Report of the

# Consultative Meeting on the

# Elimination of Mother to Child Transmission in the Lango Region

Lira Hotel 28<sup>th</sup> June 2013

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#### Acronyms

AIDS Development Partners
Anti Retroviral
Chief Administrative Officer
District Health Officer
Elimination of Mother To Child Transmission
Ministry of Health
Mother To Child Transmission
Organisation of African First Ladies Against HIV/AIDS
Safe Male Circumcision
Uganda AIDS Commission
Village Health Teams

#### 1.0 Background

The HIV Programme of the First Lady's Office in Uganda operates as the Uganda Chapter of The Organisation of African First Ladies against HIV and AIDS in Africa (OAFLA). OAFLA is committed to contributing to efforts towards an AIDS free Africa.

The Uganda Chapter (OAFLA UG) is guided by the following Vision and Mission:

*Vision:* Zero new infections leading to an HIV Free Generation by 2020.

*Mission:* To provide political leadership and a strategic platform for stakeholder engagement and community mobilization, to ensure an effective HIV and AIDS response; towards an HIV free generation.

#### 1.1 Origins of the EMTCT Campaigns

The First Lady was nominated the National EMTCT Champion in August 2012 and thereafter she embarked on Regional Campaigns to create awareness about EMTCT. These Campaigns are organised and coordinated by OAFLA UG in partnership with the Ministry of Health (MOH), the Uganda AIDS Commission (UAC), HIV/EMTCT stakeholders and the political leadership at all levels of Society.

The Campaigns have created general awareness about effective HIV/EMTCT service delivery and specifically the need for leadership involvement, starting with male involvement in the family reproductive health. They have succeeded in: engaging key stakeholders in consultations around EMTCT, creating awareness about the Option B plus and stepping up the availability of commodities in the regions' reached.

This is a report of the EMTCT Campaign in the Northern Region; the third in a series of EMTCT Campaigns to create awareness about the need for Male Involvement in the Reproductive Health of their spouses.

#### 1.2 Activities organised to mark the Regional Campaigns

The following activities were organised as part of the Regional Campaigns:

• Media Campaigns: The Regional EMTCT Campaign activities began with an intensive media drives featuring print media, radio and television messages on EMTCT as well as HIV and AIDS awareness. The messages included an appeal by the EMTCT Champion on the importance of male involvement in reproductive health and testing for HIV as couples.

- HIV and AIDS /EMTCT Services: Health Service providers all over the region stepped up service provision setting up public open air sites for HCT and other related services to promote additional access to service delivery during the campaign period.
- Dialogues for VHTs, Religious and Cultural Leaders from the Northern Region on the EMTCT Response: These Dialogues were held on 26<sup>th</sup> June 2013 to reflect on and address the challenges faced in mobilizing the Community's' response to EMTCT and HIV/AIDS and to develop appropriate strategies to enhance the role of the VHTs, Religious and Cultural leaders in the response to EMTCT.

The Dialogues were very successful and the Community Leaders pledged to work with the key stakeholders was applauded, with commitments from the Ministry of Health and the political leadership to support their work. The resounding message from this process was the need to engage, equip and empower the Religious and Cultural Leaders in their response to HIV/AIDs and EMTCT in particular. The outcomes of the VHT, Religious and Cultural Leaders Dialogue were presented in the Consultative meeting as highlighted in part 4.0 Statements in the EMTCT Response.

• **Consultative Meeting and the Public Rally:** The Main Campaign activities began with a Consultative Meeting held at Lira Hotel in Lira District and was followed by a Public Rally in the afternoon.

This is a Report of the EMTCT Campaign conducted in the Eastern Region in Tororo District on 16<sup>th</sup> August 2013. The Campaign provided a platform for the National Stakeholders to hear Commitments toward an HIV Free Generation from the Youth and the testimony of a Father practicing Male Involvement in the Reproductive Health of his entire family.

#### 1.3 Outcomes of the EMTCT Regional Campaign in Lira

The Campaign received wide acclaim across the region and was instrumental in increasing demand for commodities and services. The Stakeholder's Consultative Meeting was held at the Reproductive Health Uganda (RHU) Youth Center, in Tororo. The Meeting identified key issues that should be addressed to improve access to health care services by men and their wives, some of which were: the male ego, gender dynamics regarding male involvement, structural aspects of the health facilities that affect attendance by men, the availability of commodities and the attitudes of health workers that discourage men from accessing the health services.

The EMTCT Champion and other national leaders provided the Meeting with direction, with regard to practical strategies to enhance the public response to EMTCT. The participants also heard presentations from two youth representatives who read their commitment towards an *HIV Free Generation* and a Father who talked about his involvement in the Reproductive Health of his family.

#### 2.0 Stakeholders Consultative Meeting

The Stakeholder's Consultative Meeting was held at the Lira Hotel and was attended by key stakeholders from the 15 Districts of Northern Uganda including political leaders, officials from the Ministry of Health (MOH), key actors in the health sector from the national, regional and district levels, members of Civil Society Organisations, cultural and religious leaders as well as development partners.

#### 2.1 Objectives of the Consultative Meeting

The objectives of the Consultative Meeting were to:

- Provide a Forum for key stakeholders in the EMTCT Response to share information regarding the Response to EMTCT and HIV/AIDS in general;
- Identify and address key issues of concern to the community leadership namely Religious Leaders, Cultural Leaders and the Village Health Teams, regarding efforts to promote EMTCT and combat HIV/AIDS in the Northern Region.
- Provide a platform for the EMTCT Champion to provide leadership and direction on the HIV/AIDS Response in the Northern Region and Uganda in general.

Below is a brief account of the deliberations of the Consultative Meeting

#### 3.0 Presentations made during the Consultative Meeting

#### 3.1 Message by Bishop Lwere, Overseer National Fellowship of Born Again Churches

The Overseer of the National Fellowship of Born Again Churches, Bishop Lwere shared a message of encouragement with the: Religious Leaders, Cultural Leaders and the representatives of the VHTs who attended the Consultative Meeting. He pointed out that ownership of the HIV/AIDS response is very important if volunteers are to succeed in their work. He called upon them to emulate the work Jesus did while on earth saying that healing people is special to God and that is why, Jesus cared for the

sick. He reminded the participants that everyone will have to give an account of their lives to God someday. He went on to explain that there must be a level of sacrifice and commitment if communities are going to develop. There is need for ownership of the HIV Response in Uganda and ownership is shown by the level of sacrifice one is willing to undergo as they identify with a cause.

He explained the level of influence yielded by opinion leaders such as the religious and cultural leaders. He said they have the confidence of the people and the people trust them consequently they can use this influence to reach out to them.

"We are all here to transform our communities and there are things we can do even without being paid and without waiting for funds from donors". He concluded.

#### 3.2 Welcoming Remarks from the Chief Administrative Officer (CAO) Lira District

Mr. Rabuha represented the CAO Lira District. He thanked the Ministry of Health for choosing Lira as the venue for the North Region Launch of EMTCT. He welcomed all the guests from the Ministry of Health, Development Partners and participants from the other districts comprising Northern Uganda. He recognized the Lira Organising Committee which he said had done a commendable job in planning and executing the event. After his remarks the participants from the various districts, Politicians and Technocrats introduced themselves.

#### 3.3 Remarks by the District Health Officer - Amolatar District -Dr. Quinto Okello

Dr. Quinto Okello shared about the challenges the Northern region faced during the LRA war that also affected the Health Sector and escalated the spread of HIV. He informed the Meeting that the HIV prevalence rate in the North is second only to Kampala, while women have a higher infection rate than men. He recognized the efforts of Government in rolling out Option B+ up to the Health Center III, but noted that the Health Center II serves a bigger population.

He highlighted the achievements of the MOH since the roll out of Option B+ as: the sensitisation of communities, Training of Trainers Workshops for Health workers, the distribution of tools and medicines, outreach activities and the airing of various radio talk shows.

Dr Quinto pointed out a number of challenges faced by the District namely: the low male involvement, stigma, low adherence and retention as well as inadequate health workers. To address these problems the MOH intends to engage other sectors and to encourage political leaders to support the health sector in sensitizing the communities.

## 3.4 Remarks by Director Organisation of African First Ladies Against HIV/AIDS (OAFLA) Mrs. Beat Bisangwa

The Director OAFLA, Ms. Beat Bisangwa commended the leadership of Northern Uganda for their dedication and interest in promoting EMTCT in the Region. She explained the progress that had been made in the recent past, since the first launch of EMTCT in Ntungamo District Western Uganda. The Uganda AIDS Commission (UAC), together with other stakeholders had established the Message Clearing House to assess and approve of Messages on HIV/AIDS. This it is hoped will change the negative trend messages on HIV/AIDS have tended to take in the past, leading to confusion amongst the public and misconceptions regarding the Response.

The Campaign has also successfully accelerated a simultaneous roll out of the EMTCT Response country wide, generating further commitment from AIDS Development Partners (ADPs) and strengthening the existing team spirit amongst stakeholders.

The EMTCT response has increased conversations around HIV and EMTCT in the communities and churches. Furthermore Health Workers have been trained. She thanked the Government for its continued efforts to promote sensitization on HIV/AIDs. She concluded her remarks by thanking all the stakeholders for their active participation in responding to the call to launch EMTCT in the Northern Region.

#### 3.5 Remarks by the First Lady of Uganda and EMTCT Champion Hon. Janet Kataha Museveni

The First Lady and EMTCT Champion Hon. Janet Kataha Museveni, shared her concern over the fact that 65 babies are born HIV positive every day in Uganda. She made the case for re-instituting the "Abstinence" and "Be faithful" aspects of the HIV Policy saying that the reason for Uganda's regression in the battle against HIV/AIDS was the fact that the original strategy was rendered ineffective and watered down to the extent that today people feel ashamed of talking about Abstinence and Faithfulness. Furthermore with the introduction of bi-medical interventions the population put down their guards and the national focus turned from behavioral change to life saving methods.

It is important that all the stakeholders form a united front for Uganda to go back to this strategy and to communicate to the young people that AIDS is a killer disease, that can only be survived by avoiding it. Ugandans should promote abstinence from sex and other excesses such as drug and alcohol abuse because these aggravate the spread of the Virus. She decried the fact that unfaithfulness has opened the door for HIV/AIDS in marriages placing couples at risk, and recognised the need to ensure that condoms are made readily available to those who need them. Nevertheless the final goal for Ugandans must be to resolve to return the country to the strategies that worked and to get back to the messages that promoted behavioral change.

The First Lady called upon the MOH and other Development Partners to involve and support the Church, Cultural Leaders and the Media in the HIV/AIDS response, saying that failure to do this would lead to another 700,000 people infected. These actors can be used to promote male involvement which is largely hampered by the cultural mindsets of rural people, who believe men should not be involved in reproductive health issues. She observed that it will take a concerted and deliberate effort to educate the male population to think of themselves as partners with their wives during pregnancy, delivery and after.

"People have to be taught that it takes a couple to raise a family and this goes beyond the Government to all structures in the community", she said.

#### 3.6 Remarks by the Director General of Health Services, MOH Dr. Jane Aceng

The Director General Health Services in the MOH Dr. Jane Aceng gave a brief background to the adoption of the Option B+, pointing out that the Campaign involves four prongs. She shared the achievements registered in this Campaign as: Achievements:

- Over 3,000 Health Workers have been oriented and trained with over 600 working in the Acholi and Lira sub-regions;
- 1,600 health facilities out of the 2,087 are currently implementing Option B+;
- Health facilities provide services such as cancer screening and safe male circumcision (SMS);
- Over 1,500 VHTs and People Living with HIV/AIDS have been oriented on MTCT in Lira;
- Religious and Cultural leaders have been oriented;
- Between Sept 2012 to date, 53,453 women received ARVs and 20,152 women received Option B+; and
- There has been re-activation of the electronic and print media advocacy.

Dr. Aceng was happy to note that Uganda is already registering zero transmission of HIV at some health facilities she cited the "Reach Out Mbuya" facility. In Mulago MTCT is down to 4-5%.

There are a number of challenges that still need to be addressed in the HIV Response:

Challenges

- Complacency among communities who do not fear HIV because of a false sense of security, from the availability of ARVs;
- Inadequate coverage of services due to poor infrastructure and limited numbers of Health Workers;
- Erratic supplies of test kits because of the increase in demand due to increased enrollment. This is because a deliberate effort was made to avail treatment to everyone who needs it. This challenge is being addressed with development partners;
- Slow accreditation due to lack of equipment 90% of the HC III are accredited;
- Poor documentation leading to under reporting; and
- Weak adherence and retention. This is being addressed by appealing to male involvement.

Dr. Aceng pointed out that the MOH is committed to improving the messaging through the UAC's Committee that vets messages on HIV/AIDS. Efforts are also being made to address the poor infrastructure, the lack of motivation of Health Workers and the strengthening of the supply management systems so as to create further demand for services to ensure the testing of everyone. The MOH is also working on a network for viral load testing that will soon be rolled out.

She appealed to the CAOs, DHO's and other stakeholders to ensure that funds from NUSAF are used to build houses for Health Workers. She pledged the Ministry's commitment to work in partnership with the Religious and Cultural Leaders to promote EMTCT.

#### 3.7 Remarks by the Country Director UNAIDS Musa Bungudu

The UNAIDS Country Director, Mr. Musa Bungudu shared optimism and confidence that Uganda will eventually achieve virtual EMTCT. He made a passionate appeal to the audience to rally around the HIV response, pointing out that Uganda cannot afford to have 23,000 babies born with HIV. He reiterated the support of the AIDs Development Partners, pointing out their readiness to support the cultural and religious leaders.

Uganda should not lose sight of the VHTs challenges since they are a critical link to the communities. He appealed to the DHOs to keep track of the campaign and ensure that statistics are availed on how many people are tested and how many are on treatment. He concluded his remarks by appreciating the role the First Lady has played as Champion and appealed to all the stakeholders to join hands and ensure zero transmission of the virus to Uganda's babies.

#### 4.0 Statements on the EMTCT Response

The Representatives of the VHTs, Religious and Cultural Leaders made the following presentations arising from Statements drafted after their Dialogues the previous day:

#### a) Presentation by the Village Health Teams

The VHT stated that their role is to mobilise communities to respond to Government Health Programmes. They also play the role of advising community members on matters relating to their general health, hygiene and well being.

The VHTs of Northern Uganda have registered the following achievements in their community work.

#### Achievements

- Many community members now have knowledge on EMTCT;
- Families in the community have been supported to ensure that their health concerns are addressed;
- Counseling for those who are living positively;
- Promoting male involvement in antenatal services as well as couples testing for HIV/AIDS.

However there are a number of challenges experienced in conducting community work:

#### Challenges

- *Lack of Transport:* The bicycles allocated to VHTs were not delivered to all the VHTs; they only a few female bicycles available.
- Community demands: There are high community expectations and demands
- *Shortage of drugs:* There are very few drugs in the Health Centers.
- Harassment from health workers: Health workers harass VHTs and disregard their referral forms.
- *Relationship with the LCs:* Local Councils undermine VHTs and do not recognise their role. They expect VHTs to give them funds to do their work.
- Orientation on Option B+: VHTs require further orientation on Option B +.

- *Inefficiencies within the Health Sector:* Health workers are sometimes absent from work leaving patients unattended to. One of the VHTs child passed away because of lack of attention at a Health Center.
- *Identification tags:* It is important for VHTs to be given identification tags. This will enable the community and other stakeholders recognize them as an entity in the health sector.
- *Motivation of VHTs:* The work VHTs do is very challenging and they require motivation in terms of recognition of their achievements and attention to their welfare e.g. through the provision of raincoats and funds to help ease mobilization.

The VHT Dialogue was concluded with a number of commitments as presented to the Meeting in the earlier section above.

#### b) Presentation by Religious Leaders

Religious leaders have structures that reach down to the remotest areas of the region. The audience they command covers a large following, consisting 99% of the population in the region. This platform is used to encourage married people to *Be Faithful in Marriage* and the youth to practice *Abstinence* until they get married. Religious leaders also care for the sick physically, spiritually and emotionally.

#### Challenges in Promoting EMTCT:

- Government, development agencies and other stakeholders are just beginning to realise the value of engaging Religious Leaders to address social concerns and development work. This is a positive turn given the size of our following.
- There are limited resources for the mobilization and sensitization work. These institutions lack transport for the mobilization and implementation of activities to promote Government programmes.
- Religious leaders require additional skills and knowledge to enable them promote Government Programmes on HIV/AIDS.
- There is need for wholistic and clear messages on HIV/AIDS as some of them can be misleading. For example what is the truth about the effectiveness of circumcision and condom use?
- The people lack access to medical services. They travel long distances to reach the Health Centers which are congested, under staffed and lack the necessary drugs and test kits.

#### Recommendations

- That all the Health Centers be equipped with, staff, drugs and other facilities/logistics to meet the demand that is going to be created by this campaign.
- Religious Leaders should be recognized and engaged more, as major stakeholders and core partners in the response against HIV/AIDS.
- Religious institutions be availed resources including means of transport to facilitate the mobilization of the community and to enable the leaders engage in activities to address EMTCT.
- Capacity building to enable religious leaders talk from an informed point of view.
- Appropriate and clear messages be developed and disseminated on all the four prongs, especially on primary prevention.

#### c) Presentation by the Cultural Leaders

The Tekwaro Lango have been actively involved in mobilizing communities to respond to the HIV/AIDS. The Cultural Institutions are currently engaging the youth through the Lango Apac Students Association. They also participated in the Kings Forum on HIV/AIDs held in Hoima in which they were provided with information on the response to HIV/AIDS.

#### Challenges

- The Lango Cultural Forum has not been able to fulfill its commitments to the Kings Forum on HIV/AIDS that was held in Hoima because of lack of funding.
- There is need for training and awareness creation on issues of HIV/AIDS and EMTCT.
- The Cultural leaders require capacity building to equip the Forum with skills and knowledge on how to address negative cultural practices that impact HIV/AIDS.

#### 5.0 Closing Remarks by the Hon. Champion EMTCT

The First Lady and Champion EMTCT, Hon. Janet Kataha Museveni, called upon the people of the Northern region and Uganda in general to make the total resolve to go back to the initial strategy of Behavioral change with *"Abstinence"* and *"Being Faithful"* as the main emphasis for the HIV response.

"We must fight to see that we have healthy babies, who will live healthy lives and have healthy marriages" she said. She called upon those present to promote male involvement in reproductive health, right from conception, through pregnancy, during delivery and throughout the lives of the mothers and children. This should be done through addressing cultural mindsets. Ugandans must lay strategies to address other excesses such as drug abuse and alcoholism which promote risky behavior amongst the people. Hon. Janet Museveni thanked the people of the Northern Region for their warm welcome and for taking the time to focus on and participate in the Launch of the EMTCT in the Northern region.

#### 6.0 Conclusion

The Consultative Meeting was a huge success having achieved all its objectives. The Meeting provided a platform for the VHTs, Religious and Cultural leaders from the Region to interface with other actors in the HIV/AIDS Response. They were able to share the work they are doing in promoting *Abstinence* and *Being Faithful* and to strengthen their resolve to be part of the solutions to Uganda's Health Challenge.

Those who attended the Meeting were also privileged to be inspired by words of encouragement from Bishop Lwere, the Overseer of the National Fellowship of Born Again Christians, who urged all the stakeholders to sacrifice their time and energies towards the virtual EMTCT, in the same way that Jesus gave His all for the cause of mankind.

Additionally, the meeting was an effective platform for information sharing on the achievements registered by the MOH in the HIV/AIDS response. Furthermore the Meeting was briefed about the challenges of ensuring effective service delivery to provide total coverage of the population and the promotion of male involvement. They were also informed of the plans the Ministry has to address these challenges.

In line with her role, the First Lady of Uganda and the EMTCT Champion, Hon. Janet Kataha Museveni made a passionate appeal to all the stakeholders to go back to the original strategy of eliminating HIV/AIDs by adopting behavioral change in line with promoting *Abstinence* and *Being Faithful* for the sake of the children of Uganda.