

Community Recommendations to Government of Uganda, PEPFAR, UNAIDS, UNICEF & PEPFAR Implementing Partners on the occasion of the 'Inter-District eMTCT Learning Meeting' focusing on 25 slow progressing Districts

BACKGROUND:

We appreciate the efforts of all partners in working to end mother to child transmission of HIV. We are committed to working tirelessly in the fight to end AIDS in Uganda and we commend Uganda for development of the largest Option B+ program in the world.

Despite important progress, there are serious and persistent program weaknesses that are not receiving the focus, attention and funding that is required. As a result unintended transmissions are occurring and women with HIV are falling sick because their disease is progressing without effective HIV treatment.

As women living with HIV and their communities we highlight these weaknesses below, and make the following priority recommendations regarding Uganda's Option B+ Program:

- **PROGRAM QUALITY:** pregnant women and breastfeeding women face multiple challenges that undermine adherence and treatment follow up. When these challenges are not addressed, vertical transmission is more likely to occur, as is disease progression for women because they fall out of care. Implementing Partners in successful Districts are the ones that are investing sufficient funding in community based follow up services to ensure women have the support they need to adhere to ART, follow up with clinic appointments, and to respond to challenges regarding disclosure, violence, and other serious issues. These services are provided *not* by VHTs but by expert 'mentor mothers' who are trusted by newly diagnosed women, who are discreet, who support women in tackling challenges pregnant women with HIV can face—that can undermine the success of Option B+. **RECOMMENDATION: PEPFAR and the Government of Uganda must direct Implementing Partners (IP), in particular those in the 25 poorly performing Districts, to pay for a minimum package of community based services to prevent loss to follow up, using trained and compensated mentor mothers.**

- **COUNSELING:** Pregnant women seeking HIV testing need quality counseling so that their fears and questions are addressed. We understand facilities are crowded and health workers are overtaxed; group health talks have typically replaced pre test counseling. But successful Implementing Partners are investing in expert patients as part of evidence based task shifting; these expert patients are trained as counselors to ensure health workers can focus on essential tasks while providing women seeking testing a community based perspective and the compassion and empathy they often seek. **RECOMMENDATION: PEPFAR and the Government of Uganda must invest in counseling services that support task shifting to expert patients who have the time to address questions and concerns pregnant women face when they are choosing to test for HIV.** Proper individualized quality pre and post-counseling to mothers is a must and **without these services, women are more likely to default, and will lack the empowerment they need to prioritize their health and the health of their families.**

- **LOSS TO FOLLOW UP:** Too many programs are not spending funding on proactive efforts to prevent and respond to loss to follow up in a timely manner. **RECOMMENDATION: PEPFAR and the Government of Uganda must ensure Implementing Partners fund a minimum package of loss to follow up prevention interventions, including paying mentor mothers to do community based outreach, responding to transport and other barriers women face, and providing counseling and emergency services to women who face violence from their partners after testing positive.**

- **FINDING WOMEN WHO ARE NOT GETTING FIRST ANC VISITS:** Many HIV positive women in poorly performing Districts are not even coming for their first ANC visit and are delivering outside of facilities—they do not have access to the Mama Kits and health facilities continue demanding that they pay for necessary requirements including plastic sheets, gloves, egometrin/epitoin, basins, etc. Implementing Partners are not reaching them. **RECOMMENDATION: Implementing Partners must report what they are doing to reach women living with HIV who are currently outside the health system. Uniform Mama Kits should be available in all district health facilities offering maternal health services.**

- **RETENTION IN CARE AFTER 18 MONTHS:** HIV positive women are at high risk of loss to follow up and from HIV treatment and care when they transition from HCIIIs that provide specifically eMTCT and not general HIV care, to HCIVs after breastfeeding. **RECOMMENDATION: There should be faster accreditation of HCIIIs to provide ART so that women can remain where they were initiated on treatment, rather than having to transfer to a clinic where they do not know anyone and have to ‘start over.’ While communities wait for accelerated HCIII accreditation, Implementing Partners should invest in strong referral linkages between HCIIIs and HCIVs for transferring mothers and babies.**

- **STIGMA BY HEALTH WORKERS:** Some health workers are still extremely stigmatizing, judgmental and abusive in their treatment of HIV positive pregnant women. This drives women away from seeking care in facilities, increasing their risk and the risk to their baby. **RECOMMENDATION: Implementing Partners must invest in ongoing training of health workers and efforts to measure quality assurance and patient satisfaction.**

- **INCREASING THE NUMBER OF HEALTH WORKERS:** Decongesting clinics should be a matter of government priority in order to achieve eMTCT. **RECOMMENDATION: Government to accelerate recruitment and increase retention of midwives, nurses and other priority cadres during Financial Year 2015/16.**

- **POLICY SETTING:** Finally, as experts in service provision and as strong advocates for an end to AIDS in Uganda, we are frustrated that once again we have been excluded from participation in this forum and only had to push to gain entrance. Unless we are treated as equal partners, we will not have success in eMTCT that we need as a country. Unless we are included at every stage of service delivery, program design, implementation, policy setting, and oversight, as a country we will be moving without the real world evidence and feedback of the actual intended beneficiaries. **RECOMMENDATION: We call on all partners to commit never again to plan for such meetings without the meaningful engagement of women living with HIV and their networks.**

Other innovations such as resting homes in hard to reach areas and innovative approaches to involving men by providing tangible services such as cancer screening) should be shared among key Districts and expanded where successful. Special consideration should be made for the harder to reach Districts and those with unique situations where pregnant women have to cross game reserves, bodies of water, and have no means of transport to the health facilities. In those cases, services should be taken nearer to them, e.g. HCIIIs should be equipped. Otherwise mothers will continue to use Traditional Birth Attendants.

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