

CERTIFYING UGANDA ON THE PATH TOWARDS ELIMINATION OF MOTHER-TO-CHILD TRANSMISSION OF HIV

Perspectives of women living with HIV on human rights, gender equality and engagement of Civil Society in the validation process

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Explanation of key terms

Prevention of mother-to-child transmission (EMTCT) programs provide antiretroviral treatment (ART) to HIV-positive pregnant women to prevent HIV infection in their infants.

Without preventive treatment, the likelihood of HIV passing from mother-to-child is 15% to 45%. However, ART and other effective EMTCT interventions can reduce this risk to below 5%.

Effective EMTCT programs require women and their infants to have access to - and to take up - a cascade of interventions including antenatal care (ANC) services and HIV testing during pregnancy; use of ART by pregnant women living with HIV; safe childbirth practices and appropriate infant feeding; uptake of infant HIV testing and other post-natal healthcare services.

Option B+ World Health Organization (WHO)'s 2013 guidelines recommended that a woman living with HIV only continue on ART after breastfeeding if it would benefit her own health. However, in September 2015 the WHO released new guidelines recommending that all pregnant women living with HIV be immediately provided with lifelong treatment, regardless of CD4 count (which indicates the level of the body's immunity). This approach is called Option B+.

Validation in eMTCT and Syphilis: The term "validation" is used to refer to international verification that a country has successfully met the criteria for elimination of mother-to-child transmission of HIV (EMTCT) or for one of the three levels of achievement on the Path to Elimination of HIV and/or Syphilis. Successful prevention of MTCT is dependent on sustaining lifelong treatment for women living with HIV of childbearing age, and the early detection and cure of those diagnosed with syphilis. Countries that achieve validation still need to maintain ongoing, routine and effective program interventions, as well as quality surveillance systems to monitor elimination status.

Abbreviations

AGYW Adolescent girls and young women

ANC Antenatal care

ART Antiretroviral treatment

CITC Client-initiated testing and counseling

CSE Comprehensive sexuality education

EMTCT Elimination of mother-to-child transmission of HIV

FGDs Focus group discussions

FIGO International Federation of Obstetrics and Gynecology

FSW Female sex workers

GBV Gender-based violence

ICWEA International Community of Women Living with HIV Eastern Africa

MCH Maternal and child health

MOH Ministry of Health

NACWOLA National Community of Women Living with HIV

PITC Provider-initiated HIV testing and counseling

EMTCT Prevention of mother-to-child transmission

SALT Support on Health Though Telephone Helpline

STI Sexually transmitted infection

SRHR Sexual and reproductive health rights

UNAIDS Joint United Nations Programme on HIV and AIDS

WHO World Health Organization

1. Background

1.1 Introduction

The International Community of Women Living with HIV Eastern Africa (ICWEA) is a registered regional advocacy network and membership-based organization for and by women living with HIV. It was founded in 2005 as part of a global network of women living with HIV, whose mandate is to influence policy change and represent the voices of women living with HIV to ensure that appropriate policies are formulated and programs funded and implemented and address the unique and pertinent needs of women living with HIV.

ICWEA believes that gender inequalities and limited access to sexual and reproductive health (SRH) services, information and rights violations experienced by women is at the core of the HIV epidemic. ICWEA aims to reduce the isolation of women living with HIV and overcome the stigma and discrimination they are subjected to through influencing policy and programs to ensure they take into consideration women's needs and priorities within the human rights framework. ICWEA builds capacities of its membership to understand policy, programming, human rights and gaps related to access and utilization of health services; and to understand issues and challenges that affect women living with HIV and cause women to demand for change and increased access to quality services. ICWEA works to ensure that women living with HIV participate in policy-making processes, programming, service development and research at local, national and international levels.

This work is part of a UNAIDS -funded project entitled, "Certifying Uganda on the Path towards Elimination of Mother-to-Child Transmission of HIV", which is tracking the upholding of human rights, gender consideration and engagement of women living with HIV in Uganda's bid to be certified as having pre-elimination of mother-to-child transmission (MTCT) of HIV. The assessment aimed to enrich Uganda's EMTCT validation process by adding the voices and perspectives of women living with HIV. Hence, this work contributes to the global commitment to the elimination of mother-to-child transmission (EMTCT) of HIV and syphilis using a harmonized approach to improving health outcomes for both mothers and children.

1.2 Rationale

Efforts to eliminate vertical transmission of HIV have been boosted by several initiatives. *The global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive*¹ targeted 22 priority countries for action. This plan set targets for reducing the number of new HIV infections of children and AIDS-related deaths of mothers. In 2012, WHO produced a programmatic update on the "Use of antiretroviral drugs for treating pregnant women and preventing HIV infection in infants"², recommending the provision of ART to pregnant women living with HIV regardless of CD4 count, either for the duration of the transmission risk period (Option B) or for lifelong (Option B+). WHO formalized this recommendation in its 2013 consolidated ART guidelines, while also recommending that ART should be provided in maternal and child health (MCH) settings, allowing easier initiation of ART during pregnancy, delivery and breastfeeding.

Uganda is one the countries that swiftly followed the WHO guidance to move towards offering lifelong ART to pregnant and breastfeeding women living with HIV. The country is on track to eliminate MTCT, having achieved a reduction of 86% in MTCT between 2010 and 2016, reducing the estimated number of

¹ Joint United Nations Program on HIV/AIDS (UNAIDS). Countdown to Zero. Global Plan towards the Elimination of New Infections in Children by 2015 and Keeping Their Mothers Alive, 2011–2015. Geneva: UNAIDS, 2011. Available at: http://www.unaids.org/sites/default/files/media_asset/20110609_JC2137_Global-Plan-Elimination-HIV-Children_en_1.pdf ² WHO 2012 programmatic update: "Use of Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants", available at http://whqlibdoc.who.int/hq/2012/WHO_HIV_2012.6_eng.pdf

children getting the infection from their mothers from 25,000 babies in 2009 to 4000 in 2016. More than 90% of HIV-positive mothers are receiving ART; about 95% ANC clients are being tested for HIV; while HIV transmission at six weeks is estimated at 1%. In 2017 alone, more than 97% of HIV-positive pregnant women³ received ARVs to reduce the risk of MTCT, equivalent to about 115,000 women⁴.

Syphilis remains a global problem. An estimated 12 million people are infected each year, despite the existence of effective prevention measures, such as condoms, and effective and relatively inexpensive treatment options. Pregnant women who are infected with syphilis can transmit the infection to their fetus, causing congenital syphilis, which has serious adverse outcomes for the pregnancy in up to 80% of cases. An estimated two million pregnancies are affected annually; approximately 25% of these pregnancies end in stillbirth or spontaneous abortion. In a further 25%, the newborn has a low birth weight or serious infection – both of which are associated with an increased risk of perinatal death.

Unlike many neonatal infections, congenital syphilis is a preventable disease, which could be eliminated through effective antenatal screening and treatment of infected pregnant women. Elimination of congenital syphilis would reduce the numbers of miscarriages, stillbirths, preterm and low-birth-weight infants as well as and perinatal deaths.

In 2007, WHO launched an initiative for the global elimination of congenital syphilis, outlined in *The global elimination of congenital syphilis: rationale and strategy for action.* This pivotal strategy calls for action in four distinct "pillars":

- (1) ensuring sustained political commitment and advocacy;
- (2) increasing the access to and quality of maternal and newborn health services;
- (3) screening of all pregnant women and treatment of all positive cases and their partners; and
- (4) establishing an underlying foundation of surveillance, monitoring, and evaluation for the elimination of congenital syphilis.

WHO and the rest of the global health community have identified dual elimination of MTCT of HIV and syphilis as a priority. In 2011, WHO set a target to reduce MTCT of HIV by 90% in 2014 and developed global guidance containing integrated processes and criteria for validation of EMTCT of HIV and syphilis.

In 2014, WHO released the global and regional criteria and processes for validation of EMTCT of HIV and/or syphilis⁵ as a public health problem. To qualify, a country had to meet targets for several indicators, including *process* indicators showing high attendance of ANC and high rates of testing and treatment for HIV and syphilis, and *impact* indicators showing low rates of MTCT and an annual child case rate of fewer than 50 HIV and syphilis infections per 100,000 live births. As of October 2017, 11 countries had achieved validation of elimination of MTCT of HIV and/or syphilis and several others are set to follow suit, but these

³ Uganda AIDS Commission (2016) Uganda AIDS Commission (2016) '<u>The Uganda HIV and AIDS Country Progress Report July 2015-June 2016'</u> [pdf]

⁴ Uganda AIDS Commission (2016) 'The Uganda HIV and AIDS Country Progress Report July 2015-June 2016' [pdf]

⁵ Elimination of mother-to-child transmission (EMTCT) of HIV and syphilis: Global guidance on criteria and processes for validation, 2014.WHO http://www.who.int/hiv/pub/emtct-validation-guidance/en/

are largely countries with low and/or concentrated HIV prevalence. Countries with high HIV prevalence rates (with prevalence of 2% or higher), such as Uganda, also aspire to eliminate new infections in newborns, and have achieved some of the indicators, including low rates of MTCT and high coverage of services.

1.3 Objectives

The main objective of this activity was to assess the extent to which eMTCT programme implementation in Uganda meets the human rights, gender equality and civil society engagement considerations (as women living with HIV access eMTCT services) as defined by the World Health Organization (WHO).

The specific objectives were:

- 1) To document the experiences and perceptions of women, living with HIV, with regard to implementation of the Prevention of Mother to Child Transmission of HIV (PMTCT)/Elimination of Mother to Child Transmission (eMTCT) programs in Uganda.
- 2) To document the experiences of women, living with HIV, about access to and utilization of other sexual and reproductive health services, including treatment of syphilis and other STIs.
- 3) To capture the experiences and perceptions of women living with HIV on human rights, gender equality, and engagement of civil society in the eMTCT implementation and validation processes.

1.4 Methodology

This assessment was conducted using a qualitative approach. ICWEA and partners adapted the WHO human rights, gender equality, and community engagement tool to suit the Uganda setting (copy attached to this report). Data were gathered through focus group discussions (FGDs) with different categories of women living with HIV in six selected districts of Uganda, as well as through a consultative meeting with persons living with HIV (PLHIV), and leaders of networks of women living with HIV and key populations for their input into the whole process from the policy, program, funding and practice perspectives.

FGDs were conducted in Tororo district (eastern region); Wakiso (central region); Gulu and Lira districts (northern region); Sheema and Kanungu districts (western region) between Oct 22nd to Oct 26th 2018. The districts were selected purposively to represent and balance the major regions of Uganda, while also giving representation to hard-to-reach districts (Kanungu), and to include key populations (Tororo and Wakiso). It is notable that while Kanungu is considered a hard-to-reach district, it has a relatively succeeded in implementation of the eMTCT program. Tororo and Wakiso are among the districts with higher-than-average HIV prevalence, because of high prevalence of key populations. Tororo is a border district with a busy border crossing point at Malaba that has many sex workers. The metropolitan district of Wakiso also has a high prevalence of sex workers.

A total of 264 women, out of the targeted 270 (99,2%) participated in the FGDs. These were women of reproductive age and had had children in the last 5 years, including women living with disabilities and sex workers, and young women of reproductive age as follows:

District	Category of respondents	Number of respondents
Gulu	Adolescent girls and young women (AGYW) (13), women	49
	with disabilities (14) and older women (22)	
Lira	Adolescent girls and young women (AGYW) (09), women with disabilities (13), sex workers (17) and older women (15)	54

Kanungu	Adolescent girls and young women (AGYW), 16 women	40							
	with disabilities (09), older women (10) and KPs								
	(particularly sex workers) (5)								
Sheema	Adolescent girls and young women (AGYW),(19) women	30							
	with disabilities,(1) and older women (10)								
Wakiso	Older women (16), young women (15) and KPs	43							
	(particularly sex workers) (12)								
Tororo	Older women (16), young women (12) and KPs	48							
	(particularly sex workers) (20)	(particularly sex workers) (20)							
Total		264 out of the targeted							
		270							
Kampala/	Leaders of networks of women living with HIV and key	25							
national	populations								

No.	Districts	Category of respondents	Total Number
1	Wakiso, Tororo, Kanungu, Lira	Sex Workers	54
2	All 6 Districts	Adolescent girls and Young women	84
3	Gulu, Lira, and Sheema	Women living with disability	37
4	All Districts	Older women (above 30 years)	89
		Sub total	264
5	Kampala – National level Networks	Leaders of Networks	25
		Total	289

Participants to the national level consultation came from the following organizations i.e. Alliance of Women Advocating for Change (AWAC); Mamas Club; National eMTCT Validation Committee members; Tusitukirewamu Group; Women's Organization Network for Human Rights Advocacy (WONETHA); CCM Representative for PHAs; CCM Representative for KPs; Uganda Young Positives (UYP); Network of Disabled Women in Uganda; Freedom and Roam Uganda (FARUG); UNESO (Global Network of Sex worker projects); National Community of Women Living with HIV/AIDS (NACWOLA); National Forum of PLHA Networks in Uganda (NAFOPHANU); Uganda Network of Young People Living with HIV&AIDS (UNYPA); Friends of Canon Gideon Foundation (FOCAGIFO); Uganda Network on Law, Ethics and HIV/AIDS (UGANET); The Positive Men's Union (POMU) and the International Community of Women living with HIV Eastern Africa (ICWEA).

Written informed consent was obtained from all FGD participants. The confidentiality of participants has been ensured in this report, although their names and contacts were taken for follow up in case additional information or clarity was required. FGDs were recorded for quality control and to help with accuracy of transcription. Participants were encouraged to freely and honestly share their experiences and opinions, assured of confidentiality, and requested to keep the proceedings confidential.

This report only presents the perspectives of women living with HIV with regard to eMTCT program implementation in Uganda; and their understanding of human rights, gender equality, and engagement of civil society considerations in the eMTCT implementation2. Findings and Discussion

This section summarizes findings from the FGDs with 256 women living with HIV from six districts (Gulu, Lira, Tororo, Wakiso, Kanungu and Sheema), as well as from a meeting with national-level civil society advocates/activists and representatives of networks of women living with HIV in Uganda. The section reflects on the Human rights aspects with a specific focus on laws that impact on women living with HIV and AIDS and the gender inequalities reflected by the laws .

Existing National laws that impact on WLHIV

HIV Prevention and Control Act.

2.1 Non-criminalization of HIV/syphilis transmission

The HIV and AIDS Prevention and Control Act (2014) provides for the prevention and control of HIV and AIDS , including protection, counseling, testing, care of persons living with and affected by HIV and AIDS, rights and obligations of persons living with and affected by HIV and AIDS; established the AIDS Trust Fund; and other matters. Under section 2, the Act provides that (1) A person shall take reasonable steps and precaution to protect him or herself and others from HIV infection; and (2) A person shall use protective measures to protect him or herself and others from infection with HIV during sexual intercourse. The Act does not prescribe a specific penalty for these provisions, but under section 46, it provides that a person who contravenes any provision where no specific punishment has been prescribed shall be liable on conviction to a maximum fine of 240 currency points (UGX 580,000) or to maximum prison term of 10 years, or both.

Disclosure or release of HIV test results is provided for in section 18. Under this section, the Act provides that the result of an HIV test shall be confidential and shall only be released to the person tested. That notwithstanding, the result may be released to a parent or guardian of a minor or person of unsound mind; or (e) "any other person with whom an HIV infected person is in close or continuous contact, including a sexual partner if the nature of contact, in the opinion of the medical practitioner or other qualified officer, poses a clear and present danger of HIV transmission to that person".

Attempted and intentional transmission of HIV are provided for under sections 41 and 43. Under section 41, a person who attempts to transmit HIV to another person commits a felony and on conviction is subject to a maximum fine of 12 currency points (UGX 240,000) or a maximum prison term of five years, or both. Under section 43, a person who "willfully and intentionally" transmits HIV to another person commits an offence and is liable to a maximum fine of 120 currency points (UGX 2.4 million) or a maximum prison term of 10 years, or both.

On the other hand, the Venereal Diseases Act of 1977

The Venereal Diseases Act was inacted in 1977 this law provides for the examination and treatment of persons infected with venereal diseases and for other matters connected therewith or incidental thereto. The Act lists venereal diseases to include syphilis, gonorrhea, cancroid, lympho granuloma venereum, granuloma inguinale and includes sexually transmitted diseases such as nongonococcal, urethritis, trichomoniasis, candidiasis, condylomata acuminata, herpes simplex due to type II herpes virus, molloscum contagiosum, scabies and pediculosis pubis.

Under section 8, the Act states that any person who: "unlawfully or negligently does any act which is and which he or she knows or has reason to believe to be likely to spread the infection of a venereal disease; while suffering from any venereal disease, other than a disease certified by the medical officer of health to be incurable, knowingly harbors that disease; willfully contaminates any other person with a venereal

disease; while detained at a place of treatment, leaves that place without the letter of discharge from the medical officer... commits an offence and is liable on conviction to a fine not exceeding two thousand shillings or to a term of imprisonment not exceeding six months or to both such fine and imprisonment." The Act gives court discretion to consider additional penalty, including an order for the offender to pay all or part of the expenses incurred in the treatment of himself or herself or of any person he or she has "contaminated".

However, awareness of the laws regarding transmission of HIV and syphilis was low among women who participated in the FGDs in comparison to national level advocates and representatives of networks of women living with HIV. During FGDs respondents had an idea about the existence of a law that prohibits deliberate transmission of HIV (because some people were arrested and imprisoned), but did not know about the existence of such a law in relation to the deliberate transmission of syphilis and other STIs. Thus impacting on the emtct program.

In relation to gender-based violence (GBV), respondents indicated that sexual assault cases are considered grave, if the suspected perpetrator is known or established to be HIV-positive. Respondents did not know whether there are specific laws or judicial practices that criminalize non-disclosure of HIV/syphilis status to sexual partners. They only knew and are encouraged (by health care workers) to disclose to their sexual partners; but because of the previous experience – where women have been battered by the partners – disclosure is limited.

At the national level however, respondents were aware that it is a crime to intentionally transmit HIV. There is generally less information on syphilis and its legal and policy framework when compared to HIV. Service providers apparently give emphasis to HIV in line with the national policy on HIV testing and counselling but give relatively little attention to syphilis. Information on syphilis and other STIs is reported to be given to individuals who are already infected and present with a complaint which indicates a knowledge gap.

In addition, the national policy on the management of STIs other than HIV was not clear to the respondents, and as such respondents were not aware whether clients of eMTCT or ART were entitled to free STI testing and treatment. Respondents indicated that STI testing and treatment are not an entitlement and that it either comes at a cost or is dependent on availability of laboratory reagents and medicines. However, the high prevalence of stock-outs of medicines and health supplies means that testing and treatment of syphilis and other STIs comes at a cost by referral to offsite facilities or medicine outlets.

Cases that have been prosecuted for deliberate transmission of HIV or syphilis are few and far between but none related to eMTCT was mentioned. Respondents in Gulu reported two cases related to HIV transmission. In one case, a woman reported a man for infecting her with HIV but this case was watered down by the fact that the man had actually abandoned her for another woman. The case did not proceed beyond police. In the second case, parents of a young woman caused the arrest of her partner, a long distance truck driver, after they learnt that she was HIV-positive. The young woman was not under-age. The "suspect" was arrested and by the time of this survey, the case was in court. Majority of the FGD participants said they had not heard of anyone prosecuted for not disclosing their HIV status or whether they had syphilis. Uganda Network on Law, Ethics & HIV (UGANET) reported that they were currently handling two (2) cases in courts of law for women related to HIV transmission.

Rosemary Namubiru infected a child while trying to administer treatment by an injection, she was arrested and the matter was taken to court but I also heard that the child was found negative – FGD participant in Wakiso.

I heard that one of the clients infected a boy with HIV and was taken to Modikatipe prison. The boy was tested and found HIV positive and the woman was imprisoned. The neighbors found her in that act and took her to police - FGD participant in Tororo

2.2 Voluntary HIV and syphilis testing and treatment

The HIV and AIDS Prevention and Control Act 2014 provides that a person may take a voluntary HIV test if he or she gives his or her informed consent (s.9). A person incapable of giving informed consent may be tested for HIV if his or her parent, guardian, next of kin, care taker, or agent gives informed consent. The Act lists people incapable of giving informed consent to include minors, people of "unsound mind" and those that are unconscious. Consent to an HIV test may be dispensed with if it is unreasonably withheld or in an emergency (s.11). The Act explicitly provides that a person apprehended for a sexual offence shall be subjected to HIV testing for purposes of criminal proceedings and investigations (s.12). A person is also subject to HIV testing under court order (s.14).

The Act provides for three categories of people who are subject to "routine" HIV testing for purposes of preventing HIV transmission: the victim of a sexual offence; a pregnant woman; and a partner of a pregnant woman (s.13). The law does not define what "routine testing" is, but treatment of persons found HIV-positive under this provision is not provided for as mandatory but as a right (s.15).

In the light of these provisions and in the absence of a legal definition of "routine testing", women (respondents) rightly or wrongly perceive that it is mandatory for ANC clients to test for HIV, and others believed that both testing and treatment were mandatory for pregnant women. None of the women participating in this consultation process reported to have been told that she could refuse to have an HIV test. Instead women are told that they must protect their babies from getting HIV by undergoing the test and taking medication if they test positive — and in any case, declining the HIV test means not accessing ANC services. From the reports of respondents, it is notable that the argument given to women for the mandatory testing of HIV is about saving the baby from infection; not much attention seems to be given to explaining the value of HIV testing to the health of the pregnant women themselves. There is nowhere where women have been told that one can refuse the test. Below we quote some of their voices

"I was coerced to have an HIV test... ekyo nekiragiro (that is the rule). They gave me the drugs because the health worker insisted on initiating me on treatment. When I went home, I refused to go back to the facility because of fear and I ended up delivering the baby by self from home. However, when I started falling sick, I went to the health center and I was started on treatment," – AGYW, FGD, Sheema

"The day I was first given ARVs, I did not want them. When I tried to explain to the health workers, she told me that it was the rule and she told me to make sure I swallow it. I had no option but to accept the drugs. However, I was scared about my husband getting to know. I could not keep the medicines in the house; so I decided to hide them in the garden. Unfortunately, it was a rainy season, and after a short while the medicines had changed color," – AGYW, FGD, Kanungu

"People are always sensitized and they are not forced to test. In antenatal it is mandatory and you must go with your husbands," – Woman with disability, FGD, Lira

No health workers test us for HIV whether we like or not – an older woman in Tororo.

To be honest, in the older days it was voluntary but today HIV testing is mandatory – an older woman in Wakiso

In reality, today you cannot be given antenatal care if you have not tested for HIV - Older woman Wakiso

Under the Venereal Diseases Act 1977, testing for syphilis and other venereal diseases is mandatory for whom? The Act (s.5) requires people to submit themselves for medical examination or periodical medical tests for the purpose of ascertaining whether they are suffering from a venereal disease. Under Section 2, the Act provides that "Any medical officer of health may require any person whom he or she knows or reasonably suspects to be infected with venereal disease to submit himself or herself for examination at such time and place as the medical officer of health may direct." The Act gives enforcers of the law powers to enter and inspect any premises in which they have "reason to believe that any person suffering or who has recently suffered from any venereal disease is or has recently been present, and may require such person to submit himself or herself for medical examination... for the purpose of ascertaining whether that person is suffering or has recently suffered from or is a carrier of any such disease."

Under this law, treatment of syphilis and other venereal diseases is mandatory; enforcers have powers to detain the infected person for purposes of treatment; and a person discharged from treatment is required to submit themselves for periodic testing to ascertain whether they are free from the venereal disease. The majority of women participating in the FGDs were not aware whether it was also mandatory to test and treat syphilis, and did not report being told about its necessity.

The Act (s.3) provides that "Where the medical officer of health or health inspector examines a person and finds that the person is suffering from any venereal disease, he or she shall give such treatment as he or she may deem fit to that person; the medical officer of health may direct that while a person is being treated for venereal disease he or she may be detained in such place of treatment as the Minister may prescribe, for such period as the medical officer may determine to be sufficient time for treatment."

The Act (s.4) further requires the person who is currently suffering or has recently suffered from the disease to disclose the contact that infected them. It provides that "A person who, in the opinion of the medical officer of health or health inspector, is suffering or has recently suffered from or is a carrier of venereal disease shall be required to name the person who infected him or her with a venereal disease." Any person who contravenes this provision commits an offence and is liable on conviction to a maximum fine of two thousand shillings or to a maximum prison term of six months or to both.

The results indicate a high prevalence of disempowerment of women and those that participated in the assessment appeared to believe that instructions from health providers cannot be questioned or doubted. That notwithstanding, there was a high level of awareness of the benefits of HIV testing.

2.3 Informed consent

The Consolidated Guidelines for Prevention and Treatment of HIV in Uganda state that HIV testing services (HTS) shall be non-discriminatory and offered using a human rights approach that observes a set of five principles, including the principle of informed consent. The five principles are outlined as (the 5Cs): Confidentiality, Consent, Counselling, Correct test result and Connection to appropriate services —

- 1) Confidentiality: All providers should ensure privacy during HTS provision. All information discussed with clients should not be disclosed to another person without the client's consent.
- 2) Consent: All persons 12 years and above should consent to HTS on their own. In situations where consent cannot be obtained, the parent or guardian (of a child), next of kin, or legally authorized person should consent.

- 3) Counseling: All persons accessing HTS should be provided with quality counseling before and after testing as per the approved HTS protocol.
- 4) Correct test result: HTS providers should adhere to the national testing algorithm and must follow the standard operating procedures (SOP) for HIV testing to ensure that clients receive correct HIV test results.
- 5) *Connect to other services*: Providers should link HTS clients to appropriate HIV prevention, treatment, care and support services.

The Guidelines provide for two approaches to HTS: Provider-initiated HIV testing and counseling (PITC) and client-initiated testing and counseling (CITC). Under PITC, the Guidelines recommend the initiation of HTS by the health worker as part of standard health care. Health workers should routinely offer HTS to all individuals attending health care services with the purpose of better patient management and early HIV diagnosis. This includes patients in all clinical settings (in inpatient and outpatient departments) and all patients whether symptomatic or not. The Guidelines, however, require health workers to prioritize PITC for patients at maternal and child health clinics, adult and pediatric patient wards, TB clinics, family planning clinics, STI clinics, nutrition units, clinics managing survivors of sexual abuse and in HIV care clinics (for partners and family members). They should also assess all patients at OPD for HTS eligibility. PITC will be offered as an 'opt—out' HTS service.

In the context of eMTCT, the policy recommends routine HIV testing and it was reported that all women who get into ANC clinic are tested for HIV; and this almost implies mandatory HTS for all ANC clients. This perception has been reinforced by the HIV and AIDS Prevention and Control Act, which under section 13 provides that "The following persons shall be subjected to routine HIV test for purposes of prevention of HIV transmission – (a) the victim of a sexual offence; (b) a pregnant woman; (c) a partner of a pregnant woman."

From the responses, a few respondents from northern Uganda reported that some private-not-for-profit (PNFP) facilities carry out HIV testing without informing the client and only initiate the conversation if the blood samples test positive for HIV. If the result is negative, the client will reportedly not be informed. Respondents reported that that happens at Lacor Hospital in Gulu. They reported that HIV tests are compulsory for women seeking ANC at Lacor, Gulu Police Health Centre, and Gulu Regional Referral Hospital.

Access to other services is relatively straight forward, as women, including among key populations, reported that they decide freely to use family planning, test and treat STIs, and post-violence services. ANC clients are given information on SRH, including the need for HTS for their partners, infant feeding and nutrition, and preparation for childbirth in group sessions. Information on family planning is given mostly to women seeking child immunization services, also in group sessions, and to mothers who deliver by caesarean section. While the group approach to SRH information and services saves time and gives clients an opportunity to learn from one another, it does not create an environment for personal issues to be discussed. HIV testing for ANC clients is seen as compulsory in public health facilities in Uganda since there is no opt-out, and virtually all respondents in this study knew it to be so, as an entry point to eMTCT. The policy on syphilis testing and treatment was not clear to the respondents.

As far as family planning is concerned, women are in principle given information on available options for them to make a decision. Women reported that after they delivered, they received information and counselling on family planning and its importance, especially to women living with HIV. The majority of participants reported that they freely decided for themselves to have family planning methods after being

educated on the importance of family planning. A few participants indicated that they made a joint decision with their husbands to be initiated on family planning options. None of the participants indicated that parents or their partners made decisions for them to use any family planning method.

"For me as a 'neeko' (sex worker), I decide on my own whether I want to have a child or not. After all, if I don't do that I might end up with a child whose father I don't know. Sexual transmitted infections are common and it is upon me to seek help whenever I get signs. I also make my own decision to use condoms, although some problematic clients pull them off. I know I will not work if I become pregnant," FSW, FGD, Kanungu

However, the participants indicated that many women get unintended pregnancies even when they are on family planning. Some participants report that the options are usually limited, and service providers tend to discourage women on ART from hormonal methods. Women with disabilities reported that they seek the consent of their partners to use family planning, and in a few cases, women with disabilities and women with children with disabilities indicated that they were forced by their partners to use family planning. In Kanungu, a woman who had given birth to a baby with a disability was forced by her partner to "stop giving birth because he did not want disabled children anymore". Another said, "He forced me to go for family planning because of my disability so that I do not conceive again."

"Women who are on ARVs are mostly given IUDs because health workers tell us that injectable and implants interfere with ARVs," AGYW, FGD, Sheema

"Regarding use of family planning, sometimes the decision is by health workers and sometimes it is made by us. However, the health workers recommend and insert in majority of the women IUD because they said it is better for women living with HIV," – AGYW, FGD, Wakiso

"The IUD betrayed someone and as such she can't go for it. She was on IUD but conceived. Some health facilities decide which method to use because they think women living with HIV cannot make any decision. And some health workers have ended up terminating women's pregnancy," — AGYW, FGD, Kanungu

"We are not encouraged to go on FP services except condoms because we are told at the referral hospital that taking pills and other FP methods may complicate our situation further since they are on ARVs," – woman with disability, FGD, lira

On GBV, women report that they go to health facilities on their own when they experience violence. They make their own decision. However, in the case of sexual violence (rape and defilement), the decision to seek services is beyond their control if the case goes to police.

"I was raped, then I was taken to the police, I was referred for medical examination, at that time, I was HIV negative, but the health worker gave me drugs for people living with HIV which I swallowed for almost a month. My mother took me for another HIV test, I was still negative," – AGYWN, FGD, Kanungu

2.4 Forced, coerced and otherwise involuntary sterilization, contraception and/or abortion

Uganda does not have a Policy, Law or Act that promotes and/or enforces forced, coerced and otherwise involuntary sterilization, contraception and/or abortion. The available policies, laws or acts and related documents promote and/or expect practitioners to ensure informed consent for clients wishing to either go for sterilization or use any form of contraception. However, there are reports of forced and/or coerced sterilization of women living with HIV (ICWEA June 2015); where it was indicated that of the 72 women living with HIV of reproductive age who underwent sterilization, 18 of them had been forced and/or

coerced. It is especially common for HIV-positive mothers with disabilities, who reported that they have faced pressure from relatives and health providers against child-bearing. They felt that this pressure comes from the fact they are themselves already a burden to their families or caregivers. According to our finding and particularly for Gulu and Lira, where the civil war left many people maimed and abused, the reports indicate a relatively higher prevalence of forced sterilization and contraception. Even cases where the women are not coerced, they reported that their caregivers have initiated the conversation around stopping or avoiding child birth.

National-level respondents were aware that the Penal Code Act (Chapter 120 of the Laws of Uganda) criminalizes abortion, except when conducted to save the life of the mother. The recently launched National Sexuality Education Framework, restricts access to SRHR information by young people. It was noted that the national legal and policy framework on sterilization, contraception and abortion are not as progressive as it is at the regional and international levels, including the Maputo Protocol, the International Federation of Obstetrics and Gynecology (FIGO) Protocol, and the WHO guidelines on SRHR for women living with HIV. Indeed, Uganda has a reservation on Article 14 of the Maputo Protocol which recognizes abortion under certain circumstances as a human right of women.

Coerced abortion is reported to be rare in the communities reached. Abortion is widely perceived to be illegal in Uganda. In the study communities, while prevalent, abortion is clandestine and tends to be a personal decision because socially it is viewed as a taboo and society is reportedly always willing to embrace children.

"We need fairness over the issues of reproductive health because if one induces an abortion and you are found, you end up in prison even if the abortion was unsafe. The problem is that it requires a lot of money for a safe abortion; they will not do it below half a million shillings," — AGYW, FGD, Sheema

"There was a case where a woman with disability had her pregnancy terminated because they thought she cannot manage to carry the pregnancy to full term." – AGYW, FGD, Sheema

It was further reported that it is a common practice for health workers to emphasize long term family planning methods for some categories of mothers they deem have limited capability to care for children, those that deliver by C-section, and those living with HIV.

"Nowadays, it has been decided especially for those who go through the theatre to have family planning inserted... (the method) it is decided by the health worker. Women were told this in a meeting at ICOBI before the election of Dr Elioda in September 2018. That if one is delivered by scissor, you are discharged with one method of family planning which ever it may be either IUD, implant, etc.," AGYW, FGD, Sheema

"Even some of us who are here, have been forced to use IUD because we are on ARVs. I can share my experience: When I went to the health center for family planning methods, the care giver told me that I was going to be put on IUD. I refused and explained that I had ever heard that IUDs increases a woman' risk to infections. The health worker insisted that IUD was the best option for me. I had no choice but to accept," – AGYW, FGD, Kanungu

Health workers wanted me to terminate my pregnancy, but I informed them that I needed to consult my husband; but they asked me if my husband will help me carry the pregnancy - Young woman in Wakiso

My husband forced me to abort because he was tired of children who are girls - Older woman from Wakiso

I have a right to decide by myself on the use of contraception because I know the number of children that I want - Older woman in Wakiso

My husband forced me to abort and even on my last day at the health facility I was told by a health worker to get sterilized because I have many children - Sex worker from Wakiso

You decide with your husband. I told him that I didn't want another baby so we decided to stop -Older woman Wakiso

Most of the respondents knew their colleagues who had been coerced into sterilization; and scenarios where friends, relatives and health care workers initiated talks related to sterilization. Respondents at the national level also cited recent reports that have documented such cases: Report on forced and coerced sterilization by ICWEA; Report on abortion by CEHURD; and the stigma index report by NAFOPHANU. In Kanungu, women with disabilities reported that they are often coerced into contraceptive use because of their vulnerability to sexual violence and abuse. This practice is mostly promoted by parents and relatives, and not necessarily health providers.

2.5 Confidentiality and privacy

Respondents agree that there are laws, regulations and/or policies that require confidentiality and non-disclosure of HIV status in health-care settings. These include the HIV Counseling and Testing Policy, the HIV Prevention and Control Act, the Patients Charter, as well as the providers' professional codes of ethic and the Hippocratic Oath.

However, respondents at the national level cited recent reports of disrespect of privacy and confidentiality in health-care settings including NAFOPHANU's stigma index report (2013), respondents at the district level generally felt that their information was being kept well – the confidentiality of their medical records did not seem to be a major worry. Nevertheless, this assessment found that the ART client files are accessible to all health workers at health facilities and are not restricted to clinic staff. It was also observed that ART client files at one site were kept in a multi-purpose room that is accessible to even non-ART clients.

The major worry for FGD participants was about health workers who reside in the community. The worry is that these could be a source of gossip about the HIV status of eMTCT or ART clients, and their behaviors.

"Not all health workers, because some of us are no longer getting medicine from Kabwohe because the health workers are often asking individuals in the markets why some of us have not gone to the facility to pick their drugs," AGYW, FGD, Sheema

"There are times some counsellors come to the community looking for clients especially those who are lost at the facility," AGYW, FGD, Sheema

"Some health workers gossip about clients who are sex workers. They tend to be disgusted when you keep going back with STIs. That is how they know... they get to know when you go to the hospital with an STI and next time you are complaining about the same thing... when that happens they will ask you where you got it from and you are forced to tell her what you do. Such a health worker cannot keep a secret," FSW, FGD, Kanungu

"Fellow clients in some cases stigmatize us in the community. They go around telling people in the village how they found you at the clinic," – Woman with disability, FGD, Gulu

Our information is not confidential, because one time I went to a health worker to collect my ARVs and she asked me about a person that I didn't know was positive - Sex worker in Tororo.

Our information is kept confidential - Young woman Tororo.

A second concern regarding breach of confidentiality is with respect to clients who default on their appointments and service providers or peer leaders have to visit them or go asking for their whereabouts in the community. The third concern is about the disposal of medical records, for whatever reason. Respondents cited media reports that have in past indicated that wastepaper with medical records of HIV care clients had been used to wrap snacks sold on Kampala streets.

While the confidentiality of medical records is less of a worry to most respondents, there was a major concern about privacy. Most ART/eMTCT sites have a common area where they serve clients. Some of the service points are open sheds and clinics are scheduled on designated days. This makes it easy for the confidentiality of clients' status to be compromised by the community or fellow clients who see them at the clinic.

2.6 Equality and non-discrimination

Respondents agreed that the legal and policy environment guarantees equality and non-discrimination, including the Constitution of Uganda, the Employment Act, and the Equal Opportunities Act. Children are well catered for by the Constitution and the Children's Act. National policies and laws have however, not specifically provided for equality and non-discrimination in respect of key populations. In Uganda, homosexuality is outlawed by Section 145 of the Penal Code Act, Cap.120 under 'Unnatural Offences'. However, there are policies that have been drafted to guarantee access to services. Even then, respondents report documented cases of discrimination, disrespect of privacy and confidentiality in health-care settings, citing reports by HRAF, Stigma Index reports, Chapter Four reports and gender assessment reports.

Respondents participating in district-level FGDs generally perceive equality and non-discrimination to be fairly observed at HIV care sites. Equality at the facility is generally perceived to exist in terms of medicines and waiting time/queuing, except for stigmatized populations, such as known sex workers and sexual minorities. Nonetheless, respondents report that people with status, wealth or in emergencies, worrying condition or those who pose a danger to other clients if they queued up, are justifiably given priority. Women further report a growing practice of prioritizing women who are accompanied by their partners for ANC, a tendency to discriminate against other women who for different reasons cannot bring their partners with them.

"I reached at the health center early in the morning. I joined the queue like others. Some of the clients who arrived late but with their husbands, joined the queue for a short time, then they were called to go and see the doctor. They even left us at the health center. I felt bad. Some of us have begged our husbands to come but they refuse. We end up suffering at the health center. One gets double torture, at home and at the health center," – AGYW, FGD, Kanungu

"I arrived early at the health center. However, I saw the client who came late talking to one of the health workers and giving the health worker money. The health worker guided the client to join the queue and sat. After very short time, the same health worker came for the client and they went together. The next time I saw that client, he had his drugs and was leaving the health facility. I regretted why I was poor," – AGYW, FGD, Lira

"I tell you, sex workers experience a lot of discrimination. Sometimes the health workers demand that we go with our husbands. For me as a sex worker, when you demand that I bring a husband, what do you expect, I go to the facility well knowing that I am not married but I want a child. To make the matters worse, the health workers sometimes demand for a letter from LC to confirm that we are single parents or married but the husband is not around. This stigmatizing practice is what we hate," — FSW, FGD, Tororo

Respondents among women with disabilities felt that it is unfair for service providers not to give them priority given their challenges. In one case, it was reported that a woman with a physical disability had to wail loudly to catch the attention of service providers after being frustrated for long hours of trying to get to the service point. There have been reports of women with disabilities being rebuked by health workers when they get difficulties climbing delivery beds that are not disability-friendly. Similar reports resurfaced in this survey. In another case, one client, a woman with a hearing impairment was not appropriately attended to at Gulu RRH because no one understood her.

"Women with disabilities experience unique challenges; the deaf and dumb are worse off. No one cares... Those with physical disability get challenges at the time of delivery. Some can't climb the beds. The health workers bark at them and even rebuke them for having become pregnant," — Woman with disability, FGD, Kanungu

Other reports were of unprofessional behavior and outright indiscipline. One woman was reportedly ignored altogether because health workers overheard a conversation she had with a relative who came to visit during which she seemed to indicate that she had not been well-attended to. In another case, a woman in Kanungu was not attended to in a health facility, and fearing for the worst, she decided to relocate to another health facility. Unfortunately, she delivered the baby along the way and it died.

2.8 Accountability, community engagement and participation of people affected by HIV and other key populations

Respondents reported that the legal and policy framework on ensuring accountability in relation to eMTCT, community engagement, participation and greater involvement of people/women affected by HIV is in place. The HIV and AIDS Prevention and Control Act emphasizes the importance of HIV testing under different circumstances. The eMTCT Policy encourages ART in pregnancy so as to eliminate MTCT and promote the health of the mother (Option B+), encourages voluntary counseling and HIV testing, as well as safe infant feeding. While affected communities may be participating in policy formulation and program design, implementation, monitoring and evaluation, results indicate that this is not known by the broader grassroots communities, including many of the FGD respondents. Responses at the national level indicate that networks of women living with HIV have been fully involved in eMTCT policy debates, policy formulation and monitoring. AWAC has analyzed policies and the impact they have on youth and has developed position papers in regards to eMTCT laws and commitments; UNYPA has been active in fighting stigma among young pregnant women living with HIV to access eMTCT services at health facilities; ICWEA has published policy briefs and reports on eMTCT programming and implementation and undertaken advocacy for the rights of women living with HIV; while UGANET, Mildmay (under DREAMS initiative) and other organizations have played roles. However, awareness on this involvement was found to be poor among respondents at sub-national and lower levels. They were for instance, not aware of the change of policy regarding prescription of septrin, and had all along regarded it as a stock-out problem.

Service recipients have further contributed to the implementation of the ART program. Clients who have been on treatment for a while, demonstrated commendable adherence, live positively and are willing to reach out to other PLHIV have been recruited as "Expert Clients". They volunteer to support at triage and in the filing rooms. They also provide peer support by giving health talks to their peers, sensitize the

community on HIV, mobilize people for HIV services, follow-up HIV care clients and provide adherence support.

2.9 Gender-based violence

Uganda has laws and and policies prohibiting gender-based violence (GBV). These include the Domestic Violence Act 2010 and its regulations; the Constitution; the Penal Code Act; the GBV Policy; the National Gender Policy and the National Action Plan on Gender. There are also frameworks for responding to violence against women: The National Strategic Plan on HIV (2015 – 2020); the Constitution (with limit to *pro bono*); and the Local Council Courts and Courts of Law. Some local governments also have by-laws on GBV. In Lira, the GBV Ordinance of 2007 addresses the wellbeing of all persons to be treated fairly and for survivors to access justice, especially at the local level. The relationship between GBV and Emtct is known, according to

The laws are there but because we are female sex workers, we fear to report because of the way we shall be treated – female sex worker in Tororo

In spite of these frameworks, the results indicate a high prevalence of all forms of gender-based violence (GBV), including physical, economic, emotional and sexual violence in the survey communities. Overall, wife beating is considered normal, common and justified, especially if no major injuries are inflicted. In the districts of Gulu and Lira, respondents reported that it is common for men to beat women for denying them sex and for questioning the whereabouts of proceeds from a harvest. In Kanungu and Sheema, respondents reported men talking away women's property and throwing away women's medication.

Sexual violence among the category of respondents seems more pronounced in cases of discordancy – and especially where the woman is HIV positive and the man is either negative or of unknown status. Respondents reported disclosure to be a major challenge in their communities. This study came across only one case of an HIV-negative man in Sheema who was supportive of his HIV-positive spouse. Otherwise, most stories were of women being abused, battered or abandoned because of their HIV-positive status.

Sexual violence is reported both within and outside homes. The responses indicate that communities do not consider defilement to be a crime if the victim has not been infected with HIV or been impregnated. In such cases, parents are reportedly willing to negotiate a settlement, usually involving an exchange of money or valuables. Respondents indicated that cases that are pursued through the justice system are normally those that involve HIV-positive perpetrators and victims that have conceived.

It was noted that GBV cases are settled informally or even ignored even though they are criminal. Respondents showed they had a good idea of where to report GBV-related cases, but do not have confidence in justice institutions, particularly the police, to deliver justice due to their reputation of corruption, inefficiency, lack of capacity, poor discipline and negligence.

It was also apparent that people are resigned to GBV. The mentality is that it has to be grave for it to be reported. In some cases, it is perceived as a demonstration of love, and hence acceptable. Respondents indicated that people do not have enough information on how they should respond to GBV and GBV-related stigma. There is a widespread feeling that GBV is inevitable. Respondents cited institutional barriers to access the GBV response mechanisms. These include the HIV law, case backlog, Anti-Pornography Act; the NGO Act; and the Sexual Offences Bill.

2.10 Availability, accessibility, acceptability and quality of emtct services

Existing laws and policies on ensuring availability, accessibility, acceptability and quality of eMTCT services are not inclusive and comprehensive to cater for sexual minorities. HIV services are only available at

Ministry of Health accredited sites and other private for profit and not-for-profit accredited health facilities. While ART was more restricted to HC IVs, eMTCT services were devolved to facilities providing maternity services, with the lowest level being HC III. However, the responses indicate that commodities are not always available, particularly second and third line ARVs, prophylaxis medicines and medicines for opportunistic infections. The country has particularly experienced a prolonged stock-outs of septrin (though has been phased out of recent and restricted to a few clients). Nevirapine, which is key in EMTCT was reported to have been intermittently available in Sheema district. First line ARVs were reported to be always available, even though shortages have meant that clients are given short period refills.

Availability of second line and third line ARVs has been a bigger challenge. With regards to FP, commodities have been limited in range, and restricting choice. Respondents report that long term methods are inserted by third parties for free during outreaches, but are removed at a fee by service providers who operate far away.

Physical accessibility is challenged by the long distances some clients have to travel to get to service centers. Respondents reported that some clients have to spend as much as Ushs 20,000 to reach service points. In terms of economic accessibility, HIV care services, including eMTCT, are by policy provided free of charge. However, clients could incur a plethora of auxiliary costs, including for diagnosis and treatment of STIs, some of which are predisposing factors for MTCT of HIV. In one case of one service provider, clients reportedly pay Ushs 10,000 per year, while at another, clients pay Ushs 2,000 per visit.

"Transport costs are high, ranging between 5,000 to 15,000 Ushs. At Lacor, we pay 5,000 Ushs service fee; at TASO, it is 2,000 Ushs. And sometimes we have to pay a small service fee called 'TASO friend' which is 10,000 Ushs per year," – AGYW, FGD, Gulu

PWDs say they cannot afford such charges, even though they seem nominally low. Key populations report that friendly services remain few and far between, with the main clinic being MARPI in Kampala and dropin centers being scanty and non-functional. Access is also affected by lack of information, including inability of service providers to communicate with their clients.

"Most doctors cannot communicate with some of us who are deaf. When you go to the health facility, the service provider is struggling to understand the client and the client is struggling to explain herself. In the end no one has understood the other and then the doctor writes and you have no idea what he has written. We need to have sign language interpreters within the hospital setting or get the health workers to learn sign language in medical school," — woman with disability, FGD, Gulu

Stigma and discrimination remains a challenge for KPs and AGYW at community, family and institutional level. The government is implementing provider-initiated HTS and any form of counselling (pre- and post-test counselling) is for those newly identified HIV positive. Counselling and psychosocial support is for those living with HIV and rarely for syphilis positivity. Infant-feeding guidance is available but information is given in group sessions and not in one-on-one sessions. Services or assistance for women with disabilities is very rare; all services are open (there is nothing like services for indigenous /local women). On quality of services, the main concerns were on the shortage of counselling skills and fewer health workers that understand key populations.

2.11 Access to EMTCT and maternal health services for special populations

As already mentioned, respondent knowledge of the law is limited. There was an indication that they know about a law against homosexuality, but did not know what it is called and the status of its implementation. Initiatives for special groups are in their infancy in Uganda's HIV programming. From the findings, attendance to special groups has been both structured and ad hoc. For AGYW, respondents in

Gulu and Lira report that there have been school visits by health facilities and non-governmental HIV service providers.

Responses indicate that several key populations are not understood by respondents and are not known to have special attention, including women who use drugs; lesbian, bisexual and queer women; and transgender people.

Among the respondents, the better known KPs are sex workers, who receive services at MARPI clinic at Mulago National Referral Hospital. Unfortunately, respondents report that some of MARPI's off-site drop-in centers are not functional. Gulu was noted as having "many" organizations providing moonlight services (testing, referral for STI screening, ART, family planning and condoms) for sex workers.

2.12 Access to justice, remedies and redress

Access to justice for GBV cases is generally limited. There is a general lack of confidence in the justice institutions to deliver justice in GBV cases for several reasons. Respondents indicated that the community generally considers the police and judiciary to be corrupt institutions that are bent on taking bribes from suspects. Some FGD participants felt that survivors of GBV do not access justice because communities have generally tolerated violence and blame survivors. Women are reported subjected to physical violence when asked about proceeds from harvests, or question the sense of spending money on alcohol when the household does not have basic necessities.

"Men here (northern region) can beat you properly for any reason, such as not giving you sex and when you ask them for money they got after they have the sale of the harvest. They will force you to have sex even when you do not want, unless you want a beating," – woman with disability, FGD, Gulu

However, some responses indicated that police are under facilitated to undertake investigations and follow up cases. It was also alleged that policemen abuse suspects. There was a feeling that police and community take some GBV cases lightly, unless they involve grievous harm, HIV transmission or pregnancy. Legal aid organizations are reported to be playing a critical role, especially in northern Uganda, to supporting survivors of GBV to report cases, access psychosocial support and justice.

"We report to FIDA, Action Aid, and their empowerment groups like WELGAI. We report to the police last because we fear them, they are corrupt and require bribes to attend to all cases," – woman with disability, FGD, Gulu

It was also apparent that respondents have limited access to information and hence, did not understand the roles of some justice institutions, such as the Probation and Welfare Office. Responses also indicate a general fear of police, frustration and limited knowledge of how key justice institutions work. For instance, respondents reported that communities get frustrated whenever police release suspects soon after they are arrested. The human rights subject is never discussed at the health facilities; neither are there initiatives to sensitize communities on their human rights.

Key lessons learnt

- There is noticeable misinterpretation of some terminologies as used in the health care setting like test and treat taken to mean that newly identified HIV positive clients are compulsorily and immediately started on HIV care and treatment services. Routine HIV testing is mistakenly taken to mean mandatory HIV testing yet clients have the mandate to refuse HIV testing. Health care workers usually convince pregnant and lactating mothers that HIV testing is in the interest of saving the unborn or breastfeeding children/infants; but forget to inform them that HIV testing is also good for them.
- There is a thin line between the human rights for people seeking health care services and the mandate of health care providers to execute their mandate including saving lives or providing services deemed

- necessary for the one seeking care; when in actual sense and at that material time the client does not appreciate the essence
- The cultural and opinion leaders' opinions are at times interpreted to mean and/or can cause gender based violence; yet some opinions are implemented in the interests of the affected mother.
- People who live in urban centers and/or towns are more familiar with the laws, policies and practices
 that govern provision of eMTCT of HIV and syphilis than their rural setting counterparts. Rural setting
 respondents for this assessment did not most of the laws, policies and practices that govern provision
 of eMTCT of HIV and syphilis

3. Conclusions and Recommendations

3.1 Conclusions

The conclusions are contained in the table below

		Yes	No	Unable to verify	Comments
1	Non-criminalization of HIV,	syphil	is transmis	sion	
	Are there laws that criminalize any of the following acts?	Y	N	U	
	a) potential or perceived exposure to (1) HIV?	Yes	N	U	Whereas Section 41 and 43 of HIV and AIDS Prevention and Control Act, 2014 criminalizes attempted and Intentional transmission HIV respectively, the level of knowledge on these provisions by the eMTCT beneficiaries at national and local levels varies. The FGD participants at the grassroots had very low knowledge about it whereas the FGD participants at national level were very informed about it
	(2) Syphilis?	Y Yes	N	U	The eMTCT beneficiaries at national level were informed of Section 8 (1) g of the Venereal Diseases Act, 1977 that criminalizes transmission of Venereal diseases. However, all the FGD participants at grassroots level were ignorant of this law
	b) Are there specific laws or judicial precedents that criminalize non-disclosure of HIV/syphilis status to sexual partners?	Y Yes	N	U	HIV specific law, section 41, provides that a person who attempts to transmit HIV to another person commits a felony and shall on conviction be liable to a fine of not more than twelve currency points or imprisonment of not more than five years or both
	c) Are there prosecutions for non-disclosure, exposure or transmission of (1) HIV?	Y Yes	N	U	Section 43, provides that a person who willfully and intentionally transmits HIV to another person commits an offence, and on conviction shall be liable to a fine or not more than one hundred and twenty currency points or to imprisonment for a term of not more than ten years or to both

	(2) syphilis?	Y Yes	N	U	(1) Any person who—unlawfully or negligently does any act which is and which he or she knows or has reason to believe to be likely to spread the infection of a venereal disease (g) contravenes any of the provisions of this Act, commits an offence and is liable on conviction to a fine not exceeding two thousand shillings or to a term of imprisonment not exceeding six months or to both such fine and imprisonment.
2	Voluntary HIV and syphilis	testin	g and treat	ment	
	a) Are there laws or judicial	prece	dents, regi	ulations and	I/or policies prohibiting any of the following during antenatal care?
	Mandatory testing for HIV and syphilis?	Y Yes	N No	U	Section 12, of HIV and AIDS specific law provides that "a person who is apprehended for sexual offences shall be subjected to HIV testing for purposes of criminal proceedings and investigation. This law directly affects female sex workers who are also beneficiaries of eMTCT since sex work is illegal
					This law also provides that the following persons shall be subjected to routine HIV testing for purposes of preventing HIV transmission i.e. The victim of sexual offences; The pregnant women and The partner of pregnant women
					On the other hand, approved national Consolidated Guidelines for HIV prevention and care and treatment provides for dual testing of HIV and Syphilis for pregnant mothers and differentiated HIV testing services approaches and models which are tailored to the needs of the clients. However, at the ANC clinics, there is a mismatch between the provisions in the national policies/guidelines and practices at the health care settings as was reflected during the FGDs that were held with eMTCT beneficiaries.
	Mandatory treatment for HIV and syphilis?	Y Yes	N	U	Whereas the national policies e.g. Test and Treat which is part of the Consolidated HIV testing and care and treatment describes the procedure for HIV and syphilis treatment initiation which is supposed to respect human rights to informed and with consent, the FGD participants revealed that the practice is different from the policy provision. Initiation for HIV treatment especially among the pregnant mothers at ANC clinic was revealed to be coerced and or forced by the health care providers.

	b) Are women/pregnant women informed that they have a right to refuse testing or treatment for HIV or syphilis?	Y	N NO	U	The FGD participants revealed that HIV testing and treatment initiation for pregnant women who test HIV positive is mandatory. This shows that there is a mismatch between the policies/guidelines and the practice.
	c) Are there recent documented reports of mandatory testing and/or treatment of women/pregnant women for HIV and syphilis?	YES	N	U	 UGANET report, 2017 on Mandatory testing of the workers by the Chinese company commonly known as CCCC Mandatory testing of health workers as a pre-requirement to be eligible for recruitment for Libya deal Uganda Labor laws that subjects the UNIFORMED to mandatory HIV testing as a requirement for being eligible for enrolment.
3	Informed consent	1		1	
	a) Are there laws or judicial precedents, regulations and/or policies requiring informed consent directly from women and key populations in the maternal and child health (MCH) setting (including FP, SRH, STI, GBV, HIV C&T, ART and other HIV services)?	Y	N NO	U	 Section 9 of HIV specific law provides that a person may take HIV test if he or she gives his or her informed consent. However, the same law provides for other models of HIV testing especially provider-initiated HIV testing which was interpreted by the FGD participants that its mandatory HIV testing because of the way its implemented at the ANC clinics. The Domestic Violence Act 2010 gives various institutions the jurisdiction to handl domestic violenc cases. The institutions range from local council courts, police, and magistrates to health workers. KPs, especially sex workers, when convicted for sexual offences are subjected to mandatory HIV testing. Sex work in Uganda is illegal as provided for in the Penal Code 1957. Sections 138 and 139 of Uganda's Penal Code Act of 1950 criminalize prostitution. Under Section 138, a "prostitute" is defined as a person "who in public or elsewhere regularly or habitually holds himself or herself out as available for sexual intercourse or other sexual gratification for monetary or other material gain." Under Section 139, any individual engaged in selling sex can be imprisoned for up to seven years. The Penal Code (Amendment) Act, 2007 prohibits rape and defilement

	b) Are there laws or judicial precedents, regulations and/or policies recognizing and protecting adolescents' right to freely decide whether or not to receive health services/treatment without parental/guardian consent?				There is a National Policy Guidelines and Service Standards for Reproductive Health Services. Where the national policy guidelines and service standards for reproductive health services is operational, there is lack of national adolescent health policy The national SRHR Policy was withdrawn and it is being revised, Sexuality education framework 2018 was watered down
	c) Are there recent documented reports of violation of informed consent of women and adolescents accessing EMTCT and other HIV/SRH services? (including third party authorization requirement from husband, partner or parent)	Y	N	U	ICWEA report, 2014 entitled "forced and coerced sterilization of women living with HIV in health care setting revealed forced access to contraception on the basis of HIV status
4	Forced, coerced and otherv	vise in	voluntary	sterilizatio	n, contraception and/or abortion
	a) Are there laws or	Υ	N	U	
	judicial precedents, regulations and/or policies prohibiting forced, coerced and otherwise involuntary sterilization,		NO		

	contraception and/or abortion?				
	b) Are there recent documented reports of involuntary sterilization, contraception and/or abortion (without the consent of women living with HIV or syphilis)?	Y	N	U	ICWEA report, 2014 entitled "" Violations of sexual and reproductive health rights of women living with HIV in clinical and community settings in Uganda revealed forced access to contraception on the basis of HIV status
5	Confidentiality and privacy				
	a) Are there laws,	Υ	N	U	The HIV specific law, provides for confidentiality and privacy.
	regulations and/or policies that require confidentiality and nondisclosure of HIV status in health-care settings?	YES			The updated consolidated guidelines on HIV prevention and care and treatment, 2018
	b) Are there recent documents or reports of disrespect of privacy and confidentiality in health- care settings?	Y YES	N	U	The Sunday Vision, April 17, 2016 under the headlines "HIV patients details leak"
6	Equality and non-discrimina	ation		•	
	a) Are there laws or judicial specific provisions on:	prece	dents, re	gulations ar	nd/or policies that guarantee equality and non-discrimination, which include
	(1) sex and/or gender equality	Y YES	N	U	Article 21 of the Constitution of the Republic of Uganda protects equality and freedom from discrimination. The article provides as follows: "(1) All persons are equal before and under the law in all spheres of political, economic, social
	(2) HIV and syphilis status;	Υ	N	U	and cultural life and every other respect and shall enjoy equal protection of the
	(3) children	Υ	N	U	law.

	(4) key populations, and call for the elimination of discrimination?	Y	N NO	U	Whereas the Constitution of the Republic of Uganda guarantees the right to equality, the Penal Code, 1950 prohibits same sex relationships, sex work; the Penal Code Act of 1950 (Chapter 120) (as amended) Section 145 on Unnatural sex provides that "Marriage between persons of the same sex is prohibited; The Uganda's "narcotic drugs and psychotropic substances (control) act" which criminalizes use of illicit drugs
	b) Are there documented cases or reports of discrimination, disrespect of privacy and confidentiality in healthcare settings?	Y YES	N	U	Stigma Index report, 2014 (Please refer to recent SI report from 2018) ICWEA report, 2015 entitled "Violations of sexual and reproductive health rights of women living with HIV in clinical and community settings in Uganda UGANET report, 2017 on discrimination at work place based on HIV status
7	a) Are there laws, regulations and/or policies on ensuring accountability in relation to EMTCT, community engagement, participation and greater involvement of people/women affected by HIV?	engag Y YES	ement an	d participat	 Updated Consolidated HIV prevention, Care and Treatment guidelines, 2018 HIV and AIDS Prevention and Control Act, 2014 EAC HIV and AIDS Prevention and Management Act, 2013 2002 United Nations General Assembly - Special Session on HIV and AIDS signed by the GOU
	b) Are networks of women living with HIV involved in the development and evaluation of national laws, regulations, policies and plans for prevention of mother-to-child	Y	N	U	The level of participation varies between national and local levels. Whereas the national level FGDs revealed that networks of women living with HIV actively participate in the development and evaluation of national laws, regulations, policies and plans for prevention of mother-to-child transmission (PMTCT) programmes, the FGD participants at the grassroots indicated that their participation was on the service recipient side

transmission (PMTCT) programs?				
c) Does the national annual PMTCT progress report include civil society/community analysis of progress? (it is not clear which report is meant here?	Y	N NO	U	There is no record that civil society/community analyzed eMTCT progress reports in Uganda
d) Is feedback from civil society/community reflected in revised national PMTCT operational plans?	Y	N NO	U	It could be there because the government and development partners are supporting Family Support Groups at the eMTCT clinics; but because of lack of systematic approach to this, it is not easy to document
e) Do facilities have accountability mechanisms (such as community dialogues or health committees, charters, scorecards) to support efforts at improvement of PMTCT services?	Y YES	N	U	The following accountability mechanisms exist to support efforts at improvement of PMTCT services i.e. establishment of HUMCs/health committees; suggestion boxes at some health facilities, existence of DAC, SAC and PAC; support for community dialogues through family support groups; representation in technical working groups; representation in eMTCT community engagement committee; representation on CCM and partnership committee

	a) Are there laws, regulations, policies or judicial precedents prohibiting or banning all forms of violence against women and girls?	Y YES	N	U	Article 21 of the Constitution of the Republic of Uganda protects equality and freedom from discrimination. The article provides as follows: "(1) All persons are equal before and under the law in all spheres of political, economic, social and cultural life and every other respect and shall enjoy equal protection of the law. Article 33 of the Constitution of the Republic of Uganda provides that women shall be accorded full and equal dignity with men. Domestic Violence Act, 2007 Penal Code Act, 1950 prohibits defilement and rape Prohibition of Female Genital Mutilation Act, 2010
	b) Are there national plans of action and/or a policy for prevention of and response to violence against women?	Y YES	N	U	National gender policy 2017 Gender Equality Strategy 2014 - 2017 National HIV and AIDS Strategic Plan 2014/15- 2019/2020
	c) Are there recent documents or reports of violence against women?	Y	N	U	National Demographic and Health Survey, 2016 MoGLSD report, 2017 entitled The National Violence Against Children report ICWEA report, 2015 entitled Violations of sexual and reproductive health rights of women living with HIV in clinical and community settings in Uganda
9	Availability, accessibility, a	ccepta	bility and	quality of	services
	a) Are there laws, regulations and/or policies or judicial precedents on ensuring availability, accessibility,	Y YES	N	U	 Updated Consolidated HIV prevention, Care and Treatment guidelines, 2018 HIV and AIDS Prevention and Control Act, 2014 EAC HIV and AIDS Prevention and Management Act, 2013

acceptability and quality of PMTCT services?				
b) Do PMTCT programmes have strategies to address common barriers to access that women living with HIV and their families face, such as:	Y YES	N	U	Updated Consolidated HIV prevention, Care and Treatment guidelines, 2018 provides for differentiated care and treatments which is tailored to the needs of the people living with HIV. It provides for community and facility based models for stable and unstable clients
(1) Are there frequent stock-outs of medicines?	Y	N	U	The following stories give highlights to the challenges of drug stock outs in Uganda https://observer.ug/news/headlines/55709-arvs-stock-out-sparks-fear-of-mass-drug-resistance.html http://196.10.119.130:83/unasowebsite/wp-content/uploads/2015/11/Drustock-out-hits-Uganda-Newvision-1.pdf https://www.heps.or.ug/projects/citizen-engagement-stop-medicine-stock-outs
(2) Are there signs of stigma and discrimination in health-care settings?	Y	N	U	The most affected are key populations and priority populations such as sex workers, drug users/injectors, lesbians, adolescent girls and young women
(3) Are there costs for testi	ng and	d/or treat	ment?	
a) HIV?	Υ	N	U	Whereas the public facilities do not charge for HIV testing, some private heafacilities do. In both public and private facilities, clients pay for syphilis testing.
b) syphilis?	Y	N	U	as was testified by FGD participants in Sheema and Ntungamo that clients p 3,000/= for testing for syphilis. But it should be noted that paying for some
a) antenatal care services?	Y	N	U	in public health facilities is under-table payment because government is implementing universal access to treatment. Likewise, ANC services are free public health facilities and clients in private health facilities could pay for the service.
(4) shortage of trained health-care workers	Υ	N	U	The two links below could help to explain the magnitude of shortage of train health-care workers in Uganda (public health facilities are terribly affected).

				https://www.monitor.co.ug/News/National/Museveni-decries-shortage-health-workers/688334-3872456-afum8ez/index.html
				https://www.newvision.co.ug/new_vision/news/1460299/uganda-risks-losskilled-health-workers
(5) distance and travel costs to health facilities?	Y Yes	N	U	It is true that eMTCT services are provided at most health center IIIs and this could reduce on the transport costs; but from the FGDs conducted some mothers have to part with more than UGX 10,000 to access the services.
c) Are women living with HIV able to access antenatal or PMTCT services without fear of stigma or discrimination?	Y Yes	N	U	Populations most affected by stigma and discrimination are key and priority populations such as sex workers, drug users/injectors, lesbians, adolescent and young women
d) Does the PMTCT program	nme of	fer qualit	y services	that include:
(i) pre- and post-test counselling (if required in country)	Y	N Not	U	FGD respondents reported that most health facilities do group health talks/counselling and only offer post-test counselling to those found living v
(ii) counselling and psychosocial support for HIV and/or syphilis positivity?	Y Yes	N	U	Counselling and psychosocial support is for those living with HIV and not for syphilis positivity
(iii) infant-feeding guidance?	Y Yes	N	U	Infant-feeding guidance is provided at the EID, ANC and maternity clinics
(viii) assistance for women with disabilities?	Y	N No	U	This is one of the areas where Uganda has the greatest challenges. Women living with disability (the dump, the deaf, the blind and those totally disable have no facility based aides.
(ix) services for indigenous women?	Υ	N	U	N/A

(i) young women of reproductive age?	Υ	N	U	The recently introduced Differentiated Service Delivery Models (DSDM) for I Prevention, Care, Treatment and Support was intended to address some of challenges faced by clients. However, the implementation and rollout is slow
(ii) unmarried women?	Υ	N	U	and has faced such challenges as drug stock outs, limited human resources for
(iii) women living with HIV?	Y	N	U	health and limited storage facilities.
(iv) sex workers?	Υ	N	U	
(v) women who use drugs?	Y	N	U	
(vi) lesbian, bisexual or queer women?	Y	N	U	
(vii) transgender people?	Υ	N	U	
f) Are there initiatives in place to ensure access to services for these populations?	Y	N	U	
g)) Are there laws, regulations and/or polices or judicial precedents guaranteeing equal and universal access to SRH services including maternal health services, family planning services for women living with HIV and/or affected by HIV, with special attention to populations of women in vulnerable situations (including ethnic or religious minorities,	Y	N	U	

indigenous women, ,				
women with disabilities,				
poor women, migrant				
women, unmarried				
women, sex workers,				
women who use drugs,				
other vulnerable women)?				
•				
h) Are health-care workers a	and he	alth facility	personnel	trained in human rights issues including:
(i) sexual and	Yes	N	U	The training manuals for health care workers providing HIV and HIV related
reproductive rights?				services covers sexual and reproductive rights; informed consent; patient confidentiality and privacy; respectful maternal care; gender-based violence and promoting gender equality
(111)				
(iii) informed consent?	Yes	N	U	
(iv) patient confidentiality	Yes	N	U	
and privacy?				
· · ·				
(v) respectful maternal	Yes	N	U	
care?				
(vi) gender-based	Yes	N	U	-
violence?	1.03	'		
(vii) promoting gender	Yes	N	U	
equality?				
i) Are there laws policies ar	id/or r	ractices in	nlace that	criminalize behaviors or acts that are particularly relevant for key populations
that are especially vulnerab	-			
, ,			, 54611 45.	
(i) sex work?	Y	N	U	Whereas the Constitution of the republic of Uganda guarantees the right to
(ii) drug use?	Υ	N	U	equality,
(ii) di dg d3E:		14	J	
(iii) same-sex sexual	Υ	N	U	 the Penal Code, 1950 prohibits same sex relationships, sex work;
behaviour?				

	(iv) cross-dressing or any other behaviors or acts related to (trans) gender expression?	Y	N	U	 the Penal Code Act of 1950 (Chapter 120) (as amended) Section 145 on Unnatural sex provides that "Marriage between persons of the same sex is prohibited; The Uganda's "narcotic drugs and psychotropic substances (control) act" which criminalizes use of illicit drugs
10	Access to justice, remedies	and r	edress		
	a) Are there laws, regulations and/or policies or judicial precedents ensuring access to justice, remedies and redress, including probono legal services?	Υ	N	U	The Constitution of the republic of Uganda guarantees the right to access to justice, remedies and redress
	b) Are there procedures or mechanisms to report human rights violations related to HIV care?	Y	N	U	The Constitution of the republic of Uganda provides for the establishment of the Human Rights Commission and procedures or mechanisms to report human rights violations are enshrined therein
	c) Are there any grievance mechanisms in your country for redress of human rights violations against women living with HIV?	Y	N	U	The available mechanisms don't necessarily associate with any categories of individuals but considers Ugandans in totality
	d) Is there a way for women living with HIV to hold service providers accountable for any violation of human rights in the context of PMTCT services?	Y	N	U	There are no established procedures for women living with HIV to hold service providers accountable for any violation of human rights in the context of PMTCT services. The Patients charter guarantees the rights of patients but implementation stalled and the number of people who know anything in that charter is limited

e) Are there institutional barriers to accessing these mechanisms?	Yes	N	U	People/women living with disability are the most affected because Government of Uganda has not fully developed that component
f) Are there social, religious or cultural barriers to accessing these mechanisms, left unaddressed by laws, regulations or policies?	Y	N	U	According to the constitution of Uganda; the following applies - Cultural and customary values which are consistent with fundamental rights and freedown human dignity, democracy and with the Constitution may be developed and incorporated in aspects of Ugandan life. The State shall— • promote and preserve those cultural values and practices which enhance the dignity and well-being of Ugandans; • encourage the development, preservation and enrichment of all Ugand languages; • promote the development of a sign language for the deaf; and • encourage the development of a national language or languages.
g) Does the PMTCT programme include initiatives to increase women's awareness of their human rights, including their sexual and reproductive rights?	Y	No	U	FDG participants from all the 6 districts did not know of any initiatives to increase women's awareness of their human rights, including their sexual a reproductive rights. Nonetheless, development partners through various projects have initiatives to increase women's awareness of their human right including their sexual and reproductive rights
h) Are human rights violations within the PMTCT setting documented and monitored?	Yes	N	U	Gender Based Violence is reported on and monitored
i)Have there been sanctions or reparations for violations of rights in context of PMTCT programmes?	Y	No	U	Very rare

3.2 Recommendations

- 1) Government of Uganda, working in partnership with the respective stakeholders should review and where necessary repeal Clauses/Acts that criminalize HIV for an effective HIV response
- 2) There are laws, policies and practices to improve access to and utilization of eMTCT services but contradict each other; we recommend that the government review and harmonizes the laws, policies and practices that contradict each other.
- 3) Ministry of Health should define the some of the key terminologies found in the existing policies and also guide on the implementation of the policies an example at hand is the "routine testing for pregnant mothers visa-vi implemented as mandatory testing" so as not to cause controversy and a sources of abuse of the processes
- 4) We appeal to Government of Uganda and all other stakeholder to work together to ensure that existing laws and policies regarding HIV transmission and management of Syphilis are well disseminated up to the grass root levels.
- 5) Furthermore, we appeal to Ministry of Health to put in measures that will ensure that health facilities uphold the principles of respect for privacy and confidentiality of one's HIV status and Respect of rights for all and in addition measures that will ensure equal access to HIV and maternal health services especially the disabled women living with HIV.
- 6) We call upon the Government of Uganda to urgently institutionalize participation and engagement of women living with HIV in the eMTCT program design, implementation, monitoring and evaluation
- 7) Health workers should be trained in the human rights approaches to service delivery and sign language interpreters be recruited to facilitate service access for persons with disabilities.