recommended for 3-6 months with abrupt weaning (Barigye, H. 2012, Esiru 2012).

2.6. Adopting the 2010 WHO guidelines: Programme transition from PMTCT to EMTCT

WHO released new guidance on EMTCT in 2010 - which covered PMTCT, Early Infant Diagnosis (EID), ART and infant feeding- and the Ugandan MoH adopted these guidelines in 2011. The 2010 WHO guidelines are premised on the recognition of:

- benefits of earlier initiation of ARV prophylaxis during pregnancy in reducing mother-to-child transmission;
- effectiveness of ARV prophylaxis provided during breastfeeding in reducing mother-to-child transmission;

In 2011, after adapting the WHO guidelines, the national programme terminology and goals have transited from PMTCT to EMTCT and in this working paper we shall mostly refer to EMTCT. We will also occasionally mention PMTCT predominantly for interventions linked to Prong 3 of the WHO approach set out above.

The 2010 WHO guidelines set out an ‘Option A’ or an ‘Option B’ for addressing MTCT. Please see Table 2 for a summary of the regimens and practices linked to the various ART options. Both these options are equivalent in efficacy and have the capacity to reduce transmission to less than 5% in breastfeeding populations. For Option A women living with HIV who need ART for their own health (CD4 count <350 or WHO clinical stage 3 and 4) should start ART irrespective of gestational age and continue through pregnancy delivery and thereafter for life. For breast feeding mothers the infant takes the syrup throughout breast feeding until up to one week after cessation of all breast feeding, and for non-breast feeding infants they take daily AZT or NVP from birth until 6 weeks of age.
For Option A, the guidelines state that a pregnant woman living with HIV but not in need of ART for her own health, will use AZT from 14 weeks of age (second trimester) or as soon as she is identified in a health facility until the onset of labour and delivery. At the onset of labour, the mother receives single dose NVP, AZT/3TC during labour and delivery and for 7 days only after giving birth. A breastfeeding infant receives NVP prophylaxis from birth until one week after stopping breast feeding. In Option B on the other hand, the pregnant woman living with HIV receives ART from 14 weeks of gestation until one week after exposure to breast milk. In addition the new-born receives NVP (breast feeding populations) or AZT (non-breast feeding populations) for 6 weeks.

Countries reviewed applicability and practicability of this guidance to their country context and some countries, notably Malawi, found this new guidance not favourable for them due to high fertility rates and problems of resistance due to repeated starting and stopping of ART Option B. They developed a new regimen altogether now known as option B+. In April 2012 WHO recognised and released guidance for countries opting to adopt option B+. Uganda’s EMTCT Policy Guidelines are aligned to this WHO guidance.

<table>
<thead>
<tr>
<th>Table 2: A description of ARV Regimens Option A/Option B+/B+</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Option A</strong></td>
</tr>
<tr>
<td><strong>Regimen for Mother</strong></td>
</tr>
</tbody>
</table>
| HIV test and then CD4 blood counts or HIV clinical disease staging to determine course. HIV positive mothers with CD4 counts more than 350 or stage 1 and 2 are put on the regime below:  
• Starting 14 weeks of pregnancy, mothers receive the ARV regimen of AZT;  
• At the onset of labour, the mothers are given a single dose of Nevirapine (NVP);  
• AZT + 3TC during labour and delivery;  
• AZT + 3TC for 7 days postpartum;  
• Positive Mothers with CD4 counts that are below 350 or stage 3 and 4 are started on Highly Active Ante Retro Viral Therapy (HAART) for life. | After the HIV test, if positive, there is no requirement to do CD4 counts or clinical staging to determine the course. The HIV positive mother is started on Triple ARV from 14 weeks until one week after the mother stops breast feeding. The regimen includes three anti-retroviral medicines: TDF + 3TC + EFV. |
| **Regimen for the HIV exposed Infant** | **The new Option B+: an improvement of option B** |
| All HIV exposed infants are on Niverapine (NVP) for 6 weeks. | If the HIV test is positive, with Option B+, there is no requirement to do CD4 counts or clinical staging to determine the course. The HIV positive mother is started on Triple ARV from 14 weeks of pregnancy and for the rest of her life. |
Regimen for the HIV exposed Infant
Among populations that practice breastfeeding the infant is given a daily dose of NVP from birth until one week after all exposure to breast milk. Among populations that do not practice breastfeeding of infants; the exposed baby is given NVP for 6 weeks. (Esiru 2012, Barigye, H. 2012a, WHO 2010).

Regimen for the HIV exposed Infant
All HIV exposed infants are on Niverapine (NVP) for 6 weeks.

Source: WHO, June 2010

2.7. Decision to move to Option B+: The 2012 National Policy Guidance

In August 2012 the Uganda MoH decided to adopt option B+ as the national policy based on the understanding that B+ provides significant benefits and propels the country further towards EMTCT targets. The advantages of option B+ are mainly in having a simplified but highly effective approach throughout the entire period of potential transmission, i.e. during antenatal, labour and delivery as well as during the entire breast feeding process. Option B+ requires just an HIV test which can be availed even in the most basic health facility in the country. Because one regimen (fixed dose combination tablet) is required for ART and PMTCT, the supply chain and training is more easily integrated. In Uganda, there is a birth rate of 47.38/1,000 population and total fertility rate of 6.14 children born per woman (CIA, 2012), the new regimen avoids starting and stopping therapy when mothers get pregnant again which can have possible negative consequences (Esiru 2012, Barigye 2012). Option B+ is considered to have a comparative advantage in combating EMTCT, not only in Uganda but in other LMICs like Malawi. However option B+ is not a stand-alone ‘magic solution’ to EMTCT for the country.

To fully utilise the opportunities presented by option B+ strategies to ensure better and more widespread coverage of compressive EMTCT services under all of the 4 prongs must be stepped up. There is a need to analyse evidence and design strategies to improve coverage and reach Uganda’s most at risk and underserved populations (Johri M. 2011, Esiru 2012). With the new guidelines there is a need to implement strategies that will ensure that 90% of pregnant women living with HIV access and stay within the PMTCT cascade; this includes antenatal care (ANC), attending counselling, initiation and adherence to ART during pregnancy, labour and delivery as well as after delivery. The HIV-exposed new born (delivered by an HIV positive mother) needs to be initiated on ARV prophylaxis, undergo the HIV PCR test at the age of 4-6 weeks after birth and 6 weeks after cessation of breastfeeding, and have a final test at 18 months. Ultimately, with option B+ the HIV positive mother, baby and family need to be integrated in routine HIV/AIDS care and treatment support programmes. The EMTCT cascade is complex and necessitates community engagement, a strengthened health system, policy implementation and funding. We acknowledge that EMTCT can be marred by a multitude of obstacles; these obstacles are further analysed in Section 3 of this working paper.
2.8. Status on EMTCT in Uganda

Prong 1: The primary prevention of HIV transmission to women of reproductive age

To address gender dimensions and HIV transmission risks to women a holistic approach is needed which targets women and men, and introduces measures to empower women. With the escalation in HIV prevalence rates in Uganda, particularly among women, there is a need to scale up efforts for primary prevention in a gender sensitive manner. The mid-term review report of the NPS indicated that the numbers of new HIV infections were estimated to have increased from 115,775 in 2007/08 to 124,261 during 2009/2010. Using EPP and Spectrum, MoH estimated that there were 115,775 new infections in 2007 (87,727 adult and 25,746 in children < 15years), 124,261 in 2009 (97,163 adults and 24,548 children) and 128,980 in 2010 (UAC, 2011a). The table below presents trends, with gender disaggregation.

Table 3: Trends in HIV Incidence 2007–2010 using Mathematical Modelling

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Population</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>People newly infected with HIV</td>
<td>Total</td>
<td>115,775</td>
<td>119,258</td>
<td>124,261</td>
<td>128,980</td>
</tr>
<tr>
<td></td>
<td>Adults</td>
<td>87,727</td>
<td>91,967</td>
<td>97,163</td>
<td>102,157</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>49,566</td>
<td>51,948</td>
<td>54,873</td>
<td>57,685</td>
</tr>
<tr>
<td></td>
<td>Children &lt; 15 yrs.</td>
<td>25,746</td>
<td>24,878</td>
<td>24,548</td>
<td>24,142</td>
</tr>
</tbody>
</table>

Source: MoH Estimation and Projections Group, 2010

From 2007 to 2010 the proportion of Ugandans who know the main ways of HIV prevention (abstinence, be faithful and condom use) increased, however the comprehensive knowledge of HIV/AIDS remained low (26-44%), particularly among women. The Uganda NPS has embraced combination HIV prevention strategies such as: addressing behavioural issues; structural issues including gender inequality and harmful cultural practices; proven biomedical interventions including voluntary medical male circumcision; treatment as prevention; pre-exposure prophylaxis; and couples testing with treatment for the infected partner in a discordant couple (The National HIV Prevention Strategy 2012-2015, Simonds RJ. 2012).

Prong 2: The prevention of unwanted pregnancies among HIV positive women

The planned expansion of ARV-PMTCT uptake to 90% by itself is unlikely to achieve EMTCT without consideration of Prong 2. Comprehensive PMTCT that includes both ARV prophylaxis and FP services is needed to make such goals achievable. Modern family planning methods are safe, cost-effective and provide substantial benefits towards PMTCT and beyond. Data from a Ugandan study (Hladik et al., 2009) has demonstrated the substantial benefit of increasing family planning coverage on reducing HIV infections in children in Uganda. The study calls for better integration of family planning with PMTCT programs as an important way to achieve this benefit. Donors, policy makers, and programme planners need to acknowledge and embrace the real contribution of family planning for PMTCT, and support its expansion (Hladik et al. 2009).
Prong 3: Preventing vertical transmission from a woman living with HIV to her infant

From the UAC mid-term review of November 2011, the target for PMTCT for the National Strategic Plan 2007-2012 was to reduce HIV transmission from mother-to-child by 50% by 2012 (UAC, 2011). PMTCT services in the country continue to evolve in line with emerging evidence and international guidelines. Currently, most HCT services for antenatal women are provider-initiated, with rapid tests and same-day return of test results. Couple counselling and testing has been adopted as part of PMTCT services, but uptake remains limited. Reports at MoH show that the proportion of HIV+ mothers receiving ARVs for PMTCT increased from 35% in 2007/08 to 48.5% in 2009/10, slightly below the 50% target for 2010. The proportion of mothers who were tested during pregnancy increased as well, from 43% in 2007/08 to 59.3% in 2009/10.

Table 4: Proportion of pregnant women that tested for HIV 2006-2011

<table>
<thead>
<tr>
<th>Period</th>
<th>% of pregnant women tested for HIV during pregnancy</th>
<th>% of targeted pregnant women that were tested for HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline (2006)</td>
<td>-</td>
<td>24%</td>
</tr>
<tr>
<td>2007/08</td>
<td>82.0</td>
<td>43</td>
</tr>
<tr>
<td>2008/09</td>
<td>92.4</td>
<td>69</td>
</tr>
<tr>
<td>Mid-term target</td>
<td>-</td>
<td>50%</td>
</tr>
<tr>
<td>2009/10</td>
<td>92.0</td>
<td>59.3</td>
</tr>
<tr>
<td>2010/11</td>
<td>98.0*</td>
<td>-</td>
</tr>
</tbody>
</table>

*UAC, 2011

Source: MoH PMTCT and paediatric HIV/AIDS care programme annual report, July ’09 - June ‘10

The proportion of all expectant mothers who were tested for HIV increased from 43% in 2007/08 to 69% in 2008/09, but declined slightly to 59.3% in 2009/10. Performance on this intervention is above the mid-term target, despite the slight decline.

Table 5: Proportion of HIV positive pregnant women receiving ARVs for PMTCT

<table>
<thead>
<tr>
<th>Period</th>
<th>No/% of HIV+ pregnant mothers who received ARVs for PMTCT</th>
<th>% of all expectant HIV+ mothers who received ARVs for PMTCT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline data (2005)</td>
<td>10,289</td>
<td>12%</td>
</tr>
<tr>
<td>2007/08</td>
<td>31,990 (81%)</td>
<td>35.3%</td>
</tr>
<tr>
<td>2008/09</td>
<td>46,948 (82%)</td>
<td>52%</td>
</tr>
<tr>
<td>Mid-term target (2009)</td>
<td>-</td>
<td>50%</td>
</tr>
<tr>
<td>2009/10</td>
<td>44,167 (73%)</td>
<td>48.5%</td>
</tr>
</tbody>
</table>

Source: MoH PMTCT and paediatric HIV/AIDS care programme annual report, July 07 - June 10
Table 6: Proportion of HIV+ infants born to HIV+ mothers between 2007 and 2011

<table>
<thead>
<tr>
<th>Year</th>
<th>No. of health units with early infant diagnosis</th>
<th>Total no. of infants tested</th>
<th>No. HIV positive</th>
<th>% HIV positive</th>
<th>No. tested as % of all estimated HIV exposed children</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline (2006)</td>
<td>-</td>
<td>-</td>
<td>30</td>
<td>-</td>
<td>-</td>
<td>PMMP</td>
</tr>
<tr>
<td>2007-2008</td>
<td>193</td>
<td>11,211</td>
<td>2,175</td>
<td>19.4</td>
<td>12.3</td>
<td>07/08 PMTCT report</td>
</tr>
<tr>
<td>2008/2009</td>
<td>424</td>
<td>28,645</td>
<td>3,451</td>
<td>12</td>
<td>31.5</td>
<td>EID MoH</td>
</tr>
<tr>
<td>Mid-term (2009)</td>
<td>-</td>
<td>-</td>
<td>22.5</td>
<td>-</td>
<td></td>
<td>PMMP</td>
</tr>
<tr>
<td>2009/2010</td>
<td>616</td>
<td>39,575</td>
<td>2,951</td>
<td>7.5</td>
<td>43.5</td>
<td>09/10 PMTCT and EID reports</td>
</tr>
<tr>
<td>2010/2011</td>
<td>800</td>
<td>36,575</td>
<td>2,712</td>
<td>7.4</td>
<td>40.2</td>
<td>EID report</td>
</tr>
</tbody>
</table>

Source: based on the national estimate of 1,400,000 pregnancies annually, and with a 6.5% HIV positivity among pregnant women, ~91,000 babies are born HIV exposed each year.

Men who tested together with their pregnant partners increased from 87,844 in 2008/09 to 123,252 in 2009/10, representing 12.3% of all the new ANC seen over the period. The table below provides a summative overview of achievements against set PMTCT targets between 2007 and 2010.

Table 7: Summary of performance on key National Strategy Plan indicators for PMTCT

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of HIV-infected infants born to HIV positive mothers</td>
<td>30%</td>
<td>19.4%</td>
<td>12%</td>
<td>7.5%</td>
<td>22.5%</td>
</tr>
<tr>
<td>Number/percentage of HIV positive pregnant women who receive ARVs to reduce risk of MTCT in past 12 months</td>
<td>10,289 (12%)</td>
<td>31,990 (35.3%)</td>
<td>46,948 (52%)</td>
<td>44,167 (48.5%)</td>
<td>50%</td>
</tr>
<tr>
<td>Percentage of pregnant women tested for HIV during pregnancy</td>
<td>24%</td>
<td>43%</td>
<td>69%</td>
<td>59.3%</td>
<td>50%</td>
</tr>
</tbody>
</table>

Source: MoH PMTCT and paediatric HIV/AIDS care programme annual report, 2007 - 2010

Prong 4: Integration into ARV services

In 2012, the Uganda MoH released ‘The integrated National Guidelines on ante-retroviral therapy, prevention of mother-to-child Transmission of HIV, and infant and young child feeding’ to further guide health workers in the delivery of integrated HIV prevention, care and treatment, nutritional
care, treatment and support for PLWHIV (MoH Uganda, 2012). At the national level the Uganda first lady Mrs Janet Museveni has accepted to take on the role of National EMTCT champion.

The key question is ‘what will it take for Uganda to attain EMTCT?’ The challenge is in the implementation process, to roll out and reach the under-served populations in the most cost-effective way. Section 2.9 presents a comparison of Uganda performance and other LMICs.

2.9. Comparison of progress with other low-mid income countries

Prong 1: The primary prevention of HIV infection among women of reproductive age

Box 3: Estimated HIV Prevalence Rates among young adults 15-49, by country

![HIV Prevalence Rates Map](image)

**Source:** Waweru L., 2008

The diagram above demonstrates that in 2008 the Uganda HIV prevalence rates for women, men and children were significantly higher than the rates in several other sub-Saharan Africa countries. Moreover countries like Namibia, Zimbabwe, Botswana, Kenya, and Rwanda have registered decreasing HIV prevalence rates towards the end of the last decade (UNAIDS, 2011). It is important to re-emphasise that in sub-Saharan Africa and other LMICs, among 15-24 year olds, two females are infected for every new infection among males in the same age group. Women and girls are more susceptible to HIV infection - male-to-female HIV transmission is estimated to be twice as likely as female-to-male transmission. This implies the need for sustained HIV prevention efforts to scale up primary prevention among women of reproductive age in Uganda and sub-Saharan Africa.
Prong 2: Preventing unwanted pregnancy among women living with HIV

Reduction of unintended pregnancies among women who live with HIV is an important component in the pathway to the virtual EMTCT of HIV. The rationale is that the fewer unintended pregnancies among women living with HIV mean fewer infants born to them, and hence fewer infants exposed to HIV and potentially living with HIV. The Global HIV/AIDS Response Report of 2011 makes reference to mathematical modelling which has demonstrated that the mother-to-child transmission of HIV cannot realistically be eliminated without reducing unintended pregnancies among women living with HIV (Mahy et al. 2010). The report also hastens to note that there is limited data available on the access to, and uptake of, family planning services among women living with HIV, with most data focusing on the family planning practices among women of reproductive age without disaggregating based on sero-status. It is important to note that family planning services should be offered to all women regardless of their HIV sero-status.

A recently published survey conducted in Uganda (Jhangri et al., 2011) reveals a significantly greater unmet need for family planning among people living with HIV than among HIV-negative people (75% versus 34%). Meeting this unmet need among women of reproductive age living with HIV can significantly contribute to the EMTCT target. In some other countries, women living with HIV have lower unmet need than HIV-negative women.

Table 81: Unmet need for family planning by HIV sero-status based on demographic and health surveys in six countries

<table>
<thead>
<tr>
<th>Country and year of survey</th>
<th>Unmet need among women living with HIV</th>
<th>Unmet need among HIV-negative women</th>
<th>Change in unmet need over time among all women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenya 2008</td>
<td>21%</td>
<td>21%</td>
<td>25%(2003) to 26%(2008)</td>
</tr>
<tr>
<td>Lesotho 2009</td>
<td>16%</td>
<td>18%</td>
<td>31%(2004) to 23%(2009)</td>
</tr>
<tr>
<td>Malawi 2010</td>
<td>18%</td>
<td>21%</td>
<td>28%(2004) to 26%(2010)</td>
</tr>
<tr>
<td>Swaziland 2007</td>
<td>12%</td>
<td>14%</td>
<td>27%(2002) to 27%(2007)</td>
</tr>
<tr>
<td>Zambia 2007a</td>
<td>14%</td>
<td>20%</td>
<td>27%(2002) to 27%(2007)</td>
</tr>
<tr>
<td>Zimbabwe 2006</td>
<td>14%</td>
<td>8%</td>
<td>13%(1999) to 12%(2006)</td>
</tr>
</tbody>
</table>

Sources: UNAIDS calculations of data from Demographic and Health Surveys (Measure DHS: all surveys by country and Millennium Development Goals indicators)

The figures in the table above give the overall impression that the unmet need for family planning in the general population in these six countries has been relatively stable in recent years. The only countries in the sample in which unmet need has significantly declined among the general
population are Lesotho and Malawi and, in both countries, the unmet need is lower among women living with HIV who reported knowing their status. In Uganda the unmet need for family planning was above 50%.

**Prong 3: Preventing vertical transmission from a woman living with HIV to her infant**

According to The Global HIV/AIDS Response report of 2011 (UNAIDS, 2011) it is reported that in 2010 an estimated 35% of the estimated 123 million pregnant women in low and middle income countries received an HIV test. This increased from 26% in 2009, 21% in 2008 and 8% in 2005. This increment was witnessed in almost all regions of the world. However, much as this progress has been significant in almost all regions, it is estimated that nearly two thirds of pregnant women still do not know their HIV status, including many pregnant women living with HIV who could benefit from further health interventions such as lifelong care for HIV and interventions to reduce the MTCT of HIV. An estimated 1,006,000 (2.3%) of the 43,170,000 pregnant women estimated to have received an HIV test in LMICs in 2010 were reported to be living with HIV. This represents 68% of the estimated total of 1.49 million pregnant women living with HIV needing antiretroviral medicine to prevent the MTCT of HIV. HIV counselling and testing is an important entry point to prevention, care and treatment services. It is thus important to invest in increasing coverage of these services so as to have an increase in uptake.

In some settings the coverage of antenatal care is still low, and yet increasing access to antenatal care may be an effective way to expand the coverage of HIV testing and counselling among pregnant women living with HIV. According to the UNICEF 2010 PMTCT factsheet, in 2008 Uganda had only 51% of its antenatal care facilities providing HIV testing and ARV for EMTCT, far from universal access. Early identification of all pregnant women living with HIV is an important prerequisite to EMTCT. In 2010, the estimated coverage of HIV testing and counselling among pregnant women exceeded 50% in 13 of the 22 priority countries for EMTCT. The coverage of HIV testing and counselling among pregnant women in Botswana, South Africa, Zambia and Zimbabwe was estimated to exceed 90% in 2010. However, in Chad, the Democratic Republic of the Congo and Nigeria, less than 20% of the estimated number of pregnant women living with HIV received HIV testing and counselling. Box 4 below shows a comparative analysis of HIV testing among pregnant women from 20 high burden/priority countries for 2009.
Box 4: Percentage of pregnant women tested for HIV. 2009 data from 20 high burden countries from sub-Saharan Africa

From the box above, Botswana (93%), South Africa (95%) and Zambia (95%) lead in HIV testing for pregnant women. Uganda stands at 64% pregnant women tested for HIV, with the trends notably rising from 57% in 2008. An underlying reason for these statistics is that the countries with high levels of testing have almost universal coverage of ANC facilities offering HCT. For example Botswana had attained near universal utilisation of ANC services in 2009.

In 2010, an estimated 571,000 pregnant women living with HIV globally (38% of the pregnant women living with HIV needing antiretroviral medicine for preventing MTCT) had CD4 counts at or below 350 cells per mm³ and were thus eligible for antiretroviral therapy (based on modelled estimates). Among pregnant women who needed antiretroviral therapy, 35% (197,000) received it (Global HIV/AIDS report, 2011). In most of the high burden/priority countries for EMTCT (Uganda, Kenya, Tanzania, Zimbabwe, Burundi, Democratic Republic of Congo, Zambia, South Africa, Cameroon, Nigeria, Botswana, India, Nigeria, Mozambique, Ethiopia, Cote d’Ivoire, Angola, Ghana, Lesotho, Swaziland, Namibia, Chad), less than 50% of the estimated number of pregnant women eligible for antiretroviral therapy received it in 2010. Among these countries, it is reported that only 5 countries (Botswana, Lesotho, Namibia, South Africa and Swaziland) exceeded 80% coverage in accordance with the latest international standards. Several countries still have low coverage levels, and intensified efforts are needed to improve access to effective interventions. Nigeria, the Democratic Republic of the Congo, Uganda and Malawi are the countries that accounted for nearly 50% of the global gap in 2010 to reach 90% coverage of antiretroviral medicine for pregnant women living with HIV.

Statistics indicate that HIV testing for pregnant women is not commensurate with the percentage of infants receiving antiretroviral drugs at birth, except in Botswana and Namibia. This success is
attributable to the fact that Botswana had achieved universal coverage of ARVs for HIV positive pregnant women and exposed infants. Namibia’s success was also attributed to her nearness to universal access of ARVs for PMTCT. It is also stated that in 2009 Uganda had an estimated 53% of HIV positive pregnant women receiving ARVs, compared to only 28% of the exposed infants receiving the drugs at birth. This situation may insinuate either loss to follow-up of the mother-baby pair and/or a gap in ARVs for PMTCT coverage needed for the country to scale up the coverage of ARV treatment for mothers. Statistics indicate that there has been a significant increase in the number of pregnant women being tested, and HIV positive pregnant women on ARVs, however the number of infants given ARVs at birth is still very low.

**Prong 4: Providing appropriate support, care & treatment to mothers living with HIV and their families**

Early infant diagnosis (EID) of HIV infection is very important in measuring the outcomes of antiretroviral therapy in the prevention of vertical transmission of HIV from the mother to the infant. It is also important to note that an infant born to mothers living with HIV does not necessarily mean that they become infected. It is only through EID that infants’ HIV sero-status can be confirmed. According to WHO’s 2010 guidelines on antiretroviral therapy for HIV infection among infants and children, it is recommended that HIV-exposed infants be tested by 4–6 weeks of age using polymerase chain reaction (PCR). The guidelines further emphasise the importance of testing HIV-exposed infants early so that, if they are diagnosed as HIV-positive, they can immediately start antiretroviral therapy; this is regardless of clinical or immune status, to improve chances of survival. These guidelines also prescribe a second confirmatory HIV test that should not delay starting antiretroviral therapy.

Significant progress has been made globally in scaling up the coverage of early infant diagnosis. In 2010 in 65 LMICs providing data (up from 54 countries in 2009), 28% (24–30%) of infants were reported to have been tested for HIV within the first two months of birth, versus 6% (5–7%) in 2009. This increase resulted in part from including 2010 data from nine priority countries for EMTCT that did not report on this indicator in 2009 (Global HIV/AIDS Response Report, 2011). It is reported that the EID coverage in Uganda stands at 19% (Esiru G., 2012); the reasons for low uptake are not clear, but it is likely that it is the result of a combination of obstacles including loss to follow up, as will be discussed in subsequent sections. This low rate of EID coverage makes it difficult to adequately measure vertical transmission of HIV (Esiru, 2012).

In the early 2000s Uganda’s performance indicators were ahead of most LMICs. Uganda had been a success story with many LMICs adopting Ugandan response models. However, in recent years a number of EMTCT performance indicators for Uganda have lagged behind other LMICs. In the next section we use evidence to analyse reasons why, and borrow lessons from successful strategies and programmes elsewhere to inform the policy and implementing partners in Uganda.
Part 3: Analysis of Knowledge to Improve EMTCT Coverage and Retention in Uganda and other LMICs

3.1. Thinking and investing strategically for EMTCT

Uganda needs to invest strategically in children and HIV/AIDS, especially the Elimination of Mother-to-Child Transmission. The UNAIDS executive director Michel Sidibé has called on global unity on EMTCT: “By uniting our forces across boundaries, institutions and communities we will leverage this historic opportunity to welcome the first generation born free of HIV by 2015” (UNAIDS & Obeid, 2012).

UNICEF upholds that the 2015 EMTCT targets are feasible and that success will call for thinking and acting differently, and the use of innovative approaches to reach marginalised underserved populations. According to UNICEF, the attainment of EMTCT targets will not require new scientific breakthroughs; it requires innovative financing and community action to enable people - women, men, youth and infants - to take advantage of available HIV prevention and treatment therapy (IRIN PLUS, 2010). In Part 3 of this working paper we present an analysis on evidence and knowledge related to strategies and programmes to improve EMTCT coverage and retention in LMICs.

The presented evidence is based on a robust review of documents and literature, observations and lessons from field visits and consultative meetings that were conducted by the KMCC Initiative in six out of the eight pilot districts for the intensified comprehensive HIV prevention strategy for Uganda. The consultations were held in Gulu, Arua, Kasese, Kabale, Mayuge and Rakai districts. KMCC also held consultative meetings with implementing partners and policy decision makers at the national level. The list of participating institutions can be found in annex 2 of this report. District level meetings involved consultations with district PMTCT teams, to get a clearer understanding of issues on the ground. Results from “grey” unpublished literature were triangulated with lessons from local and international literature as part of an intense knowledge management process for EMTCT in Uganda.

3.2. Overview of obstacles and solutions to increased EMTCT coverage and retention

This analytical and conceptual framework is premised largely on recommendations from the systematic review by Johri and Arrey in 2010, which identified 19 articles published in 9 journals
from 1996 to 2010, 16 concerning sub-Saharan Africa (Johri, 2011). From a cost-effective perspective, Johri concluded that interventions to prevent HIV MTCT are compelling on economic grounds in many resource-limited settings and should remain at the forefront of global and national HIV prevention efforts. Key recommendations were that future efforts should help to ensure that EMTCT interventions for LMICs reach their full potential on coverage and retention by focussing on unanswered questions in the four areas that are presented below:

- local assessment of rapidly evolving HIV MTCT options;
- strategies to improve coverage and reach under-served populations;
- evaluation of a more comprehensive set of MTCT approaches, including primary HIV prevention and reproductive counselling;
- integration of HIV MTCT and other sexual and reproductive health services.

Source: 2010 systematic review by Johri and Arrey (Johri M, 2011)

Uganda has taken a big leap forward for EMTCT by deciding on option B+ as a key part of the national Prong 3 policy. Real success will inevitably necessitate integration of HIV/AIDS care and treatment services, ART, and all the four prongs of comprehensive EMTCT programmes. This will embrace sexual reproductive health (SRH), maternal new-born child health (MNCH) services within the LMIC health systems, and improved coverage and retention (WHO 2010, Esiru 2012).

Moreover, a number of studies show evidence that ‘poor coverage and retention of pregnant women’ impact transmission more than the type of prophylaxis regimens used, whether it is Option A, B or B. This means that either option is good provided it attains critical coverage and retention levels. The barriers to EMTCT uptake and retention can be at individual, family or community level, or at health system, implementation or policy level, or most likely, a combination of several. Obstacles such as distance, competing demands, costs, illness, stigma, unattractive facilities, and disempowerment are further explored below. LMICs should invest in careful analysis of obstacles at all levels as this will help EMTCT programmes and interventions to overcome the local service gaps and barriers to coverage and retention (Simonds, 2012).

While optimising interventions is critical, models show that achieving the EMTCT targets will require reaching more than 90% of pregnant women with a sequence of inter-related services (Barker, Mphantswe, and Rollins, 2011). This entails pregnant women accessing the health system through ANC followed by continued retention across multiple encounters, along with community support (Simonds, 2012). EMTCT programmes in LMICs must now think of access and strategies for coverage and retention for underserved women, men and children living in rural remote settings, the displaced people and the most-at-risk populations (MARPS) of women and men (UAC, 2008). Access, coverage and retention for the women and men, youth and children from “working class” urban families are more feasible, but still challenging. Health systems should now increasingly invest in socially, economically and geographically accessible services to the underserved populations and the MARPs, and increase coverage and retention accordingly. For the Ugandan context, MARPs have been defined under part two of this working paper (MoH 2012b, UAC 2008). For the purpose of this
working paper, the definition for the underserved populations is “populations that do not have adequate access to medical care; this includes rural/peri-urban, low-literacy, blue collar, and poor marginalised women and men of reproductive age” (Medical Dictionary, 2012).

The stepwise pathway for the prong 3 PMTCT cascade includes:

- utilisation of ANC services;
- quality counselling, perform HIV test and administer same day test results for the pregnant mother;
- the HIV positive mother gets initiated on ARVs as per the National Guidelines preferably same day;
- mothers followed up according to focused ANC schedule until delivery;
- the HIV positive pregnant mother must have a facility based delivery to benefit from intrapartum interventions on PMTCT;
- she then is followed up after delivery according to the PNC and immunisation schedules on PMTCT regimens;
- the mother needs to bring the baby back to the facility at 4-6 weeks, for the early infant diagnosis, PCR dry blood spot test and she receives results as per facility guidelines;
- the mother needs to follow guidance on breast feeding, and follow through subsequent PMTCT steps up to when the baby is 18 months old, and tested again, and then integrate in the ART services (Esiru, 2012).

ANC is the entry point for EMTCT however, having ANC as the entry point implies several underlying assumptions. These include the assumptions that pregnant women are aware of issues around EMTCT, that they are voluntary and willing users of EMTCT, that they have the choice, and that the services are accessible to them. While certain literature indicates that an increasing number of pregnant women know their status before pregnancy, other studies have indicated that around 30% of the target population is not knowledgeable of risks related to the transmission of HIV from a pregnant woman to her unborn infant (mid-term review of The Uganda National Prevention Strategy, 2011). Furthermore, many are just not aware of EMTCT interventions and they would not be voluntary ANC/PMTCT service users (MoH Uganda 2012, UAC 2011).

The next sections present political, economic, social, and technology analysis of the obstacles to EMTCT based on emerging evidence and lessons on options. This can be used to help identify strategies to improve EMTCT coverage and retention in LMICs that are of relevance to the Ugandan context.
3.3. Health systems and structures

The importance of systems and structures
As members of the UN, national governments in LMICs have ratified and committed to implementation of EMTCT and other global targets. This said governments retain the discretion over how programmes are implemented. A common finding amongst the literature is that most attention on EMTCT strategies has been focused on prong 3 (Johri M 2011, Falnes 2011, Bajunirwe 2005, Barigye 2012, Betancourt 2010). This reflects on the policy and programmatic approach where there has generally been a lack of integrated HIV, SRH and MNCH services.

Positively, within MoH in Uganda there is coordination and implementation of all the 4 prongs of EMTCT, however the prongs fall under separate departments. In Uganda, EMTCT prong 3 is under STD/ACP in MoH, while prong 1 covering primary prevention is coordinated under the health education unit. Prong 2 and other sexual reproductive health services and safe motherhood have a separate department within MoH, whilst prong 4 covering ART services has separate coordination management arrangements. The urgency and importance of efforts to systematically integrate ANC, HIV and SRH services are emphasised in various places in the analysis below.

Moreover, there is growing evidence that health systems delivering PMTCT services in LMICs continue to underperform (Youngleson 2010, Sprague 2011). For example, within the district level in Uganda, the level of functionality of the district health system varies significantly across the country and within districts. Districts tend to lack the capacity to coordinate, integrate and deliver services; such inefficiency is further amplified in newly created districts. A substantial number of districts lack infrastructure, have staff shortages and senior level positions are often filled by under-qualified individuals (MoH Uganda, 2010). The human resource for health (HRH) system is very weak and the comprehensive EMTCT cascade largely relies on the midwife as the interface between the pregnant woman and the health system. Health facilities are typically underfunded and have inadequate infrastructure and management systems for essential medicines including ARVs, and have few health supplies including HIV test kits and CD4 count machines. Worse still, household and community involvement in health management and systems are limited to consumption / user level and community members tend to shun services if they are perceived to be of poor quality (MoH Uganda 2010, MSH & Save the Children et al. 2012).

Most districts in Uganda have EMTCT implementing partners (IPs) funded by donor agencies such as CDC and USAID. MoH works closely with the IPs to ensure service delivery (Kidega et al., 2012). Initially, service coverage was restricted to hospitals and health centre (HC) levels IV and III, however there are policy moves to provide EMTCT services at HCII levels (Kivumbi, 2011). The decentralised health response in Uganda faces a number of challenges, for example obstacles linked to programme leadership, coordination and governance.

Examples of common impacts of poor programme leadership, coordination and governance include:
- inadequate funding and staffing at MoH, affecting support supervision activities (Kidega et
al., 2012); poor communication of policy changes, for example some health units still use single dose nevirapine yet the country moved away from that option years ago (Barigye H., 2012b); delayed and slow disbursement of funds for PMTCT activities, and very poor financial accountability; some IPs bypass the district health office and work directly with the implementing sites, breaking district ownership and creating parallel leadership coordination structures (UAC, 2011a); internal staff transfers within specific health facilities, for example a midwife trained in EMTCT service delivery being transferred within the same health facility as a theatre nurse. This affects continuity of service delivery and necessitates re-training (Barigye, 2012); some DHOs have lamented that they do not access data nor reports emanating from a number of sites for IPs (Barigye H., 2012b).

It is very important for MoH and local governments, district and health sub-district leadership to coordinate with IPs and to strengthen buy-in, ownership as well as supervision and accountability arrangements. District EMTCT leadership and coordination roles need to be strengthened and recognised by IPs, as this will contribute to strengthened national and district health systems. Stronger national and district leaders’ ownership of EMTCT programmes is the key to sustainability, and a remedy to service deterioration when IP projects close. The UAC, MoH and AIDS development partners’ leadership in Uganda are working to remedy this, through campaign themes to “re-engage the leadership at all levels to revitalise the response” (UAC, 2011).

In section 2 of this report we elaborated on the policy transition from PMTCT programmes to EMTCT in Uganda. Consultations with six Ugandan districts at implementation level have identified challenges related to the frequent changes in policy and national guidelines. While these changes are meant for better results, views from the districts indicate that implementation of the new changes is hampered by lack of resources to disseminate, train and mentor HRH at all levels on the new policy guidelines (Barigye et al., 2012b). Additionally, a recent analysis on the Ugandan policies at national level on readiness to achieve EMTCT that was conducted by EGPAPF, demonstrated (EGPAF, 2012) key policy- and systems-related issues that have the potential to hamper efforts toward EMTCT in Uganda which are:

- Different conceptions and lack of knowledge and understanding of the components essential for EMTCT among key decision makers and implementers. The implication of this challenge is a diminished collective support for EMTCT. This gap identified by EGPAPF is in a way exhibited by discrepancy between the NSP (UAC, 2011) and the national plan for EMTC (MoH); where in there is some variation on what these key bodies identify as priorities to support for EMTCT.

- Political leadership and governance to mobilise and galvanise support for EMTCT are limited at multiple levels of government, especially the highest levels. This was also a major finding from a district and national EMTCT consultative process in 2012 (Barigye, 2012a). On the
other hand, recent reports in Uganda show that the First Lady accepted the role of National EMTCT champion (Esiru, 2012) and there is a need to replicate these championing efforts at district and sub-district levels, and with various communities such as the businesses and villages as per the EGPAF report.

Weak health care infrastructure has slowed the progress of EMTCT efforts, including policy dissemination difficulties, coordination and accountability between the district and national levels. There is limited support and resources at the district level and low overall funding availability, an EGPAF finding which resonates with findings from Barigye et al.

**Improving systems and structures**

To strengthen National Level Policy coordination for EMTCT the EGPAF report has recommended the following investments and strategies (EGPAF, 2012):

- **Communication**: effectively package messages about EMTCT to different audiences to facilitate their awareness, understanding, and prioritisation of this issue. Uganda needs to launch a national campaign targeting EMTCT;

- **Leadership role**: enlist leaders at multiple levels to mobilise support for EMTCT, identifying “champions” for EMTCT;

- **Strengthen the health care system and its management**: through enhancing accountability and feedback mechanisms between central and local levels of the health system;

- **Improve the multi-sectoral coordination role of the UAC**: create a high-level national task force to provide leadership and coordination for EMTCT;

- **Synergies and collaboration**: strengthen UAC-MoH partnership and synergies, as well as strengthening the roles of other actors, including CSOs.

Addressing these policy challenges necessitates joint work by UAC, MoH and MoLG, the three key statutory bodies. The EGPAF recommendations resonate with national level coordination arrangements spelt out in the Global Plan on EMTCT (UNAIDS, 2011). The urgency around social mobilisation and implementing a national EMTCT campaign concur with recent district level recommendations by Barigye et al (Barigye, 2012a) and with the MoH paper on Option B+ (Esiru, 2012). The Uganda MoH has listed the programming implications related to Option B+ roll-out that include:

- coordinating of training activities for HRH on Option B+;
- ensuring adequate stock management;
- ensuring appropriate integration of B+ into existing facility infrastructure;
- strengthening of health and community systems with community mobilisation to utilise services (Esiru, 2012).
In addition to what MoH identifies as programming priorities, the District Health Teams (DHTs) need to reflect and understand more about operational / implementation implications of the decision to move to Option B+ and to take necessary remedial actions in partnership with service providers and with the communities (Simonds, 2012). There is a need to understand the “how to”, the strategies, otherwise the option B+ roll out risks facing new or similar obstacles.

Another area that needs attention is monitoring and evaluation (M&E) and data management. The national data collection tools have undergone a number of revisions which necessitate resources for training and effective use. Lack of resources can hamper district utilisation of newer guidelines. There is also a gap in sharing data between implementing partners and the government (Barigye et al., 2012a).

Table 9: Summary of 6 Protocol Changes, Resource Additions and Quality Process Improvements that led to improvement in PMTCT indicators

<table>
<thead>
<tr>
<th>Documented Improvement</th>
<th>Associated Protocol Change</th>
<th>Associated Resource Allocation</th>
<th>Associated Process Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Antenatal care</strong></td>
<td>Mothers attending ANC at less than 20 weeks improved from 18% to 33%</td>
<td>None</td>
<td>Multiple antenatal sites across primary care clinics in sub-district improves access; Strategic placement of nurse to high volume antenatal clinics to eliminate backlog and wait time for antenatal booking</td>
</tr>
<tr>
<td>% of clients receiving AZT before the onset of labour increased from 72% to 89%</td>
<td>Gestational age for start of AZT lowered from 32 weeks to 28 weeks gestation</td>
<td>Improved early antenatal booking procedures as described above</td>
<td></td>
</tr>
<tr>
<td>Intrapartum /labour ward care</td>
<td>Post natal follow up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------------</td>
<td>----------------------</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>% of HIV positive pregnant women receiving HAART before onset of labour increased from 10% to 23%</td>
<td>HAART clinic at primary care site with large antenatal clinic and high HIV prevalence rates</td>
<td>Improved communication between ANC and ARV clinic, antenatal clients walked over to ARV room; ‘Mother’s Day’: dedicated ARV clinic day each week for pregnant women needing HAART; Mother2mothers programme gives support and education to women on PMTCT programme.</td>
<td></td>
</tr>
<tr>
<td>Increased percentage of PMTCT clients receiving dual ARV therapy NVP from 73% to 87% AZT from 42% to 84%</td>
<td>Number of babies entered into PMTCT register increased from 29 to 36 per month at a test site</td>
<td>Labour Ward PMTCT checklist; Monthly Labour Ward PMTCT; data review meeting at sub-district office.</td>
<td></td>
</tr>
<tr>
<td>% of babies receiving PCR test for HIV increased from 82% to 97%</td>
<td>Infant PCR testing brought forward from 14 to 6 weeks</td>
<td>Improved PMTCT information flow from labour ward by stapling ANC card to infant health card.</td>
<td></td>
</tr>
</tbody>
</table>

*Source: Youngleson MS, 2010*
3.4. Financial resources invested

In 2010 Johri et al. established that interventions for EMTCT are cost-effective in a variety of LMIC settings, as measured against accepted international benchmarks (Johri M, 2011). The box below presents the general picture on annual share of Government of Uganda (GoU) funding versus donors for HIV/AIDS funding.

Table 10: Annual Share of Government of Uganda in HIV/AIDS Funding

<table>
<thead>
<tr>
<th></th>
<th>2007/08</th>
<th>2008/09</th>
<th>2009/10</th>
<th>2010/11</th>
<th>Totals</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>GoU</td>
<td>14</td>
<td>28</td>
<td>36</td>
<td>38</td>
<td>116</td>
<td>9%</td>
</tr>
<tr>
<td>Bilateral</td>
<td>243</td>
<td>293</td>
<td>274</td>
<td>304</td>
<td>1,114</td>
<td>86%</td>
</tr>
<tr>
<td>Multilateral</td>
<td>13</td>
<td>7</td>
<td>34</td>
<td>18</td>
<td>72</td>
<td>5%</td>
</tr>
<tr>
<td>Totals</td>
<td>270</td>
<td>328</td>
<td>344</td>
<td>360</td>
<td>1,302</td>
<td>100%</td>
</tr>
</tbody>
</table>

Source: Mid-Term review of the HIV/AIDS NSP 2011

The 2011 UAC mid-term review noted the donor dependence of the programme, with an investment of up to US$ 931.8 million for the total national AIDS response. This highlighted the key financial and investment issues that need to be addressed including:

- over dependence on external funding, with sustainability issues;
- limited resource allocation for critical capacity building in governance, leadership and accountability;
- limited resource base and capacity for HIV/AIDS coordination at the district level;
- low ownership of programmes and poor coordination between multiple partners and districts, undermining national stewardship;
- limited accountability (UAC, 2011a).

3.5. Logistics and supplies management

The supplies system

In Uganda, the supply chain system for essential medicines and health supplies (EMHS) is composed of a multiplicity of independent, mostly parallel sub-systems that has made it so complex that it is difficult to map. This situation has developed over time and stems from the public delivery system’s inability to efficiently satisfy target-driven ministry and donor-funded activities. In addition, supply chain policies have gone back and forth. For example, the policy for EMHS distribution in the last 20 years started with an emergency programme funded by DANIDA that operated as a push system parallel to the distribution of other medicines and health supplies from the then Central Medical Stores. This distribution system was later integrated into the national supply system in early 2002, where facilities pulled supplies (quantity projected by the health unit), and was later supplemented by a push system (quantity projected by the central supply) for mainly donor-funded high-value
 commodities. In 2010, another shift replaced the ‘pull system’ with a ‘push system’ for the HCII and HCIII facilities, citing the facilities’ inability to order supplies (MoH & SURE, 2011).

A common scenario in a number of districts is the report that CD4 tests are not readily available in public health facilities except at the regional Joint Clinical Research Centre (JCRC) laboratory or at the district hospitals. Lack of point of care CD4 testing could result in loss to follow-up of mothers. This is a major constraint to a health service that is implementing Option A where the regimen a pregnant woman uses depends on her level of CD4 cells (Barigye H (a), 2012). Shortage of HIV test kits still occurs more so at the lower HC levels, meaning that pregnant women need to be referred for HIV testing. For example, one district has reported that only 23% of health facilities had no stock outs of six tracer drugs in the FY 2010-11, although this was an improvement from 10% in 2008-2009.

Some health centres attribute shortages to the push system of delivering commodities. In the push system, a predetermined quantity and type of pharmaceuticals and diagnostics are provided to health facilities of the same level without consideration of likely utilisation. Moreover, audits of supplies data often show that supplies bear little relation to actual activity, especially when paper systems are used to capture data and data captured is not fed back to providers of testing kits. The ability to provide a good service could be improved by introducing better stock control systems. Practices for reduction of stock outs include buffer stocks which are used to bridge the gap when shortages occur (Barigye H., 2012a). The information below presents an elaboration on how stock outs affect EMTCT. Please note that from October 2012, with the roll out of Option B+, buffering will be done at national level, between warehouses and not at the health facility level, as was the finding by Barigye et al. 2012.

**Impacts of stock outs / shortage – supplies and staff**

In a South African study, a significant proportion of HIV-positive pregnant or postnatal women interviewed failed to receive an HIV test during their first ANC visit, mainly due to shortages in staff and supplies. All counselling and testing is provided by a single nurse who also has other duties. If the nurse is not available, the service is not available. This generally means that there is no HIV testing for women who attend in the afternoon, weekend or on public holidays. This problem is compounded by high vacancy and turnover rates amongst staff (Sprague, 2011).

In Zambia, 20% of patients tested did not return for their results which led to the development of same day reporting. In addition, stock outs of HIV testing kits resulted in the interruption of service provision. Additional training for health care workers was developed to facilitate better stock management (Torpey, K. et al., FHI Zambia, 2010). Lessons from the 2011 policy analysis for Uganda pharmaceutical supply system (MoH & SURE, 2011) identified several issues that need further scrutiny to ensure best solutions and efficiency in supply chain systems:

- **Push/pull distribution:** There is a need to determine the best balance of central ‘pushing’ of medical supplies and local ‘pulling’ of supplies;
Centralised vs. decentralised operations: As part of the health sector reform, many tasks and responsibilities have been decentralised to the district level (including medicines funding) through the primary health care vote and district distribution. However, the primary health care vote was recently centralised into Vote 116, while distribution is still decentralised. Storage is partly centralised and partly decentralised. An analysis of procurement, storage, and distribution needs to assess the degree of decentralisation that ensures optimal resource utilisation;

Level of autonomy: The autonomy of NMS has varied considerably, and there are issues around NMS viability and long-term sustainability;

Public, private, and non-governmental organisation roles: Uganda has had to increase the workload to manage the scale-up of treatment programs. To best cope with this new demand on the supply chain, the responsibilities and roles of NMS and other providers need to be revisited to make best use of the available and existing capacity of different providers;

Mix of in-house and contract services: The need for NMS to outsource services needs to be analysed, building on outsourcing experiences from other countries.

The relevant message from the MoH and SURE report on logistics improvement was that for any supply chain system to work efficiently, a strong link must exist between forecasting, quantification, procurement, warehousing, inventory management, and the logistics management information system. The system should be as lean as possible and with effective coordination (MoH & SURE, 2011)

3.6. Human resources for health

The importance of HRH
Despite the high burden of HIV/AIDS Sub-Saharan Africa which is home to 11% of the global population has only 3% of the world’s health-care workers (WHO, 2006). Staff shortages in LMIC settings are a major obstacle to the scale-up of HIV care and treatment services including EMTCT. Moreover, this shortage of trained health care providers in LMICs has been known as an obstacle for development indicators for decades. One possible reason for this stalemate is that the number of people completing health-related training has not kept up with the increasing needs (Butera, 2010). Other reasons include Government fiscal policies capping the recruitment of HRH (Barigye, 2012) and others are related to motivation of HRH.

For decades now LMIC Governments and EMTCT stakeholders have known that the added workload brought on by AIDS has increased the strain on an already fragile health system and over-stretched health-workers. In Tanzania, a study has showed that the average staff workload at MNCH clinics ranges from 37.8% at facilities that do not provide PMTCT to 50.5% at clinics in which trained health-care workers provide EMTCT services. This suggests that health professionals may be less motivated to undertake EMTCT-related activities if not compensated for the extra work load.
In Uganda, lessons from a recent district level EMTCT readiness consultation found that in Kasese district (south-western Uganda), only 21% of the HRH vacancies had been filled as per the MoH staffing structure. Additionally, the State of Midwifery Training, Service and Practice in Uganda Assessment Report by UNFPA states that there was an estimated deficit of close to 2,000 (36%) of midwives in Government health facilities countrywide. The shortage is coupled with absenteeism and late reporting to duty of the existing HRH. The situation worsens in rural remote places like Karamoja where up to 91% of positions for midwives at health centre (HC) IIIs, and 70% of posts at HCIII are not filled (Waninda J., 2012).

The midwife in-charge discussed the extensive workload associated with the management of HIV-infected women at the various stages of pregnancy, from labour and delivery to breast feeding. For each woman, the midwife requires skills, time and resources to provide adequate counselling, HIV testing, ARV therapy/prophylaxis, Dry Blood Spot collection and transportation etc. Missing a step at any of these stages would compromise the quality of services (Barigye H., 2012a) (Barigye H., 2012b).

The work is simply too much, "We are overworked," says another midwife from the National referral hospital. “The environment is so stressful” (Nabiruma D., March 2012).

**The impact of poor HRH**

Literature has demonstrated that a single system or individual-level delay reduces the likelihood of women accessing EMTCT interventions (Sprague, 2011). The system or HRH delays, when concurrent, often signals a denial of access to services. Additionally, there is a considerable amount of research on the impact that low levels of staffing has on treatment programmes. Low levels of HRH resourcing are associated with:

- long waiting times;
- poor counselling;
- poor interaction with patients;
- lack of availability of service;
- delay in commencing treatment, sometimes until after birth;
- poor quality services and many errors;
- late opening or closure of some health facilities.

*Source: (Barigye 2012, Touré 2010)*

**Improving HRH**

The systematic review on HRH on several studies in Sub-Saharan Africa by Touré et al concurs that to attain EMTCT targets, there is a broad scope for health systems reforms to address constraints and weaknesses within EMTCT and ART services, integrated with MNCH and long-term HIV care and treatment (Touré et al. 2010, Sprague 2011, Barigye, 2012a). Comprehensive EMTCT strategies aiming to maximise HRH motivation in LMICs must involve a mix of both financial and non-financial incentives. The establishment of robust ethical and regulatory standards in public-sector HIV care
centres could reduce barriers and help LMICs achieve the 2015 Global and MDG targets (Touré, 2010). Additionally, reports from rural and primary health-care centres in Rwanda, Lesotho, Malawi, Uganda and elsewhere demonstrate that nurses can prescribe ART safely and effectively to HIV-infected adults and children, as long as they receive adequate training and support. A cost-minimisation model has also shown that task-shifting during the follow-up of patients on ART can substantially reduce costs. Innovative staffing strategies that use off-duty workers, trained traditional birth attendants (TBAs) and networks of PLWHIV (Barigye, 2012a) to provide MNCH and PMTCT services could help alleviate the shortage of human resources in many MNCH centres. Additionally, midwifery services need to be recognised, and upgraded as a key service provider in the district and local government systems, more so midwives located in hard to reach underserved places at HCII level. Innovative strategies for sustainable health systems capacity and uptake to mitigate the impacts of low levels of HRH resourcing include:

- A clear strategy design, leadership buy-in, addressing information gaps;
- Establishing robust ethical and regulatory standards in the public-sector;
- Providing technical assistance and mentorship as in-service capacity building for HRH and linking performance management to facility-wide human resources interventions;
- PMTCT Continued Medical Education (CME) meetings, promotion of utilisation of data collection tools;
- Integrating EMTCT services into existing MNCH, SRH, ARV and TB structures;
- Building local capacity to use systems improvement methods with reliable improved monitoring for performance management, using robust systems for data collection and utilisation;
- EMTCT protocol changes; addition/reallocation of resources;
- Minimising policies that keep trained staff rotating and of the creation of a need to constantly train new staff in clinical guidelines;
- Multi-tasking, improving the patient flow;
- Task shifting, e.g. use lay counsellors to conduct counselling and incorporating non-health workers, including supporting off-duty shifts for existing staff to provide additional coverage for health facilities (Uganda has recently adopted the policy for nurses prescribing ART);
- Linking with better policies for the training, certification and retention of community health workers and other informal providers of PMTCT services;
- Ensuring autonomy over resources at lower levels;
- Developing accountability systems;
- Improving HIV services in labour wards;
- Ensuring quality HIV and infant feeding counselling;
- Mobilising traditional and opinion leaders;
- Building strong relationships between government and implementing partners;


Literature has demonstrated that a positive staff attitude can have a big impact on patients, making worker motivation a key component in delivering EMTCT. From the theories of economics, it is
known that individuals only choose to work if the overall financial and non-financial benefits of their labour outweigh the associated opportunity costs. This means that interventions for HRH should consider the financial and non-financial motivation needs. A short analytical review on worker motivation, performance improvement and a case study on a systems approach based on research by Youngleson et al. 2010 are annexed to this working paper.

Professional motivation is defined as an individual’s willingness to work towards the goals of an organisation. In order for health-care workers to be effective, they must be motivated and willing to implement the reforms proposed by health policy makers. HRM and support systems can increase motivation by improving working conditions and involving staff in management decisions. Reviews of health-care worker motivation in resource-limited settings have shown that a wide range of factors on both the individual and group level, as well as in various social and cultural contexts, are likely to influence their expectations and effectiveness when providing care. However, these studies have rarely assessed HIV care or PMTCT specifically. The WHO has put forth four criteria for evaluating performance of health-care workers: availability, competence, responsiveness and productivity.

Several international development organisations have also adapted a “Performance Improvement Model” for use in LMIC settings. This model outlines five key factors that influence performance outcomes: job expectations; performance feedback; environment and tools; motivation and incentives; and knowledge and skills. One group used this model in Armenia to assess the factors affecting performance among MNCH health-care providers. They found that among people providing antenatal and postpartum care, performance was associated with practical knowledge and the ability to use everyday tools, recognition for good work, and performance feedback. These findings suggest that a set of incentives could help in introducing and scaling up- effective PMTCT programs. Without adequate remuneration, health-care workers are unlikely to perform their tasks effectively, nor are they likely to commit to their jobs in the long term, regardless of their responsibilities and initial level of commitment.

It may therefore be possible to create explicit financial incentives, for instance by increasing salaries or providing bonuses to those working in underserved communities or rural regions. Although wage concerns are important, they are not the only problem for already over-stretched health-care workers. Other important factors include professional fulfilment and opportunities for career advancement. Non-financial incentives may include compensation payments that improve living conditions, such as free housing, transportation or electricity, professional support and supervision, streamlined management, opportunities for continuing education and training, relocations, or promotions. However, it is important to note that non-financial incentives weigh as much as the financial ones and both need to be linked together.
3.7. Gender sensitive community engagement and communication

The importance of communities
Communities are groups of people linked by common ties. Within the HIV response these communities include networks of PLWHIV, community leaders, service users, faith-based organizations, and advocacy groups. Gender sensitive community engagement is a process of the community working collaboratively with governments, donors, medical service providers and legislators to empower women to access health care through rights based approach (IATT, 2012b).

Box 5: Sequence of prevention of Mother-to-Child Transmission of HIV services in community and facility

<table>
<thead>
<tr>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home and community</strong></td>
</tr>
<tr>
<td>• Learn of and seek services at antenatal clinic</td>
</tr>
<tr>
<td>• Take ARVs, other medications during pregnancy and breastfeeding</td>
</tr>
<tr>
<td>• Go to facility for safe delivery</td>
</tr>
<tr>
<td>• Go to maternal and child health facility in follow up</td>
</tr>
<tr>
<td>• Engage with ongoing community-based services for counseling, retention and adherence support, and social services.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Antenatal care site</strong></td>
</tr>
<tr>
<td>• Receive routine antenatal care services</td>
</tr>
<tr>
<td>• Receive health and HIV education</td>
</tr>
<tr>
<td>• Test for HIV and learn results</td>
</tr>
<tr>
<td>• Receive services for HIV+ women:</td>
</tr>
<tr>
<td>- Evaluate for ART eligibility</td>
</tr>
<tr>
<td>- Start ART if eligible</td>
</tr>
<tr>
<td>- ARV for PMTCT</td>
</tr>
<tr>
<td>- Counseling for infant feeding options</td>
</tr>
<tr>
<td>- HIV medical/psychosocial care</td>
</tr>
<tr>
<td>• Test partner and children for HIV.</td>
</tr>
<tr>
<td><strong>Delivery site</strong></td>
</tr>
<tr>
<td>• Test for HIV if not already done</td>
</tr>
<tr>
<td>• Take intrapartum ARV</td>
</tr>
<tr>
<td>• Have safe delivery</td>
</tr>
<tr>
<td>• Receive support for infant feeding.</td>
</tr>
<tr>
<td><strong>Maternal-child health site</strong></td>
</tr>
<tr>
<td>• Receive nutritional support</td>
</tr>
<tr>
<td>• Receive family planning services</td>
</tr>
<tr>
<td>• Receive postpartum and well child care</td>
</tr>
<tr>
<td>• Obtain early infant HIV diagnosis</td>
</tr>
<tr>
<td>• Receive HIV evaluation and treatment</td>
</tr>
<tr>
<td>• Receive tuberculosis prevention services.</td>
</tr>
</tbody>
</table>

Source: Simonds R J, 2012

Communities can play a vital role in reducing vertical transmission of HIV and keeping women and mothers alive. For example, they can do this through acting as extension workers to support frontline health care workers, helping to create monitoring links between community and faith-based organisations and facility-based services, and holding governments accountable for quality care. Communities can increase uptake of services including ARV adherence by participating in campaigns for behaviour change and reduction of stigma, providing peer support, maximising the use of...
community assets and resources, creating an enabling environment by advocacy action, and promoting community engagement in policies and strategies (IATT, 2012b).

**The need for gender sensitive HIV/AIDS IEC around EMTCT**

Community activities need to be coupled with quality information, education and communication (IEC) campaigns. Gaps in awareness and knowledge of EMTCT can be demonstrated through indicator measurement and research. For example, a cross-sectional study in Mbarara in Uganda (Bajunirwe F., 2005) found that 12% of mothers did not think that it was possible for the HIV virus to be passed to the unborn baby, and 8% did not know whether the virus can be passed from mother-to-child. This study, however, found that the level of knowledge did not differ significantly between the mothers in the rural setting compared to those in the urban areas. In this study, 11% of mothers thought that breast transmission of HIV was not possible and 12% did not know whether breast milk could cause HIV transmission or not, amidst a significant percentage that did not respond to this question. Likewise, the study found no significant differences in the level of knowledge between the rural and urban mothers regarding breast milk as a possible route of transmission (Chi square $p = 0.65$). The study implies that methods used in urban settings should be effective in rural settings too.

Also linked to gaps in awareness and knowledge of EMTCT, studies have highlighted that the scaling up of EMTCT services is undermined by a variety socio-cultural factors. Gender inequalities and other social-cultural factors must be addressed to develop an effective comprehensive implementation programme that integrates prong 3 with prongs 1, 2 and 4 of EMTCT. In Uganda, a recent study found that districts were characterised by the lack of IEC materials for the general community. It was observed that even when an implementing partner (IP) produces materials, these are not well integrated into district team plans; it is the IP who tends to disseminate these materials, reflecting a gap in public ownership of EMTCT IEC and the lack of funds to the district for IEC material dissemination. Moreover, IEC materials from MoH are often in dialects like Luganda, which are not the local dialect, rendering these IEC materials useless (Barigye H., 2012b). Behavioural change communication (BCC) materials need to raise awareness and knowledge of HIV, awareness of the vertical transmission risks from mother to baby, awareness of the status of being pregnant at an early stage, awareness of ANC units as entry points to PMTCT services, and awareness of location of these ANC units. This is potentially a major factor which will affect the choice of pregnant women to attend ANC services, to undergo screening for eligibility to PMTCT services, and the choice for women who already know that they are HIV+ to enrol in ART programs, assuming they are not already under treatment.

Moreover, the literature suggests that in many cases due to low resourcing on HRH, patients do not receive one-on-one counselling, but are provided with pamphlets about HAART (Barigye, 2012). In LMICs, many expectant mothers are illiterate and cannot read these or are embarrassed to take the pamphlets home where others may find them. Radio shows and casual village conversation is often the main source of information about HIV/AIDS and HAART and this can be problematic; for example, a common misconception is that ARVs make the patient weak and actually kills those ingesting it. One survey indicates a lack of understanding of PMTCT with majority of respondents
believing that the expected time to be receiving HAART was when they became bedridden. There are therefore some significant challenges surrounding awareness to determine HIV status.

Evidence from a 2005 Ugandan study on 404 women at a large urban hospital and three rural clinics that had recently started implementing PMTCT found that the level of knowledge of MTCT and preference for rapid HIV testing were equally high in both areas, but that rural women had a higher tendency to think that they should consult their husbands before testing. Health facility-based deliveries were significantly lower among mothers in rural areas compared to those in the urban setting. Overall, significant predictors of willingness to test for HIV were post-primary education (OR = 3.1 95% CI 1.2, 7.7) and knowledge about rapid HIV tests (OR = 1.8, 95% CI 1.01, 3.4). The strongest predictor of willingness to accept an HIV test was the woman's perception that her husband would approve of her testing for HIV. Women who thought their husbands would approve were almost six times more likely to report a willingness to be tested compared to those who thought their husbands would not approve (OR = 5.6, 95% CI 2.8, 11.2). Spousal involvement and same-day HIV test results were found to be more likely to ensure high uptake of HIV testing services (Bajunirwe, 2005). These results and many more have strong indicator of how much gender roles influence health seeking behaviour, however, little emphasis given to addressing these roles, during IEC might be business as usual.

Education level is a factor that is associated with having a positive attitude and the willingness to take an HIV test. Whereas some studies have shown that a lower education level is associated with higher likelihood to request for HIV testing, the Bajunirwe study showed the opposite, with those having at least a post-primary education more likely to choose to test compared to those with lower education (Bajunirwe, 2005). Ugandan findings are supported by a study among Hispanic farm workers in South Florida (Dinh TH., 2005) in which participants with at least 12 years of education were four times more likely to test compared to those without the same education. In a Vietnamese study, low education was associated with not returning for results (Okoouzni, 2000). Benefits of education and other MDG issues on EMTCT are well articulated in the UNAIDS report, it takes a village (UNAIDS, 2010). Table 11 below further demonstrates analysis on willingness to take an HIV test.

**Table 11: Demonstration on knowledge, attitudes and acceptance for rapid HIV testing among rural and urban mothers in Mbarara, Uganda (Bajunirwe F, 2005)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Rural n = 212 n (%)</th>
<th>Urban n = 192 n (%)</th>
<th>p* value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knew about rapid tests for HIV</td>
<td>115 (61)</td>
<td>124 (59)</td>
<td>0.58</td>
</tr>
<tr>
<td>Would accept HIV test if offered</td>
<td>159 (89)</td>
<td>178 (86)</td>
<td>0.40</td>
</tr>
<tr>
<td>Ever been tested for HIV</td>
<td>41 (24)</td>
<td>48 (23)</td>
<td>0.88</td>
</tr>
<tr>
<td>Think it is important to test for HIV</td>
<td>163 (96)</td>
<td>195 (98)</td>
<td>0.55</td>
</tr>
<tr>
<td>Would prefer same day results</td>
<td>169 (89)</td>
<td>184 (88)</td>
<td>0.57</td>
</tr>
<tr>
<td>Would advise someone to take an HIV test</td>
<td>184 (98)</td>
<td>205 (98)</td>
<td>0.88</td>
</tr>
<tr>
<td>Heard a radio programme on MTCT</td>
<td>152 (81)</td>
<td>175 (84)</td>
<td>0.45</td>
</tr>
</tbody>
</table>
In the absence of systematic gender sensitive IEC campaigns to create the needed awareness, there are lots of myths surrounding HIV/AIDS prevention, care, treatment and support information (UAC, 2011). Campaigns and social mobilisation strategies have been documented as effective ways of raising awareness and enrolling more women into ANC and ART. Lessons can be learned from elsewhere. For example, in order to improve HIV and PMTCT awareness in Zambia, ZPCT provided health education at community and facility levels with a focus on information programmes to improve the knowledge among both women and men regarding PMTCT services. In addition to attracting more pregnant women to be tested and reduce stigma, traditional and religious leaders were engaged in community sensitisation and mobilisation. This was further developed to encourage all spouses to accompany their partners to ANC and to be actively involved. Another promising practice for Uganda was the campaign “know your status”, by Baylor (U), in Gulu and Kasese, targeting the Early Infant Diagnosis. More case studies on promising practices are presented under Annexure 2.

Emerging evidence implies that effective community mobilisation can be through multi-models, including the network model that was implemented by the International HIV/AIDS Alliance in Uganda. The networks project, through community mobilisation, reached an estimated 1.3 million people with at least one health service. By clustering 750 groups of PLWHIV into larger coalitions, the project supported existing groups to amalgamate their collective strengths and skills in outreach, referral and literacy activities; and improved reach and coverage of HIV services through strengthened linkages with healthcare facilities (Mburu & Iorpena, 2012).

A recent analysis of the ‘networks model’ by Mburu et al. (2012) suggests that it could contribute to EMTCT as a replicable and sustainable community mobilisation approach. In particular, the networks model increased the uptake of decentralised interventions for preventing vertical transmission of mother-to-child through community referrals, promoted male involvement through peer sensitisation, and linked communities to advocacy channels for advancing maternal health and prevention of vertical HIV transmission. The key lesson from the network project is that through the meaningful involvement of PLWHIV, the networks model offers a mechanism for strengthening community and male involvement in EMTCT. The role of communities and networks of PLWHIV in planning, service delivery and monitoring of national targets for EMTCT can be further

| Had health talk from health worker on MTCT | 91 (48) | 90 (43) | 0.35 |
| Husband aware she came to antenatal today | 166 (91) | 173 (87) | 0.18 |
| Believe should consult husband before HIV test | 132 (72) | 132 (64) | 0.09 |
| Husband may not approve of testing | 31 (18) | 41 (21) | 0.53 |
| Husband would accept HIV test for himself | 122 (71) | 138 (73) | 0.60 |
| Would accept medication for PMTCT | 171 (98) | 181 (99) | 0.50 |
| Think that pregnancy should be terminated if mother is HIV infected | 37 (20) | 37 (17) | 0.60 |

* All p values are obtained from chi square tests for independence
strengthened through greater community engagement in service delivery and advocacy and through the regular sharing of data between communities and health facilities (Mburu&Iorpenda, 2012).

Meaningful involvement of PLWHIV - family planning as a choice
A 2009 study in Uganda found that most HIV-infected Ugandan women of reproductive age are unaware of their HIV status and many would opt for family planning (FP) if they knew their serostatus or had better access to FP (Hladik W., 2009). The 2009 finding contrasts recent studies, for example in Rakai District, data indicated that there were more pregnant women with a known HIV status than there were newly diagnosed (Barigye H., 2012a). An immediate and targeted measure calls for better and real integration of family planning services into post-natal care for HIV-positive and indeed all sexually active women of reproductive age. Family planning should be rights based, empowering women to decide when and whether to have children, whether she is HIV-positive or not.

Further still, there is limited evidence and knowledge on the integration of family planning into AIDS care programs or into psycho-social interventions for PLWHIV. From a policy and programming level, PMTCT funds have not been available for family planning services in Uganda in the past and some donors do not allow for the procurement of family planning commodities. Yet, the WHO guidelines call for comprehensive programming for EMTCT. Donors, policy makers, and programme planners need to acknowledge and embrace the real contribution of family planning to EMTCT and support its expansion (Hladik W, 2009).

Typically, family planning services target the general population. In Kasese district for example, STRIDES supports most of the family planning work using a comprehensive approach for the general population, and does not have a particular emphasis on PLWHIV. Yet HIV counselling and testing programmes actively offering family planning choices to PLWHIV have the potential to avert many subsequent unwanted HIV-positive pregnancies. Moreover, given the risk of HIV transmission associated with unprotected sex, the promotion of dual family planning (the combined use of a barrier with a hormonal family planning method) would achieve reductions in both vertical and horizontal HIV infections. Also, a general investment to expand family planning services for all sexually active persons may yield the broadest benefits for HIV-positive and negative women alike, averting transmission in HIV-discordant relationships and unintended pregnancies (irrespective of HIV status) and its many consequences. Additionally, the social mobilisation failures discussed above contribute to the low uptake of family planning to prevent unwanted pregnancies. This is against the background that the Ugandan socialisation and gender norms create the perception and promotion of “the having of many children” as a tradition. Thus voluntary family planing uptake among the youth (UNFPA) and PLWHIV in Uganda remains a challenge (Barigye H., 2012a), more so among the young women and men that are positive as a result of vertical transmissions. Most pregnancies are desired, more so among the young HIV positive women who acquired HIV vertically from their parents. Another area is male involvement

“The family planning registers are among the rarer used registers in the health centre”
Quoting IP from one of the districts visited (Barigye, 2012)
and gender sensitive community mobilisation, to counter the negative attitudes towards family planning. These are key to improving voluntary family planning uptake.

Borrowing lessons from the network project (Mburu & Iorpenda, 2012) the meaningful and greater involvement of PLWHIV (MIPA/GIPA) in voluntary family planning programmes remains an unexplored strategy. Additionally, the values and benefits of MIPA within the 4 prongs of EMTCT cannot be over emphasised. For prong 1, PLWHIV have a role to play under positive prevention and IEC in general. For prong 2, there is a need to integrate PLWHIV as key actors; the past successes of MIPA/GIPA initiatives can be harnessed under prong 2. For prong 3, PLWHIV communities and networks are vital for the success of the PMTCT cascade; they can support entry into the health systems, work as lay counsellors, and act as mother mentors or network agents, support retention throughout the 18 months after child birth, support counselling and sustain the needed link back to Prong 2 - the prevention of unwanted pregnancies. Under prong 4, PLWHIV are a crucial link for HIV positive mothers to the care and psychosocial support groups, hence contributing to stigma reduction (Barigye H (b), 2012). For improved EMTCT initiatives, the MIPA-GIPA principle is key.

Successful strategies to address family planning among young women and men include:

- reproductive health education in the schools;
- programmes for out-of school youths and early married girls;
- social marketing of condoms, using mass and entertainment media to disseminate messages;
- telephone hotlines to provide anonymous counselling;
- peer educators in the community or workplace;
- Care at multipurpose youth centres;
- promoting abstinence alone ignores reality and the FP needs of married people, but promoting condoms as total protection may encourage high-risk behaviour;
- GIPA/MIPA in voluntary FP programmes - participatory approaches must include the youth, women and men as partners in planning and implementation (Barigye, 2012);
- programmes should also address issues of puberty and relationships, the skills to negotiate sex and condom use, and gender norms that shape boys’ notions of masculinity and limit girls’ control over sex.

3.8. Male involvement and family centred EMTCT programmes

The importance of involving men in EMTCT

A large number of studies have highlighted the difficulties that women have in getting their male husband/partner to attend ANC and to be tested for HIV both of which are linked to positive outcomes for women and children in PMTCT. In addition, many articles explore the difficulties that HIV+ women have in accessing on-going care if they have not disclosed their status with their partner and received psycho social support. A number of studies are able to show an association
between male attendance at PMTCT and better mother and child outcomes, possibly due to better adherence/compliance with guidelines.

The lack of male involvement in sexual and reproductive health services (SRH) is a known constraint and should be of no surprise, since comprehensive EMTCT programmes primarily targets women in reproductive age groups (WHO, 2010). A more gender sensitive definition for prong 1, and for most sexual reproductive health services, would be articulated and implemented as targeting girls, women, boys and men of reproductive age, factoring in gender and age. Without incorporation and mainstreaming of gender into HIV/AIDS, SRH and MNCH programmes, policy makers, implementers and the community will continue to grapple with issues around lack of male involvement.

HIV status disclosure is known to relieve women from emotional stress and to enable them to receive psychological and material support from their social environment. Especially in rural settings, disclosure can facilitate issues like obtaining approval from the husband as the main decision maker to seek healthcare. Transportation to the hospital or access to cash for transport costs is often controlled by the male/husband and has been reported as a particular factor preventing women from accessing EMTCT. Across various studies, partner participation is associated with positive outcomes, such as greater use of ARVs and higher acceptance of post-test counselling among pregnant women, as well as with increased spousal communication about HIV and sexual risk. Moreover, when couples receive pre- or post-test counselling together, greater use of alternative feeding methods and greater acceptance of HIV testing have been observed among women. Partner participation is also often utilised as an entry point for the provision of additional PMTCT services to both male and females (Falnes 2011, Aluisio A. 2011).

Common barriers to male involvement include:

- lack of disclosure of HIV status by women;
- the arena for testing, the antenatal clinic, has been defined as a typical female domain where men are out of place (Falnes EF., 2011);
- health workers, men and women, lack knowledge of the role men in sexual reproductive health (SRH); men say they have long thought that PMTCT was for women, but now they realise they have a role - Peer Male, Mahalapye- Botswana (AED, 2009)
- lack of time by health providers to engage men because of the work load;
- cost of transport for two people instead of only the pregnant woman;
- gender issues, the entrenched cultural norms about the role of men in SRH (Barigye H., 2012b);
- programmatic failures in systematically integrating and mainstreaming gender and age.

Similar to other studies, a study in Tanzania found that on the contrary, men are not resistant to their partners being tested (and gave their permission), but rather they are often supportive (there may be a difference between hypothetical and reality if the woman is found to be positive). However, very few men participate in ANC and testing and many remain unaware of their own status. Whilst they think HCT is acceptable as part of ANC, many men disapprove of their wife going
for HCT, based on trust issues, although this is often seen as a better option for the man. It is generally not socially considered acceptable or effective for the woman to ask her partner to be tested and commonly reported that someone else should ask. The mother-in-law or sister-in-law is another key family member for EMTCT, more so in rural settings and can be considered for family centred care, with caution and in consultation with the pregnant woman; as in some cases in laws can contribute to worsening gender inequalities. On the other hand, ANC tends to be seen as a female arena and men want to be seen by as few people as possible. One study found that routine testing for HIV of women at the antenatal clinic was highly acceptable and appreciated by men, while other programme components, notably partner testing, condom use, infant feeding and survival recommendations were met with continued resistance (Falnes EF. 2011, Aluisio A. 2011).

**Botswana case study: Emerging trends in PMTCT male involvement**

(1) **Adapting Communication Approaches:** To counter some of the resistance to greater male involvement in PMTCT, Botswana Christian AIDS Intervention Programme (BOCAIP) has adapted communication approaches to allow time to develop rapport and trust among men, to occur in settings which are conducive to serious conversations, to more precisely target partners of PMTCT clients, and to better suit the lifestyles and interests of Botswana men. A peer in Ramotswa has found that “sometimes they (men) are already engaged in other topics of interest to them. In such a case it’s always better to wait for that conversation to die down before starting to discuss PMTCT”. Another peer male also in Ramotswa discovered that “the best time to talk to them is at their homes when they are relaxed and not busy”. In Bobonong district, peer mothers and peer males have developed a system to more precisely target male partners of PMTCT clients. At the Borotsi Clinic, the peer mother obtains the home and workplace addresses for partners to PMTCT clients, and passes this onto the peer male with consent of the client. These locations are then targeted by the peer male for outreach, so that partners to PMTCT clients can be reached in group settings, and without the appearance of being deliberately targeted. Integrating outreach and HCT into male-centred community events such as football matches is also proving successful. Anecdotal information from Tebelopele, Botswana’s largest non-government provider of HCT services, suggests that such events are boosting the proportion of men receiving HCT, as well as couples.

(2) **Engaging Men in Communities and Facilities:** In January 2010, the nearly 1,200 contacts between peer males and other men were evenly divided between community and clinical settings. While 62% of men reached were not at that time linked to a PMTCT client, it was considered that for the future they might have a partner in the PMTCT programme. It is encouraging to note that 17% of peer males’ interactions were with partners of PMTCT clients and that 10% were with male relatives.

(3) **Successful Integration with Government Structures and Services:** In order for this programme to be sustainable, peer males must provide valuable complement to the work of existing government cadres that support PMTCT services. Peer males work closely with lay counsellors at the clinics, a cadre of government staff placed in each PMTCT site to provide HIV testing, counselling and follow-up support. Lay counsellors in Maun reported that the active referral of clients by the peer males to the lay counsellors has improved their work. Among topics covered, safer sex proved the most
popular topic over this period, followed by HIV testing and adherence. The activities of the peer males have been bolstered by the distribution of promotional materials for the health facilities, including t-shirts with the slogan developed by the MoH: “I am a real man, I love my child”; The nurse in charge of the SRH department at Tsabong hospital, praised the peers for frequently giving health talks at the clinics and for actively seeking clients. Clinic staff are now including the peer males in the clinic schedule for health talks. The nurse in charge of Omaweneno Health Post commended the peers for maintaining client confidentiality. The Tsabong district PHC Manager praised the close communication provided by the programme, including feedback from observations at the sites. The Men’s Sector Committee, a national and district structure convened by the National AIDS Coordinating Agency (NACA) and aimed at improving male involvement in HIV/AIDS prevention activities, has been an important government initiative. Across the country the peer males are being enrolled in these district level Men’s Sector Committees in order to leverage resources and to maximise the impact of the programme. This relationship is already bearing fruit. The Shoshong soccer tournament held in January this year by the Mahalapye Men’s Sector Committee in collaboration with BOCAIP served as a platform to integrate messages on male participation in PMTCT.

(4) The Results of Having Men as Champions of Change: Within a very short time, participation of males in PMTCT issues has increased across four indicators monitored from November 2009 to January 2010: knowledge of one’s HIV status, tested together with a partner, disclosed to a partner, and accompanied a partner to PMTCT at least once. In January 2010, 99 men reported accompanying a partner to PMTCT services, up from just 15 two months earlier. Even more encouraging is the significant increase in men who reported participating in couple’s HIV testing, which presents an early opportunity for men to become further involved in caring for themselves, their partners and their children.

Improvement on pregnant women’s freedom to choose ANC could be offered through male involvement which is enhanced through family centred approaches. A systematic review of literature on family centred approaches call for a paradigm shift in PMTCT programming, which considers the needs of entire families, rather than placing a singular focus on preventing MTCT during pregnancy and delivery (Betancourt, 2010). HIV is a family illness, and PMTCT represents an entry point for improving overall family health and functioning. While family-centred models are relatively uncommon in the literature, those models that do exist show promising results. A family-centred approach to HIV prevention and care is essential, compelling and far overdue, while also underscoring the continuing paucity of programmes and policies that actually work towards the realisation of this ideal (Betancourt, 2010).

In Uganda, for example, Mermin et al. (2005) evaluated several interventions that could be used to form a “preventive care package” (Betancourt, 2010). Extension of VCT to 6,000 family members of HIV-positive individuals was coupled with provision of Cotrimoxazole for those found to be HIV positive, as well as the distribution of more basic health interventions like home-based water purification systems. This study presents strong evidence of the benefits of addressing the health
status of all family members. Although the intervention was not specific to PMTCT, such approaches are readily applicable to family-centred PMTCT and speak to the potential for family-based interventions to have strong uptake and a “cascade” of positive effects within the family system (Betancourt, 2010).

**Family centred EMTCT approaches**

In paediatrics, family-centred care is based on the understanding that the family is the child’s primary source of strength and support. Core principles of family-centred care include:

- respect for each child and his or her family;
- recognising and building on family strengths; and
- providing and/or ensuring formal and informal support (e.g. family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood (Committee on Hospital Care, 2003).

Family centred care is the entry point to reach other family members, untested children and linking families in EMTCT with on-going care and support, treatment social protection. The benefits of family centred care are in line with the WHO PMTCT Strategic Vision (WHO, 2010) which asserts that “priority will be given to strengthening linkages between PMTCT and HIV care and treatment services for women, their children and other family members in order to support an effective continuum of care”. Family centred care has the potential to facilitate the prevention of primary infection (prong 1), to prevent unwanted pregnancies (prong 2), to ameliorate and protect the health status of the mother and child (prong 3), and to enrich the capacity and functioning of an HIV affected household (Prong 4). Empowering men to participate by creating a space within a PMTCT programme that is male friendly should be feasible and should be highly prioritised for a PMTCT programme to achieve its potential (Falnes EF., 2011). The mainstreaming and integration of gender should commence under prong 1, expand to prong 2, and then prong 3 and 4.

A package on gender sensitive family centred comprehensive EMTCT service delivery approaches can be designed and incorporated in all communication, training and monitoring tools. National and district budgets can be put aside for the mainstreaming of gender, family centred care and for activities that specifically attract men as partners in an integrated health, HIV/AIDS and development programme. MoH, UAC, district health and HIV/AIDS teams can expand partnerships and work closely with the Ministry of Gender, implementing partners, CSOs and gender experts. These measures can enable a policy transition to mainstream and integrate gender and family considerations in policy and in practice.

**Key observations on communities:**

- community engagement is relevant and needed for the scale-up of comprehensive four-prong EMTCT programmes;
- engaged leadership at all levels – facility, community, district and national – is an important key to the success of community engagement;
meaningful community engagement requires a capacity-building approach and sustained investment of financial and technical support;
- effective community engagement requires a rights-based approach that empowers individuals and communities to take greater control of their health and health care;
- meaningful involvement of networks and communities of people living with HIV will enhance; PMTCT scale-up;
- local pre-intervention participative research is an essential first step in the capacity-building process and helps to ensure the relevance and sustainability of programmes;
- building on existing community structures – rather than working in parallel to them – improves programme efficiency, effectiveness and sustainability;
- monitoring, innovation and information sharing will be critical to the scale-up of promising practices in community engagement, including for the introduction of mobile and other technologies to improve programme management and implementation.

3.9. The need for accessible EMTCT services

Access to routine ANC remains a challenge, with only 32% of pregnant women in developing countries receive four or more antenatal care visits, the minimum number of visits recommended by UNICEF (WHO, 2010). A qualitative study in South Africa (Sprague, 2011) defines individual factors undermining access which encompass psychosocial concerns, such as fear of a positive test result or a partner’s reaction, and stigma (Sprague, 2011), (Tshabalala MT, 2012). Access is affected by: transport and cost; language barriers; knowledge; stigma; mental health or depression. Proximity to a health centre is also a major determinant of access and difficult for those in the rural areas where only 26% of the population lives within 5km of the nearest centre. Inadequacy of PMTCT services at health centre II compromises the scale up of PMTCT services, and this worsens in places like Kasese district in Uganda, with a hilly mountainous difficult terrain where pregnant women face a challenge of moving to distant health facilities for PMTCT services (Barigye H (a), 2012). A study conducted in South Africa’s east Ekurhuleni (Tshabalala MT, 2012) reveals additional barriers such as long waiting hours at a health facility, and the perceived nurses’ attitude. Other reasons provided include fear of disclosure of pregnancy, and limited resources. In Zambia and other LMICs where there is systematic support for outreach of ANC/EMTCT services to the community (where distance to the facility was a problem) have showed improved coverage of services.

Linked to access is the obstacle of pregnant women reporting late to the ANC unit; if they are HIV positive, they enter the EMTCT cascade at a later stage. Whilst the data suggest that late presentation for ANC is a common problem in Africa, there appears to be little research and knowledge about in this area. A multivariate analysis from a study aimed at identifying factors associated with access to HIV care and treatment in PMTCT in Zimbabwe (Muchedzi A., 2010) revealed that participants who understood the referral process were 3 times more likely to access HIV care and treatment and participants enrolled in an HIV support group were twice as likely to access care and treatment. Those living with a male partner were 60% less likely to access care and treatment. Much as this study concluded that majority of the study participants had accessed care amidst the many challenges, it also highlights health systems barriers that hinder some of the
mothers from accessing care and treatment services. These include the perception of a tedious registration process and/or long queues, competing life priorities (e.g. seeking food or shelter, caring for other children in the home and caring for sick relatives) and inadequate referral information.

### 3.10. The EMTCT ARV/ART care and treatment cascade

**Option A, B or B+: Choice of ARV/ART for mother and baby**

Some previous sections have highlighted challenges related to initiating HIV-positive pregnant women on ARV/ART treatment. Key issues linked to the use of ARV for the mother and baby which have already been discussed include accessibility of services and the lack of HRH numbers, motivation and training. Other important issues are the choice of ARVs at implementation level, Option A or Option B, and adherence to the regime. There is the risk of missed opportunities for inclusion in EMTCT services when women get infected with HIV and sero-convert from negative to positive status over the course of the pregnancy. Other challenges are facility/logistical in nature, ranging from CD4 and viral load testing, appropriate training, policy mandate, ARV treatment drugs, and/or the staff capacity to prescribe ART (EGPAF, 2010). This section presents lessons and options that can address these obstacles.

As elaborated on in Part 2, in Uganda the prong 3 bio-medical PMTCT interventions commenced with clinical trials on the administration of a single dose of the non-nucleoside reverse transcriptase inhibitor (NNRTI) nevirapine (NVP) to both mother and new-born, which demonstrated in 2000 that the transmission risk could be reduced by over 40%. Single-dosed NVP (sdNVP) was cheap and easy to administer, and affordable in LMICs. However, later research demonstrated that transmission reduction was considerably more effective when combining sdNVP with two nucleoside reverse transcriptase inhibitors (NRTIs), such as zidovudine (AZT) and lamivudine (3TC). At the same time, sdNVP was noted to be prone to resistance formation and could impede subsequent treatment involving NVP or other NNRTIs. Also, combining NVP with NRTIs showed evidence to reduce the emergence of NNRTI-resistant mutations. Therefore, since 2006, WHO has recommended a triple combination bio-medical prophylaxis regimen consisting of two NRTIs (antenatal AZT, intra/postpartum AZT+3TC) and one NNRTI (Intrapartum sdNVP) as the standard PMTCT regimen wherever this is feasible (Barigye, 2012) (Kirsten I, 2011). All this research and action lead to the 2010 WHO guidelines, that recommend Option A or Option B or B plus.

The complexity of administration of ARV/ART Regimens under Option A has influenced National policy in many countries, including Benin, South Africa, Malawi and now Uganda and the adoption of Option B+. A review of literature on programmatic lessons from Malawi indicates that Option A has too many restrictive conditions; for example, Option A requires CD4 testing at all ANC sites or the referral for clinical staging, yet implementing experience is that CD4 machines break down and where there are no machines there is a need for speedy sample transportation, which is not always possible, leading to poor quality control results. Option A also necessitates modification of breast feeding habits, and has complicated regimen protocols and extended use of infant syrup (MOH
Malawi, July 2012), (Putu D, 2010). Referral for CD4 counts is another barrier that worsens access, utilisation, coverage and retention rates associated with Option A.

When compared to Option B, Option B+ offers lifelong ART (Esiru 2012, WHO 2010). Option B+ lowers lifetime transmission rate, leads to less risk of resistance and provides continuity of treatment throughout childbearing years. Further still, Option B+ makes breastfeeding safe, which is important for LMICs, where very few mothers have any other feeding option. Also, curtailing breastfeeding is highly stigmatised and has led to more malnourished babies (MoH Malawi, July 2012). Additionally, Option B+ helps keep mothers alive (Hargrove JW., 2010); and the results of the HPTN052 trial demonstrate that if an HIV-positive person adheres to an effective ART regimen, the risk of transmitting the virus to their uninfected sexual partner can be reduced by 96% (Cohen MS. 2011, Sidibe 2011).

The benefits of the game changing strategy to EMTCT Option B+:

- provides a HIV test as the only condition for diagnosis and thus can be easily done at the smallest health centre; it offers ease of use (Esiru 2012, MoH Malawi 2012);
- has a simple standard regimen; one size fits all; and opportunity for the simplification of the supply chain;
- offers a clear public health message: ART is for life (MoH Malawi, July 2012);
- offers the consequential integration of PMTCT and ART, an opportunity for more efficiency through the “4-ones”: one- guideline, one- training, one-supervision system, one-supply chain;
- offers cumulative benefits from a growing proportion of HIV+ women already on ART when getting pregnant;
- enhances ART decentralisation; “ART at (almost) everybody’s doorstep”; reducing the wave of ART patient transfers and easing issues around weak staffing and infrastructure at remote health centres (Esiru, 2012).

Though Option B+ is simpler, but not necessarily an easy fix, the cumulative costs of medicines under this option are more than 3 times as high as either Option A or Option B by year 4 (Esiru, 2012). In Malawi, the role out of Option B+ has necessitated an additional USD 30 million for ARVs, retraining close to 5,000 health workers (MoH Malawi, 2012). Also, the universal test and treat approach presents a risk of starting false positives on ART for life (MoH Malawi, 2012). WHO has identified unknowns around Option B+ that will require further research and implementation experience - these include acceptability, adherence, retention, drug resistance, safety (during pregnancy and long-term exposure during BF) and impact on prevention (Shaffer, 2011).

Adherence to the ARV/ART care and treatment regimens

There is a considerable amount of research in this area. A Tanzanian observational study (Kirsten I., 2011) of a cohort of 122 pregnant women willing to start combination prophylaxis in Kyela District Hospital identified risk factors for decline of pre-delivery prophylaxis. These included maternal age
below 24 years, no income-generating activity and enrolment before 24.5 gestational weeks, with odds ratios of 5.8 (P = 0.002), 4.4 (P = 0.015) and 7.8 (P = 0.001) respectively. Similar to many studies elsewhere, women who stated to have disclosed their HIV status were significantly more adherent in the pre-delivery period than women who did not (P = 0.004). During labour, the intra- and after deliver, the postpartum period and rather low drug adherence rates during hospitalisation indicated unsatisfactory staff performance. Only ten mother-child pairs, representing 10% of the cohort, were at least 80% adherent during all intervention phases; only one single mother-child pair (<1%) met a 95% adherence threshold. Evidence emanating from this study implies that achieving adherence to combination prophylaxis is challenging. The findings also underline the need for additional supervision for PMTCT staff as well as for clients, especially by encouraging them to seek psycho-social support through status disclosure. Limited structural conditions of a healthcare setting should be taken into serious account when implementing EMTCT (Kirsten I, 2011). Failure to disclose was identified as a key factor, and reasons behind the failure included the fear of violence, abandonment, divorce or withdrawal of economic support. Most HIV-positive women requested health workers’ support in disclosure (Rujumba J, 2012). Stigma from the community is also a factor that influences an HIV+ women decision to seek and adhere to treatment. Adherence rates may be overstated because they only measure collection rather than ingestion of ARVs. Directly Observed Treatment Strategies (DOTS), as in TB Control programmes, has better advantage in measuring adherence rates, EMTCT programs could borrow lessons from TB or HAART DOTS (H. L. Behforouz, 2004).

Example of factors affecting adherence to care and treatment regimen:

- lower amongst younger women, women with no income;
- failures on the part of health centres; issuing wrong dates; failure to dispense;
- earlier start on ARVs in the gestational period;
- lack of disclosure/couple testing;
- less complex regimes;
- treatment for the mother other than just prevent vertical transmission
- enrolling the whole family into HCT and treatment
- male / family involvement; community support; family commitments (affecting access);
- lack of food, adverse reactions, forgetfulness;
- fear and stigma;
- side-effects / resistance.

Source: Kirsten I, 2011, Rujumba J, 2012

**Postnatal EMTCT follow up of the mother and baby pair-retention**

EMTCT programmes in sub-Saharan Africa have experienced significant loss to follow-up of HIV-positive pregnant women between diagnosis and screening for treatment eligibility, and between screening and initiating treatment. The loss to follow up worsens in the Post Natal Care (PNC) period. Within the health systems, PNC is provided as part of routine maternal and new born child healthcare (MNCH), with the reach across Africa estimated at 24%. There is a reasonable amount of research in this area which is based on the fact that in Sub-Saharan Africa, most births happen
outside a health centre and without a skilled birthing attendant. Lack of facility deliveries is linked to many social economic and systems gaps. One study suggested that facility level births could be improved by performance related finance /pay for HRH, for motivation. Evidence indicates that some countries dispense Nevirapine (NVP) during ANC for self-administration during labour and one study in Lusaka demonstrated that 68% of women given this option do follow instructions. The role and impact of traditional birth attendants (TBAs) is unclear and remains ambiguous across Africa. In Uganda, TBAs are out of the health system.

**Box 6: Graph demonstrating retention trends in a cohort of 1,182 HIV-infected pregnant women identified in 8 months in Rakai District: September 2011 to May 2012.**

![Graph demonstrating retention trends](image)

<table>
<thead>
<tr>
<th>Series1</th>
<th>HIV-infected women</th>
<th>HIV-positive deliveries</th>
<th>HIV-exposed infant took nevirapine</th>
<th>HIV-exposed infants with DNA PCR results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1105</td>
<td>371</td>
<td>385</td>
<td>182</td>
<td></td>
</tr>
</tbody>
</table>

*Source: Barigye H, 2012*

The above box is an example of loss to follow-up in a sample of 1,182 HIV-positive pregnant women identified over 8 months (September 2011 to May 2012). In the postnatal period, only 385 babies (33%) received prophylactic Nevirapine and only half of these received the PCR test for EID in the same period, reflecting failed retention in the system (Barigye, 2012a). Lessons from the Ugandan 6 district consultation process indicates that reasons for loss to follow-up include:

- poor quality of counselling: this leads to low demand for follow up visits by the mother and baby;
- disclosure: women who had not disclosed their HIV-infection status were reported to find it difficult to come back to continue with PMTCT services after giving birth;
- geographical barriers: women living in difficult terrains such as the hilly Kabale or Kasese were challenged to come for post-partum PMTCT interventions;
- stigma – women were unwilling to access services for fear of being stigmatised.

Innovative retention strategies from these six districts include the use of ‘edutainment’ (entertainment and education) to advocate for male involvement in sexual and reproductive health services in Rakai district. Innovative retention strategies include priority treatment given to women
accompanied by a male partner for ANC services, tracing women through use of phone calls, use of “ART aides” (a calibre of community volunteers), peer support clubs for old and new clients of PMTCT services, mother mentors and mama clubs. Women living with HIV receive further counselling, information and other forms of psychosocial support from peer support groups before and after giving birth.

A study in Rakai district in Uganda showed evidence that infant mortality among formula-fed infants born to HIV infected mothers was over 6 times higher compared to mortality of breast-fed infants (Kagaayi J, 2008). These results were in agreement with earlier studies conducted mainly among trial participants in urban settings. However, the excess mortality associated with formula feeding in this rural setting is substantially greater than that reported in the earlier urban studies. This suggests that the risk of mortality with formula-feeding could be much greater in rural populations with limited access to clean water and medical care. Formula-feeding was associated with a higher risk of infant mortality than breastfeeding in this rural population (Kagaayi J, 2008). Counselling is a key factor associated with improved adherence to the infant feeding guidelines, but the quality of counselling is often low. Male involvement in ANC appears to have an important role to play in terms of improving infant health outcomes, (Alusio A., 2011). Tracking of exposed infants is very poor which is attributed to difficulty in identifying exposed infants, lack of awareness amongst staff and lack of follow up procedures for HIV+ mothers. A review of systems and processes can lead to an instant and dramatic improvement in levels of EID. One study in South Africa attributed poor testing to the need to refer exposed infants to another centre and to the fact that staff do not always direct HIV+ mothers appropriately. The potential for involving mothers-in-law in the infant feeding component, where she still has influence in some areas, should be further explored (Falnes, 2011).

**Links between EMTCT and ART programmes**

Uganda has already designed the national guidelines for integrated ART, EMTCT and Infant and Young Child Feeding (MoH, the Republic of Uganda, 2012). For the benefit of implementation and roll out, we present here some lessons from EGPAAF programs. In Mozambique for example, staff from EGPAAF and the Provincial Health Directorate in one province moved from linking PMTCT and ART services to actually offering HIV care and treatment in PMTCT service sites. This emphasises the benefits of integration, in the provision of PMTCT services. In another two districts, ANC services were linked to external HIV services (HIV-positive women were sent to an outside laboratory or HIV clinic for CD4 testing and referred for ART services). It is not; however, very clear whether this innovation actually created more challenges of access. In another district, the ANC clinic actually provided screening, clinical HIV staging and ART on site. As a result, it is reported that this district attained a higher percentage of women screened, but achieving universal initiation of ART remained problematic due to other factors such as the poor quality of counselling, unavailability of qualified human resources, and other sociocultural inhibiting factors. In Rwanda, EGPAAF piloted the provision of “pre-ART” services (semi-annual clinical/CD4 staging, Cotrimoxazole prophylaxis, treatment of opportunistic and sexually transmitted infections, and TB screening) in voluntary counselling and testing/PMTCT sites. It is reported that this resulted in a higher percentage of eligible patients effectively referred for ART. Similarly, in Swaziland (with approximately 42% of pregnant women are HIV-positive and 40% of those women are estimated to be eligible for treatment) only 5% of
treatment-eligible women initially began ART prior to implementation of measures to increase ART uptake. After EGPAF introduced ART services into the maternal and child health (MCH) clinic of the busiest primary care centre in the country, the percentage of eligible women initiating ART rose to 28% (up from 5%) after only 10 months. This is another clear demonstration of the benefits of service integration (EGPAF, 2010).

Although rare in comparison to mother-to-child transmission of HIV, children have also been infected through other modes of transmission, including transfusion, medical injections, other blood contact, and sexual abuse. Health systems should remain vigilant to these possible causes and continue efforts to strengthen health care safety and prevent sexual abuse (ANECCA, 2011), (Simonds RJ., 2012). Another gap for Uganda and LMIC is that there was scanty literature on the practice of repeat HIV test for pregnant mothers who tested negative in early trimesters. The risk in this is the blindness to HIV infection that could occur during the course of pregnancy or blindness to sero-conversion; which leads to failure to include the newly infected pregnant mothers within the EMTCT cascade, exposing their babies to the risk of vertical transmission.
Part 4: Conclusion- Implications for Uganda

4.1. Policy and national level implications

In the early 2000s, Uganda was ahead of most LMICs with many EMTCT success stories and model programmes. However, in recent years, a number of EMTCT performance indicators for Uganda have lagged behind other LMICs. For example, Zambia tests 95% of expectant women for HIV (compared to 64% in Uganda) and Namibia has near universal access to ARVs for pregnant mothers (compared to an estimated 53% in Uganda).

In line with global commitments for EMTCT, it is plausible but by no means certain that the Uganda MOH will achieve the global EMTCT targets by end of 2015. By setting strong policy direction and having the First Lady as the national champion, Uganda is thinking and investing differently for EMTCT. Moreover, since the piloting of PMTCT in Uganda in 2000, there has been tremendous scale up so that there is close to 60% EMTCT population coverage today. The challenge now is in sustaining the achievements made and extending success to at least 90% coverage and retention of mothers, in order to achieve and sustain the 2015 EMTCT targets. Policy, programming focus and investments need to support the implementation of effective strategies to reach to the hard to reach MARPs and underserved populations in particular. But before this can be done, more work is needed to understand better who the MARPs and underserved populations are and where they live.

The recent decision to move to Option B+ is a key game changer that has the potential to deliver great results if financial resources are found and used well and human resources are available and effectively used. However, for the optimal national response, there are a number obstacles and limitations which need to be addressed at the individual, family, community, facility, district and national policy level.

At policy level, key actors including top political leadership at MOH, UAC, MOLG, Ministry of Gender and MOFPED need clarity and common agreement on the importance and urgency of EMTCT and its role in national development. Messages about EMTCT should therefore be effectively packaged to various decision making audiences to facilitate their awareness, understanding and prioritisation of this issue. Moreover, the implementation of health and HIV/AIDS policies needs to be enhanced through clear mechanisms for coordination, mutual accountability and feedback between central and local levels of the health system. There is a need to give greater autonomy to districts that are performing well, and to consider payment by results to create greater incentives to move towards the virtual EMTCT.

To attain EMTCT, there is the need to create a high-level national task force in line with the Global Plan on EMTCT to provide leadership and coordination for EMTCT. Therefore in line with a major recommendation of the Elizabeth Glaser Paediatric AIDS Foundation (EGPAF), the multi-sectoral coordination role of the UAC needs to be reviewed and strengthened, and a clear mode of operation
should be developed with close involvement of MOH and other key stakeholders. Further still, synergies and collaboration between UAC-MOH-MoLG need to be leveraged. For EMTCT, there is a need to institute clear technical matrix management and accountability arrangements between District Health Officers, who are managed through the Ministry of Local Government, and the technical teams at MOH head office, with overall UAC coordination.

MOH needs support for the most impactful EMTCT policies and programmes with lobbying for any increases to resources might be needed, for example considering that Option B+ is more expensive. There is a need to support stronger MOH and district level supervision, monitoring, evaluation and knowledge management approaches. The District Health Teams need to reflect and understand more on implementation implications of the decision to move to Option B+ and to take necessary remedial actions in partnership with service providers and with the communities. Steps are also needed to attract and retain more health workers.

Ideas for health systems strengthening have been analysed and need now to be prioritised, starting with ensuring broad leadership buy-in for EMTCT at national and at district levels. Strategies to strengthen HRH motivation and performance are required, especially for the midwives who form a major systems interface with the community. Strengthening of robust ethical and regulatory standards for staff is needed, together with technical assistance and mentorship to strengthen in-service capacity. More effective performance management is needed, linking incentives to the more effective performance of individuals and health facilities. Policy changes facilitating task shifting and in service training should be implemented. There is a vast array of EMTCT data which facilities aim to collect, but all too rarely is this provided in a timely, accurate and complete basis to the centre, and this needs to change. The data also need to go back in well analyses ways to those who collect it as part of a stronger performance management system.

The attainment of EMTCT targets will require better logistics and supplies management, involving greater participation, feedback and autonomy over resources at lower levels. For any supply chain system to work efficiently, a strong link must exist between forecasting, quantification, procurement, warehousing, inventory management, and the logistics management information system. The Uganda logistics and supplies system should be as lean as possible with process improvements to make it more efficient and with maximum coordination of the various actors.

There needs to be sustained building of stronger relationships between governments and implementing partners. And the need for integrated service delivery models cannot be under emphasised. Now is the time for much more integrated service delivery for health and HIV/AIDS in general and for HIV testing, care and treatment and EMTCT in particular. Under AIDS care, ART must be integrated with EMTCT, and vice versa. Donors, MOH and the districts need to invest in the implementation of the national guidelines for integrated SRH, ART, EMTCT, infant and young child feeding.
It is also important to note that in order to mainstream gender equality into the EMTCT response, there needs to be far greater involvement of men in the EMTCT process and further development of family centred approaches to tackling prevention of HIV transmission, building on the successes of other countries.

Finally, there are major policy implications about improving access to EMTCT ranging from availability of family planning, HIV testing, ARV supplies, safe childbirth and post natal care.

4.2. Facility and community level implications

This working paper has presented evidence of the importance of gender sensitive community engagement for the attainment of EMTCT. Successful community engagement will involve capacity building of community level members to engage with EMTCT, social mobilisation and social marketing of services on the one hand and empowering community leaders on the other. Addressing barriers at the community level, holding providers accountable for service delivery and strengthening community engagement will push EMTCT results further.

Without community participation, the Global Plan will struggle to reach its targets to reduce by 90% the number of new HIV infections among children and reduce by half the number of AIDS related maternal deaths by 2015. This is due to the importance of community support for sustained behavioural change.

Champions and leadership begins at the individual and family/home level and expands into communities. EMTCT takes a powerful meaning when it is owned by a community. It can then be more effectively integrated with other development targets and used to address obstacles such as access to services, male / family Involvement, men as champions for change, primary prevention, family planning and adherence to treatment regimens. Communities need to knowledgeable about HIV transmission and be aware of high quality EMTCT services in order to demand them. Moreover, communities will be the source of the best ideas for dealing with such challenges as stigma, discrimination, empowerment of women and involvement of male partners in ANC. In addition, critical services such as psychosocial support and HIV testing must be available in communities.

This working paper supports the urgency and importance of designing a national and district level EMTCT campaign that reaches the MARPs and underserved communities. On top of meaningful engagement of PLWHIV and community ownership, innovative approaches like “AIDS workplace
programmes” to reach to the informal sector can be very relevant. Moreover, communications materials must be tailored for local settings, and preferably designed locally, at district level, with the active involvement of community resource persons. Campaigns and social mobilisation strategies can be very effective ways of raising awareness and enrolling more women into ANC and ART.

The mainstreaming and integration of gender dimensions of EMTCT needs to commence under prong 1, expand to prong 2, and then to prongs 3 and 4. A package on mainstreaming gender in the comprehensive EMTCT package should be designed and reflected in all communication, training and monitoring tools. This needs to set out mechanisms for empowering mothers with support from fathers and other members of the community.

National and district budgets need to reflect gender mainstreaming, for example with components that specifically attract men as partners in integrated health, HIV/AIDS and development programmes. MOH, UAC, District Health and HIV/AIDS teams need to expand partnerships and to work closely with the Ministry of Gender, implementing partners, CSOs and experts so that this policy transition takes place and gender considerations are integrated into policy and practice.

Community engagement should embrace the meaningful involvement of PLWHIV, both males and females and explore the scope for increasing voluntary utilisation of family planning services. EMTCT programmes need to cascade access and retention rates among the MARPs, underserved and most disempowered women, as well as to reduce stigma and discrimination of HIV positive individuals. Evidence from elsewhere suggests that community outreach to integrate voluntary family planning services into AIDS care programs, or into psycho-social interventions for PLWHIV, can have significant benefits. Donors, policy makers and planners need to support the expansion of integrated programmes.

HIV/AIDS have major family level implications and evidence suggests that service providers need to leverage family centred care to facilitate the prevention of primary infection (prong 1), the prevention of unwanted pregnancies (Prong 2), the amelioration and protection of the health status of the mother and child (Prong 3), and the enrichment of capacity and functioning of an HIV affected household (Prong 4). Additionally, for communities to “access ART at the door step”, the Universal Test and Treat Address, there is the need to address barriers to access, strengthening HC IIs, HRH, logistics and infrastructure, as well as implementing innovative outreach services to deliver Option B+ and to cater for a social-economically diverse community.

Finally, the roll out of Option B+ needs to be delivered whilst applying innovative retention strategies. There is a major challenge in that many women are not retained long enough in the EMTCT system, or do not join early enough. Further exploration and roll-out is required for effective male involvement in sexual and reproductive health services, better communication strategies including the use of mobile phones, enhanced use of “ART aides-DOTS” and other community volunteers, further development of peer support clubs for old and new clients of PMTCT services,
greater use of mother mentors, and more psychosocial support to women living with HIV from peers before and after giving birth.

EMTCT necessitates the recognition and motivation of the multi-tasking midwife, who is the backbone to quality counselling, promotes HIV testing, administers ARV therapy/prophylaxis, carries out measures to enable early infant HIV diagnosis, and oversees / links the health centre with the logistics system, averting stock-outs of supplies and ensuring transportation of specimens. Thus, the midwife is the backbone for EMTCT service delivery. Good quality midwifery services strengthen the utilisation of ANC in general and EMTCT in particular, retaining more mother-baby pairs in the health system. Beyond EMTCT, the midwifery role is a key contributor to MDG targets. As 2015 draws near, motivated midwives will continue to play a key role in “Safe Motherhood” and the reduction of maternal mortality rates. Additionally, motivated midwives will contribute to new-born survival, and help reduce new-born and infant mortality rates, as well as contributes to EMTCT. Uganda must invest in innovative strategies and address the shortage of midwives urgently.

National and district leaders now more than ever need to recognise the role of midwives and to support this key role accordingly. A combination of financial and non-financial incentives are required to motivate midwives, ranging from infrastructural development (like solar panels and water supply for midwife houses or health centres), to better data management systems, staff shifting and more staffing, better pay and benefits etc.

4.3. Areas needing further research and learning
This working paper has identified various areas of knowledge which could usefully be explored further, including:

- development of models for reaching the MARPS and underserved mothers for EMTCT;
- understanding of what works and what does not work for GIPA/MIPA integration in family planning, SRH and EMTCT services;
- operational research to increase the efficiency and effectiveness of the roll-out of Option B+, with particular focus on acceptability, adherence, retention, drug resistance, safety (during pregnancy and long-term exposure during breast feeding) and impact on prevention;
- an analysis of the impact and cost-effectiveness of the Option B+ package as part of integrated ART, EMTCT, MNCH, SRH and IYFC programmes;
- studies on systems strengthening, focussing on expanding / making better use of the health workforce;
- performance related financing systems / payments for EMTCT results;
- ways of improving the take up of PNC.

4.4. Data and knowledge management
The need for continued improvement in data collection, analysis and reporting systems cannot be over emphasised. During this information age, starting from the lowest level of data collection, innovative simplified data collection and transmission tools should be explored to ease the process
and to reduce the burden on the limited HRH. At district and national level, support would be valuable to improve the relevance, accuracy and timeliness of data provision and use.

Moreover, as EMTCT services scale up, measurement issues will change from a focus on counting the number of services delivered and other inputs to a focus on assessing population-based service-delivery coverage, and on measuring the impact of programmes on reducing HIV infection and increasing HIV-free survival. To support this, approaches such as HIV case surveillance and mortality registries will increase in importance, as will monitoring retention in care and ARV adherence. It will also be important to use surveillance to assess any potential negative effects of programmes, such as adverse pregnancy outcomes, drug reactions or ARV resistance.

4.5. Potential future support to EMTCT from the KMCC Initiative

This working paper envisages that in the coming years to 2015 and beyond, EMTCT will be an area for continued innovation, learning, generation and communication of knowledge. Therefore, Uganda HIV/AIDS stakeholders and other LMICs will need to invest in strengthening capacities for M&E, data analysis and interpretation, and knowledge management and communication.

The KMCC Initiative has been set up to respond to demands from Ugandan stakeholders to support knowledge management and communication capacity for a more effective HIV/AIDS response. We hope that this working paper will help to identify some of these capacity building needs.
Annex 1: References

- Committee on Hospital Care (2003). Family Centred Care and the paediatrician’s role. In *C. o. Care, Paediatrics*. 691-696.
Falnes et al. (2011). The potential role of mother-in-law in PMTCT a mixed method study from the Kilimanjaro region, Northern Tanzania. BMC Public Health 2011. 11:551


MoH, Malawi (2012). *The Rationale for Option B+ in Malawi*. IATT Webinar Presentation (pp. 7-16). Lilongwe: Department of HIV/AIDS; MoH Malawi.


Rujumba, JNS. (2012). “Telling my husband I have HIV is too heavy to come out of my mouth”: *Pregnant women’s disclosure experiences and support needs following antenatal HIV testing in eastern Uganda*. Uganda.


Torpey, K. et al. (2010). *Increasing the uptake of prevention of mother-to-child transmission of HIV services in a resource limited setting*. BioMed Central Ltd.


UNFPA (nd) Family Planning and Young People, their choices create the future. Fact Sheet. UNFPA.


## Annex 2: Contributors to this working paper

### List of persons and institutions consulted at district and national level

<table>
<thead>
<tr>
<th>Name</th>
<th>Designation</th>
<th>District/Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Godfrey Esiru</td>
<td>National PMTCT Coordinator</td>
<td>Ministry of Health AIDS Control Programme</td>
</tr>
<tr>
<td>Dr Olive Sentumbwe</td>
<td>Family Health Country Advisor</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>Dr Lydia Mungherera</td>
<td>Executive Director and person living with HIV</td>
<td>Mama’s Club</td>
</tr>
<tr>
<td>Dr Barbara Namata Mbogga-Mukasa</td>
<td>Executive Director</td>
<td>Mildmay Centre Uganda</td>
</tr>
<tr>
<td>Dr Ivy Kasirye Kaddu</td>
<td>Head of Paediatric Clinic</td>
<td>Mildmay Centre Uganda</td>
</tr>
<tr>
<td>Ms Samalie Nabaasa Mafirigi</td>
<td>Programme Manager</td>
<td>Mildmay Centre Uganda</td>
</tr>
<tr>
<td>Ms Stella Kentutsi</td>
<td>Executive Director</td>
<td>National Forum for People Living with HIV/AIDS Network in Uganda (NAFOPHANU)</td>
</tr>
<tr>
<td>Ms Cissy Namuzimbi</td>
<td>Programme Manager</td>
<td>NAFOPHANU</td>
</tr>
<tr>
<td>Ms Margaret Happy</td>
<td>Advocacy Manager</td>
<td>NAFOPHANU</td>
</tr>
<tr>
<td>Ms Betty Iyamuremye</td>
<td>Communications Manager</td>
<td>NAFOPHANU</td>
</tr>
<tr>
<td>Dr David Serukka</td>
<td>Executive Director</td>
<td>Protecting Families Against HIV/AIDS (PREFA)</td>
</tr>
<tr>
<td>Dr Engwaau Francis</td>
<td>Programme Manager</td>
<td>PREFA</td>
</tr>
<tr>
<td>Ms Loyce K. Arinaitwe</td>
<td>Programme Manager</td>
<td>PREFA</td>
</tr>
<tr>
<td>Mr. Alexander Mugume</td>
<td>Deputy Chief of Party-Technical</td>
<td>STAR EC</td>
</tr>
<tr>
<td>Dr Francis Herbert Kazibwe-</td>
<td>HIV/AIDS Specialist, PMTCT-EID, HCT</td>
<td>STAR EC</td>
</tr>
<tr>
<td>Ms. Jennifer Gaberu</td>
<td>Team Leader</td>
<td>ViiV Project- International HIV/AIDS Alliance in Uganda</td>
</tr>
<tr>
<td>Dr Albert Twinomugisha</td>
<td>Senior Medical Officer</td>
<td>Reach Out Mbuya</td>
</tr>
<tr>
<td>Dr Cyprian Twinomujuni</td>
<td>Regional Coordinator, Southern</td>
<td>PREFA</td>
</tr>
<tr>
<td></td>
<td>Name</td>
<td>Position/Role</td>
</tr>
<tr>
<td>---</td>
<td>-------------------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>19.</td>
<td>Dr Patrick Anguzu</td>
<td>District Health Officer (DHO)</td>
</tr>
<tr>
<td>20.</td>
<td>Sr Aciiro Munduga Joyce</td>
<td>Assistant DHO Maternal and Child Health/PMTCT Focal Person</td>
</tr>
<tr>
<td>21.</td>
<td>Dr Ronald Khamasi</td>
<td>Regional Coordinator, West Nile Region</td>
</tr>
<tr>
<td>22.</td>
<td>Sr. Agupinia Joyce</td>
<td>Registered Midwife and In-Charge</td>
</tr>
<tr>
<td>23.</td>
<td>Ms. Balera Sabrina</td>
<td>Enrolled Midwife</td>
</tr>
<tr>
<td>24.</td>
<td>Mr. Geria Alex</td>
<td>Information Assistant</td>
</tr>
<tr>
<td>25.</td>
<td>Mr. Jack Kokole</td>
<td>Chairperson</td>
</tr>
<tr>
<td>26.</td>
<td>Ms. Canoroma Jane</td>
<td>PMTCT Mothers Representative</td>
</tr>
<tr>
<td>27.</td>
<td>Mr. Rokoni Ronald</td>
<td>Executive member</td>
</tr>
<tr>
<td>28.</td>
<td>Mr. Adibo John</td>
<td>Chairperson</td>
</tr>
<tr>
<td>29.</td>
<td>Ms. Ocokoru Alice</td>
<td>PMTCT mother</td>
</tr>
<tr>
<td>30.</td>
<td>Dr Odu Bernard</td>
<td>Hospital Director</td>
</tr>
<tr>
<td>31.</td>
<td>Sr. Mary Ocokoru</td>
<td>Ag In Charge of PMTCT Services</td>
</tr>
<tr>
<td>32.</td>
<td>Sr. Ngamita Jane Opio</td>
<td>Registered Midwife</td>
</tr>
<tr>
<td>33.</td>
<td>Ms. Geesje den Breejen</td>
<td>Manager</td>
</tr>
<tr>
<td>34.</td>
<td>Dr Paul Onek</td>
<td>DHO</td>
</tr>
<tr>
<td>35.</td>
<td>Sr. Okijangole Jenny Rose</td>
<td>Assistant DHO Maternal and Child Health/ Nursing</td>
</tr>
<tr>
<td>36.</td>
<td>Mr Yoweri Idiba</td>
<td>District Biostatistician</td>
</tr>
<tr>
<td>37.</td>
<td>Dr Esther Achan</td>
<td>Head of the Infectious Diseases Clinic/ Clinical Care Coordinator</td>
</tr>
<tr>
<td>38.</td>
<td>Mr John Opwonya</td>
<td>HIV/AIDS Focal Person</td>
</tr>
<tr>
<td>39.</td>
<td>Mr. Benson Orach</td>
<td>Manager Community Partnerships</td>
</tr>
<tr>
<td>40.</td>
<td>Ms. Akello Sophie</td>
<td>Enrolled Nurse and In-charge</td>
</tr>
<tr>
<td>41.</td>
<td>Ms. Pamela Abony</td>
<td>Chairperson</td>
</tr>
<tr>
<td>42.</td>
<td>Dr Isiko Paul</td>
<td>DHO</td>
</tr>
<tr>
<td>43.</td>
<td>Sr Kawala Betty</td>
<td>District PMTCT Focal Person</td>
</tr>
<tr>
<td>44.</td>
<td>Mr Kato Clement</td>
<td>District Biostatistician</td>
</tr>
<tr>
<td>45.</td>
<td>Mr Daniel Bazibu</td>
<td>HMIS Focal Person</td>
</tr>
<tr>
<td>No.</td>
<td>Full Name</td>
<td>Position/Title</td>
</tr>
<tr>
<td>-----</td>
<td>------------------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>46</td>
<td>Mr. Balondemu Enoch</td>
<td>In-charge/Clinical Officer/District Focal Person STAR EC</td>
</tr>
<tr>
<td>47</td>
<td>Sr. Kalemba Fatuma</td>
<td>Nursing Officer in charge of Sexual and Reproductive Health Services</td>
</tr>
<tr>
<td>48</td>
<td>Mr. Babolana Paddy</td>
<td>Coordinator</td>
</tr>
<tr>
<td>49</td>
<td>Mr. Babolana Paddy</td>
<td>Coordinator</td>
</tr>
<tr>
<td>50</td>
<td>Mr. Baliddawa John</td>
<td>Mr Baliddawa John</td>
</tr>
<tr>
<td>51</td>
<td>Mr. Oketcho Joseph</td>
<td>Vice Chairperson</td>
</tr>
<tr>
<td>52</td>
<td>Mr. Mugagga Daniel</td>
<td>District PMTCT Focal Person</td>
</tr>
<tr>
<td>53</td>
<td>Mr. Muzamiru Bamuloba</td>
<td>District Health Inspector</td>
</tr>
<tr>
<td>54</td>
<td>Ms. Nekesa Janet</td>
<td>District HMIS Focal Person</td>
</tr>
<tr>
<td>55</td>
<td>Mr. Katabazi Sankara Sam</td>
<td>Records Officer</td>
</tr>
<tr>
<td>56</td>
<td>Sr. Birungi Joyce</td>
<td>In charge PMTCT</td>
</tr>
<tr>
<td>57</td>
<td>Ms. Maxencia Nansamba Kityo</td>
<td>Enrolled Nurse/In charge of PMTCT</td>
</tr>
<tr>
<td>58</td>
<td>Sr. Mbabazi Florence</td>
<td>Nursing Officer and In Charge</td>
</tr>
<tr>
<td>59</td>
<td>Mr. Fred Kagimu Bikande</td>
<td>Technical Advisor</td>
</tr>
<tr>
<td>60</td>
<td>Ms Barugya Stella</td>
<td>District Maternal and Child Health/ PMTCT Focal Person</td>
</tr>
<tr>
<td>61</td>
<td>Sedrack Bakulirahi</td>
<td>District Biostatistician</td>
</tr>
<tr>
<td>62</td>
<td>Sr. Bakengana Zebia</td>
<td>Principal Nursing Officer</td>
</tr>
<tr>
<td>63</td>
<td>Mr. Tumwiine Michael</td>
<td>HIV/AIDS Focal Person</td>
</tr>
<tr>
<td>64</td>
<td>Sr. Masika Rebecca</td>
<td>Senior Nursing Officer In charge of PMTCT</td>
</tr>
<tr>
<td>65</td>
<td>Mr. Shem Bwambale</td>
<td>Clinical Officer In charge of PMTCT</td>
</tr>
<tr>
<td>66</td>
<td>Ms Lavinya Kyankinwa</td>
<td>Enrolled Midwife</td>
</tr>
<tr>
<td>67</td>
<td>Ms Betty Mbambu</td>
<td>Programme Coordinator Maternal and Child Health</td>
</tr>
<tr>
<td>68</td>
<td>Mr. Byaruhanga Bosco</td>
<td>Coordinator</td>
</tr>
<tr>
<td>69</td>
<td>Sr. Immaculate Mandera</td>
<td>Assistant Health Officer in charge of maternal and child</td>
</tr>
</tbody>
</table>
Health/Nursing

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Position</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>70</td>
<td>Mr. Enoch Twesigye</td>
<td>Senior Clinical Officer/ District Surveillance Officer</td>
<td>Kabale District</td>
</tr>
<tr>
<td>71</td>
<td>Sr. Mary Betubisa</td>
<td>District Nursing Officer</td>
<td>Kabale District</td>
</tr>
<tr>
<td>72</td>
<td>Mr. Alex Akampuriira</td>
<td>District Laboratory Technologist</td>
<td>Kabale District</td>
</tr>
<tr>
<td>73</td>
<td>Dr John Wanyama</td>
<td>Ag Hospital Director</td>
<td>Kabale Regional Referral Hospital</td>
</tr>
<tr>
<td>74</td>
<td>Sr Jane Kabagambe</td>
<td>In charge Maternal and Child Health</td>
<td>In charge Maternal and Child Health</td>
</tr>
<tr>
<td>75</td>
<td>Dr Tubyasa Mugagga</td>
<td>Clinical CARE Coordinator HIV/AIDS Services</td>
<td>SUSTAIN Project, Kabale Regional Referral Hospital</td>
</tr>
<tr>
<td>76</td>
<td>Mr. Aaron Mutambi</td>
<td>Community Linkage Coordinator</td>
<td>SUSTAIN Project /Integrated Community Based Initiative (ICOBI), Kabale District</td>
</tr>
<tr>
<td>77</td>
<td>Mr. Byamukama Geoffrey</td>
<td>Chairperson</td>
<td>Kabale District Network of People Living With HIV</td>
</tr>
<tr>
<td>78</td>
<td>Mr. Ngenda Philip</td>
<td>Coordinator</td>
<td>Kabale District Network of People Living with HIV</td>
</tr>
</tbody>
</table>

The writing team

This report has is a result of joint efforts by a team, with contributions as listed below:

Lead Report Writer and Compilation  
Dr. Harriet Kivumbi, International Health HIV Specialist

Primary Review / Report Editing  
Mike Thomson, Director Delta Partnership

Quality assurance  
Dr. Godfrey Esiru- Obstetrician and Gynaecologist; and National PMTCT Coordinator

Dr. Ivy Kasirye- Paediatric HIV Specialist, the Mildmay Uganda

Prof Janet Seeley- Professor of International Development, University of East Anglia, Norwich, UK and Head of the Social Science Programme, MRC/UVRI Uganda Research Unit on AIDS

Dr. Harriet Kivumbi

Design study methodology  
Dr. Harriet Kivumbi, William Kidega-KMCC Knowledge Manager, Mike Thomson and inputs from Dr Jim Weale, Rob Worthington and the QAG
National and district Level consultations  Dr. Henry Barigye-Paediatric HIV Specialist, William Kidega, Denis Jjuuko-KMCC Communication Manager

Designed conceptual framework and the ‘theory of change’  Nilesh Goswami- Delta Partnership consultant with support from William Kidega, Denis Jjuuko, Henry Barigye, Mike Thomson and Harriet Kivumbi

Review and edit team  Dr Gitau Mburu Senior Advisor: HIV and Health Systems, International HIV AIDS Alliance, Hove, UK. Kate Iorpenda, Senior Advisor: Children and Impact Mitigation, International HIV AIDS Alliance, Hove UK

The Quality Assurance Group  Nilesh Goswami

Dr. Henry Barigye, William Kidega, Denis Jjuuko

Formatting and business support  Hannah Swan, Delta Partnership
Annex 3: A selection of good practices contributing the EMTCT in Uganda

While Uganda as a country now struggles to address a rising epidemic, the 2011 Mid Term Review Report (MTR) of the National Strategic Plan 2006-2012 (NSP) (UAC, November, 2011), has cited various approaches and interventions that have worked well in Uganda. In this annex we present selected examples and align them to the four prongs of a comprehensive EMTCT programme.

**Prong 1: Primary prevention of HIV infection among women of childbearing age**

From 1986, at the onset of the National HIV/AIDS response, the Government of Uganda under the leadership of the UAC, MoH and implementing partners (like TASO, PACE/PSI, AIC, Office of the First Lady, Straight Talk Foundation and other CSOs, FBOs and CBOs) have carried out information, education and communication campaigns for the primary prevention of the transmission of HIV. An example campaign of good practice is set out below.

The Young, Empowered and Healthy (YEAH) Initiative aims to reach young people via other young people through strategic health communication programming. This is a sustainable mechanism to support coordinated social and behaviour change for young people (15-24 years old) in Uganda. There has been the design, implementation and evaluation of two national multi-channel social and behaviour change communication efforts by and for youth. The first campaign of the YEAH initiative was the “Something for Something Love” which addressed exploitative relationships where something is given in exchange of favours, material objects or money. The second campaign was “Be a Man” which addressed masculinity and male gender norms. The MTR indicates that qualitative and quantitative assessments of YEAH suggest that the campaign helped to influence positive behaviour change among the young people reached with messages.

**Prong 2: Preventing unintended pregnancies among women living with HIV**

- The Long Term and Permanent Family Planning Marketing Strategy: The Delivery of Improved Service for Health (DISH) project embarked on a strategy to increase utilisation and awareness of long term and permanent family planning methods such as tubal ligation, Norplant and vasectomy through outreaches, mass media communication and community involvement. The programme was so successful it exceeded its projected goals in three months (DISH, cited 23rd September 2012).

- Adolescent friendly reproductive health services: In conjunction with the MoH, the DISH project implemented a strategy to increase utilisation of reproductive health services, to improve attitudes of health providers towards adolescent needs and to increase community knowledge about adolescent reproductive health. The successful strategy revolved around the training of service providers and peer educators, communication and promotional...
materials, community involvement and a launch of available teen services via a "Teen Bash" (DISH, cited 23rd September 2012).

The Uganda Child Spacing Programme 2006-2011, (Wellshare, cited 23 September 2012) sought to increase awareness, knowledge, and access to family planning methods in Mubende and Sembabule districts of Uganda. Outcomes of the programme included training 265 family planning community health workers to provide counselling, contraceptives, and referrals. This resulted in a tenfold increase in “couple years” of protection by 2011. There are four main strategies that contributed to the success of the programme:

- Community-based distribution;
- Community empowerment and leadership;
- Partner ownership;
- Quality assurance, including continuous assessment and education of staff and volunteers.

Anecdotal evidence documented by Barigye et al, indicates that (Barigye H (b), 2012) in Arua district, PREFA actively involves Village Health Teams (VHTs) in PMTCT service delivery at the community level. Without facilitation VHTs were largely inactive. To motivate them PREFA offers training and a monthly stipend of about Uganda Shillings ten thousand an equivalent of £3 per month: and in some cases a bicycle. Trained VHTs attend quarterly meetings and share village per village data such as:-
- Number of pregnant women;
- Number of pregnant women attending antenatal clinics (ANC) visits at least 2 times;
- Number of pregnant mothers confirmed HIV seropositive;
- Number of HIV positive mothers who received ARV drugs for PMTCT;
- Number of HIV positive pregnant mothers who received an HIV a CD4 test;
- Number of babies born to HIV positive mothers, who had HIV tests (EID);
- Number of all pregnant women who delivered in the health unit.

Prong 3: Preventing HIV transmission from a woman living with HIV to her infant

Protecting families against HIV/AIDS (PREFA): This initiative is supporting PMTCT expansion in Uganda, assisting Uganda’s efforts in enhancing access to quality HIV/AIDS prevention, care, treatment and support to families with particular emphasis on PMTCT. It also supports implementation of a broad-based community component that includes mobilisation, sensitisation and home to home counselling and testing as well as referral of clients to health facilities. PREFA is reported to have substantially contributed to enhanced PMTCT awareness and up-take of services in the districts it supported.

Increasing awareness and enhancing linkages for EID: Traditional and Modern Health Practitioners Together Against AIDS (THETA) is implementing a programme at the community level aimed at increasing awareness for and uptake of PMTCT services, and enhancing linkages for EID using community structures (Barigye H (a), 2012).

Motivation of VHTs strengthened community level support to HIV-infected women to access PMTCT
Integrated Community Based Initiatives (ICOBI) is also implementing a similar programme in western Uganda, working with community structures including VHT.

**Peer-mothers and father mentors:** Several programmes have started using peer mothers and peer fathers to improve uptake of services and retention of mothers and their exposed infants. The peer mother mothers are also called mentor mothers, mama clubs etc. These have been used at Makerere University – John Hopkins University (MUJHU), PREFA, TASO etc. These are organisations of HIV positive mothers in childbearing age, organised around income generating activities such as hair braiding, beadwork, and food preparations. The Mama’s club members are trained in and given information on HIV prevention including condoms for dual protection and PMTCT. Starting with one club at TASO Mulago in 2004, to 2 clubs in 2007, it is anticipated that the clubs will spread to all the 11 TASO centres (UAC (a), 2011).

**Prong 4: Providing appropriate treatment, care and support to mothers living with HIV and their children and families.**

**Integration of Early Infant Diagnosis (EID) into immunisation services:** Baylor Uganda has integrated HIV testing for infants within the immunisation services at about 70 facilities in the Eastern, West Nile and Rwenzori Regions. Baylor Uganda has also introduced “Know Your Child Status” campaigns aimed at encouraging parents already in care to have their children tested for HIV and referred into care if infected (Barigye H., 2012b) (UAC, November, 2011). MoH has also advocated for inclusion of EID into mass immunisation campaigns - “Child Days Plus”. MoH has trained providers and prepared 268 EID sites to participate in EID/Child Days Plus integrated activity. DBS samples were collected at 1,072 immunisation outreaches in 2010.

**The Circle of Hope comes to Life:** This aims at reducing children’s vulnerability to HIV, extend the life of the parent-child relationship, promote positive living, prepare the family for transition and ensure the rights and future of affected children. Children are placed into circles of support, including families, communities, governments and international NGOs. The approach has been used to explore the integration of ART and social support into existing PMTCT. The approach includes health interventions, household economic security initiatives and psychosocial support.

**Networking among facilities to reduce stock of out supplies:** Several facilities that have been visited within the districts have established networks that enable borrowing of drugs in order to offset gaps and stock out of supplies. Although this has been reportedly working well, it has potential problems and challenges when no additional coordination exists at the higher district level. This is an innovation that could be used to improve coordination of the entire supply system since reports of overstocked supplies and expiries are not uncommon.

**Home-based care (HBC) for positive living:** HBC is implemented by providing care and support to PLWHIV in their own homes. Community volunteers are trained to bring practical support and information to families and individuals affected and infected by HIV, to make home visits to promote safe practices to enable people make informed decisions that support disclosure of HIV status to
partners and family members, to provide psychosocial support to individual and families and to make referrals to health facilities. Some agencies variously refer to them as Network Support Agents (NSAs). Some are selected among members of the Village Health Team (VHT) or are peer educators living with HIV/AIDS themselves.

**Interpersonal psychotherapy:** Interpersonal psychotherapy is a time-limited psychotherapy that was originally developed as an individual treatment for unipolar non-psychotic depression. It has been tested in numerous open and randomised clinical trials and found to be efficacious for a number of mood and non-mood disorders among adolescents and adults. The IPT-group structure starts with two initial individual sessions to learn about the person’s depression and problems. The structure takes 1 ½ hour weekly group sessions for a period of 16 week led by the IPT-group leader. Results affirm that it is feasible to train non-clinicians to support and assist depressed adults in rural, low-resource settings.

**Family-centred approach in the provision of holistic care package:** This involves identification of the ‘index’ family member (the first individual - child or adult - to come in contact with the health facility system), usually through HCT. The ‘index’ individual is then used to obtain information on the other family and household members, defining both sexual and non-sexual relationships. Spouse(s), children, siblings, parents and other people living in the household of the index client or related to the client (sexually or non-sexually) are identified and followed up. It encourages disclosure with the family and therefore allows the HIV positive individual to have more than one treatment supporter within the family. This has proved to be particularly important for adherence support for children on ART.

**The Memory Book and Will-Making:** PLWHIV attached to an agency or community members, in general are sensitised and trained in will making and encouraged to process legal documents including birth certificates for their children. As an output, members of PHA groups also individually write memory books which could be referred to by their children so as to be able to trace lineage, and to claim any attendant rights. This practice has generated considerable results in social support and protection of HIV affected children (UAC (a), 2011).