
## Who We Are

Women Living with HIV (WLHIV) in Uganda (young, older women, women living with disabilities) drawn from the Networks and Organizations of Women living with HIV and representing all the regions of Uganda participated in a consultative meeting for priority setting from our perspective for informing the process of development of the revised Uganda National Strategic Plan 2015/16 – 2019/2020 and for the Global Fund Concept Note on September 15, 2014 at Modest Inn – Kampala – Uganda. This meeting was held in line with the multi-sectoral approach and in line with the New Funding Model (NFM) for Global Fund for Tuberculosis, HIV and AIDS, and Malaria Prevention.

## Why Women Living With HIV

Statistically, women are severely affected by HIV, Tuberculosis (TB) and Malaria than their male counterparts. For instance, Ugandan adults aged 15-49, 7.3% are HIV positive, with prevalence being higher among women (8.2%) than men (6.1%). In Uganda, 570 new infections are occurring among young women aged 15-24 each week. The Government of Uganda must get serious about implementing programmes that prioritize the needs of women and girls and advance their sexual and reproductive health and rights. The Uganda Police Force annual report 2012 indicates that domestic violence is one of the most commonly reported cases of violence. For instance, in 2009, 159\(^2\) deaths were recorded resulting from Domestic Violence and 165\(^2\) similar deaths in 2011. The Uganda PLHIV Stigma Index survey report 2013 shows that 11% of the respondents revealed a health care professional coerced them into being sterilized because they were diagnosed HIV positive. Recently, the government simultaneously embraced harmful, human rights violating, and discriminatory laws and policies that will disproportionately impact negatively on female than their male counterparts. However, amidst all that, the Networks of Women living with HIV are not funded through the existing funding mechanisms in Uganda to respond to the needs and issues faced by women (ICWEA 2014). The processes of developing the revised National Strategic Plan 2015/16–2019/2020 and concept note provides an opportunity for addressing the gaps and missing links in the response against the three diseases of Malaria, Tuberculosis, and HIV including addressing the Sexual Reproductive Health and Rights.

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\(^1\) Uganda Police Force Annual report, 2010.
\(^2\) Uganda Police Force Annual report 2012.
Harmful legal and policy environment

The recently enacted HIV Prevention and AIDS Control Act 2014 was assented to despite the objections of key stakeholders in the HIV response in Uganda, such as the AIDS Control Programme of the Ministry of Health, the Uganda AIDS Commission, gender experts, Health Service Providers, Civil Society Organisations and People living with HIV. The experts argued that the HIV specific Act that provides for mandatory HIV testing and disclosure of the test results without consent to third parties coupled with criminalization of HIV would take Uganda’s AIDS response in the wrong direction. The gender, human rights and public health analysis of the provisions of contention in the Uganda’ HIV Specific law clearly indicates that the HIV response will negatively be impacted by people shying away from prevention, treatment, care and support services which may end up escalating the HIV Prevalence. Secondly, the most vulnerable particularly women and young girls will be made more vulnerable to HIV, Gender Based Violence, Domestic Violence and stigma and discrimination.

Stigma and discrimination

Criminalization targeting people living with HIV and intense fear and recrimination targeting sex workers is still high. The example is the outrageous trial of the HIV positive nurse Rosemary Namubiru, who was accused of “criminal negligence” in the workplace when a patient in her care was accidentally exposed to her blood, and whose HIV status meant she never got a chance of a fair hearing or a presumption of innocence.

Gender based violence

Women living with HIV were so concerned about the increasing cases of gender-based violence they experience which is based on HIV status. Gender inequality and unequal power relations between women and men have reinforced the vulnerability of Women living with HIV to gender based violence on the basis of HIV status. Women living with are often economically dependent on men for their livelihood, even where their labour accounts for the bulk of household income, a situation, which is taken together with gender based violence and negative cultural practices, forming a vicious cycle of powerlessness and vulnerability that further exposes women. Now that the legal environment provides the health care provider the responsibility to disclose one’s HIV status to third parties not limited to sexual partners without consent would be to exacerbate this vicious cycle, and in some cases would tantamount to a death sentence in cases of extreme violence.

HIV PREVENTION

Sexual and Reproductive Health and Rights violation

Women living with HIV raised concerns relating to increasing violations of their sexual and reproductive health rights. These included: Stigma and discrimination at the maternal and child health care delivery points where Women living with HIV encounter hostile attitudes and discrimination from health care providers who refuse to provide them with services during pregnancy and child birth, instead refer them to be served by the mentor.
mothers and expert clients. Women living with appreciate the good work provided by the mentor mothers and expert clients, but they were so concerned by the non recognition and non-remuneration by the Ministry of Health of mentor mothers/expert patients attached to the facilities yet they complement the efforts of the health care workers, and do most of the work concerning PLHIV. Women were further concerned about limited access to Sexual Reproductive Health and Rights services such as STI screening and treatment, cervical cancer screening and treatment and family planning options and commodities.

CARE AND TREATMENT

Declining quality ART services for women living with HIV

Women living with identified key pertinent issues which affected access to ART including eMTCT/PMTCT services and these include: poor nutrition; the mandatory testing of women and immediate initiation of ART with no mechanism to support them disclose their results to their spouses so as to sustain their marriages without intimate partner violence; the limited information on eMTCT/PMTCT. Most facilities do not have a unified mechanism put in place to track mothers and children to address loss to follow up of the mothers and pediatrics and yet there is limited involvement of women living with HIV in the planning, implementation, monitoring and evaluation of the National eMTCT Programme.

In addition, non-film coated Tenofovir and Lamivudine 300mg/300mg, which is extremely bitter raised ARVs quality concerns and has impacted negatively to treatment adherence. Finally lack of access to CD4 count and viral load testing machines from the facilities where some women access their treatment was raised as of great concern.

COMMUNITY AND HEALTH SYSTEMS STRENGTHENING

The model of service delivery does not respond to the needs and priorities of Women living with

The model of service delivery which is facility based does not respond to the needs and priorities of Women living with. Women living with were concerned with the introduction of facility based model of HIV service delivery and abolition of a community based model of service delivery that was tested and proven to work in Uganda and was replicated in other countries. Majority of women economically depend on their male counterparts, they have to walk long distances to the accredited health facilities and they are already overburdened by the caring role and heavy workload which have contributed to loss to follow up.

Lack of financing networks of Women living with HIV by National funding mechanisms including the Global Fund:

Women were concerned that there is no specific allocation from the GF money to the networks of Women living with HIV to enable them demand for greater transparency, accountability and integrity in the delivery of health services in Uganda.

Stock out of life-saving and family planning commodities including limited options

Stock out of HIV test kits, ARVs especially pediatric, and limited access to family planning (FP) options through which they can choose including mamas kits were identified.

We recommend that the following priorities are included in both the new NSP 2015/16 – 2019/2020 and the Concept Note for the Global Fund.
Women living with HIV in Uganda Key Priority areas for the GF Concept Note and Revised

- Full government funding for quality prevention, care, treatment and support services for all

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<th>Thematic areas</th>
<th>Priority areas</th>
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| **SOCIAL SUPPORT AND PROTECTION**     | • Transforming and challenging a harmful legal and policy environment  
• Addressing powerlessness and vulnerabilities that reinforce gender based violence experienced by Women living with HIV  
• Targeted programmes on livelihood that support women living with HIV (economic empowerment)                                                                                                      |
| **HIV PREVENTION**                    | • Providing respected, comprehensive Sexual and Reproductive Health and Rights services including for cervical cancer  
• invest in controlled female preventive methods and technologies including increasing Family Planning options for women Address information gaps for women living with HIV in prevention, treatment and care and support services |
| **CARE AND TREATMENT**                | • Massive overhaul to ensure delivery of quality ART services for women living with HIV including for treatment of Opportunistic Infections like cervical cancer  
• Easy access to CD4 count and Viral load machines                                                                                                                                                                                                                                                              |
| **COMMUNITY AND HEALTH SYSTEMS STRENGTHENING** | • Allocating funding to the networks of women living with HIV as a community structure to demand for greater transparency, accountability and integrity in the delivery of health services in Uganda and to help minimize lost to follow up  
• Ensuring accessibility and availability of HIV test kits for eMTCT, life saving and family planning commodities and options through effective supply chain management system.  
• Support advocacy and programmes targeted at enhancing human rights in Policy, Programming and service delivery.                                                                                       |

*With financial support from:*

[Image] Aids Legal Network

[Image] Robert Carr Fund for civil society networks