

SOCIAL-CULTURAL AND GENDER-RELATED BARRIERS THAT AFFECT THE ENROLLMENT AND RETENTION OF WOMEN AND GIRLS LIVING WITH HIV IN HIV PREVENTION, TREATMENT AND CARE SERVICES IN UGANDA

March 2017



International Community
of Women Living with HIV
Eastern Africa (ICWEA)



International Community of Women Living with HIV Eastern Africa (ICWEA)

Please contact us at:

International Community of Women living with HIV Eastern Africa (ICWEA)

Plot 1106 Ssenge – Kawanda Road

Off Kayunga, Kampala – Hoima Road, Wakiso District

P.O. Box 32252

Kampala, Uganda

Phone: +256 414 531 913

Fax: +256 414 533 341

Email: admin@icwea.org

Website: www.icwea.org

with support from



United Nations Entity for Gender Equality
and the Empowerment of Women

Acronyms and Abbreviations

AIC	AIDS Information Centre	TASO	The AIDS Support Organization
AIDS	Acquired Immunodeficiency Syndrome	UAC	Uganda AIDS Commission
ANC	Antenatal care	UBOS	Uganda Bureau of Statistics
ART	Antiretroviral Therapy	UN	United Nations
ARVs	Antiretrovirals	UNAIDS	Joint United Nations Programme on HIV&AIDS
CBOs	Community-based Organizations	UNYPA	Uganda Network of Young People living with HIV
CSOs	Civil Society Organizations	VHTs	Village Health Teams
DHE	District Health Educator	WHO	World Health Organization
DHO	District Health Officer		
DHS	Demographic Health Survey		
eMTCT	Elimination of Mother to Child Transmission of HIV		
FGD	Focus Group Discussion		
FSW	Female Sex Worker		
FY	Fiscal Year		
GoU	Government of Uganda		
HIV	Human Immunodeficiency Virus		
ICWEA	International Community of Women living with HIV Eastern Africa		
MDGs	Millennium Development Goals		
MoFPED	Ministry of Finance Planning and Economic Development		
MoH	Ministry of Health		
NDP	National Development Plan		
NGOs	Non-Governmental Organizations		
PLHIV	People living with HIV		
PWID	People who inject drugs		
RFP	Request for Proposal		
RH	Reproductive Health		
SBCC	Social and Behavior Change Communication		
SDGs	Sustainable Development Goals		
SGBV	Sexual and Gender-based Violence		
SMMC	Safe Medical Male Circumcision		
SSA	Sub-Saharan Africa		
STIs	Sexually Transmitted Infections		
SW	Sex Workers		

ACKNOWLEDGEMENTS

International Community of Women living with HIV Eastern Africa (ICWEA) would like to thank all individuals and institutions who contributed to the success of this study.

We are most grateful to UN Women who provided financial and technical support that made this study possible.

We are also grateful to our other partners including UNAIDS; Ministry of Health; Ministry of Gender, Labor and Social Development; Uganda AIDS Commission; Uganda Network of Young People living with HIV (UNYPA); The National Forum of PLHA Networks in Uganda (NAPHOPHANU).

We appreciate the support of the District Networks of people living with HIV who guided the study team in the respective districts. We are equally grateful to all the study participants from the districts, sub-counties, CSOs, health facilities, communities and national level agencies who responded to our questions and provided valuable data for this study.

The staff of ICWEA made a great input into this study and is greatly acknowledged; and we are also indebted to other people that contributed to the success of this study.

Finally, we thank our Consultants, Dr. Denis Muhangi of Makerere University and Mr. Asaph Turinde Kabali of Team Initiatives Ltd, who facilitated the execution of this study.

TABLE OF CONTENTS

Acronyms and Abbreviations	3	2.2.3 Enablers at the Societal Level	49
Acknowledgements	4	2.3 Good practices adopted by HIV Service Providers to effectively engage and retain women and girls living with HIV in HIV Services	53
Table of Contents	5	2.3.1 Introduction	53
Definitions	6	2.3.2 Follow-up of lost clients using phone calls	53
Executive Summary	8	2.3.3 Physical follow up of lost-to-follow-up clients	54
1.0 INTRODUCTION	10	2.3.4 Establishment of Adolescent Friendly Services/Youth Corners at HIV&AIDS Service Points	55
1.1 Background	10	2.3.5 Psycho-social Counseling	55
1.2 Justification	11	2.3.6 Decentralization of HIV&AIDS services	55
1.3 Study Purpose and Objectives	11	2.3.7 Social Support Arrangements	56
1.4 Literature Review	12	3.0 CONCLUSIONS AND RECOMMENDATIONS	57
1.5 Approach and Methodology	13	3.1 Conclusions	57
2.0 RESULTS	15	3.2 Recommendations	59
2.1 Barriers to the Enrolment and Retention of Women and Girls living with HIV in HIV Prevention, Treatment and Care Services	15	REFERENCES	66
2.1.1 Individual Level Barriers	15	ANNEX 1: Data Collection Tools	65
2.1.2 Institutional/Service Level Barriers	29		
2.1.3 Societal Level Barriers	34		
2.2 Enablers of Women and Girls living with HIV's enrolment and retention in HIV Prevention, Treatment and Care	43		
2.2.1 Enablers at the Individual level	43		
2.2.2 Enablers at the Institutional level	46		

DEFINITIONS¹

Term	Definition
Cascade of HIV prevention and care	The continuum of care that people living with HIV are supposed to go through in order to live a long and healthy life, which entails HIV testing and diagnosis, getting connected to care, retention in care, receiving support while in care, accessing ART and support while on treatment (Wilton and Broecker, 2013).
Counseling	An interpersonal, dynamic communication process between a client and a trained counselor, who is bound by a code of ethics and practice to resolve personal, social or psychological problems and difficulties. In the context of an HIV diagnosis, the objective of counseling is to encourage the client to explore important personal issues, identify ways of coping with anxiety and stress and plan for the future (keeping healthy, adhering to treatment, and preventing transmission).
Differentiated care	A responsive, client-centered approach that simplifies and adapts HIV services across the cascade to better serve individual needs and reduce unnecessary burdens on the health system. Differentiated care models include health care-worker managed groups, client managed groups, and the facility-based individual and out of facility individual models. Source: https://www.iasociety.org/Models
Discrimination	Any form of arbitrary distinction, exclusion or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group – in the case of AIDS, a person’s confirmed or suspected HIV-positive status – irrespective of whether or not there is any justification for these measures.
Gender	The social attributes and opportunities associated with being male and female and the relationships between women and men and girls and boys, as well as the relations between women and those between men. These attributes, opportunities and relationships are socially constructed and are learned through socialization processes. Gender is different from sex which refers to biologically determined differences that are used to label individuals as males or females.
Gender-based violence (GBV)	GBV “describes violence that establishes, maintains or attempts to reassert unequal power relations-based on gender.” It encompasses acts that inflict physical, mental or sexual harm or suffering, threat of such acts, coercion and other deprivations of liberty.
Gender-related barriers	The legal, social, cultural or economic barriers to the access of services, participation and/or opportunities that may be imposed on individuals or groups-based on socially constructed gender roles.
HIV-negative	A person who shows no evidence of infection with HIV on a blood test (e.g. absence of antibodies against HIV). HIV-negative is the same as sero-negative. The test result of a person who has been infected but is in the window period between HIV exposure and detection of antibodies is also negative.
HIV-positive	A person who has had antibodies against HIV detected on a blood test or gingival exudate test (commonly known as a saliva test). HIV-positive is the same as seropositive. Results may occasionally be false-positive, especially in infants age up to 18 months who are carrying maternal antibodies.

¹ These definitions are derived from UNAIDS Terminologies Guidelines 2015 (UNAIDS, 2015), and Jain et al (2015) unless otherwise stated.

Lost to follow-up	Patients/clients who at one moment were actively participating in or registered to receive a service, but who have since become unavailable at the point of follow-up, or have not come for services until completion, instead dropping out of care/treatment.
Masculinities	Socially constructed definitions and perceived notions and ideals about how men should or are expected to behave in a given setting. Masculinities are configurations of practice structured by gender relations, and can change over time.
Mobile worker	Persons who may cross borders or move within their own country on a usually frequent and short-term basis, without changing their primary residence or home base for a variety of work-related reasons.
People living with HIV (PLHIV)	A person who has been diagnosed as having HIV. Such a person may continue to live well and productively for many years.
Safer sex	The idea that choices can be made and behaviors adopted to reduce or minimize the risk of HIV transmission. Safer sex strategies include postponing sexual debut, non-penetrative sex, correct and consistent use of male and female condoms, and reducing the number of sexual partners.
Sero-status	A generic term that refers to the presence/absence of antibodies in the blood. In the context of HIV infection, it refers to the presence/absence of HIV antibodies in one's blood.
Sex work, commercial sex	The sale of sexual services
Stigma	<p>A dynamic process of devaluation that significantly discredits an individual in the eyes of others. It is a description of a person's attributes by others, as discreditable or unworthy. In the context of HIV infection, the following types of stigma may be distinguished:</p> <p>Anticipated stigma: real or imagined fears of societal attitudes and behaviors if HIV status is disclosed</p> <p>Perceived stigma: the perception of how people in one's community feel and react toward people living with HIV.</p> <p>Experienced stigma: forms of stigmatizing behaviors or discrimination not typically actionable under law and experienced by people living with HIV or individuals associated with HIV.</p> <p>Internalized stigma: 'the acceptance by an individual that the external stigma (the stigma exercised by others towards her/him) is true and justified, that is, acceptance of society's judgment of oneself as being of a "lesser status". Internalized stigma can manifest itself as low self-esteem and sense of worth, self-blame, and self-isolation/withdrawal.</p>
Test and treat	Voluntary HIV testing and the offer of antiretroviral therapy after diagnosis, irrespective of WHO clinical stage or CD4 cell count.
Voluntary medical male circumcision (VMMC)	The surgical removal of the foreskin, the tissue covering the head of the penis where the cells that are highly receptive to the human immunodeficiency virus are located.
Vulnerability	Unequal opportunities, social exclusion, unemployment or precarious employment (and other social, cultural, political, legal and economic factors) that make a person more susceptible to HIV infection and developing AIDS. The factors underlying vulnerability may reduce the ability of individuals and communities to avoid HIV risk, and may be outside of their control.

EXECUTIVE SUMMARY

Introduction

This study was conducted by the International Community of Women living with HIV Eastern Africa (ICWEA) in collaboration with UN Women to document the social-cultural and gender-related barriers to the enrolment and retention of women and girls living with HIV in HIV prevention, treatment and care services. The study was conducted in four districts of Uganda, namely Arua, Soroti, Mbarara and Masaka. The study employed a qualitative approach and data was collected through a total of 16 focus group discussions (FGDs) conducted separately with women living with HIV (8), girls living with HIV (4), and male partners of women and girls living with HIV (4). In addition, the study team conducted 26 in-depth interviews with selected key informants at the community, health facility, and NGO and district levels. It also interviewed key informants from key national government, CSOs and donor agencies.

Key Findings

Social-cultural and gender-related barriers that undermine the enrolment and retention in HIV services of women and girls living with HIV exist at individual, institutional and societal levels, with some overlaps and cross-influences across these levels. At the individual level, the key barriers included anticipated and internalized stigma which prevents women and girls from seeking services for fear of being seen and known to be having HIV. Coupled with this is the fear of violence from partners, fear of rejection by partners and family members, and fear of accusation and ridicule from family members and peers, all of which make it difficult for women and girls to disclose their positive HIV status and seek HIV-related services.

In addition, the desire to have children makes it unrealistic for women to continue using protective measures such as condoms. Yet all these factors are deeply rooted in strong cultural and gender norms that ascribe certain expectations, behaviors and roles to women and girls. For instance, women and girls' fear of rejection by male partners is rooted in women's economic dependency on men. This economic dependency is, in turn, rooted in women's lack of employable and entrepreneurial skills and their occupation of largely home-making and subsistence roles rather than income earning roles. Similarly, women's desire to have children originates largely from their social constructions that equate femininity and good wifehood to child bearing. In face of these, women and girls often abandon HIV care and treatment in order to conform to these gender and cultural expectations. Other barriers at this level include financial difficulties which drive women and girls into transactional and sex work, where they are in a weaker position to negotiate condom use.

At the institutional level, the key barriers identified include the deteriorating quality of HIV services compared to the services provided in the last 10 to 15 years, especially, the weakened counseling and care packages. The limited presence and quality of youth friendly services is also a key issue. Recent changes in the modes of service delivery towards 'differentiated models' such as decentralized care and group-based care are promising good improvements and practices in access to care and treatment but some clients are concerned about their confidentiality and anonymity and these issues that need to be addressed. The limited options for women controlled HIV preventive tools and technologies remains an outstanding problem.

At societal level, the key barriers include external stigma and discrimination that women and girls face at the hands of their family and community members and in public spaces. Women and girls face greater levels of stigma because of cultural expectations on how women and girls should behave, and the continuing perception that HIV is a result of promiscuous behavior. There are also cultural factors that undermine enrolment and retention in HIV services, including beliefs in witchcraft; preference for traditional healing as opposed to modern medicine; practices of wife inheritance, payment of bride price

and polygamy, which leave women with little decision-making power about their sexuality. Cultural meanings of marriage are also incompatible with preventive measures such as use of condoms. On the other hand, masculinity norms also limit men's enrolment for HIV services, which in turn affect the enrolment and retention of their female partners. Religion (particularly Pentecostals) was found to be double edged, encouraging utilization of HIV services in some cases, but preaching miraculous healing in some sects.

The key enabling factors at the individual level that promote and motivate women and girl's enrolment and retention in HIV services include the personal desire to live longer, the desire to raise ones' children, the need to bear HIV free babies, and the awareness and appreciation of the benefits of HIV&AIDS services. At the societal level, the key enabling factors include support from family members and social entities such as community and family support groups. The good practices used by service providers to promote enrolment and retention of women and girls, as well as other PLHIV services include use of mobile phones, physical visits and follow-up, establishment of youth friendly services, support groups, counseling & introduction of innovations under the 'differentiated model' such as decentralization of services and group-based care models.

Conclusions

Overall, the results of this study reveal deep rooted social, cultural and gender-based factors that undermine the enrolment and retention of women and girls in HIV services. These factors have differential impact on different categories of women and girls, given the widespread heterogeneity among women living with HIV; married women; younger, single women and sex workers. Yet HIV services are not adequately responsive to the varied needs of these different categories of women.

Recommendations

The recommendations respond to the barriers identified at individual, institutional and societal levels; however, because of overlaps, some recommendations focus on multiple barriers at different levels while others

are cross-cutting.

1. Identify and intensively strengthen capacity of a critical mass of women/ girls advocates who will continuously stand-out to defend and protect the human rights of their peers; including the right to access and consistently utilize health services including HIV and HIV related services
2. Support societal/social and community systems for empowering women and girls to demand, protect and promote their human rights – by eliminating cultural/social practices that demean women and girls
3. Establish family and community level supported disclosure mechanisms to enable those living in denial to open-up about their HIV status; and consequently utilize HIV care and treatment services. -
4. Initiate and implement community/family/educational institutional level anti-stigma campaign to promote general acceptability and empowerment of women/girls living with HIV
5. Support economic strengthening programmes that directly benefit young women and adolescent girls including those living with HIV. Economic empowerment reduces vulnerability and improves resilience to manage risk.
6. Government and development partners provide technological and financial support to train adolescent girls and young women living with HIV in vocational and other entrepreneurial skills that would improve their economic base.
7. Strengthen family and community role in supporting women and girls living with HIV to participate and constantly remain in HIV care and treatment programs.
8. Train and sensitize health-care providers on non-stigmatizing and non-discriminating health care services for all including key populations (especially sex workers, lesbians and adolescents and young women).

1.0 INTRODUCTION

This report presents the results from a study carried out to document “social-cultural and gender-related barriers that hinder women and girls living with HIV’s effective participation in HIV Prevention, Care and Treatment Services in Uganda”. The study was conducted by the International Community of Women living with HIV Eastern Africa (ICWEA) in partnership with UN Women (who provided financial support). The report is organized under three sections: (i) introduction which includes the background to the study, study objectives, literature review and methodology used to undertake the study; (ii) Findings; (iii) conclusions and recommendations arising from the study.

1.1 Background

Uganda has moved a long way in addressing the HIV&AIDS pandemic. Indeed, Uganda was a success story in the fight against HIV&AIDS in sub-Saharan Africa after significantly reducing the prevalence of HIV from 18% in 1992 to 6.4% in 2005². This was due to, among others, the country’s readiness to adopt a multi-sectoral approach to the epidemic in 1992 having realized that HIV&AIDS was not only a health problem but also a development challenge that had implications on the performance of other strategic sectors of the country. For example, there was a rise in the HIV prevalence from 6.4% recorded in 2005 to 7.3% in 2011³. The 2011 AIDS Indicator Survey reported a higher prevalence among women (8.3%) than men (6.1%). In terms of incidence, there has been a decline from 0.83% in 2009 to 0.77% in 2013 despite concerns pertaining to pockets of new infections particularly among key populations such as sex workers (SWs) and fisher folks.

Some of the factors advanced to explain cases of new infections include “high risk sexual behaviors coupled with low knowledge of one’s HIV sero-status; low individual level risk perception; ones level of knowledge and understanding of HIV, and especially its relationship to perceived personal risk of HIV infection; and its influence on negative and stigmatizing attitudes towards people living with HIV (PLHIV); high sexually transmitted infections (STIs) prevalence; low utilization of antenatal care (ANC) and delivery services; low uptake of safe medical male circumcision (SMMC) services; high numbers of HIV positive patients not on antiretroviral therapy (ART); sexual and gender based violence resulting from gender inequalities; high alcohol consumption; and poverty”⁴. Furthermore, the report identified the absence of common technical programming guidelines for sexual behavior change communication (SBCC) as a particular challenge that needed to be addressed in order to improve monitoring and evaluation of attendant interventions.

The national projections-based on spectrum estimates indicate an increasing number of people living with HIV in Uganda, from 1.4 million in 2011 to 1.5 million in 2014⁵. The Government of Uganda through the Ministry of Health and other partners has over the last 25 years made HIV care services available to many parts of the country. With the adoption of 2013 WHO ART guidelines, there has been increased enrolment of adults and children living with HIV on ART from 570,373 in 2013 to 898,197 by June 2016^{6,7}. However, utilization and accessibility of HIV services by women and girls living with HIV remains low.

2 National HIV and AIDS Strategic Plan 2015/2016 – 2019/2020

3 2011 Uganda AIDS Indicator Survey

4 2014 Uganda HIV and AIDS Country Progress report

5 UAC (2015). The HIV and AIDS Uganda Country Progress Report 2014

6 UAC (2015): The HIV and AIDS Uganda Country Progress Report 2015

7 UAC (2016): The Uganda HIV and AIDS Country Progress Report July 2015 – June 2016.

Existing data show that some mothers who start on ART are eventually lost to follow up, while many adolescent girls enrolled in care find it difficult to adhere to their medication. For instance, whereas the country achieved 97% enrolment of HIV positive mothers on ART, the retention of mothers and their babies was very low, resulting in only 38% of the HIV exposed infants being tested for HIV at 18 months⁷. Similarly, an assessment conducted with support from UNICEF showed that over 25% of the HIV positive mothers initiated on ART did not return for their first month visit, while other data show that only 56% of eMTCT mothers picked their refills six months after initiation on ART. While the reasons for the “dropout and disappearance of those already in care” – a phenomenon usually termed as ‘lost-to-follow-up’ - could be diverse, these have not been extensively investigated. Antiretroviral therapy has transformed HIV from a terminal illness to a chronic one – meaning that individuals who have HIV can live with it for many years and enjoy productive lives, as long as they manage the illness well. In addition, ART reduces the risk of HIV transmission from a person living with HIV to their sexual partners. Once enrolled on ART and care, individuals need to be retained in care for life in order to achieve the benefits of HIV treatment and avoid development of resistance. Retention in care for all patients provides additional benefits through ancillary services, social support and secondary prevention messages that can help patients manage their situation⁸. However due to varying reasons and circumstances both in the community and at the service points, these individuals are unable to stay in care for life. This study in particular focuses on social-cultural and gender-related factors that serve as barriers or enablers to the enrolment and retention of women and girls living with HIV in HIV prevention, care and treatment services.

1.2 Justification

An evaluation from public health facilities done in Uganda revealed alarming rates of lost to follow-up mothers living with HIV between 25% and 58.8%⁹. This finding relates well with other studies in Sub-Saharan Africa that demonstrated that national HIV and PMTCT programs are challenged with retaining in care of mothers and their infants, yet limited with interventions to improve retention and reduce lost to follow up¹⁰. There is evidence suggesting that existence of gender-related and social-cultural factors continue to disadvantage women and girls ability to remain in care and treatment services. In turn, these factors negatively impact on their ability to stay in care and utilize the available treatment and care services, or provide care and other forms of support to others. For instance, a recent study by ICWEA documented a wide range of violations of women living with HIV’s human and/or health rights within clinical settings (ICWEA, 2015) that could partly explain the above scenario. However, the full extent of this problem is not fully understood; thus complicating any efforts to design relevant interventions aimed at improving participation, retention in care and levels of adherence to treatment among people living with HIV. This study was therefore intended to fill this gap by generating the evidence that would inform efforts by ICWEA, other implementing partners, the Government of Uganda and funding agencies to plan and implement the most effective, culturally and gender responsive strategies to improve prevention, care and treatment outcomes among women and girls living with HIV.

1.3 Study Purpose and Objectives

The purpose of this study was to identify, analyze and document the social-cultural and gender related barriers that affect the enrolment and retention of women and girls living with HIV in HIV prevention, care and treatment services including retention within health care in Uganda. In addition, the study sought a better understanding of how and why women and girls living with HIV fall out of the cascade of HIV prevention and care¹¹. The specific objectives

8 Geng et al. (2010): Retention in care among HIV infected patients in resource-limited settings: emerging insights and new directions. *Curr HIV/AIDS Rep.* 2010 November; 7(4): 234–244. doi:10.1007/s11904-010-0061-5.

9 Describing Point of Entry into Care and Being Lost to Program in a Cohort of HIV Positive Pregnant Women in a Large Urban Centre in Uganda; 2017

10 Describing Point of Entry into Care and Being Lost to Program in a Cohort of HIV Positive Pregnant Women in a Large Urban Centre in Uganda; 2017

11 The HIV prevention and care cascade refers to the continuum of care that people living with HIV are supposed to go through in order to live a long

were:

- 1) To identify and document the social-cultural and gender-related barriers to enrolment and utilization, i.e., start and continuation of HIV prevention, care and treatment services among women living with HIV.
- 2) To identify and document factors that facilitate or enable enrolment and retention in HIV prevention, retention in care and continued utilization of HIV services by women living with HIV.
- 3) To identify and document good practices employed by different implementers and service providers, as well as cultural and religious institutions to ensure effective enrolment and retention of women and girls living with HIV in HIV prevention, care and treatment services.
- 4) To make recommendations for a minimum package of services that encompasses availability, affordability, acceptability and quality of care to address social-cultural and gender related barriers to the enrolment and retention in HIV services of women and girls living with HIV.

1.4 Literature Review

Some studies have documented the impact of gender and social-cultural norms on access to and utilization of health services including HIV related services (Loufty et al., 2015, Ramjee & Daniels, 2013; Ulibarri, Roesch, & Rangel, 2015; Gupta, 2000; WHO, 2011). Gender and cultural norms may present opportunities (Ramjee & Daniels, 2013) but can also be potential barriers to quality HIV care and treatment (WHO, 2011; 2012). Hegemonic norms in particular have a negative effect on the uptake of such health services for men but mostly for women and girls, by affecting their ability to navigate prevention and treatment options (Bond, Hoddinott & Viljoen, 2016, p.431). Yet women living with HIV face a double burden – a result of the infection because they are women (Gupta, 2000). In contexts dominated by patriarchal culture like it is in a number of African societies, inequalities between men and women exacerbate women's inferiority and their disparate health status (Ramjee & Daniels, 2013). Sociocultural norms have

and healthy life, namely, HIV testing and diagnosis, getting linked to care, retention in care, receive support while in care, access ART, and support while on treatment. (Wilton and Broeckeaert, 2013)

been reported to compromise women's access to information (Fletschner & Kenney, 2011) yet lack of information has been shown to limit access to care and treatment. In some instances, gender norms restrict women from accessing financial resources that are necessary to access care (Lippincott – Williams & Wilkins, 2014). The negative effects of this have manifested in the lack of transport to access health services which in turn affects retention (Mugisha, Ocerro & Semafumu, 2009). The unequal status of women and girls has been documented to promulgate their lack of power to negotiate for safer sex practices including condom use, which increases their risk of infection (WHO & Pangaea Global AIDS Foundation, 2012). It also impacts on their ability to access other key HIV related services including counseling, testing and treatment which grossly contribute to negative health outcomes (WHO & Pangaea Global AIDS Foundation, 2012; WHO, 2011). These factors lead to disengaging from care and loss to follow up (WHO, 2011).

When it comes to sexuality, women may not have a role in sexual decision making (Buvé, Bishikwabo-Nsarhaza & Mutangadura, 2017; Duffy; 2005). This can be a result of or compounded by violence in the different forms that may prevent women from negotiating for safer sex or even disclosing their positive HIV status (Loufty et al., 2015; Ulibarri et al., 2015). Lower consistent and correct condom use has been reported among adolescent girls living with HIV than their male counterparts in Uganda (Mbalinda, Noah Kiwanuka, & Eriksson, 2015). Although gender and social-cultural factors are not the only factors, they could offer an explanation to this difference. Women living with HIV are blamed for breaking sexual norms and bringing HIV into the family (Loufty et al., 2015). Taking from the Foucauldian perspective, they may be seen as transgressors of social norms (Carrasco, 2016). Concerns around power relations have also been cited to hinder women from practices that could prevent re-infection. Social norms expressed through power structures have the potential to pervade all levels of society and even infiltrate individuals' psyche (Carrasco, 2016, p.118) and have the ability to influence how men and women relate. It creates stigma and is compounded by it (Lippincott –Williams & Wilkins, 2014). For example, women themselves perceive HIV as a taboo, reinforcing its association with marginalized groups (Ramjee & Daniels, 2013). With this they may develop mental constructs of themselves as being sluts which may discourage disclosure while encouraging denial of the infection (Ramjee & Daniels, 2013).

Indeed, stigma and discrimination or the fear of them has been noted to undermine people's ability to adopt HIV preventive and management measures (UNAIDS, 2007). UNAIDS (2007) also notes that women tend to experience greater stigma and discrimination than men and its harshest and most damaging forms. The Uganda PLHIV Stigma Index study (NAPHOPHANU, 2013) reported persisting levels of stigma in Uganda. The commonest forms included gossip, reported by 60%, and verbal harassment, insults and or threats reported by 37% of the PLHIV who participated in the study. The same study also reported experiences of social exclusion from social gatherings (16%), religious functions (7%), and family activities (10%) in the preceding 12 months. Similarly, the Uganda AIDS Indicator Survey of 2011 found that about one in five adults believed that people living with HIV should be ashamed of themselves and blamed for bringing the disease into the community. Such attitudes have the potential to undermine PLHIV's openness about HIV and their willingness to seek services (MoH et al., 2012). Reproduction also creates its own issues. For instance, women living with HIV in child bearing age are confronted with the dilemma stemming from familial and society pressures to bear children and the reality about the possibility of re-infection (Wekesa & Coast, 2014).

In sexuality, power determines the process and motive of engaging in sex and has implications for those involved (Gupta, 2000). A study by Ulibarri et al (2015) found power relations, as one factor that was significantly associated with unprotected sex among female sex workers in Mexico. Structural interventions that attempt to change the social norms that worsen HIV vulnerability have been explored. For example, the South African IMAGE project sought to decrease gender-based HIV vulnerabilities such as sexual violence, women's lack of knowledge about HIV and its transmission and women's economic dependency on men (Ramjee & Daniels, 2013). This may help in addressing gender-related barriers to access to prevention, treatment and care (Loufty et al., 2015).

Approaches that consider HIV treatment and care as prevention have been emphasized (Bond Hoddinott, & Viljoen, 2016). Similarly, measures to address gender and cultural factors have been promoted, but a lot remains to be done. For example, WHO (2011) recommended addressing the gender/power concerns in improving retention among women and girls living

with HIV in the different communities. The Knowledge Management and Community Capacity Initiative [KMCCI] (2012) recommended increased male involvement and gender sensitive community work that address the underlying negative norms as key. Family members have a key role to play. Where they show significant support, this facilitates the uptake of HIV related services. Addressing the entrenched social inequalities through social protection for women living with HIV in rural areas has been shown to improve their treatment adherence and health outcomes (WHO & Pangaea Global AIDS Foundation, 2012). Behavioral and structural interventions have been investigated to reduce women's vulnerability to HIV acquisition but also HIV incidence in general (Ramjee & Daniels, 2013). Many structural influences are beyond women's control and affect women in many parts of the world (Ramjee & Daniels, 2013).

Overall, the above review indicates that some literature already exists about the role of gender and social-cultural factors in affecting utilization of HIV services and retention of women in HIV care and treatment services. However, the specific mechanisms through which such factors may operate in the Ugandan context are not clearly understood. Given the cultural and other social differences across different contexts, understanding the specific dynamics in each context is critically important.

1.5 Approach and Methodology

The study adopted an exploratory, cross-sectional design. Within this broad design, qualitative and participatory methods of data collection were used. Primary data was complemented by literature review. The study was conducted in four districts of Uganda, namely Masaka, Mbarara, Soroti, and Arua. These were purposively selected based on ICWEA's previous work in the districts. In particular, they were also among the districts where the study on violations of sexual reproductive and other human rights of women living with HIV in clinical settings was conducted. In addition, the districts represent the four main geographical regions of Uganda, with different social, economic and cultural contexts.

The entry point for the study in each district was the District Networks of People living with HIV. In consultation with the District Networks and the District Health Offices, the team identified key HIV service providers to be

consulted and selected sub-counties, parishes and villages from where other study participants were drawn. In each district, two sub-counties, one rural and one urban, were selected for data collection. Table 1 shows the sub-counties where data was collected.

Table 1: Sub-counties sampled for Data Collection

District	Urban	Rural
Arua	Oli Division	Adumi Sub-county
Soroti	Northern Division	Gweri Sub-county
Masaka	Nyendo-Ssenyange Division	Kabonera Sub-county
Mbarara	Kakoba Division	Ndejja Sub-county

Study participants were purposively selected-based on information provided by the guides such as peer workers. The sampling process took into account the need to include women and girls of diverse characteristics, such as those from rural and urban. The research team also made efforts to include women with multiple vulnerability such as female sex workers (FSW) and women with disability living with HIV.

The team conducted 4 FGDs per Sub County (2 FGDs with women living with HIV, 1 FGD with girls living with HIV and 1 FGD with partners of women/girls living with HIV). 348 participants participated in the FGDs at the sub county level. Women who were recruited to participate in the study were aged 25 – 49, who were either married or previously married, and defining themselves as women. The girls living with HIV who were included in the study were not married and aged 15-24. The male partners of women and girls living with HIV who were included in the study were aged 18-54, and were included irrespective of their HIV status.

In addition, during the FGDs, the research team identified potential cases that were followed up for more in-depth case interviews. In each district, the research team interviewed key informants including members of District Health Teams such as District Health Officers and HIV Focal Persons, District Networks of PLHIV, Community Development Officers at district and sub-

county levels, village health teams and health workers in the HIV clinics at different levels of health facilities. Key informants who were interviewed at the national level were drawn from key agencies including government ministries, Civil Society Organizations (CSOs) and UN agencies.

Data for this study was collected by a team of researchers who included women living with HIV. Data was collected using qualitative methods, namely desk reviews, FGDs, key informants, in-depth interviews and case study documentation. FGDs were conducted with (i) women living with HIV, (ii) girls living with HIV, and (iii) partners of women/girls living with HIV. In-depth interviews were conducted with key informants from districts and at the national level, HIV service organizations, District PLHIV Networks, religious and cultural leaders. A desk review of relevant documents was also conducted. In addition, in-depth case review was conducted with selected cases that illustrate the issues of interest to this study.

Data processing and analysis for this study was iterative and started during data collection and continued thereafter. Following data collection, notes from KIIs, IDIs and FGDs were transcribed, assembled and typed. This was followed by data processing and analysis which involved coding along key themes in the study. Relevant verbal citations (*quotes*) were identified and where appropriate been included in the report.

Ethical approval was sought from the TASO Institutional Review Board (IRB) and registration done with the Uganda National Council for Science and Technology (UNCST). During the research process, the research team adhered to all standard ethical guidelines in the conduct of research with human populations.

A key limitation of this study was that it relied solely on a qualitative methodology and no statistical data was collected to enable quantification of results. Future studies could include quantitative data to provide a more balanced picture.

2.0 RESULTS

2.1 Barriers to the Enrolment and Retention of Women and Girls living with HIV in HIV Prevention, Treatment and Care Services

The barriers to the enrolment and retention in HIV&AIDS prevention, care and treatment services for women and girls living with HIV were identified at individual, institutional and societal levels. Some of the barriers/factors tend to apply at more than one level. At the same time, there are critical influences between barriers at one level and other levels and vice versa. For instance, many individual barriers are also rooted in the context of societal barriers. Similarly, the effect of societal barriers may be mediated by an individual's character or motivation to change the status quo. It is also important to note, from the outset, that there are strong overlaps between gender and culture, and that indeed; gender structures in any given society are part and parcel of that society's culture. As such, the barriers related to gender and those related to culture cannot be neatly separated. In this report, we attempt to distinguish them but also maintain the overlaps where they exist. In the subsequent sections, we discuss these barriers according to the different levels.

2.1.1 Individual Level Barriers

Individual level barriers are those that are concerned with the person's own lifestyle, knowledge and personal attributes, as well as the decisions and choices they make with regard to everyday life experiences, challenges and opportunities. The definitive feature is that of the individual and what he or she chooses to do or not to. In other words, the person has a high degree of leverage regarding their participation in HIV&AIDS activities though he/she is still exposed to external influences. The main individual level barriers identified in this study include anticipated and internalized stigma, fear to disclose one's positive HIV status, the desire to have children, financial difficulties, and mobility.

2.1.1.1 Anticipated and internalized stigmas

One of the individual level barriers to the enrolment and retention of women and girls living with HIV in prevention, treatment and care services is what is termed as "internalized and anticipated stigma"¹². Anticipated/perceived and internalized stigmas were found to be a key barrier with regard to HIV prevention, treatment and care. Such stigmas are reflected in a situation where some of the women get to know that they are living with HIV; however, they do not want to be seen taking ARVs or visiting the health facilities for HIV services because they fear that other people will think negatively of them. Anticipated stigma may prevent some women from taking an HIV test to know their status. But beyond this, even those who are courageous to take an HIV test, or who get tested during ANC visit may find that they are living with HIV but then take no further action afterwards. Some even decide to keep quiet completely only to die in silence or only talk about their status when they are about to die as some study participants explained.

There are women who don't want to be seen every other time at the health center for fear that many people will get to know about them; some even send their friends to pick ARVs for them. (FGD, Women living with HIV, Adumi Sub-county, Arua District)

Because of self-stigma, fear of family rejection and being called and named 'immoral', 'promiscuous' or 'adulterous', those who are HIV positive prefer to stay off

12 Internalized stigma is 'the acceptance by an individual that the external stigma (the stigma exercised by others towards her/him) is true and justified, that is, acceptance of society's judgment of oneself as being of a "lesser status"' (Jain et al, 2015:1).

In the context of HIV, anticipated stigma refers to 'real or imagined fears of societal attitudes and behavior' if HIV status is disclosed.

treatment and care. They only turn up when it is too late while some die in complete silence. (Interview, Key Informant, Mbarara District)

This internalized stigma was found to be rooted in gender and other social/cultural structures of society. Indeed, what is often called 'self-stigma', referred to by the key informant cited above, is a misrepresentation because all stigma is engendered by experiences and forces external to the person feeling stigmatized. Some of the gender and cultural rooted fears that underlie internalized and perceived stigma as reported by the study participants are described below.

Fear of accusation and rejection: Married women living with HIV fear what their husbands and family will say and how they will react when they discover that they are living with HIV. She may be accused of bringing HIV to the family, or intending to 'kill' the husband/partner. Married women are more likely to know their HIV status first before their husbands because of the mandatory HIV testing policy that they are subjected to when they go for ANC (in case they are pregnant). Since most men do not accompany their wives to ANC, the wife will find out about her HIV status when she is alone. It is likely that the one whose HIV positive status is known first will be suspected of having contracted HIV first and therefore be believed to be the one that brought it to the other partners. Therefore, if the family where the woman is married finds out about her HIV positive status, they will accuse her of wanting to 'kill' their son. The family of the husband/partner may try to protect their son, the husband/partner, and accuse the wife (who is from a different clan, and therefore an outsider) of bringing HIV. Following the accusations, she may be chased out of the home, or the husband/partner may abandon her and the children and move out of the house to live elsewhere. Many women who find that they are HIV positive anticipate that kind of reaction from the family; therefore, opt not to disclose their status. They may not be able to attend or effectively continue utilizing HIV services in absence of disclosure.

... they fear that men will chase them away with their children where will she go? So they wait until the sickness has shown up on the man so that the man thinks he is the one who brought HIV, then the woman appears innocent. (FGD, male partners of women living with HIV, Adumi sub-county, Arua District)

Indeed, these fears are not misplaced; they are based on past experiences of women who have either been abandoned by their husbands or chased away from their homes after revealing that they had HIV. One of the women testified to such an experience.

My husband's relatives chased me from their home. They told me I was wasting time taking ARVs. I decided to come back to my parents. (FGD, Women living with HIV, Adumi sub-county, Arua District).

When my husband came to know that I was living with HIV he decided to abandon me. I was tested in antenatal clinic, the nurses told me to tell him to come for a test and he refused ... (FGD, Women living with HIV, Oli Division, Arua District)

Study participants observed that the fear of rejection also applies to women who after the death of their husbands or after separating from them, remarry or intend to remarry. In such cases, they do not want their HIV status to be known because this would put their new or anticipated relationship in jeopardy. Moreover, HIV is still in many people's minds largely associated with promiscuous behavior, which fuels stigma among people known or suspected to have HIV. As a result, women living with HIV may keep away from HIV services because they do not want their status to be known since they would be thought to have been promiscuous.

HIV is associated with promiscuity and sex work. In our Lugbara culture, a woman to have sex outside marriage is an abomination and since HIV is mostly contracted through sex it appears if a woman is the first to declare her status, she will be thought to have had sex outside marriage and therefore taken to be a 'prostitute'. She would rather keep quiet until the husband is diagnosed with HIV. (FGD, Women living with HIV, Adumi Sub County, Arua District)

In our community here, when a lady is known to be positive she automatically loses her dignity. First of all, you are taken to be a 'prostitute' because HIV is what you have earned as a reward. Even young boys start embarrassing you in public; anyone else will not respect you. For example, my co-wife went around telling everyone that I infected her and her husband ... (FGD, Women living with HIV, Adumi Sub County, Arua District)

In the case of younger adolescent girls and boys, anticipated stigma was also partly blamed for neglecting treatment and care because they do not want to be associated with HIV&AIDS. However, for some girls, it is more of internalized stigma, whereby they come to the point when they think that everyone around them knows or suspects their status and if they are not comfortable with that they retreat from life. They may decide to stay in-doors, stop treatment or withdraw from any social activities that they were previously engaged in or where they should be taking part.

Study participants reported that girls in school, especially those in boarding schools may particularly find difficulties in keeping up with their medication in the midst of other students. They want to fit in with the rest of their peers and friends, but with the existing levels of stigma, they cannot do this when they are known to be HIV positive. Moreover, in most schools, students are not allowed to keep medicine; all medicine is kept with the school nurse. With such a policy, a student who is living with HIV and has to continue with medication while at the same time abiding by the school rules has to experience forced disclosure of their HIV status to the school authorities. They also have to put up with having to go to the school nurse every time they have to take their medicine. Although they have to get permission to keep their medication, they would still have to disclose their HIV status to the head teacher, often against their will.

Fear of rejection among adolescent girls: Study participants reported that adolescents living with HIV who are in relationships or about to enter into relationships do not want to be associated with HIV or ART clinics forcing many to abandon treatment. They fear that their current or potential suitors will lose interest or abandon them if they discover or even suspect that they are living with HIV.

Teenagers (especially the girls) abandon treatment because they fear to be associated with HIV&AIDS. They fear it a lot because they are in relationships or about to enter into relationships; so, they abandon treatment. (Group interview with the health workers, Mbarara District)

It's the adolescent's age and the pressure of not wanting to lose their boyfriends. This forces them to abandon treatment. Girls who are HIV positive may also be influenced by peers to abandon treatment if their friends with a similar HIV status are not on treatment. (Interview, Teenage Peer Counselor, Mbarara Town)

This fear among adolescents was found to be widespread given that many adolescents in Uganda start sexual activities quite early. The Uganda Demographic and Health Survey 2011 shows that 12.2% of young women aged 15-19 were sexually active by age 15 (UBOS and ICF International, 2012). This evidence of the early onset of sexual activity suggests that many young people are already in sexual relationships and do not want to jeopardize them by being associated with HIV. Moreover, HIV is largely assumed to be for older, married people, and therefore young people do not want to be seen to break the norm.

Adolescence is also a stage when young people are energetic, vibrant and adventurous and feel that they are on 'top of the world'. At the same time, they are also rebellious and trying to assert their independence from parents and from the world. Therefore, the young people's failure to come to terms with their HIV status during this time is partly a natural part of their rebellious stage in life.

There is a sense of feeling among these girls to enjoy life to its fullness, together with their peers. Carrying and taking ARVs every day for life is not compatible with this feeling among the girls. It is this [feeling] that forces many to drop out of the care and treatment. (Interview, Key Informant, Mbarara District)

Coping with anticipated stigma - A futile escape: In some cases, it was reported that due to internalized stigma, some women had opted to get HIV related services from far places, away from their areas of residence even when similar services are available near their homes. They do this in an effort to keep anonymous, to attend services where nobody knows them or nobody can identify them. FGD participants in different districts all cited examples they knew of people who had attempted to collect ARVs from distant sites, leaving the nearby ones. However, this coping mechanism was reported to have its own limitations and therefore likely to affect continuation of treatment and care. For instance, getting treatment from far away was associated with the risk of failure to meet transport costs to the preferred distant service centers, thus compromising their attendance to scheduled clinic days.

There is a couple who don't live far from here, they were diagnosed with HIV and they actually they started picking their ARVs from Adumi health center. Recently, they are not seen, so one of the health workers sent information through me to the peer educator to look for them. We later got to know that they had transferred to the AIC in Arua town. The wife told us that her husband doesn't want people to see them picking ARVs from Adumi health center, which is nearby. (FGD, Male partners of women living with HIV, Adumi Sub County, Arua District)

Furthermore, key informants reported that due to anticipated stigma, some women and young girls who are on ART fail to take their medication at the time they are scheduled to do so when other people are around, such as during communal activities, because they do not want to be seen taking ARVs.

Similarly, women and girls were reported to skip taking their medication during social functions like burials, and weddings that tend to attract many people. It was reported that sometimes because of the prevailing circumstances, some HIV positive people including women and young girls may not take their ARVs as recommended or even avoiding taking the medicines. Some people would even fear to move with their ARVs into such places to avoid being identified as HIV positive.

Social functions like burials, weddings, etc. make PLHIV unable to take the ARVs as prescribed. Some people only take when they have found a good meal to eat. Some of our people temporarily change the home where they are staying, for example, having to look after their sick loved ones in some other families and they fear to move with their ARVs. (Group interview with the health workers, Mbarara District)

Such functions are cultural and relatives are expected to participate in them. In most Ugandan cultures, weddings, funerals and last funeral rites last a couple of days and if one is a frequent participant in these events, many days of treatment may be lost sometimes leading to abandoning of care and treatment.

2.1.1.2 Fear to disclose one's HIV positive status

Non-disclosure is one other dominant reason with regard to poor treatment uptake and retention amongst women and girls living with HIV. Disclosure if done appropriately encourages people to access HIV prevention and care services, and opens up the epidemic – ultimately reducing secrecy, stigma and discrimination. On the other hand, denial and secrecy about HIV status may deter care-seeking and utilization of HIV prevention and care services (UNAIDS,

2000). Women who have not disclosed their status to their partners and family members find it difficult to regularly swallow their medicine, and end up missing or abandoning treatment and care altogether. The fact that they have not disclosed and are not ready to disclose means that, most likely, they do not want to be seen collecting or taking medication or participating in HIV related services. In addition, women who have not disclosed to their male partners may fail to get money for transportation to collect their medication or the time to do so.

Yet failure to disclose is often rooted in anticipated stigma discussed above, and other complex gender and social factors. For instance, it was found out that many married women fear to disclose to their husbands or partners because they are not sure of the reaction. "What if the husband accuses her of bringing HIV and abandons her? What if the husband leaves her to take up another wife who is not HIV positive? What if the husband stops meeting her financial needs?" Others fear that their husbands may ask them to leave or chase them away.

Economic dependency of women on men and the fear to lose a benefactor: Study participants revealed that because many women depend on their husbands for money and survival in general, they have to weigh the consequences of disclosure of their HIV positive status. In a country like Uganda where many women are economically dependent on men, the thought of losing the breadwinner stops many women living with HIV from disclosing their status.

...some women fear even to disclose to their husbands who are their bread winners for fear that they may lose their marriage because being married is so central to the lives many women; whoever gets married ensures that they sustain it at all costs. (Interview, Key Informant, Mbarara District)

The male partners of women living with HIV also confirmed the behavior that characterizes a good number of men whose wives disclose their HIV positive status.

Yes, some men frustrate the women living with HIV. They intimidate them. Men fear public openness about their HIV status; therefore, they stop the women from seeking services. Others set for them difficult conditions because they believe women are their properties. (FGD, Male Partners of Women living with HIV, Gweri Sub County, Soroti District)

This economic dependency is in turn rooted in women's lack of employable and entrepreneurial skills. Their occupation is largely comprised of home-making and subsistence roles, rather than income earning roles; they also lack access and control of economic resources and have limited access to opportunities.

Box 1: The Complexity of Disclosure

Disclosure of one's HIV positive status is generally a complex undertaking and not a one-step process. HIV status is intensely personal information and the act of disclosure can lead to both positive and negative results. This is why people living with HIV are entitled to control over this crucial decision and should be provided with all the necessary support and information to decide if, when and how they will tell other people about their HIV status. Much of the discussion about disclosure tends to be about people who do not disclose their HIV status before they engage in behaviors that predispose them to higher risk of transmitting HIV. The focus on a few HIV-positive people who put others at risk of HIV transmission has distorted the discussion and made life more difficult for PLHIV. It has reinforced the climate of fear, stigma, and discrimination that surrounds HIV infection and could have contributed to violence against some PLHIV especially women (Canadian HIV/AIDS Legal Network, 2014). UNAIDS and WHO encourage beneficial disclosure. This is disclosure that is voluntary; respects the autonomy and dignity of the affected individuals; maintains confidentiality as appropriate; leads to beneficial results for those individuals and their families and sexual and drug-injecting partners; leads to greater openness in the community about HIV; and meets the ethical imperatives of the situation where there is need to prevent onward transmission of HIV (WHO and UNAIDS, 2000.)

Amidst these fears, some women tend to delay treatment and care decisions, waiting upon their husbands to test and disclose for them to also begin treatment. Unfortunately, some of the men do not test or disclose almost immediately and these women stay without treatment as long as their husbands have not tested and disclosed.

Failure to disclose is among the dominant reasons. Failure to disclose affects uptake and adherence. There are costs involved for women living with HIV to come to the health facilities and lack of money for transport to these health facilities is one of the hindrances because these would miss their appointments for ARV refills. Who will give them money for transport if they have not disclosed to their husbands? The limited financial power of females means that many women end up missing their medication/treatments because they can only take the ARVs if the husband gives them money for transport or if he consents". (Interview, Key Informant, Mbarara District)

Some women prefer not to disclose because of their previous experiences because those who have ever disclosed to their former husbands, they lost their marriages. Some change their physical addresses by moving into new areas where they are not known. When they get other men to marry them, disclosure is not an option and this makes them even abandon the ARVs or take them while hiding; yet it is hard to adhere in circumstances where ARVs are taken in hiding. Others reported that even if it is their first marriage, the fear of losing it is high.

Disclosure to male partners was reported to be even harder for women in polygamous marriages. Women in such marriages already face rivalry, hatred and competition from their co-wives; therefore, they fear that disclosing their HIV status to their husbands will put them in a disadvantaged position vis-a-vis their co-wives.

Fear of violence: Women's failure to disclose their HIV status is also in some cases due to fear of violence. For many women and girls who are in sexual or marital relationships, they have already had an experience of violence from their partners or have heard of incidents of violence among their friends and peers. Given this experience, they fear that disclosing their HIV status to their partners will result into more violence, which will probably end in a break up. This fear of violence is a gendered issue. Much of the violence that women and girls face at the hands of their male partners is unidirectional, i.e. meted by the man on the woman rather than the reverse. Whatever is the reason for violence, the underlying factor is that men batter or physically abuse their female partners because they believe they have power and control over them, and they should control their actions.

... there was a lady who was diagnosed with HIV when she was pregnant. The health workers told her to come with her husband at the next ANC visit. When she tried to explain to the husband, the man grabbed all the medicines and threw them in the toilet, and instructed her never to tell anybody that she had HIV. At the Health Centre, they were looking for her in vain. Later on, they requested me and the peer educator to make a follow-up ... we found the man had gone to Congo to construct a house so that they can move. The lady narrated to us what happened while crying. She told us to hurry, worried that if her husband found anyone in his compound talking about HIV he would kill that person. (FGD, Women living with HIV, Adumi Sub-county, Arua District)

Fear to disclose in discordant relationships, especially among adolescents: The fear to disclose one's HIV status to a male partner is even greater if there is discordance, i.e. if in one way or the other the woman/girl knows that the male partner is HIV negative. The fear in this type of relationship is mainly attributed to the woman who will certainly be accused of being the one that brought HIV. Complexities around fear to disclose were found to be varied among women

and girls in different circumstances. Disclosure in discordant relationships was found to be more complicated for the younger girls living with HIV. Evidence from some studies conducted a couple of years ago suggests that up to 33% of young people perinatally infected with HIV were sexually active and 52% were in relationships (Birungi et al., 2008). Key informants in this study estimated that over 70% of the young people living with HIV who are in relationships are in discordant relationships. Every girl going through adolescence is trying to establish her identity as a grown-up girl, find her self-esteem, and find her place among her peers. Many would think about the prospect of having a boyfriend at this stage. The intrusion of HIV in a girl's life at this stage is thus a very complicated matter. Thus, majority of girls living with HIV at this stage whose male sexual partners are HIV negative – or whose status they do not know, fear to disclose to their male sexual partners for several but inter-related reasons. They fear rejection; the boyfriend may discard her if he learns that they are HIV positive. In addition, many girls dread being rejected because they love the boyfriend, or they are financially dependent on him, or their peers will ridicule them.

Yes, for me I have a boyfriend but sometimes you don't know his status and you know that any time you will be dropped when he discovers that you are sick. They say that we will kill them. (FGD with Girls living with HIV, Mbarara District)

Fears to disclose among girls living with HIV are not only related to boyfriends and relationships, but to parents as well. Girls who have acquired HIV during their teenage or early adulthood cannot easily face their parents or caregivers to say that they have HIV. They fear that they may be seen as a disgrace, considered a waste, or chased out of home altogether. Thus, there are also differences between young girls prenatally infected and those who acquire it during adolescence. To those who are born with HIV, issues of disclosure to the parents, siblings or family members will probably have already been overcome by the time they become adolescents. In addition, they may get used or found solutions to challenges of side effects or managing relationships with their childhood friends and peers. For those who acquire HIV during teenage years, these issues are just starting and more challenging. Whom do they disclose to? How will the parents react? How do they react to the medication? How do they cope with their recent shock of learning that they are HIV positive?

The girls who enter a new relationship while knowing that they have HIV+ are faced with the challenge of disclosure to their partner. But those who discover their HIV positive status while already in a relationship face an even bigger challenge. They may not know whether they got HIV from their current relationship or past relationships. Therefore, they may not know whether it's them, or their partner who brought HIV. Like all people who have just discovered that they are HIV positive, the source of the infection is an inescapable question that these girls will have to battle with, even before they come to the question of disclosure. The uncertainty about the source of the infection may make disclosure even more difficult. If they are the source, they may not be ready to take the blame or to face the consequences which may include rejection, verbal abuse or violence. Delays in disclosure will often lead to delays in seeking care and treatment.

Girls living with HIV who expect their on-going relationship to end in marriage or who have already agreed with their male partners to marry face enormous difficulties disclosing their status. Their fear of rejection is even greater because rejection will mean that the prospect of marriage may collapse as one girl explained.

... we have boyfriends and serious ones but the challenge is telling them the truth. I have a friend who is serious with his boyfriend; the family of the boy even knows her and the boy wants to marry her. This is a guy who is promising to marry you and he is committed to the relationship, so you wonder how you start telling him. ... when he is HIV negative and you tell him that you are HIV positive, he will not remain with you. (FGD with Girls living with HIV, Mbarara District)

In the Ugandan setting, marriage is more of a cultural and social affair than a personal one. If the fiancée is already known to the girl's friends and peers or is already introduced to the girls' family and relatives, the girl may not risk her chances at this stage by disclosing her status. This means that the secrecy about her status will be carried on to the marriage. Whereas she had more space and flexibility to take her medication while she and the fiancée were living apart, keeping the secret becomes more difficult once they start living together. Some girls will at this point discontinue HIV care and treatment in order to preserve their secret and their marriage.

From all the above, it is clear that disclosure of a woman/girl's HIV positive status to her male partner or even to family members is very challenging. This challenge is rooted in being a female and the dependencies and norms that go along with it; therefore, in absence of disclosure, utilization of HIV&AIDS services is greatly undermined.

2.1.1.3 Desire to bear children

The study found that some women and young girls living with HIV will not use protection during sexual encounters because of the desire to get pregnant and bear children. This desire is especially greater among the newly marrieds but can also be found among many other women generally. This was reportedly happening even among discordant couples with full knowledge of their partner's positive HIV status. Whereas the risk of producing an HIV-infected baby can be minimized through early treatment with ARVs especially under the current service model of Test and Treat, many women living with HIV or whose partners are living with HIV are not fully aware of the relevant information that they need to deliver an HIV-free baby. As a result, in their overwhelming desire to get a baby, they do not take appropriate measures to protect themselves, their partners and their intended baby.

There was a lady whose husband told her, 'you know now I am HIV positive and it is better we use a condom if we are to have sex and since you are still negative, let us maintain that', but this woman said, 'ehh ...condom? Do you think that I don't want to produce? Why did you marry me? My work is to produce and I will produce children until I get tired'. (Interview, Key Informant, Arua District)

The desire to have children in the Ugandan context is mainly cultural. Women and girls are culturally expected to bear children and are raised to believe that they will not be complete until they are married and have children. Women have to bear children to prove their femininity and their fecundity as infertility is often blamed on the woman. A married woman who has no children cannot claim to be stable in the home where she is married, and is scared that her husband will find another woman to bear children for him. Thus, even married women who already have some children will desire more and may do anything to get them, even if it is at the risk of contracting HIV. The same was reported to apply to younger girls who are in relationships.

Sometimes some girls want to produce; they say that even if they are sick they cannot die without leaving a baby behind, so they go live [engage in sexual intercourse without protection] with men to conceive. (FGD, Girls living with HIV, Mbarara District)

These findings highlight the need for more awareness about existing options for having HIV-free babies.

2.1.1.4 Preference for unprotected (condom-less) sex

Preference for sex without condoms was also identified as one of the barriers to HIV prevention and positive living among HIV positive women and young girls. People living with HIV are advised to use condoms in order to prevent further infection or not to infect their partners. In this study, some examples were

cited by study participants of HIV negative men and women who insist on unprotected sex with their sexual partners even when they are fully aware that their partners are HIV positive.

I know of a discordant couple; the man put the wife on pressure for sex with no condoms even when he knew the wife's positive status. The woman wanted to protect the man and wanted to use condoms throughout but the man refused ... (Interview, Peer Worker, Mbarara District)

... I have a friend who is positive but is not in this group, she has a man who is negative but for him he said he does not want condoms so they do it like that (FGD, Girls living with HIV, Mbarara District)

Women in FGDs however cautioned that in such cases, the man might know that he is also HIV positive though he keeps it a secret; therefore, he does not care much about further prevention. Relatedly, some women perceive condoms as something for sex workers and they disapprove use of condoms in marital relationships.

Some women hate condoms because they regard them as a tool for sex workers and in so doing abandon their responsibility to protect others and be protected. Some women think use of condoms will reduce them to sex workers, not wives. (Group interview with Health Workers, Mbarara District)

Such beliefs about condoms and the sanctity of marriage are rooted in religious and cultural teachings about marriage. For example, these teaching are about how two married people become one flesh; how nothing should separate two people joined in marriage; and how a woman's body belongs to her husband and vice versa. They are also rooted in the fear that if they use condoms, the man may eventually find another woman with whom he can have unprotected sex. In addition, the choice/opition to use condoms by one partner may be taken as a sign of lack of trust or intimacy.

Others are opposed to condom use because of different reasons such as fear that condoms can burst while others claim that they react to the rubber of the condoms. Others compare using condoms to eating sweets in plastic cover (kavera). Beliefs about reduced sexual pleasure and satisfaction if condoms are used are in most cases not-based on personal experience but on stories from peers and socialization. All these reasons make some women unable to protect themselves or their loved ones against HIV&AIDS in cases where either or all of them are HIV positive.

2.1.1.5 Financial difficulties and Transactional Sex

Financial challenges among women living with HIV and young girls were also reported to be a key barrier to HIV prevention. Some women living with HIV and girls in major towns and rural trading centers were reported to have resorted to transactional sex as a means of survival. Desperate to earn a living, such women and girls are in a weak position to negotiate condom use and only aim to earn some money irrespective of the risks involved.

... Our area has so many women with no income and they engage in unprotected sex to raise money to survive and feed their families. ...some ladies are widows. We also have child-headed homes and so to take care of orphans with scarcity of money these days many have resorted to selling your bodies. (Interview, Religious Leader, Adumi Sub County, Arua District)

In Mbarara, girls living with HIV reported how economic hardships and lack of economic support from their families drives them into sex work and failure to protect themselves.

You get bad words from family members ... they see you as a missed call [a lost opportunity], you request for basics and they do not give you. Due to that lack, when you get someone to give some 20,000/= you cannot again put rules that 'wear a condom'. P2: ... They [parents] can make you suffer and you end up running away from home so that you look for what to do in town. You might even end up as a house girl and sometimes your boss uses you and he might also be sick and those men don't mind about protection. You cannot refuse because you want the job. (FGD, Girls living with HIV, Mbarara District)

District) in Mbarara also reported how they end up having sex with men such as truckers, and older men, who themselves have high chances of carrying HIV. In other cases, it was reported that widows living with HIV get into transactional or even sex work, while others try because they need a man to meet their financial needs. In such cases, they will not disclose their HIV status. If they have been on treatment, they may equally abandon it in order to keep the new husband.

... when my husband got to know my status, he abandoned me in the house and that is when I started messing with other men to make money for survival. (FGD, Women living with HIV, Oli Division, Arua District)

Widows tend to go and have other new partners because they need to meet their basic needs; poverty among us WLWHIV forces us to get new partners. Disclosure becomes a challenge when WGLHIV get new partners. (FGD, Women living with HIV, Soroti Municipality)

In Soroti, it was reported that some bars employ young girls but do not pay them any salary. Instead, the girls are told that they have been given the space to make their own money, that is, through sex work. This scenario exposes such girls to a very vulnerable position as their only source of survival. They have no power to refuse unprotected sex because they are desperate to earn a living. It was reported that some of such girls are HIV+.

In some cases, such girls may even get pregnant. They also face multiple dimensions of vulnerability because they do not know which man is responsible for the pregnancy, or at times a man may not accept responsibility. These girls may not be able to seek appropriate care and services due to lack of money for transport, lack of social support and the sheer magnitude of problems that erodes their self-esteem.

Due to economic hardships, it was reported that some women run away from their work stations to hide in other places in case of failure to pay loans which makes adherence difficult.

Today in every family here in Arua, women are the ones doing all the work to get the daily food; so, they have to go and labor somewhere including petty businesses. Since they have taken loans from SACCO¹³s, they have to work so hard to repay that money and if they fail to pay, they just run away to Sudan. They may not access the HIV services they were getting here. (Interview, Key Informant, Arua District)

In the case of outright sex work, it was reported that male clients pay a higher amount for sex with no condoms compared to sex with condoms. Since sex workers target to maximize their earnings, they are forced to offer unprotected sex, even when they are HIV positive and when they do not know the HIV

¹³ Savings and Credit Co-operative (SACCO) - Savings and Credit Co-operative (SACCO) is a type of co-operative whose objective is to pool savings for the members and in turn provide them with credit facilities.

status of their male clients.

The situation we have in this community is that unprotected sex fetches more money. Therefore, sex workers have two options either to use condoms and get paid less or go without condoms and get more. (Interview, Religious Leader, Arua District)

2.1.1.6 Mobility

Women's mobile lifestyles due to work and cultural demands were also reported to conflict with strict adherence to treatment, sometimes ending up in total withdraw from care and treatment. For instance, female sex workers who participated in FGDs reported the challenges they find in adhering to treatment and keeping appointments due to their mobile nature. The nature of their work dictates that they are always on the move. They may get clients who want to travel with them at short notice, without allowing them time to pack their medicines or collect refills. Wherever they go, they may not accurately estimate or determine how long they will stay there or when they will return to their base station. As one female sex worker narrated, it is difficult to consistently adhere to HIV treatment in this kind of business.

I do not take medicines consistently because my work which is of a mobile nature; I am always on the road. I take some time not at home and in most cases the medicines get finished when I am away. For example, I can go to Ssanga and spend there a week and when I am on my way I meet another customer from Ntungamo then I go to Ntungamo, from Ntungamo I go to Lyantonde, like that. This makes it difficult for me to take my medicines as recommended. (FGD with Sex Workers living with HIV, Mbarara Town)

But mobility is not only for sex workers; it also applies to women who move a lot because of work related reasons, whether they are in formal or informal employment. In Arua, which is a border district, it was found that women engaged in cross-border trade also faced unique challenges due to their movements. This is because when they are crossing into another country they cannot ascertain how long they will be there. Some end up taking longer than planned and their scheduled dates for ARV refills may occur while they are still in another country, leading to non-adherence.

This is a border and many of us do business; if you are not careful you can miss your medicine for several days because you are on a business trip. (FGD, Women living with HIV, Adumi sub-county, Arua District)

... women and girls who are in this cross-border business take medicine for may be one or two months and once it gets finished and they have not yet cleared their businesses that side in Congo or Sudan, they don't come back in time to collect more medicine. This may be due to the high cost of transport. Some come back only when their health has deteriorated. (Interview, Key Informant, Arua District)

As already reported in previous sections, women have to attend many cultural events such as funerals, weddings, or visit the sick, which take them away from their homes and sometimes disrupt their schedules for receiving treatment, picking refills, and confidentiality. All these movements indicate the need to make HIV services more flexible to allow mobile women to access ARVs for a few days in the places they are visiting, so that they do not miss their treatment.

2.1.1.7 Inadequate Information and Treatment Illiteracy

Limited awareness about HIV&AIDS was highlighted as a barrier to the usage of HIV&AIDS services. Study participants reported that some of the women and girls living with HIV are not sufficiently knowledgeable about the available HIV services including SRHR, OIs like STIs, Tuberculosis and cancer screening. In

addition, they are not aware about the service options offered and the importance of different services. This limits the utilization of services.

Sensitization about HIV&AIDS has gone down while in some places this has completely stopped. In the 1990s, TASO and AIC and others used to organize monthly public sensitization meetings at parish levels. These were sources of vital information to people but these have since stopped and our people lack information about the services available while some do not appreciate the existing services. So far, over 6 years have passed, since such open public meetings and sensitizations on HIV&AIDS were held in this area. You see HIV&AIDS is with us, we need to talk, talk and talk about it. (Interview, Peer Counsellor, Mbarara District)

In the absence of adequate knowledge, some women and young girls living with HIV think that it is better not to test and know your status than knowing it. Many stay away from testing services and other HIV related services. Such people may not take any precautions to protect themselves from further re-infection or to protect their sexual partners.

I was diagnosed with HIV in the antenatal clinic... I delivered my baby, good enough he was negative. Later, I went unprotected with some man and I got this baby. God should forgive me; I did that before I was made to understand that one can actually continue to contract new types of viruses if she had sex with someone that has another type of virus. (FGD, Women living with HIV, Oli Division, Arua District)

Furthermore, some cases of PLHIV who take ARVs and feel and look healthy think that they are healed and abandon treatment were reported. This situation normally happens when the viral load is suppressed and their CD4 count raises to high levels. Some of the PLHIV continue to drink a lot of alcohol that may weaken their immune systems, fail to adhere to treatment schedules, or activate other health problems such as liver disease.

Most people abandon taking their ARVs, when their CD4 cells increase and their viral load is very low. They look healthy; they think that they have healed and stop the medicine. (KII with an expert client, Mbarara District)

In other cases, some of the women and girls living with HIV do not believe that they can live a healthy and long life if they adhered to treatment and other positive living practices. Instead, they argue that they will die soon whether they take the medicine or not, and as such they abandon the treatment. Such girls have probably seen other PLHIV that were on treatment but died. Unknown to them is that these could have died due to other complications, and indeed lack of proper adherence.

2.1.1.8 Treatment Fatigue

HIV treatment with ARVs is a lifelong process that requires strong motivation and commitment. The standard narrative of the treatment cascade has been that people should be tested for HIV, and if found positive they should be linked to care, get retained in care, receive support while in care, start treatment and stay on treatment. This narrative assumes that appropriate support will be available to the person who has tested positive for HIV, and that it will be sufficient to keep them motivated to continue treatment and participating in care. This study found that treatment fatigue – the decreased desire and motivation to maintain adherence to treatment (Claborn *et al.*, 2015) – was one of the reasons that led women and girls to drop out of HIV services. The study participants described this as “exhaustion” or “getting tired of swallowing medicines”. It was noted that some PLHIV, especially the young girls who were born with HIV, at a given moment ask, ‘why should one take medicines for a disease they never contracted on their own or for a situation they never contributed to?’ They blame their parents for being the source of the illness and decide to abandon treatment and care.

We had a problem with a young girl who is in secondary school. She decided to hide the medicines and she was not taking them. She said she was tired of medicines

and she was annoyed with the mother because she believes that she got HIV from the mother ... (Interview, Key Informant, Arua District).

Yet others reported that women/young girls living with HIV get tired of taking ARVs and decide to take breaks. This may take time, and then they get back to taking their medicines later. To some, the fear of the burden of taking ARVs all through one's life makes them unable to adhere or even start on treatment.

Treatment fatigue was found to worsen if one experienced side effects from the medicines, faced inconvenience in the schedules to take medicines or failed to cope with required lifestyle changes including use of condoms. Fatigue was also likely to be most felt where women living with HIV did not have adequate social support, faced stigma from those who live, work or spend time with them or had outright opposition from their sexual partners or the significant others.

In other cases, treatment fatigue seemed to combine with hopelessness and the resignation from life-based on their persistence illness and lack of adequate information and encouragement. In such cases, the persons in question feel that they are useless and do not care if they died.

...Some girls say that 'am already sick and am supposed to die' and they say that 'even if I take the ARVs I am to die, so let me die'. (FGD, Girls living with HIV, Mbarara District)

But fatigue with treatment and care were also found to probably be related to the quality of counseling and care services given to PLHIV. Some study participants reported that the quality of counseling had diminished.

You just get tired because it is always the same information the nurses give you. (FGD, Women living with HIV, Adumi sub-county, Arua District).

As noted from the above voice, it appears that the counseling service needs to catch up with the developments in HIV treatment and care and be able to address the evolving needs of clients at different stages of their journey with HIV. Similarly, policy makers and scientists are challenged to innovate and provide newer treatment regimens to overcome the side effects and treatment fatigue reported by people living with HIV.

2.1.1.9 Inadequate food and nutrition

Failure for women and young girls living with HIV (who are on ARVs) to get adequate food is also making some of them fail to adhere well to treatment prescriptions as provided by medical personnel. Some of the young girls who are on treatment are staying with their old grandparents who may not be very keen to ensuring that they take their medicines on time. Others are on the streets and others are from child headed families with the challenges of accessing adequate food making them unable to take their treatment as recommended.

Some of the caregivers of girls living with HIV are elderly Jajas (grandparents) who cannot keep keen eyes on their children to ensure they take their medicines. Some of these children are on the streets, some stay with people who are not their relatives. They say that the reason they are not taking the ARVs consistently is at times, they sleep hungry. ...last week there is a little 10-year-old girl who came here and she broke down and started crying because her viral load has never been suppressed. We were asking about the problem and she said she is the eldest at home and she is the one who provides food for the followers. All the parents died and have left them alone. (Interview, Key Informant, Arua District)

2.1.1.10 Alcoholism

Alcoholism was highlighted as one of the barriers to HIV prevention and adherence to treatment and care. Excessive alcohol consumption not only reduces the effectiveness of medical treatment but also puts individuals at risk of contracting and/or transmitting HIV. Intoxication due to alcohol, whether on single occasions or regularly, leads to reduced self-control and difficulties to follow up on routines and duties. Furthermore, heavy drinking is often associated with a less regular life style and problems accruing from daily care, leading to a bad nutritional state. When people are drunk they tend to forget or even do not appreciate the importance of protection, treatment and care adherence. Men who are drunkards are said to fail to perform their marital duties leaving their wives sexually unsatisfied which make them roam outside marriage for sex. Women who are in such a situation many not protect themselves and may not negotiate condom use.

When men or even women are drunk, condoms are not an issue because they forget about them. Some remember and regret afterwards. With regard to young girls, when they drink a lot of alcohol, they want to enjoy the world and protection is not an issue. (Interview, Key Informant, Mbarara District)

We, men drink beer and fail to perform our marital responsibilities including sexual satisfaction of our partners. They become sexually starved and meander looking for sexual services outside marriage with no or little ability to insist or negotiate condom use. Alcoholism also causes women problems. When they drink, they do not think logically and cannot negotiate condom use or refuse unprotected sex. (FGD, Male partners of Women living with HIV, Ndeija Subcounty, Mbarara District)

In Arua, it was reported that drunkenness led some women to sleep in unsafe places. Some are forced to sleep on the streets because of being drunk. Ladies who are in this state would be sexually assaulted and gang-raped by people they even do not know.

Just up there at the trading center, right now a number of women are drunk; if they are drunk anything can happen. (Male partners of women living with HIV, Adumi Sub-county, Arua District)

There is a lady here at the center, whenever she gets drunk, she goes and sleeps anywhere in the bush, and she knows her positive status. At times when it is a market day or a big day, she allows many men to go with her, young, old and middle aged, all of them; so long as you want to sleep with her. I also remember a scene where a gang of boys made a school girl drunk and gang-raped her. So, because of such character of drinking, prevention of HIV&AIDS is difficult and adherence to treatment becomes very difficult. (Interview, Religious Leader, Adumi Sub County, Arua District)

Yet in many parts of Uganda, alcohol drinking is a social and cultural practice, which is often done in groups. Many people drink alcohol in order to keep up with the expectations and company of their friends and peers.

In summary, the most outstanding individual level social-cultural and gender related barriers to initiation and retention in HIV prevention, care and treatment for women and girls living with HIV include societal rejection, accusation and associating HIV with irresponsible behaviors; failure to disclose HIV sero status for fear of associated violence and desire to have children; over-dependence on male partners (family level decision making is male dominated) for economic and social support and fearing that disclosing HIV sero status would put them at a disadvantage including losing marriage; fear to associate with high risk groups

(PLHIV groups are regarded risky by SACCO leaders); while adolescent girls fear losing boyfriends or failing to get future marriage partners; school going girls fear stigma and discrimination from peers and school authorities; while sex workers fear losing clients.

2.1.2 Institutional/Service Level Barriers

The institutional level barriers are related to the organization and delivery of HIV and AIDS prevention, treatment and care services at various levels and in different settings. They include the relationship between clients and the providers of HIV and AIDS services. The key institutional or service level barriers identified by this study include the poor quality of services and the service package, inadequate youth friendly services, distance to services, the legal environment, and women's limited control of HIV prevention tools and technologies.

2.1.2.1 Poor Quality of Services and poor HIV Services Package

Study participants generally pointed to deterioration in the quality of HIV&AIDS services over the years. Issues raised included those about stock outs of ARVs, poor health workers' attitudes, under-staffing and inadequate counseling services. Drug stock outs at some of the service centers were reported as a hindrance to consistent utilization of HIV services. Some health facilities with stock outs resort to temporally referral for purposes of ARV refills but some clients fail to get the necessary support to the referred places leading to non-adherence.

... whenever we have stock outs especially of second line ARVs, we refer PLHIV to Mbarara referral hospital for refills of at least one month. This is a known practice and the referral hospital is ok with it. However, some of our people are poor. When we refer them, they fail to go there because of transport. (Group Interview with Health Workers, Mbarara District).

There was also reported lack of trust in health workers by clients, much of it related to poor confidentiality amongst some staff which keeps off some of the women from accessing and utilizing HIV services. Rudeness and unprofessional conduct of some of the health workers at the health facilities especially public facilities were also cited as a barrier to utilization of HIV related services.

Some of the health staffs are rude to us, the sex workers, especially when they get to know or tell them frankly that we are a sex worker. They do not appreciate why some of us are sex workers. So, when some of us are abused by some health staff we take it that all staff at all the health centers behave the same way. This makes many of sex workers to avoid the services. (Interview, Female Sex Worker Mbarara town)

When you have an issue you want to ask, some of the medical personnel do not respond to you. For example, I contracted candida and it was so painful and itching me all the time. When I asked the clinician, he refused to tell me and just said go to the window, pick your medicines and go home. Another time I wanted family planning services, when I asked, the nurse told me that 'you mean the HIV you have is not enough for you and now you want cancer from family planning'? (FGD, Girls living with HIV, Mbarara District).

The discrimination and rude conduct of health workers against FSW cited here may also apply to other key population groups such as LGBTI and people who inject drugs (PWIDs).

Issues of mistrust and confidentiality concerns were also found to have been aggravated in cases where services have been decentralized to lower levels as

has been done by TASO. Clients who do not want to pick their medicines from within their communities where they are known were reported to be shunning the decentralized centers where they have been transferred to. These changes seem to have been introduced as part of the shift towards the 'differentiated model' (see definitions) of care that is being piloted in many parts of the world; nonetheless, clients have complaints about certain aspects of it.

Some clients do not trust the health staff at nearby centers so many abandoned care when they were transferred. In fact, in this trading center, when TASO told the people to transfer to this health center III many PLHIV refused to come or to be transferred. TASO had to get an alternative place. (Interview, Peer Counselor, Mbarara District)

The HIV service delivery model of 'come pick and go' which is also part of the differentiated models was blamed as a barrier to HIV&AIDS services usage. The services offered were reported not to be comprehensive and holistic enough to attract service users since TASO does not look at the needs of an individual in a comprehensive and holistic way.

Our service package is "come pick and go", but we do not look at the individual comprehensively. ... our treatment and care package needs to look at the client comprehensively including the home environment, nutrition, psychosocial support etc. all of which will go a long way to improve prevention, care and treatment and attract service users. (Interview, Key Informant, Mbarara District)

Lack of adequate human resources in some health centers and ART clinics compromises their effectiveness. Such service centers are associated with congestion and long queues of clients. They are also associated with long waiting times which tend to drive away clients. Key informants in all districts decried the inadequate staff at service points, which affects the delivery of services. Of particular concern was the fact that most women living with HIV seek services from public health facilities, yet public health facilities do not employ HIV&AIDS counselors. Some clients avoid the clinic on their scheduled return days due to long queues. All these factors compromise adherence to treatment.

One area of human resource is a very big problem; we don't have enough staff, yet when some of these women come, they need quick service. When you delay to work on them, you start seeing gaps in the lines because others have gone away. Even when you see them going and you try to call them to come back, they tell you the queue is still long; we shall be back soon, they end up not coming. (Interview, Key Informant, Arua District)

Women living with HIV themselves confirmed the long hours they spend when they go to the ART clinics.

The journey to Arua hospital is only 20 minutes, but we are only delayed at the hospital, because of the number of people who come for ARV refills. We have Congolese, Sudanese; it is a whole day's program. ... I pick my refills from Oli H/C IV, which is just a five-minute walk or even less, but whenever it is my appointment day for picking medicines, I have to set it aside. (FGD, Women living with HIV, Oli Division Arua District)

Study participants also decried the decline in the quality of counseling services, while others reported that counseling was no longer available due to understaffing and increased workload at the service outlets.

Unfortunately, even quality counseling has vanished within these health centers. The practice is test, give results and treat. Counseling has disappeared from our system. (Interview, Peer Counselor, Mbarara District)

Other study participants referred to the time when TASO and other organizations used to provide food and other basic items to HIV patients and how these incentives helped many women to remain in care. These provisions have since ceased, and there is a belief that their absence had demotivated clients from attending services as reported in the extract below.

... when there were services, when there were NGOs that were committed to empower people living with HIV and their networks, these people were really very interested. But currently these NGOs are not there; therefore, there is no motivation ... When we mobilize them so that they can receive services, they think that it is a waste of time because this motivation is not available. (Interview, Key Informant, Arua District)

Without such incentives, the participation of people living with HIV seems to progressively shrink.

Issues were also raised with regard to availability of free condoms. Although there was reported free condom distribution in some areas especially bars and lodges that are vital for some key populations like sex workers, some bar and lodge owners remove them from free boxes and sell them. This makes some people especially sex workers unable to access free condoms when they need them.

The other challenge is that services are not enough for us, the sex workers. As a Peer Worker, I move supplying condoms to the bars and lodges. However, some of the lodge and bar owners remove the condoms we supply to them for free and put them on counter for sell. Some of our members may get clients but they may not have access to free condoms at the time they need them and end up abandoning prevention. (Interview, Peer Worker with FSW, Mbarara District)

Overall, the findings above reveal deterioration in the quality of HIV&AIDS services experienced by clients over the years. The findings also reveal a failure of the counseling services to move at the same pace with the advances in the HIV epidemic and knowledge, tools and technologies available for its management. These findings call for new efforts to revamp the quality of HIV&AIDS services and to transform the counseling service to match the emerging shifts in HIV&AIDS management in order to better meet the needs of clients. The new 'differentiated care' service delivery models such as decentralized service model and the group models while promising to reduce long-standing challenges should also continuously identify and address emerging challenges that they have sparked off.

2.1.2.2 Inadequate Youth Friendly Services

Another emerging issue is the limited coverage of youth friendly services which affects adolescent girls' access to and utilization of services. Adolescents by nature do not want to seek HIV&AIDS services from the same places where the adults go. Yet in some of the service centers, there are no designated service points for adolescents; they are served from the same service windows as adults.

Adolescents have been failed by the system. We always mix adolescents with all other people who need the services forgetting that these girls want separate service centers that offer adolescent friendly services. (Interview, Key Informant, Mbarara District)

Where we go for services, they have not started separating the youth from their parents. Separation is done for only children aged up to two]. I have ever seen a

challenge in this because one time I met my friend's daughter. She opened up to me that she feels uneasy to be found by her mother because she had not disclosed to her that she was also infected. Because her mother is HIV positive she doesn't want to worry her. (FGD, Women living with HIV, Nyendo, Masaka District)

Girls themselves confirmed their discomfort about getting services from places where they may easily be identified.

... many youths do not want to be known that they are sick; therefore, when some other person is around, it means that he/she will not swallow the medicines. If someone is in the queue to pick medicines and sees someone whom she did not want to know about her HIV status, she will leave the line and run away. It means that she will not take the medication the following days. (FGD, Girls living with HIV, Mbarara District).

Even where youth corners have been established, the mode of service delivery matters as the girls who participated in some of the FGDs reported.

... for condoms they put them on the corners for us to pick but you feel shy to pick condoms when everyone is seeing you. (FGD, Girls living with HIV, Mbarara District)

In situations where there are no youth friendly services, the situation is worse for young girls that face multiple vulnerability. One key informant explained:

Consider a girl who is young (under 18 years), living with HIV and is pregnant; she will be asked so many questions by the health service providers; as a result, she may never come back.

This concern was also highlighted by girls who participated in FGDs in Mbarara, who cited rudeness from health workers. During interactions with girls living with HIV, it was revealed that when they miss their appointments, they are punished by sending them away without medicines for some period leading to non-adherence. Some of the youth in the study noted that some service centers with youth corners do not treat the youth well. Some, in particular, alleged sexual advances and harassment from male health workers. This finding corroborates with findings from elsewhere, including the ICWEA study on violations of sexual and other human rights of women living with HIV.

Some health workers are mistreating us because we refuse to have sex with them. For me, there is a counselor whose advances I refused and one time, I delayed to come for my ARV refills and exceeded the days, they gave me a punishment of a whole week before getting the medicines. (FGD, Girls living with HIV, Mbarara District)

Some services are there, but the way they are provided is not good. For example, the nurse can bring family planning pills and put them on the table and call you loudly by name, thus 'you who have a merciful uterus [meaning someone who is generous to men or sexually loose], come and pick the pills'. Or she can announce that you people who want condoms, they are in the other corner, which makes us ashamed to go and pick them. (FGD, Girls living with HIV, Mbarara District).

Confidentiality in service provision emerged as another key consideration for clients to feel comfortable when accessing services. Recent changes in the delivery of services where clients are asked to form groups for ARV collection were found to be the latest challenge for some clients as reported in some of the FGDs.

This program, which involves us forming groups of six people and requiring one person to pick ARVs for the whole group is not favorable. We need our privacy. (FGD,

All these factors may demotivate young girls from continuing with HIV care and treatment services.

Overall, this study found limitations regarding the quality of HIV services provided but also attempts to transform HIV care by introducing innovative models and approaches such as decentralized care and group-based models of care. However, clients report some challenges with these new models which highlights the need to ensure close monitoring and learning from the new models so as to generate lessons for refining them to meet the varied needs of clients.

Furthermore, the findings reveal that there is a lot of heterogeneity among women living with HIV, namely married women; younger, single women; sex workers and so on, yet services are not adequately responsive to the varied needs of these different categories of women. One way to minimize the barriers preventing women from seeking HIV services will be to respond to the diverse needs of different categories of women.

2.1.2.3 Limited Women's Control over HIV Prevention Tools and Technologies

Key informants in this study raised concerns about the existing HIV prevention methods and tools such as male condoms which reduce the risk of HIV transmission by 96% and safe male medical circumcision which reduces this risk by 60% are almost entirely under men's control. Women literally have very limited control over the use of these methods. If men choose not to adopt and use these methods, their female sexual partners are left unprotected. Indeed, the low adoption of safe male medical circumcision in many parts of Uganda means that men are not doing enough to protect themselves and to protect their female partners. Whereas female condoms are designed to shift the power for HIV control to the women, the female condoms are not popularly used in Uganda. ART - another major prevention tool has mainly focused on women, mainly tested and enrolled through antenatal care. But women have no means of getting their male sexual partners to test or get onto ART. The paradox is that, because men tend to have many sexual partners, even if all of them are on ART, they can be re-infected if their male partner has HIV and is not on treatment.

Overall, this paradox points to the point that the enrolment and retention of men with HIV into HIV services is crucial for the success of efforts to protect women from HIV. Actors in the field of HIV prevention and care therefore need to find innovative ways to get men to test for HIV and to continue in care. In addition, these findings point to the need to provide more options and choices to women for protecting themselves and their loved ones, away from those dominated and controlled by men.

2.1.2.4 Distance to HIV services

While there have been efforts to decentralize HIV&AIDS services to get them closer to the people, this study noted that some women living with HIV and young girls still live far from these services and hence have to move long distances to service points. Access problems may be aggravated in the case of women and girls living with HIV who at the same time are living with disabilities.

They are unable to get transport for themselves to the HIV service centers which makes them unable to keep their appointment days; therefore, they do not adhere well. (Interview, Peer Worker, Arua District)

2.1.2.5 Demand for Transfer Letters

To others, challenges to access HIV services result from the fact that when they relocate from one place to another, they do not come with transfer letters. Yet

the current government policy is that HIV patients who relocate must present transfer letters before they are taken up at new centers. These circumstances force many to abandon HIV care and treatment services if they come from far and do not get a transfer letter.

The requirement of transfer letters before getting services at a different service outlet is a big hindrance. There was one client who was getting treatment from Arua hospital and she was complaining of the distance. She wanted to transfer herself to this health center but the policy says you get ARVs from another facility when you have been officially referred from your usual facility. She stayed off treatment for 7 months. So, when I asked her why it is so, she said she was unable to connect to Arua Hospital. She said she can afford transport to Adumi health Centre yet she was not registered at Adumi HC IV. (Interview, Peer Worker, Arua District)

2.1.2.6 Legal Environment

Female sex workers living with HIV also reported how they suffer at the hands of state institutions such as the police and other security agencies that arrest them without notice and imprison them without allowing them to access their medicines and other HIV services. One sex worker narrated how she ended up spending several months without taking her ARVs.

I was in Sanga and my ARVs had got finished. Then one day police came and found us in the bar very late and they picked us. They picked 16 of us together with men. In the morning, we were produced in court and taken to prison here in Mbarara Central Prison. We were imprisoned for three months. During all these three months, I was not taking my ARVs at all. (In-depth Interview, Sex Worker living with HIV, Mbarara Town).

Whereas it may be possible, within the existing laws, for prisoners to access medical services, a number of factors may combine in such circumstances to deprive vulnerable women of their entitlements. Issues of stigma, poor HIV awareness amongst prisons personnel, lack of HIV services within prisons settings, issues of confidentiality may all combine to complicate access to HIV services in these circumstances. A sex worker who is HIV positive and is under a criminal offence may not easily overcome these hurdles to access services.

Several key informants also raised concerns about inadequate services and responses to women and girls living with HIV who are raped or face gender-based violence. Victims of rape and violence do not know where to seek help, or when they try to seek help, a combination of stigma and bureaucracy from service providers frustrates them.

In summary, the most outstanding institutional level social-cultural and gender related barriers to initiation and retention in HIV prevention, care and treatment for women and girls living with HIV include limited availability of women controlled HIV preventive tools and technologies

2.1.3 Societal Level Barriers

Societal level barriers are those that relate to the influence of the wider socio-economic environment on the life of the individual. Hence, the individual is not seen as a separate entity, but rather as part and parcel of complex social system that shapes his/her life. The societal level barriers identified in this study include stigma, discrimination and limited family support; cultural factors; gender identities, beliefs and norms; and religious factors.

2.1.3.1 Stigma, discrimination and limited family support

In this section, we focus on external stigma¹⁴ at a societal level. When these people act on their prejudice, stigma turns into discrimination. This study noted that HIV-related stigma usually arises from fear and ignorance about the disease and/or hostility and existing prejudices about the groups most affected by it. Stigma leads to discrimination, which affects the willingness of people from seeking information about HIV, treatment and care. Social stigma and punitive civil environments may lead to delays in seeking HIV and STI testing, and subsequent initiation of ART and adherence by HIV positive women and young girls. Women and girls who are seen engaging in HIV services and are therefore identified to be HIV positive may be treated differently by their friends, family members and society as a whole. In many cases, family members become perpetrators of maltreatment against those they are supposed to protect.

Some of the relatives fail us. I was told by the counselor in Mubende to choose one person to refer to when I am sick or who can always help or advise or remind me to take the medicines. So, I picked my sister. Then she went and told my mom and my mom went on telling everyone about my condition. All my relatives got to know about my condition and started talking about my misbehavior, that I was a sex worker and that is why I got the disease. So that may cause some people to throw away the medicine just like that. Some people even abuse and stigmatize us and end up failing us. (FGD, Girls living with HIV, Kabonera Sub-county, Masaka District)

... sometimes our family members are so discouraging, they say we are 'moving corpses'. Even the community around still have negative attitude towards us who have HIV. [For example], a woman may want to have a stable marriage, she may even want to settle with a man but you find her name is rumored about by the entire village. Someone will say 'I rather stay quiet'. ... my brother has been the biggest challenge in our home; because of his torture, my own sister over dosed herself and was even admitted, she almost died. He says we are 'moving corpses', sex workers who deserve to be on streets not at home. (FGD, Women living with HIV, Oli Division, Arua District)

...some of our neighbors say nasty words ... they normally point at us using their tongue that look at that one, she already died long time. If you are not strong you start hiding yourself. (FGD, Women living with HIV, Oli Division, Arua District)

These examples expose practices such as rumor mongering, stigma, discrimination and the associated consequences, resignation and failure to adhere to treatment. Other cases where relatives were involved in grabbing land and other properties of widows and orphans were also reported by study participants.

As shown above, women and girls living with HIV and PLHIV in general may become the subject of rumors and group talk. People may not be willing to share basic items such as food utensils with them, and in other cases people may call them names. The Uganda PLHIV Stigma Index study conducted by NAPHOPHANU found that the commonest forms of stigma and discrimination are gossip (60%), followed by verbal harassment, insults and or threats (37%) (NAPHOPHANU, 2013). For instance, one expert client who was also interviewed as a key informant in this study narrated how she is called names by *boda boda* (motor cycle taxi) riders and how they ridicule her whenever she passes by their stage. She warned that if you are not strong hearted you can easily give up the engagement in services to avoid such public humiliation.

¹⁴ Stigma is a form of prejudice that discredits or rejects an individual or group of people because they are seen to be different from others or from the "norm."

FGD participants also reported how their family members treated them once they discovered they were living with HIV. Some HIV positive women and girls were reported abandoning taking their medications because of a hostile home environment that may exist in a home.

I have my sister who is HIV positive but has spent two months without taking her ARVs because family members seriously abuse her, that she is already dead, that she got what she wanted from men, that her grave is waiting upon her; as a result she has hated herself yet she is pregnant. She is in bad state now. As for me, my sister in-law and my mother in-law talk about me very much that I have killed their son ... The whole village now knows than I am HIV positive. (FGD, Women living with HIV, Mbarara Town)

My family members locked the toilet so that I don't use it. I had a specific plate to eat from; if by accident I used another plate, they would throw it in the toilet. Up to now, there are people who say I am a witch because I have HIV. I would feel very bad ... I did not deserve that treatment. (FGD, Women living with HIV, Adumi Sub County, Arua District).

Stigma faced by women and girls living with HIV at the family and community levels was also noted to have strong gendered roots. For instance, it was noted by some key informants that women and girls living with HIV face much higher levels of stigma compared to males living with HIV. Girls are culturally expected to be well behaved, get married and bring cows to their parents, and be good home makers. Women are expected to be subservient and obedient, and become good role models for children. When information comes out that a woman or a girl is HIV positive, the family reacts with shame and disappointment that is rooted in their expectations of a girl or a woman's conduct. A positive HIV status is associated with promiscuity and violation of the norms that govern being a good girl and a good mother. For a girl to get HIV is seen as bringing shame to the family in the eyes of the community, and comes with serious consequences in terms of how one is treated. One girl narrates below:

... my parents look at me as a wastage and a shame to them in the whole village because of my sickness. They can make you suffer and you end up running away from home so that you look for what to do in town. (FGD, Girls living with HIV, Mbarara District)

Stigma and discrimination were reported to persist not just among family and community members but also at workplaces and within institutional settings. Some key informants reported how PLHIV are denied jobs and employment opportunities on the basis of their HIV status. Examples were cited of some public institutions that do not recruit PLHIV like the army, police, prisons and some private organizations. They carry out secret tests under the cover of medical examination and those found HIV positive are denied entry.

...people are denied jobs because of being HIV positive; it is all over in the private sector many people are not getting jobs. Imagine, we have people who are denied jobs simply because they are HIV positive. It began slowly by refusing them into the military, police and prisons departments; and the private sector has now followed suit. I know of some private sector players who screen for HIV and those found positive are not given jobs although they do not tell them that it is because they are HIV positive. I am also aware that those who take Ugandans to Arab countries exclude those who are HIV positive. ...we have made discrimination part of our culture including in national service organizations. (Interview, Key Informant, Mbarara District)

Overall, the results of this study show that stigma against women and girls living with HIV is still very prevalent at family, community and institutional levels. In many cases, the stigma also generates discrimination.

2.1.3.2 Cultural factors

One of the cultural factors found by this study to affect enrolment and retention in HIV services, which has also been documented elsewhere (MGLSD, 2013), is the belief in witchcraft and use of traditional medicine. It was reported that many people with HIV tend to believe that they have been bewitched; therefore, they seek remedy from traditional healers rather than health facilities. A number of traditional healers and herbalists also take advantage and some claim that they treat HIV. In other cases, HIV patients simultaneously use modern and traditional medicine, sometimes opting to stop the modern medicine depending on how they interpret their healing process and what is working or not working for them. Some abandon treatment and care completely, and resort to herbal remedies as testified by one of the study participants below.

I stopped taking ARVs because the traditional healer told me that I did not have HIV. I have even seen it myself; I no longer suffer from those funny illnesses I used to have. I have really come to conclude that it was the spells [evil spirits or charms] that were disturbing me but not HIV. He [the traditional healer] assured me that the herbs will help to clear all sorts of diseases, so I am not bothered about HIV anymore. (Interview, Woman living with HIV, Mbarara).

The role of culture is also apparent in marriage and its influence on decision making in marriage settings. One of the examples highlighted by participants in this study is the power of in-laws in the decision-making of couples. Marriage in the Uganda setting is not just a matter of two people but rather a family affair, especially the man's extended family. The cultural expectations about child care, e.g., breast feeding, bathing children, etc. were reported to sometimes conflict with the requirements of eMTCT and other HIV prevention and care interventions. In the past, when the eMTCT guidelines required no breastfeeding at all or breastfeeding for a short time, it was particularly hard for HIV positive mothers who had not openly disclosed but wanted to prevent infecting their children with HIV. The in-laws of the woman would question her if she did not breastfeed the baby or bathe the baby in local herbs known as *ekyogelo* and *eshabiko* in Luganda and Runyankore, respectively.

When HIV positive mothers were not allowed to breastfeed at all and later on allowed to only breastfeed for only three months, it was particularly hard for mothers, especially to those who had not disclosed to their terrible in-laws. The in-laws would wonder and suspect why the mother would not breastfeed. The mothers had to hide and then whenever such mothers would become sick handling them would become a big problem. This is still the case to-date among some mothers and married women although they can now breastfeed for some time even when they are HIV positive. (Interview, Key Informant, Mbarara District)

In-laws will also often be the first to accuse the women of 'bringing HIV' and advocate for her dismissal from the marriage, if they learn about her positive status.

Similarly, in many Ugandan cultures such as the Baganda, a married woman is expected to visit in-laws and relatives on different occasions and for different reasons including rituals. For instance, a woman has delivered a new baby; she is expected to visit with the new baby. Such visits may interfere with schedules and appointments for attending HIV services and adherence to HIV treatment.

In most cultures in Uganda, every married woman is expected to give birth within about the first two years of marriage. To conceive naturally would mean having sex without condoms. To some people, sex with no condoms is a sign of love; therefore, to convince one that they are loved is to have sex without a condom. Most victims of this practice are young girls including those living with HIV who yearn to prove to their boyfriends that they actually love them. In this case, protection is not an option.

Culturally, women are meant to produce children. So, married people are not expected to use things like condoms. Culture dictates that if you are married you are supposed to bear children. A woman is not complete unless she bears children. Besides, if the man wants more children, the woman should listen to the man. (Interview, Cultural Leader, Soroti District)

Sometimes it is hard to use protective measures especially if you have been culturally married; as a woman you will be expected to have children and you can't produce children with protective measures, you must at some point have unprotected sex. (Interview, Key Informant, Arua District)

Although wife inheritance is no longer common, it was reported to be still taking place in parts of Teso and other areas. This normally happens when a woman's husband dies; the brother of the husband inherits the widow. In cultures that practice wife inheritance, the woman is considered part of the husband's property and is therefore bequeathed to another male family member upon the husband's death. A woman living with HIV who has been inherited or who is a candidate for inheritance may abandon her HIV treatment or other forms of engagement with services in order to take up her new marriage.

The issue of wife inheritance is still here. In my sub-county and in my village, this is a true story, I know someone whose husband died of HIV; the brother inherited the same woman. So, inheritance is still common. (Interview, Key Informant, Arua District)

Wife inheritance is usually sanctioned by the cultural/clan leaders, the family of the man, and sometimes even the family of the woman. The woman being inherited may have very little choice in the matter. In Soroti, it was reported that sometimes it is an obvious case of forced inheritance against the woman's wish,-based on the belief of the family of the man that they paid for that wife in form of bride price; therefore, she has to remain married in their family. In many cases, inheritance of widows by their in-laws is aimed to prevent the women from getting re-married to other men from different clans who or whose children may then claim the property of the deceased husbands. In such circumstances, a woman who is living with HIV and is inherited by her dead husband's brother may conceal information about her HIV status, and abandon treatment and care in order to take up her new husband without any encumbrances. Even such a woman wanted to turn down the proposal for re-marriage or to set terms and conditions that are necessary for HIV prevention and treatment adherence, cultural pressures may not allow this to happen, given that she may not have the space and voice to present her preferences.

Closely related to the above is the cultural practice of paying bride price at marriage, usually in form of cows and other accompanying items. This practice is prevalent in many Ugandan cultures, with the effect that when the man's family has paid bride wealth for the wife, she is considered to have surrendered all her rights and subjugated herself to the man and his family. Payment of bride price increases the women's subordination to the husband and his family. This control extends even to sexual matters, to the extent that the wife does not have much say in sexual matters; it is the man to decide since he paid for her. For instance, male partners of women living with HIV in Soroti reported that a woman cannot tell her husband to use condoms when the man paid bride price for her.

Payment of bride price by men leads to consider women as their property; hence, the men tend to dictate on sexual matters. If a woman suggests condom use, the man will say 'I married you, and I did not take condoms to your parents as dowry but cows. So, I will never use a condom with you because you are mine'. (FGD, Male Partners of WHLHIV, Soroti District)

In Arua, it was also found that women for whom bride price had been paid are culturally respected and are expected to conduct themselves with a high level of dignity; and being known to be HIV positive ruins that respect.

Women whose bride prices have been paid feel shy to declare their positive HIV status, they feel they deserve that respect and if they are seen going for treatment they will lose their respect. People only show up when they are really sick. (FGD, Women living with HIV, Adumi sub-county, Arua District).

Another long-standing aspect of the Ugandan culture that has implications for the health care seeking behavior of women living with HIV is polygamy. Polygamous marriage is practiced in many Ugandan cultures and is accepted in some religious faiths such as Islam. Women married under polygamous arrangements who find that they have HIV have enormous challenges not only in disclosure but also in seeking HIV services, given the complexity and rivalry in their marriages. Being the first to be identified as having HIV amongst one's co-wives may open a big marital turmoil that a woman may not want to face. It was found that women married in such arrangements will delay disclosure and HIV services seeking or even abandon it completely.

In many societies in Uganda, because of gender norms, women can engage in such practices as buying of condoms; it is for men not for women. Moreover, seen through cultural spectacles, use of condoms in marriage is not acceptable because they are not regarded for married people. Condoms are also associated with promiscuity. Thus, in this study we got many examples where men and women just refused to use condoms with their spouses even if they knew one or both of them had HIV.

I and my wife are discordant... we were advised to use condoms, we went on using condoms but later my wife refused to use condoms. She said if she was to get HIV, she would have got it long time before I was diagnosed with HIV. Good enough when I was diagnosed with HIV she was around ... so she knew my status from the start. (FGD, Male partners of women living with HIV, Adumi Sub County)

In our culture, if you talk about somebody using a condom that person will be labeled a sex worker especially when a female goes to buy condoms. (Interview, Key Informant, Arua District)

These examples demonstrate that culture also plays a role with regard to use of HIV preventive services and practices.

In addition, most cultures in Uganda dictate that women have to be submissive to men. As a result, many women cannot negotiate condom use and when a man demands for sex, the woman is expected to oblige with no terms. When a man himself does not want to use a condom, then preventive sex is in many cases impossible.

Culturally, here women are submissive. Even the educated ones will fear to negotiate for safer sex. Look at this girl in the rural area, when a man says I want sex, she has to offer. They don't have the confidence and the power to say that "yeah this is me, this is my life; I have the responsibility to protect it". And all this is promoted by the cultural values. (Interview, Key Informant, Soroti District).

2.1.3.3 Gender Identities, Beliefs and Norms

a) Women's weak economic and social position

Women's economic dependence on men puts them in a weak position to make decisions regarding HIV prevention and care seeking behavior. Women's subordinate social and economic position is yet embedded in a cultural structure, which treats women as objects of men, thus subjecting them to practices such as polygamy and wife inheritance, all of which are not easily compatible with effective engagement and retention in HIV&AIDS services.

(b) Men masculinities

In the Ugandan cultural context, 'real men' are socially constructed as being strong, emotionally independent, tough and fearless. This image, coupled with their socially assigned role as breadwinners, leads to many men to continuously reassert their masculinity. In the process of doing so, men tend to have poor health care seeking habits and present themselves as strong and resilient to illness. Therefore, men may not test for HIV, or those who test and find that they are HIV positive may behave in different ways in order to maintain their indomitable image. Many may not seek treatment until they are on their death bed.

During FGDs, women participants reported that many men who find that they are HIV positive keep quiet about it and do not attend HIV services. Some remain in denial state and refute the existence of HIV; they behave as if they are not at risk of contracting HIV. Others secretly seek services, often from far-away places. Others stop their HIV positive wives from seeking services in order not to raise suspicion amongst community members about their own status. These factors all contribute to both men and women's delay and in many cases failure to seek HIV services.

Men are very stubborn in their nature, you may find a man very sick and you tell him please go to hospital and test. Such a man will refuse and deceive you that I tested from here and there and I found out that I was fine, yet you see him getting weaker and finished each day that goes by. (FGD, WLHIV, Kabonera Sub County, Masaka District)

There is a lady who was refused from swallowing medicine by the husband I advised her to go for medication and keep the medicine at her friend's place; she now takes them from there. If I had not advised her, she would still not be taking any medicines. (FGD, Women living with HIV, Ndejja Sub County, Mbarara District)

In Arua, both male and female participants in the FGDs reported that many men flee to the Democratic Republic of Congo (DRC), sometimes with their families to escape the shame and humiliation if they are known or suspected to have HIV.

... there is a couple who decided to cross over to Congo, the woman was diagnosed with HIV during antenatal, when she came and told the husband, he warned the wife never ever to go for ARVs, he even warned peer educators not to visit them. (FGD, Male partners of women living with HIV, Adumi Sub-county, Arua District)

When they flee, they may go to places where together with their wives, they may not access HIV services at all.

In other cases, men were reported to use force to obtain sex from their wives or other sexual partners. The use of force in marital or other long-term relationships is also rooted in men's beliefs that they are entitled to sex from their wives/sexual partners anytime they want it, and the belief that the role of the wife is to please or sexually satisfy the husband.

Sometimes our male partners force us to have sex without protection, especially when he has high libido for sex. Men always want to take decisions on how to have sex; sometimes men tend to use their positions to oppress us (women). (FGD, WLHIV, Soroti Municipality)

... we were advised to use condoms but sometimes he refused to use condoms; he forced me into unprotected sex, and I would be angry. So, when I went to pick my medicines from Arua hospital again, good enough he was the one who took me, I reported the matter to the health worker and they tried to counsel both of us, but eventually we separated; we no longer stay as husband and wife. (FGD, Women living with HIV, Adumi Sub-county, Arua District)

This sexual violence makes it difficult for women and girls to protect themselves from further re-infection. A woman/girl cannot refuse her husband/male partner sex even if she knows that he has been unfaithful or has HIV. Men's masculine conduct as described above and in Box 2 is important because it emerges from this study that men's failure to enroll and continue in HIV services closely affects their female partner's enrolment and retention. Indeed, women who participated in FGDs acknowledged that it is useless for a woman to continue practicing HIV prevention and treatment if her male partner is not. Women in Kabonera Sub-county in Masaka described this futility as *okwoza noyanika muttaka*, literally meaning, washing your clothes clean and you spread them on soil to dry. In this study, we came across several women who testified that for them to continue with HIV treatment and other positive living behaviors; they had to separate from their uncooperative and sometimes hostile husbands. Conversely, men who test together with their female partners and receive results together, continue in care, encourage and motivate the retention of their female partners.

However, men also have a vulnerable and fearful side. In many cases, men fail to disclose their HIV status to their wives, or live denial that they have HIV. Others fail to seek HIV services out of fear that their wives would leave them if they found out that they had had extra-marital relationships and brought HIV into the family.

Some of the husbands of some women living with HIV were reported to be forcing their wives who test positive and disclose to them to stay away from ART clinics and HIV related services. These men fear that once their wives visit the ART clinics, everyone in the community will conclude that their husbands are HIV positive as well, which will weaken the men's masculine construct. The quote from one of the HIV Peer Educators below tells a lot.

One day, a lady whom I know came to me and told me personally: 'for me, I came to the antenatal clinic and found myself HIV positive and I went back to my husband, told him that I am HIV positive. The man said that you went and got your HIV from somewhere; don't say that I am the one who gave you the disease. He told me not to go and get medication because if people knew that I was getting medication, his friends would also say that he was HIV positive'. So, the woman sometimes sneaks and comes for treatment, but at times when the husband is there, she misses the ARVs. (KII with a Peer Educator AIDS Information Centre, Arua District)

Overall, the above discussion reveals that we cannot talk about women's enrolment, adherence and retention in HIV services without talking about that of their male partners. It is evident that men's health care seeking behavior for HIV services, which is rooted in their masculinity, greatly affects the health seeking behavior of their female partners. Whereas the government of Uganda

Box 2: Men's poor care seeking behavior - I got married to my man and produced children with him. Little did I know that he was already HIV positive. When I went to hospital for antenatal, they tested me and I was found HIV positive and I started ARVs. I went home and told him about my positive results but he refused to go and test as well until he developed a serious TB. Because he was very weak, he decided to go to the hospital; he was tested and found that he had HIV and started taking ARVs. Now we are happy, healthy and living positively. But really, men are very hard and stubborn. They wait until they are on their death bed to accept their situation. (FGD participant, Women living with HIV, Kabonera Sub County - Masaka District).

has formulated the National Male Involvement Strategy and the Male Involvement Guidelines (2014), these are yet to be widely disseminated, understood and applied.

2.1.3.4 Religious factors

A number of informants in this study reported that religious leaders at some churches tell people living with HIV to stop antiretroviral treatments claiming they had already been healed through their faith in God. Some religions are known to advise their followers to refrain from using any form of treatment whenever they are sick, and instead concentrate on prayers.

Some people are being deceived by religious leaders; they say Jesus has healed them; and they abscond from their treatment. Some even take their ARVs to the pastors to be burnt; before you know it someone has died or is badly off. ... there is a pastor, ... my neighbor who has HIV used to go to him, this lady said she is healed and stopped treatment, but every day she is becoming weaker and weaker. (FGD, Women living with HIV, Oli Division, Arua District).

Other examples were cited of religious groupings in Mbarara (the *Abatafa* in Kashari and the *Abasisimuki* in Ibanda) and Hoima (the followers of Bisaka, a religious leader) who believe in miraculous healing and do not seek modern medical care.

Some religions tell us that they heal HIV and that we should stop taking ARVs. For example, I know one person who stopped taking the drugs and is waiting for God's healing. The health workers followed her up, but she refused. (FGD, Girls living with HIV, Mbarara District).

Religious fanaticism and cults [influence adherence]. For example, there is a religion in Ibanda called Abasisimuki, they do not take any medicine when they fall sick. They believe that they pray to God and get healed. Similarly, the followers of Bisaka in Hoima do not take medicine. (Interview, Key Informant, Mbarara District).

Following promises from some religious leaders to cure them of AIDS, when some PLHIV who have been on ART achieve a suppressed viral load, they believe they have been miraculously cured of HIV&AIDS and they stop treatment. The study team came across a case of a sex worker in Mbarara who was HIV positive and on ART. After receiving preaching from some pastors that HIV is curable, she abandoned treatment in the belief that she was healed of HIV.

Among many religious circles, having HIV is still perceived as a result and proof of sinful behavior, i.e. promiscuity. This perception prohibits some women from declaring their positive HIV status or attending HIV services because they do not want to be seen as having sinned. Similarly, procurement of condoms is associated with the intention to commit adultery, and many women and girls living with HIV may be shy to ask for condoms, whether from health facilities or from commercial outlets.

... for many people here, we perceive that if someone is buying condoms, it is obvious that it is immorality and that you are going to have sex which is not encouraged. ... this can actually hinder access and use of condoms even if the person is HIV positive. (Interview, Key Informant, Arua District)

Furthermore, in some religious faiths such as the Catholic Church and Muslims, use of condoms is not encouraged. Condoms were originally introduced as a birth control and these religions were opposed to birth control and they have since maintained their stance. Promotion of condoms in such settings is also perceived as promoting recklessness and promiscuity. In these circumstances, religion may play a counterproductive role with regard to protection against

HIV.

If you go to the Catholic Church or the mosque and deliver health education on condoms, they may kick you out. Religious people always say that in the Bible or Quran condoms are not there and women were made for men; so, why are we using condoms? They consider it sinful to use condoms. They tell us when two people are joined together no man should separate them. (Interview, Key Informant, Arua District)

This contradiction between HIV prevention and religious beliefs is important since many people living with HIV also tend to turn to religion for solutions. In their renewed effort to be at peace with their God, they may not want to do anything that is considered sinful.

In summary, the most outstanding societal level social-cultural and gender related barriers to initiation and retention in HIV prevention, care and treatment for women and girls living with HIV include societal associated stigma and discrimination, limited family support, beliefs in witchcraft (some people think they are bewitched), preference for traditional healing as opposed to modern medicine, and cultural practices like wife inheritance, bride price payment and polygamy which leave women with little decision-making power about their lives. Masculinity norms limit men's enrolment for HIV services, which likewise affect enrolment and retention of their female partners. Religious sects particularly Pentecostals who preach miraculous healing and this affects participation and retention of certain populations. Uganda is likely to register grim consequences of the HIV.

2.2 Enablers of Women and Girls living with HIV's enrolment and retention in HIV Prevention, Treatment and Care

One of the objectives of this study was to identify and document facilitative factors for the active participation of women and girls living with HIV in prevention, treatment, care and support activities. Findings from this investigation indicate that these facilitators operate at different levels: the micro (individual), institutional and societal levels.

2.2.1 Enablers at the Individual level

Individual/client-based enablers are concerned with the person's own lifestyle, knowledge and personal attributes, as well as the decisions and choices they make with regard to everyday life experiences, challenges and opportunities. The definitive feature is that of the individual and what he or she chooses to do or not to.

2.2.1.1 Personal motivation to live longer

This study found that women and girls' active engagement in the cascade of HIV&AIDS services from prevention through to treatment, care and support was strongly associated with one's desire to stay alive and healthy. Different respondents including HIV positive women and girls and key informants alike talked about the desire to maintain a healthy and productive state of life as one of the key motivations that guide those who seek services and adhere to HIV treatment.

All through my life, I was told I would die if I do not take the ARVs; therefore, I have remained on treatment and I take them as recommended by the doctors because I don't want to die. (HIV positive client and Adolescent Counselor, Mbarara District)

Others argued that women generally have better health care seeking behavior compared to men, and this contributes to their retention in HIV services.

The central theme in such revelations and those of other respondents is life, its significance and hence the desire to protect it by practicing secondary prevention and ensuring adherence to recommended treatment regimens. It is important to appreciate that such a motivation to live does not exist in a vacuum; it is an outcome of decades of sensitization against HIV&AIDS related stigma and discrimination. Indeed, HIV&AIDS campaign messages have long aimed to challenge the pervasive fallacy that HIV infection impairs productivity. The participation of women and girls in HIV activities and the attendant desire to stay healthy and productive is therefore, evidence of some success registered in that campaign.

2.2.1.2 Knowledge and appreciation of benefits of HIV&AIDS services

It was also established that the motivation for involvement in HIV&AIDS activities including initiation of and adherence to treatment, is related to the observed benefits it provides. Some of the benefits mentioned include being rejuvenated, looking good and healthy, and the ability to perform daily functions and take care of children.

I am forced to take these medicines because I have seen several people being bed-ridden due to non-adherence. I know one man whose people had prepared for his death. I would go to his home in the morning, lunch time and evening. I would give him food every day before medicines and after; now, he is back to his work and happy. He tells people that there is no one who owns his life like me. Really, he was finished because the bones were visible and everyone would see him dying anytime. I fought to see that [mentions his name] is alive. So, after seeing such people alive and having hope again, I also can't play around with my ARVs. (HIV positive woman, Bukoto, Masaka District)

...the ones who have been adhering to their medication, they have seen the benefits of taking ARVs. Others have even been giving testimonies that they have stayed for over 20 years with HIV and we have never fallen ill and we have never been admitted because we are taking our medication well as we agreed with the doctors and the counselors (Peer Educator, Arua District).

These excerpts indicate a sound appreciation of the benefits associated with adhering to HIV treatment. Similar views were also expressed regarding commitment to prevention such as using condoms during sexual intercourse.

I would say prevention is better even if you are already infected. If I have HIV or even my partner has it, it isn't good to mix these infections. The viruses are not the same and if we share them, my life will definitely be at stake but if we use a condom our lives are much safer. (Female youth, Bukoto, Masaka District)

Even for us who are already HIV positive can have children who are negative; if we take our medicine on time, give these babies their medicines on time, avoid sex with different men. If a man is your husband, use condoms when you must have sex. ... if you know that you have HIV and you feel you want to make love, you need to use condoms; if he refuses don't allow. Don't even think of that money, who knows his viral load is beyond yours so might add on yours if you go unprotected. If you are positive and this person is negative, then why do you want to infect him? It is better you declare your status and he makes a personal decision whether to have sex with you or not. (FGD, Women living with HIV, Oli Division, Arua District)

As mentioned earlier, this motivation to practice prevention and adhere to prescribed treatment has been greatly inspired by awareness campaigns emphasizing the benefits.

Others reported that they have witnessed the adverse effects of not taking medication, which demonstrates to them the importance of adherence.

What I would say is that I have seen people who have failed to take or adhere to treatment; they have died. And before they die, they have developed complications upon complications. So, for me, I have vowed to [adhere to treatment] until I go [die]. (Female Teacher living with HIV, Soroti District)

2.2.1.3 “Doing it for the kids” - Desire to live for the children

The personal motivator for women’s involvement in HIV prevention, treatment, and care activities is the consideration for the health and wellbeing of their children. This study found that a lot of the motivation underlying women’s uptake of HIV activities derives from their desire to live and provide for their children.

I know that if you take ARVs properly, you become healthy and can take care of your children and grandchildren. It helps us to live longer and even get a chance to see our children grow. You can work and help yourself, help the kids go to school and provide for them. (Woman living with HIV, Kabonera Sub County, Masaka District)

Respondents expressed the desire to nurture and provide for their children as the motivation for their involvement and commitment to HIV prevention, treatment, and care programs. Some said they did not want to die and leave their children as orphans. This was also confirmed by key informants and male partners.

These voices explicitly convey an overwhelming desire among women living with HIV to live for the sake of their children; an issue that was widely expressed throughout the focus group discussions. The use of expressions like “having a home”, “seeing children grow”, “fear of leaving behind orphaned children” and/or “leaving them disadvantaged” among others, shows how important the issue of raising children is to parents. As reflected in these examples, the main thrust is that of seeing children grow and thrive; and participation in HIV prevention, treatment, and care activities is seen as a vital path to that end.

2.2.1.4 Desire to produce HIV Free Children

Among pregnant women and other women who plan to have children in future, a key motivator for seeking HIV services is the desire to produce HIV free babies. This is made possible by initiatives such as eMTCT, where women living with HIV can be helped to deliver an HIV free baby. This possibility was well understood by all the women who participated in this study, and many who were adhering to treatment cited it as one of their motivations.

I wanted to have children but I did not want to give birth to sick babies. When you adhere well to treatment and if you are still young, you can ably give birth to normal bouncing babies free from HIV. I have four kids and they are all healthy and free from HIV. (Woman living with HIV, Kabonera Sub county, Masaka District)

Unfortunately, it was reported that in some cases, such mothers abandon treatment after they have delivered their HIV-free babies!

We get women during antenatal clinics whom we test and they resume the treatment. However, as soon as their children are out of danger because of eMTCT, they stop the treatment only to reappear after some years and sometimes in bad shape. (Group Interview with health workers, Mbarara District).

Certainly, personal and physiological/biological characteristics such as age also play a role in determining the ability of individual women to practice certain preventive behaviors. For example, older women reported how they are able to abstain from sex even when they are married compared to younger women

who still have a stronger sex drive. Similarly, older women with children were generally reported to have better adherence to treatment compared to young, unmarried women and girls, often due to the desire to keep alive and strong so as to take care of their children.

Other women reported that they are motivated by their dreams to make money, acquire assets, establish their own homes or live a fulfilling life like any other human being.

2.2.2 Enablers at the Institutional level

The institutional level enablers are related to the organization and delivery of HIV&AIDS prevention, treatment, and care services at various levels. They underscore the relationship between clients (women and girls) and the initiatives by institutions/professionals to extend services designed to address the client's needs.

2.2.2.1 Influence of HIV&AIDS Counseling Services

The view that counseling by healthcare providers and expert clients played a strong role in motivating women and girls to seek HIV&AIDS services was expressed by various respondents. This was particularly common with regard to acceptance of treatment for those who had been diagnosed with HIV.

I also lived in denial at first, but after I was attacked by cryptococcal meningitis. I went to IDC Mulago and then they counseled me and told me that I need to start my medication and that it was not the end. Then from there, I started to feel well and I started to realize the importance of taking medication. For me, I thought that after I was diagnosed with HIV that was the end of me; so I just wanted to die. I didn't want people to know what I would die of. I wanted them to come and find that I was already dead. But because of the counseling and talks from the counselors, I said that let me continue with my medication, and I will also educate others. In fact, I did it; the child whom I produced when I was HIV positive, up to now, she is very fine. She is 13 years now and she is HIV negative. (Peer educator, Arua District).

Such examples clearly illustrate how quality counseling can translate a state of hopelessness and emptiness into one of hope and optimism. Through counseling, women and girls living with HIV and their partners are empowered with information that helps them to appreciate the significance of participating in HIV services.

2.2.2.2 Influence of testimonies and role modeling by PLHIV and expert clients

Within the broad realm of counseling, the unique importance of testimonies by PLHIV and expert clients was identified as a facilitator for participation in HIV&AIDS services, especially pertaining to accepting to take a test and subsequent uptake and continuation of antiretroviral treatment.

... those who have lived with HIV for long give their testimony how they have walked this hard journey full of embarrassments, abuses, and torture. We pick our pieces up and start this hard journey. Some tell us that if it were not for the treatment, they would have died long time ago. This gives us hope that if you take your ARVs regularly, you can actually live longer. (FGD, Women living with HIV, Oli Division, Arua District)

We, the counselors and peer educators and the few volunteers have been going to talk to the women and girls so that they can understand their situation. The reason why women and girls can listen to us is because we first give our own examples. You tell them, 'you see me here, I was diagnosed in 2000 but if I did not to

take my medication, I wouldn't be like this'. (Peer Educator, Arua District)

Other women reported that they are encouraged by the role models provided by their colleagues who have been in care and treatment for many years, and who look healthy and strong. The role modeling by the expert clients and others was thus a strong motivator.

Some of us get motivation from our friends who have lived with HIV for long. When you see someone has been living a positive life for many years and she is still on treatment, you who just began last year you pick the courage to continue so that your life is prolonged. ... We are encouraged by others to work harder. You may think your situation is the worst but when you move around and find your colleague selling merchandise in the market or digging her garden, you get motivated and if you were about to give up on life, you wake up. (FGD, Women living with HIV, Oli Division, Arua District)

From the example above, it is evident that PLHIV testimonies are vital in helping involuntary clients to appreciate the positive outcomes of accepting to enroll and continue utilizing HIV prevention, treatment, and care.

2.2.2.3 Innovations in HIV&AIDS service delivery models and responsiveness to client needs

In order to attract more women and girls to participate in HIV&AIDS activities such as counseling, testing and enrolment on ART, service providers such as hospitals have introduced arrangements/customs designed to suit the specific realities and address practical challenges faced by women and girls living with HIV such as high transport costs and HIV stigma. For instance, youth/adolescent friendly services exist to target and address the challenges faced by young people as noted below.

In the facilities, we have a strategy to improve on adolescent friendly services so that we can attract young girls and boys. You see, coming to test with the elders may not work; that is why we said that there should be a specific place where they can access the services in a friendly manner; where they can open up and even bring their friends so that those who are positive can be enrolled on care. So, most of the facilities have friendly services and they have even trained the staff to deliver them. (Interview, Key Informant, Arua District)

This is a youth friendly clinic. The youth/clients who are HIV positive have their own specific days of service. We provide counseling, clinical assessment and treatment in form of ART on adolescent clinic days. (Interview, Health Worker, Mbarara District)

Whereas such youth friendly facilities are specifically established to target young people and therefore increase their uptake of HIV services, the community outreach strategy on the other hand aims to bring services closer to the people.

We move within communities to counsel people and encourage them to go to hospitals to test for HIV. Some ladies accept and start ARVs but men refuse because they fear. (Woman living with HIV, Kabonera Sub county, Masaka District).

There is a community outreach where we go as a team to do HTC and health education. At the end of the day, we give condoms and we link people who are found positive to care and treatment straight away. We also have the program of the Orphans and Vulnerable Children where we went yesterday. We have to go to the homes of these children who are orphaned and vulnerable due to HIV to screen their blood for HIV such that they can be supported. (Interview, Key Informant, Arua District).

As expressed in these excerpts, community outreach programs are organized to target and encourage involuntary and other vulnerable groups/clients to participate in HIV activities. In some cases, this has been complemented with school-based outreaches. For instance, in Arua, peer leaders supported by PACE and AIC reported that they have visited some schools and provided counseling and HIV prevention information with emphasis on abstinence. Girls are also taught how to maintain hygiene, especially during their menstruation periods.

Among other things, a person's adherence to treatment is partly affected by the client's experience with a particular type of ARVs. In this study, women and girls reported that their adherence to ART was influenced by health workers' willingness to prescribe treatment regimen with minimum negative side effects.

They gave me a particular tablet which would make me nauseated; since I couldn't do my work freely, I told the doctors about it. So, they changed it and I have never got any problems again. (HIV positive woman, Bokoto, Masaka District).

Ah, when I was put on ART, I reacted to the first type I was given, it made me lose a lot of blood. I became so anemic that I was admitted and got blood transfusion. After the transfusion, the doctor said, 'I am going to recommend that they change for you that medicine!' So using the doctors' report, they introduced me to another type of medicine that am using up to now. (Female Teacher living with HIV, Soroti District).

These two cases show a partnership between health workers and clients in order to improve clients' experience of HIV treatment. Both parties share the goal of maximizing effectiveness of treatment and overall satisfaction.

As part of the move towards a 'differentiated models' of care, some service providers have established an arrangement that allows clients to pick up prescriptions for those unable to receive their own medicines, even though some of the young people are not comfortable with this arrangement due to confidentiality issues.

That is why our partners have been exploring a mechanism of bringing people in groups so that if one is not feeling well, one person from that catchment area may come and take ARVs for the whole group or for those who are not able to come. We think we will reduce the problems of missing appointments. (Interview, Key Informant, Arua District).

Where this system is in place, it provides flexibility as well as convenience to clients who may be experiencing difficulties in adhering to treatment. This is particularly relevant for the terminally sick and those involved in cross border trade in towns such as Arua. As discussed elsewhere in this report however, it raises issues of confidentiality.

2.2.2.4 An efficient follow up and tracking system

A number of facilities reported having an established mechanism designed to track clients in order to follow up those who miss and ensure adherence to treatment. In most cases, this arrangement utilizes community-based volunteers such as Village Health Teams (VHTs) and Peers Workers.

... We have personal details of the clients; so, we try to reach them using telephones. We also have peers who do home visits and provide home-based care. (Interview, Health Worker, Mbarara District).

We use monthly reports by community workers like Community ART Support Agents (CASA), Community Client Led ART Distributor (CCLAD), and Mentor mothers

who follow up clients under the Elimination of Mother-To-Child Transmission (EMTCT) program. (Adolescent Peer Workers, Mbarara District).

2.2.3 Enablers at the Societal Level

Unlike the individual and institutional factors, societal enablers take into consideration the influence of the wider socioeconomic environment on the life of the individual. Hence, women and girls are not seen as separate entities, but rather as part and parcel of a network of other systems, interacting to influence the outcome of their life.-based on this understanding, this study identified a number of societal positive influences on women and girls' participation in HIV / AIDS prevention, treatment, and care and support initiatives.

2.2.3.1 Support by members of the family

In almost all communities, the family system constitutes an important part of the social fabric and a source of support for its members, especially those considered most vulnerable to different forms of abuse, violence and exploitation. Study participants reported that supportive family members remind their HIV positive members to take medicine, they offer social and psychological support all of which gives motivation and confidence for better adherence.

This study received testimonies showing voluminous support extended to women and girls living with HIV by family members. Many women reported receiving both tangible and intangible support from their family members.

First of all, my husband is a very supportive man. Since we learnt of that thing [having HIV virus], he is so supportive. Sometimes, he reminds me, 'you have not swallowed medicine. Let's go and swallow medicine. Even if it's time to go for medication, he is the first person to say it, 'Ah it's time for collecting medication. Let's go', and we go together. That is what has helped me so much. My parents are also very much supportive; once they hear that I am sick, even with malaria, they are there. (Woman living with HIV, Soroti District).

Initially, I had a lot of stigma; although I continued with ARVs, I was not taking them as prescribed because I used to ask myself, 'why live with HIV yet I did not bring it upon myself'. I had no hope, but I got a lot of support from Dad and my siblings to continue taking the medicines. I remember, I never used to take medicines with water; then they made sure that there was millet porridge for me to use. I continued in school while on treatments. (Adolescent Counselor, Mbarara District).

These quotations illustrate the value of the support rendered by family members to women and girls living with HIV. In all the three, family members are shown to provide the much needed encouragement in times of despair. Ultimately, this empowers those affected and motivates them to continue to utilize treatment and other HIV activities.

In addition to such emotional and psychosocial support, members of the family were reported to provide financial and other material provisions to meet the basic needs of women and girls living with HIV. Specifically, some of those interviewed reported that their relatives had provided tuition fees for children, food for the family, as well as other personal effects and household supplies such as soap, lotion and kerosene.

The biggest issue is food. When you have taken the medicine, you don't have what to eat to accompany it. That is the problem I have seen and if you don't help yourself you can die because you can feel so hungry when you have taken the medicine and you feel like dying. Sometimes my sister calls me to find out how I am doing and I tell her that I am fine except that I lack of food and she sends me like 50,000/= to buy maize flour to encourage me to take the medicine. (Woman living with HIV, Bukoto, Masaka District).

Given the socioeconomic vulnerabilities faced by people living with HIV, especially women and girls, support of the nature described above can go a long way in improving their coping capacities, and therefore promote positive living. As evidenced in this study, there is a high likelihood for people living with HIV to disregard participation in HIV activities such as prevention, treatment and care in the face of external pressures of a socio-economic nature.

2.2.3.2 Support by other social entities

Besides the nuclear family system, individuals are part of the wider social system, which also comprises other social entities such as youth groups, membership organizations, religious and cultural groups among others. In this study, we established the existence of different groups such as PLHIV Networks, discordant couple groups, positive living groups, abstinence groups, etc. Most of these groups have been established to extend various forms of social, material and psychosocial support to PLHIV, including women and girls as explained below.

We have groups of positive women who have organized themselves to start a SACCO. Through this SACCO, they have gained a lot in terms of counseling and words of encouragement from fellow women in the same situation who have lived with HIV for long. Many of them who were at the verge of dropping out have gained momentum to move on with the treatment. (FGD, Male Partners of Women living with HIV, Adumi Sub County, Arua District).

There is the discordants club which is active within this catchment area. They normally meet every two weeks and share their challenges and experiences and educate others and encourage one another to live with HIV; they encourage those couples to support each other. (Peer Educator, Arua District).

We have a group that we always go to every month. In that group, we get very good encouragement. That's where we are encouraged especially by our co-coordinator. She has made us very strong and I thank God for her. She is a good woman. I believe in her, she can reach you at any time . . . (Female Teacher living with HIV, Soroti District)

These voices reveal the different forms of support provided to women and girls who are members of groups for people living with HIV. These include encouragement, re-assurance, sharing challenges and instilling hope. A number of respondents reported that this kind of support was very instrumental in helping to counteract stigma and eventually rekindling the motivation to live positively.

Apart from psychosocial support, women and girls acknowledged that PLHIV groups provided financial assistance and other material support such as raw seeds, food and clothes.

We have two groups: one for our ARV collection; it consists of women living with HIV who help each other when need arises. The other group is for the whole sub-county and deals with things like seeds and other economic activities. (Woman living with HIV, Kabonera Sub County, Masaka District).

In some places such as the communities we visited in Arua, women and girls were equally benefitting from the saving schemes implemented by PLHIV networks and other support groups. As indicated above, such initiatives support them in meeting their financial obligations to buy food, pay school fees and cater for other household needs. This also deepens their engagement in HIV&AIDS programs, especially promoted by these groups. Indeed, the above excerpts confirm the motivation of saving groups and PLHIV networks to steer their members' participation in activities of an economic and social nature. Some groups were also commended for organizing exchange activities, which enable women and girls living with HIV to learn from the experience of others and draw inspiration for involvement in HIV/AIDS related activities such as education and sensitization. Overall, the study participants reported that women who belonged to some form of support group were adhering to treatment and continuing in care, while those who did not belong to any such group were

likely to keep in hiding or abandon care and treatment altogether.

On the other hand, girls living with HIV in Kabonera Sub-county, Masaka District, did not have as much social support as the older women. They did not belong to any groups and they did not know many of their peers that were living with HIV. The absence of social support mechanisms for girls means that they can easily drop out of services.

Apart from PLHIV support groups and networks, religious institutions were also reported to be providing moral support to women and girls living with HIV as commended.

One time, when I was in Amnitimadera, a team from church visited me because I was a strong member of the church but when I disappeared, they got concerned and asked where I had gone. [Someone told them] 'She has lost her husband and she has also disappeared from church'. So, they looked for me. They came to Amnitimadera and prayed with me and they said that they were going to continue praying with me. Shortly after, I got the transfer to the other side. That was a good concern from church. (Female Teacher living with HIV positive, Soroti District).

It is worth observing that religious people command a lot of respect in society and influence opinion. Therefore, a message that encourages women and girls living with HIV to take their medication alongside prayer promotes positive ART behavior, especially with regard to levels of adherence.



Box 3: Multiple motivations for adherence and retention

My name is Maria (not real name). I am 40 years old and I live in Adumi Sub County, Arua District. I have been separated twice; from my first husband with whom I had five children, and then from another one where I was a co-wife. At the moment, I live with two of my children, my sister's children and my grandchildren. Together, we are a family of eight. My other two children stay with my parents. I decided to separate from my second husband so that I can take care of myself, take my medicine and educate my children.

I tested HIV positive in 2009 when I was already living with my second husband; therefore, I cannot tell if my first husband had HIV or not. I was tested at an outreach organized by Arua hospital AIDS Program (AHAP) together with my husband and co-wife; however, both of them were negative. We were then counseled and I was advised to start on the treatment, which I willingly accepted and started on 16 March 2009. My husband was so supportive and he advised me strongly to start on treatment. He was actually the one who used to take me to Arua hospital to pick my ARVs. When I declared my status to my relatives, my sister and my children, they were so much disturbed especially my children because they knew that their only source of livelihood was gone. However, I was determined to live longer to take care of my children, so I started to take my ARVs. Yes, if it were not for the ARVs, I would have already died.

Since 2009, I have never dropped out of treatment. Sometimes, I forget, but when this happens, it cannot take more than an hour for me to recall. ARVs have become part of my menu (laughs...). The medical workers clearly told me that being HIV positive does not mean a death sentence, and I have also seen some of my colleagues testifying that they have lived with HIV for over 30 years. I remember the day I tested positive, a peer educator in that team gave her testimony. She talked of how she was about to die before she begun ARVs and then she told me how she managed to educate her children up to University. With that testimony, I picked courage and a positive attitude towards treatment. I am now alive, I have pushed all my children up to S.4 and my prayer is that I send them for a course to the Primary Teachers' College.

I feel fine and strong. I have learnt to keep active because the nurses tell us to engage in physical work to avoid diseases like high blood pressure which may come as a result of idleness. They also teach us to work hard so that we don't beg. For me, I have been hard working, so that I don't take my ARVs on an empty stomach. I think that there is need to record touching testimonies of people living with HIV so that they can be played on radio stations to motivate some of us.

I am now doing hotel business; it is where I manage to get income to feed my family. All my children are close to me and they even know where I keep my medicines. They are aware of the specific time, even the number of times I take the medicines in a day and they keep reminding me. Just last night, we slept at a vigil and as soon as I arrived home, my daughter told me to swallow my medicine before I sleep. I also joined a SACCO, where we support each other as group members. When a colleague is unwell we visit and we encourage ourselves to take ARVs daily. Ever since I began taking ARVs, I have never missed to receive medicines because of stock outs, but even if that were to happen, I have friends with whom I take the same type of ARVs and they can share their stock with me until I get my refill. Besides, I also go to church in my community and they also give us hope; they say that even if one has HIV, she can live long as long as they follow instructions given by health workers.

The above case documents a strong commitment to and involvement in HIV activities, despite the numerous challenges. It shades light on the interplay within individual, institutional and societal systems and the role each plays in supporting women and girls' participation in HIV prevention, treatment, and care and support initiatives. Undoubtedly, it is also a story of hard work, hope and optimism to achieve success, despite the socioeconomic impact of HIV on individuals and families.

2.3 Good practices adopted by HIV Service Providers to effectively engage and retain women and girls living with HIV in HIV Services

2.3.1 Introduction

This study sought to explore the good practices adopted by HIV service providers to effectively engage and retain women and young girls living with HIV in HIV prevention, treatment and care services. The findings are discussed below.

2.3.2 Follow-up of lost clients using phone calls

One of the good practices revealed by this study has been the use of phone calls to reach out to women and young girls living with HIV for retention into in HIV prevention, treatment and care services; and/or remind them to keep their clinic appointment. This has been made possible because of the liberalization of the communication industry that saw many telecommunication companies launch networks almost throughout the country. This has not only made most people accessible by phone but also call rates have been reduced quite significantly. In addition, handsets have also become cheap; as a result, it has become handy for one to own a phone handset. Therefore, a phone contact is often captured at any registration with service providers. Even those that do not have a handset have either a relative or one of their own in a home with a phone where they can be reached. In this regard, this study has established the use phone calls as a means for service providers to continue to engage with both HIV positive women and young for HIV prevention, treatment and care services. It was reported that HIV positive women and young girls for one reason or another often do not turn up for their scheduled appointments at the HIV&AIDS service points prompting HIV service providers to reminder or follow them up with a phone call. During interviews with HIV service providers, the popularity of the use phone call as a means to reach out to their clients (HIV positive women and young girls) to keep them active in the utilization of HIV prevention, treatment and care services was noted.

We have the clients' bio-data of all those registered in care. We have a phone and airtime offered to us by MJAP to make phone calls to these clients. Every file has a phone number. MJAP also sends a person with a motorcycle to come and pick the files of the lost clients and follows them to their homes. This system is effective and works well. (Group Interview, Mbarara District).

Discussions with HIV positive women and girls also acknowledged that indeed service providers require them, at enrolment into their programs, to provide a phone contact in case of a need for follow-up. During discussions, HIV positive women and young girls acknowledged having been followed up by service providers through the use of phone calls among other means.

Yes, they used to call me up to the end of the last year, 2016. They asked me why I don't pick my medicines. ... (In-Depth Interview, HIV positive Woman, Nyendo, Masaka District).

While most informants hailed the use of phone calls as an effective means to reach out to women and young girls living with HIV, it was noted that not all their clients have phones while others reside in areas whose networks are not stable. There were also reported challenges to do with poor batteries, lack of electricity and other challenges, which compromise the effectiveness of phone calls to engage with their clients. It was also noted that some clients

intentionally indicate a wrong contact because they may not want to be reached.

To a great extent, it is effective and it is working for us. The challenge is that some have no phones and some have no physical permanent addresses since they move from house to house. Some of our clients get lost completely. (Group Interviews with health workers, Mbarara District).

The challenges raised here with regard to use of phones underscore the need to assess women clients for their capacity to access and use different communication options such as smart phones, ordinary phones, etc., and other appropriate channels to reach out to them.

2.3.3 Physical follow up of lost-to-follow-up clients

One other popular practice used by service providers to promote retention of PLHIV in care was the physical follow-up visits into the homes of such clients. These visits are usually conducted by either the staff of the HIV&AIDS service providers or through community-based volunteers such as peer counselors and VHTs. This study also noted that in a bid to effectively implement follow-ups on their clients, District PLHIV Networks and Networks of Women living with HIV have put in place arrangements to follow up their members. In addition, different HIV service organizations have created their own structures to facilitate this practice under different names, namely Community Linkage Facilitators (CLFs), Mentor Mothers, Peer Counselors, VHTs, etc.

The various structures were reported to be instrumental in finding out, among other things, how the women and young girls living with HIV are getting on or why they are not fulfilling appointments. They also provide any needed support - giving information on where available services, linking them to partner organizations and service points as well as providing psychosocial support and counseling services. Some of these structures are also given condoms so that they can distribute to the clients and advise the people to go to the health facilities and pick these condoms whenever they want them. It was further noted that the physical follow-ups help where clients fail to respond to a phone call as noted in some of the study participants' voices below.

We live with these people and we know them; therefore, we visit them to see how they are and their health. We advise them on proper adherence and prevention methods to avoid re-infection or infecting their loved ones. We zoned our village and each VHT has about 30 households. We find some of these people with psychological issues and counsel them; and if need be, we refer them to the nearest health facility for further management. (Interview, Key Informant, Mbarara District).

Discussion with members of these structures and other key informants revealed that these structures are playing an important role.

We have continued to make home visits to check on adherence and provide them with counseling. We do follow-up and they tell us that they are following our instructions. When we pass at the neighborhood, the neighbors tell us that the clients are still practicing those behaviors. (Expert Client / Peer Educator, Arua District)

Despite the instrumental role of these local structures, their effectiveness was reported compromised by dwindling financial and material support.

2.3.4 Establishment of Adolescent Friendly Services/Youth Corners at HIV&AIDS Service Points

Although adolescent friendly HIV service points were reported not to be widespread, they represent some of the efforts by service providers to meet the specific needs of young people and therefore ensure their continued use of HIV and other services.

In some centers such as Uganda Cares at Masaka Hospital, they have designated specific clinic days for young people, although adults are also present on these days.

In some districts such as Mbarara, adolescent friendly services were reported to be limited and not fully functional due to resource constraints.

At some of our health service centers, we have specific clinics targeting the youth. The biggest challenge is that funding is not sufficient. Well, partners are trying to support us but a lot is still missing. (Interview, Key Informant, Mbarara District).

We have a youth corner but not really offering youth friendly services. None of our staff has been trained to offer youth friendly services. (Group Interview, Health Workers, Mbarara District).

Reports indicated that adolescents were shunning HIV service points because of lack of confidentiality. They feel uncomfortable mixing with the rest of the other PLHIV seeking treatment, care and support.

2.3.5 Psycho-social Counseling

One other common practice adopted by many HIV&AIDS service organizations if not all of them is psycho-social counseling. This has not only helped HIV positive women and young girls to cope with the epidemic, but it has also enhanced the uptake of prevention, treatment and care services because of the encouragement and hope it gives them. It strengthens adherence and improves health seeking behavior of HIV positive women and girls. Discussions with HIV positive women and young girls, praised the practice.

Counseling has been so helpful to me. These nurses are always available and whenever am stressed, I look for them. Recently, they diagnosed me with Hepatitis B. I was very disturbed and in deep thoughts; I cursed God and posed a question which nobody has answered, 'what kind of sin have I committed that strong illnesses look for me'. However, when I went to Oli H/C IV, the nurses helped me a lot; they told me if I take my medicines as instructed, hepatitis can be cured. (FGD Women, Oli Division, Arua District).

Despite the importance of counseling to HIV positive women and girls, it was also reported that it is currently not well implemented due to understaffing which limits the time available to counsel each client.

2.3.6 Decentralization of HIV&AIDS services

In a bid to decongest HIV&AIDS service centers and get services closer to the people, some HIV service organizations especially TASO have implemented policies to decongest their district or regional centers by allowing transfer of clients to other closer HIV&AIDS service points. This practice was hailed by some of the service providers because it does not only reduce on the workload but it is also affordable and accessible to both women and young girls living with HIV. They noted that they do not have to spend a lot in terms of money and time to move to service points. Some clients also confirmed how they have been successfully transferred to service points near their homes.

Most of us were shifted here to Bukoto Kabonera HC III. So, its where I now get my treatment from. (Expert Client, Bukoto, Kabonera, Masaka District)

Despite the good intentions of the directive, it requires all the PLHIV including women and young girls at regional, district health facilities and partner service centers to be transferred to their nearest health facilities. The challenge with this directive is that some of these nearest health facilities are manned by staff that was not trusted by PLHIV and in other cases. Therefore, issues of stigma and confidentiality within client's villages became an issue and some ended up dropping out of treatment and care.

2.3.7 Social Support Arrangements

This study also noted that women and young girls living with HIV have been encouraged to form social support groups. In these groups, women and girls are involved in number of activities that benefit members including counseling, reminders and loans. Discussions and interviews with various informants acknowledged the instrumental role played by these groups as noted as follows.

We have psycho-social support groups among people who have HIV. We have what we call the family support groups where if someone has HIV in that family, the people in that family should be informed of his or her health condition – with the person's consent - and people can work together to ensure that the person lives positively and has a productive life. (Interview, Key Informant, Arua District).

We have also tried to work with the sub-counties in order to have PLHIV networks in most of the sub-counties where we are able to have dialogues and have platforms, where we can have adherence meetings with them and all these are intended to try to improve the wellbeing of PLHIVs. (Interview, Key Informant, Arua District).

The social support groups were hailed by women living with HIV as having been very instrumental in enabling them to maintain their engagement with HIV services.



3.0 CONCLUSIONS AND RECOMMENDATIONS

3.1 Conclusions

Stigma and fear to disclose one's HIV status, both rooted in strong cultural and gender norms are the biggest barriers to participation in HIV&AIDS prevention, treatment and care and utilization of HIV related services in Uganda by women and young girls living with HIV. Stigma goes with discrimination and creates fear of family rejection and a social naming such as labeling those who are HIV positive 'immoral', 'promiscuous' or 'adulterous'. This study has demonstrated that these social evils related to both personal and societal stigma force many mothers and young girls living with HIV not to disclose their positive HIV status, yet lack of disclosure is associated with poor adherence to treatment and poor retention. As a result, others do not want to be associated with ART clinics and completely avoid HIV related services until they are too weak while others die in complete silence. Yet stigma and lack of disclosure are clearly rooted in existing social, cultural and gender structures that put women in a weak position to make decisions regarding HIV prevention and service utilization and support themselves economically.

Long-standing cultural practices such as widow inheritance and polygamy continue to exist in most Ugandan cultures and contribute to women's failure to continue utilizing HIV services. The social nature of the marriage institution itself imposes undue pressure and expectations on women, making it difficult for them to make choices and decisions about seeking HIV services.

It is clear that the barriers facing women are not the same for all categories of women. There are eminent differences in barriers for older young girls as compared to older women. There are also unique and heightened barriers for women and girls that have multiple economic and social vulnerabilities such as teenagers who are pregnant, women and girls with disability, housemaids, barmaids, female sex workers, women in polygamous relationships, girls from poor families and the unemployed. Economic hardships operate in different ways for married women compared to younger unmarried girls. The married women who are economically dependent on their husbands fear to disclose their HIV status to their husbands for fear of losing the economic support and indeed marriage. In the absence of disclosure, they may not be able to continue their utilization of HIV services. On the other hand, the younger girls facing economic hardships are forced into transactional sex, including real sex work, with diminished ability to negotiate for safer sex. Yet, services are not adequately responsive to the varied needs of these different categories of women. One way to minimize the barriers preventing women from seeking HIV services will be to respond to the diverse needs of different categories of women.

The study further noted that Uganda's HIV&AIDS service package of 'come, pick and go' does provide comprehensive treatment and care to those with HIV&AIDS including women and young girls. The treatment and care package is about providing ARVs and lacks other essential ingredients because it does not consider amongst others the home environment, nutritional support, and psychosocial support, school fees for the affected children, which would go a long way to improve prevention, adherence, treatment and care of those who are infected with HIV&AIDS. Some of the HIV positive women do not trust health staff to keep their secrets. All these only result into some of them failing to get medicines in time while others decide to keep away from HIV related services.

The use and adherence to ART is the best prevention and treatment option available so far for HIV positive women and young girls. ART is associated with improving the CD4 count and reduces the viral load hence a reduced risk to infecting others. Yet, this study found that men's involvement in uptake and use of HIV related services is still low. Most cultures and men's masculinity in Uganda require men to be and act in control; possess the know-how; strong,

resilient, disease free, highly sexual and economically productive. However, such traits are in direct conflict with the 'good patient' persona who is expected to accept being HIV positive, take instructions from nurses and engage in health-enabling behaviors such as attending regular hospital visits and refraining from alcohol and unprotected extra-marital sex. Men even go to the extent of stopping their own wives and partners to stop HIV services while some women do not adhere to their treatment regimens, while others do not disclose because they fear their husbands. This conflict between local understandings of manhood and representations of 'a good patient' provides an explanation as to why so many men do not make use of HIV services yet their participation and full involvement is very key for the adherence and retention of their female partners. Men's failure to enroll and continue in HIV services closely affects their female partner's enrolment and retention. Conversely, men who test together with their female partners and receive results together, and continue in care, encourage and motivate the retention of their female partners.

This study has also established that women's and girl's participation in HIV activities is not an obvious and one-off process despite the benefits that it provides to individuals, families and communities at large. In addition, such participation is not just an outcome of any one single factor, but rather a combination of factors operating at different levels and influencing the subjects in a complex manner.

At the individual level, the desire to live and take care of children, coupled with knowledge and experience of the benefits of HIV&AIDS services seem to provide the greatest impetus for involvement in HIV related activities. Nonetheless, the availability of services like counseling and the flexibility with which they are provided, and the health workers and support group members' dedication to follow-up on reluctant and vulnerable clients are also important motivators. Together with both moral and practical support from family members and PLHIV groups, women and girls' involvement in HIV activities is further enhanced. All this confirms that the individual is just a player within a broad network of multilevel systems. The ability to promote sharing of experiences that exemplify struggle and success against HIV within this network may be one way to create the momentum for the participation of women and girls especially those struggling to overcome stigma and other socio-economic obstacles.



3.2 Recommendations

The recommendations below are based on the above findings. While we attempt to arrange the recommendations to respond to the barriers identified at individual, institutional and societal levels, there are strong overlaps and some recommendations are targeted to tackle multiple barriers at different levels. In addition, since the findings show overlaps and inter-connectedness of some barriers at different levels; e.g., individual barriers being rooted in societal structures, the recommendations also need to inter-connect and tap the resources and actors at different levels. In addition to the three levels (individual, institutional and societal), we also provide cross-cutting recommendations.

1. Identify and intensively strengthen capacity of a critical mass of women/girls advocates who will continuously stand-out to defend and protect the human rights of their peers; including the right to access and consistently utilize health services
2. Support societal/social and community systems for empowering women and girls to demand, protect and promote their human rights – by eliminating cultural/social practices that demean women and girls
3. Initiate and implement community/family/educational institutional level anti-stigma campaign to promote general acceptability and empowerment of women/girls living with HIV
4. Establish family and community level supported disclosure mechanisms to enable those living in denial to open-up about their HIV status; and consequently utilize HIV care and treatment services. -
5. Support economic strengthening programmes that directly benefit young women and adolescent girls including those living with HIV. Economic empowerment reduces vulnerability and improves resilience to manage risk.
6. Government and development partners provide technological and financial support to train adolescent girls and young women living with HIV in vocational and other entrepreneurial skills that would improve their economic base.
7. Strengthen family and community role in supporting women and girls living with HIV to participate and constantly remain in HIV care and treatment programs.
8. Train and sensitize health-care providers on non-stigmatizing and non-discriminating health care services for all including key populations (especially sex workers, lesbians and adolescents and young women).

Table 4: Proposed package of services for different categories of women and girls living with HIV and their male partners

General HIV&AIDS/SRH Services for all groups	Target-Group-Specific Services					
	Married women	Women and girls in discordant relationships	Adolescent girls	Mobile women and girls	Female Sex Workers and other KPs (LGBTI, PWID)	Male partners
<ul style="list-style-type: none"> ⦿ IEC/BCC ⦿ Condom promotion ⦿ HCT ⦿ STI Screening & treatment ⦿ Safe Male Circumcision ⦿ PMTCT ⦿ TB treatment ⦿ Treatment of OIs ⦿ ART ⦿ Cotrimoxazole prophylaxis ⦿ CD4 Count ⦿ Family planning services ⦿ Post-Test Services ⦿ OVC support 	<ul style="list-style-type: none"> ⦿ Male and Female Condoms ⦿ Regular medical check ups ⦿ Regular follow-up ⦿ Economic strengthening support ⦿ Sexual/gender-based violence counseling (SGBV) and support ⦿ Social empowerment through support groups 	<ul style="list-style-type: none"> ⦿ Supported disclosure ⦿ Support to develop couple risk reduction plans ⦿ Male and Female Condoms ⦿ Regular medical check ups ⦿ Risk-reduction counseling ⦿ Regular follow-up ⦿ Economic strengthening support ⦿ Pre-Exposure Prophylaxis (PrePs) ⦿ Awareness creation on PEP and emergency contraception ⦿ Sexual/gender-based violence counseling (SGBV) and support ⦿ Social empowerment through support groups 	<ul style="list-style-type: none"> ⦿ Male and Female Condoms ⦿ Risk-reduction counseling ⦿ Alcohol and drug harm reduction counseling ⦿ Awareness creation on PEP and emergency contraception ⦿ Regular follow-up ⦿ School re-entry support ⦿ Sexual/gender-based violence counseling (SGBV) and support ⦿ Social empowerment through adolescent support groups 	<ul style="list-style-type: none"> ⦿ Male and Female Condoms ⦿ Pre-Exposure Prophylaxis (PrePs) ⦿ Awareness creation on PEP and emergency contraception ⦿ Sexual/gender-based violence counseling (SGBV) and support 	<ul style="list-style-type: none"> ⦿ Male and Female Condoms ⦿ Regular medical check ups ⦿ Risk-reduction counseling ⦿ Alcohol and drug harm reduction counseling ⦿ Provision of lubricants ⦿ Pre-Exposure Prophylaxis (PrePs) ⦿ Awareness creation on PEP and emergency contraception ⦿ Regular follow-up ⦿ Care for sex workers living with HIV (SWLHIV) ⦿ Alternative livelihoods support ⦿ Sexual/gender-based violence counseling (SGBV) and support ⦿ Social empowerment 	<ul style="list-style-type: none"> ⦿ Male and Female Condoms ⦿ Regular medical check ups ⦿ Risk-reduction counseling ⦿ Alcohol and drug harm reduction counseling ⦿ Awareness creation on PEP and emergency contraception ⦿ Regular follow-up ⦿ Sexual/gender-based violence awareness ⦿ Social empowerment through male clubs

Table 5: HIV Services Strategies for different categories

	Outreach, mobile clinics, and workplace-based services; events-based services	Peer to peer mobilization and counseling	Support groups	Couple counseling and HIV testing (CHCT)	Vouchers for temporary ARV access	Condom & lubricant dispensers, etc.	Group approach for ARV refill collection	Separate room/ separate waiting area and service point	Longer clinic opening hours	Written invitation to partner to attend services	Computer and phone-based reminders of appointments, refill schedules, etc.
Adolescent girls	++	+++	+++			+		+++	+++		+++
FSW (and other KPs)	+++	+++			+++	+++			+++		
Married women		++	+++	+++			+++				
Discordant couples		++	+++	+++						+++	
Mobile women					+++				+++		
Men	+++	+++	+++	+++	+++	++		+++	+++	+++	++

Key:

- +++ - Highly appropriate
- ++ - Moderately appropriate
- + - Slightly appropriate

REFERENCES

- Birungi H., Mugisha JF., Nyombi J., Obare F., Evelia H., & Nyinkavu H. (2008). Sexual and reproductive health needs of adolescents perinatally infected with HIV in Uganda. FRONTIERS Final Report. Washington DC, Population Council.
- Buvé A, Bishikwabo-Nsarhaza K, Mutangadura G (2002) The spread and effect of HIV-1 infection in sub-Saharan Africa. *Lancet*, 359(9322):2011–2017.S
- Canadian HIV/AIDS Legal Network (2014): HIV Disclosure and the Law: A Resource Kit for Service Providers. <http://www.aidslaw.ca/site/wp-content/uploads/2014/06/Legal-Network-HIV-disclosure-to-sex-partners.pdf> Accessed 27/03/2017.
- Carrasco, M.A., 2016. No Esta Sola: Social Cohesion, HIV Stigma, and HIV/STI Prevention among Female Sex Workers Living with HIV in Santo Doming. PhD. 2016. Johns Hopkins Bloomberg School of Public Health. Baltimore, Maryland.
- Claborn K.R., Meier E., Miller M.B., and Leffingwell T.R. (2015): *A systematic Review of Treatment Fatigue among HIV-infected Patients Prescribed Antiretroviral Therapy*. *Psychology, Health and Medicine* 20 (3), 255-65.
- Duffy L: Culture and context of HIV prevention in rural Zimbabwe: the influence of gender inequality. *J Transcult Nurs* 2005, 16(1):23–31.
- Geeta Rao Gupta, 2000. Gender, Sexuality, and HIV/AIDS: The What, the Why, and the How. Plenary Address XIIIth International AIDS Conference Durban, South Africa. International Center for Research on Women (ICRW) Washington, D.C. U.S.A. July 12, 2000.
- Fletschner, D., & Kenney, L., 2011. Rural women's access to financial services Credit, savings and insurance. ESA Working Paper No. 11-07, March 2011. Agricultural Development Economics Division. The Food and Agriculture Organization of the United Nations.
- Guionnet A. et al., 2011 Immigrant women living with HIV in Spain: a qualitative approach to encourage medical follow-up. *BMC Public Health* 2014;14:1115 <https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-14-1115> accessed on 22nd march 2017
- Jain A., Carr D., and Nyblade L. (2015): *Measuring HIV Stigma and Discrimination among Health Facility Staff. Standardized Brief Questionnaire User Guide*. Washington D.C.: Futures Group, Health Policy Project.
- KMCCI, 2012. Eliminating Mother-to-Child Transmission of HIV in Uganda by 2015: What will it take? Knowledge Synthesis Working Paper. Final Draft – 24th November 2012.
- Kuwane B, Appiah K, Felix M, Grant A, Churchyard G (2009) Expanding HIV care in Africa: making men matter in Johannesburg. *Lancet* 374: 1329.
- Loutfy, M., Khosla, R., & Narasimhan, M., 2015. Advancing the sexual and reproductive health and human rights of women living with HIV. *Journal of the International AIDS Society* 2015, 18(Suppl 5):20760

- MGLSD (2013): Socio-cultural norms, values and practices that impact of HIV and AIDS, maternal health and gender-based violence in Busoga Cultural Institution. Unpublished Report by Trade and Business Development Centre. Kampala.
- MoH et al. (2012): Uganda AIDS Indicator Survey 2011. Kampala, August 2012.
- Mugisha, K. et al., (2009). Retention of HIV Positive persons in Antiretroviral Therapy Programs in Post Conflict Northern Uganda – Baseline survey of 17 Health Units. Northern Uganda Malaria AIDS and Tuberculosis Program.
- NAPHOHANU (2013): The PLHIV Stigma Index, Country Assessment, Uganda. The National Forum of People living with HIV Networks in Uganda. Kampala.
- Nyondo A. A., Muula A. S. and Chimwaza A. F. (2013): Assessment of strategies for male involvement in the prevention of mother-to-child transmission of HIV services in Blantyre, Malawi. *Global Health Action*, 6. Published online 2013 Dec 16. Accessed at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3866839/> April 3, 2017.
- UAC (2016): The Uganda HIV and AIDS Country Progress Report July 2015 – June 2016. Uganda AIDS Commission, Kampala.
- Uganda Bureau of Statistics (UBOS) and ICF International. (2012). Uganda Demographic and Health Survey Kampala: Uganda Bureau of Statistics and Macro International Inc.
- Ulibarri et al., 2015. "Amar te Duele" ("Love Hurts"): Sexual relationship power, intimate partner violence, depression symptoms and HIV risk among female sex workers who use drugs and their noncommercial, steady partners in Mexico. *AIDS Behav.* 2015 January; 19(1): 9–18. doi:10.1007/s10461-014-0772-5.
- UNAIDS (2000): Opening up the HIV/AIDS epidemic. Guidance on encouraging beneficial disclosure, ethical partner counseling and appropriate use of HIV case reporting. Geneva, Switzerland.
- UNAIDS (2003): Stigma and Discrimination. Fact Sheet. http://data.unaids.org/publications/Fact-Sheets03/fs_stigma_discrimination_en.pdf. Accessed March 14, 2017.
- UNAIDS (2014): Reduction of HIV related Stigma and Discrimination. Guidance Note. http://www.unaids.org/sites/default/files/media_asset/2014unaidsguidancenote_stigma_en.pdf Accessed March 14, 2017.
- UNAIDS (2015): UNAIDS Terminology Guidelines. Joint United Nations Programme on HIV/AIDS. Geneva.
- Virginia Bond, MA (Hons), PhD,1,2 Graeme Hoddinott, MSocSci, 3 Lario Viljoen, MA, 3 Melvin Simuyaba, BSW, 2 Maurice Musheke, MPH, PhD, 2 and Janet Seeley, MPhil, PhD,1,4 on behalf of the HPTN071 (PopART) Study Team; 2016. Good Health and Moral Responsibility: Key Concepts Underlying the Interpretation of Treatment as Prevention in South Africa and Zambia Before Rolling Out Universal HIV Testing and Treatment. *AIDS PATIENT CARE and STDs* Volume 30, Number 9, 2016. Mary Ann Liebert, Inc. DOI: 10.1089/apc.2016.0114.
- Wekesa E, Coast E (2014) Fertility Desires among Men and Women Living with HIV/AIDS in Nairobi Slums: A Mixed Methods Study. *PLoS ONE* 9(8): e106292. doi:10.1371/journal.pone.0106292
- WHO & Pangaia Global AIDS Foundation, 2012. Optimizing HIV Treatment Access and retention in Care: linking Community Level Interventions with Health

Care Delivery Systems in Sub-Saharan Africa. Draft Meeting Report. 26th – 28th March 2012, Harare, Zimbabwe

WHO and UNAIDS (2000): Opening up the HIV/AIDS epidemic. Geneva.

WHO (2011): Retention in HIV Programmes: Defining the Challenges and Identifying Solutions. Meeting Report. 13th – 15th September 2011, Geneva

WHO (2012): Male involvement in the prevention of mother-to-child transmission of HIV. Geneva.

Annex 1: Data Collection Tools

International Community of women living with HIV Eastern Africa (ICWEA)

Documenting cultural and other social gender-related barriers that hinder WGLHIV effective participation in HIV prevention, treatment and care services in Uganda

FGD Guide for Women Living with HIV

Record ages of participants

- Ice Breaker: Talk about any neutral subject, e.g., the weather, recent events in the country or the community.

HIV Prevention

- What do you understand by HIV prevention?
 - For people who might already be living with HIV, what does prevention of HIV mean?
 - How important is the issue of HIV prevention for people living with HIV?
 - (If re-infection is not mentioned) What do you understand by re-infection?
 - Also probe about protecting/not infecting others if not mentioned.

- To what extent do women living with HIV in your community prevent further infection or infecting their partners?
- How do women living with HIV in your community prevent further infection or infecting their partners?
- Are there some women living with HIV who do not use protective measures against HIV infection?
- Under what circumstances may women living with HIV not protect themselves or their partners from HIV infection?
 - Probe for variations – e.g. among discordant couples; fear of violence; stigma; Health Care worker attitude, etc.
- What specific challenges or barriers stop women living with HIV from protecting themselves from re-infection or their partners from HIV infection?
- Who decides whether a woman (living with HIV) can practice HIV prevention or not? Is the decision made by herself or someone else?
- What kind of people influence women and girl's decisions to practice HIV prevention?
- How does each of the mentioned categories of people influence these decisions?

Treatment

- Are all women living with HIV in your community on anti-retroviral treatment?
 - Those who are on treatment, where do they get the treatment from?
 - How far is it from here? How long (in minutes/hours) does it take to get there?
- How consistently/regularly do women who are on treatment take their medication?
 - To what extent do they adhere to the recommended drug intake instructions?
 - In cases where there is no adherence, what are the reasons for non-adherence?

- What are the reasons do some women who are not on treatment provide?
- What roles do family members play in supporting treatment seeking and adherence to treatment by women and girls living with HIV?
- In what ways do family members discourage or fail treatment seeking and adherence to treatment by women and girls living with HIV?
Probe for the role of these other people: health workers, religion, culture, friends, other community members, etc.

Care

- What care services are available to women living with HIV in your community? **Probe for:** psychosocial support (including counseling), home-based care, nutrition support, legal support & protection.
- Are all women living with HIV in your community receiving the care they need?
- Those who are receiving care, where do they get the care services from?
- How far is it from here? How long (minutes/hours) does it take to get there?
- What are the reasons given for some women who are not accessing care?
- For women who have previously been enrolled in care, at what stage do they drop out?
- What roles do family members play in providing care or supporting access to care for women living with HIV?
- What roles do family members play in discouraging care for women living with HIV?
Probe for the role of these other people: Health workers, friends/peers, other community members, religion, and culture.

- For women who are actively seeking and utilizing HIV prevention, care and support services, what is their greatest motivation? Why are they able to do this?

Thank you

International Community of women living with HIV Eastern Africa (ICWEA)

Documenting cultural and other social gender related barriers that hinder WGLHIV effective participation in HIV prevention, treatment and care services in Uganda

FGD Guide for Girls Living with HIV

Record ages of participants

- Ice Breaker: Talk about any neutral subject, e.g. the weather, recent events in the country or the community

HIV Prevention

- What do you understand by HIV prevention?
 - For people who might already be living with HIV, what does prevention of HIV mean?
 - What do girls living with HIV think about HIV prevention?
 - How important is the issue of HIV prevention for young people living with HIV?
 - (If re-infection is not mentioned) What do you understand by re-infection?
 - Also probe for protecting/not infecting others if not mentioned
- Are girls living with HIV engaged in sexual relationships?
 - Please tell us more – how do girls living with HIV negotiate/manage sexual relationships? What kind of people are their sexual partners? Do girls living with HIV disclose their HIV status to their sexual partners? How do girls disclose? What information do they disclose?
- To what extent do girls living with HIV in your community prevent further infection or infecting their partners?
- How do girls living with HIV in your community prevent further infection or infecting their partners?
- Are there some girls living with HIV who do not use protective measures against HIV infection?
- Under what circumstances may girls living with HIV not protect themselves or their partners from HIV infection?
 - Probe for variations – e.g. among discordant relationships, stigma, HC worker attitude, etc.
- Where do young girls get HIV prevention services from?
 - Are there specific services targeting young people, e.g. youth corners providing youth friendly services (condoms, information, recreation, STI screening and treatment, etc.)?
- What specific challenges or barriers stop girls living with HIV from protecting themselves from re-infection or their partners from HIV infection?
- What can be done to overcome these barriers?
- What kind of people influence girl's decisions to practice HIV prevention?
- How does each of the mentioned categories of people influence these decisions? (probe for peers/friends, family members, sexual partners, health workers, religion, culture, etc.)

Treatment

- Are all girls living with HIV in your community on anti-retro viral treatment?
 - Those who are on treatment, where do they get the treatment from?
 - How far is it from here? How long (minutes/hours) does it take to get there?

- Are there any youth friendly HIV/SRH services?
- How consistently do girls who are on treatment take their medication?
 - To what extent do they adhere to the recommended drug intake instructions?
 - In cases where there is no adherence, what are the reasons for non-adherence?
- What are the reasons why some girls are not on treatment?
- What roles do family members play in supporting treatment seeking and adherence to treatment by girls living with HIV?
- In what ways may family members discouraging treatment seeking and adherence to treatment by girls living with HIV?
Probe for the role of these other people: Health workers, religion, culture, friends, sexual partners, other community members,

Care

- What care services are available to girls living with HIV in your community?
- Are all girls living with HIV in your community receiving the care they need?
 - Those who are receiving care, where do they get the care services from?
 - How far is it from here? How long (minutes/hours) does it take to get there?
 - Are there youth-friendly HIV /SRH services (e.g. STI screening & management targeting to young people)?
- What are the reasons given by some girls who are not accessing care?
- For girls who have previously been enrolled in care, at what stage do they drop out?
- What roles do family members play in providing care or supporting access to care for girls living with HIV?
- In what ways may family members discourage care for girls living with HIV?
Probe for the role of these other people: Health workers, friends, sexual partners, other community members, religion, culture, and peers.

- For girls living with HIV who are actively seeking prevention, care and treatment services; what is their greatest motivation? Why are they able to do this?

Thank you

International Community of women living with HIV Eastern Africa (ICWEA)

Documenting cultural and other social gender related barriers that hinder WGLHIV effective participation in HIV prevention, treatment and care services in Uganda

FGD Guide for Partners of Women/Girls Living with HIV

Record ages of participants

- Ice Breaker: Talk about any neutral subject, e.g. the weather, recent events in the country or the community

HIV Prevention

- What do you understand by HIV prevention?
- For people who might already be living with HIV, what does prevention of HIV mean?
 - (If re-infection is not mentioned) What do you understand by re-infection?
 - Also probe about protecting/not infecting others if not mentioned
- How important is it for women/girls living with HIV to practice HIV prevention measures?
- To what extent do women/girls living with HIV in your community prevent further infection or infecting their partners?
- How do women/girls living with HIV in your community prevent further infection or infecting their partners?
- Are there some women/girls living with HIV who do not use protective measures against HIV infection?
- Under what circumstances may women/girls living with HIV not protect themselves or their partners from HIV infection?
- What specific challenges or barriers stop women/girls living with HIV from protecting themselves from re-infection or their partners from HIV infection?
- What kind of people influence women and girl's decisions to practice HIV prevention? (Probe: health workers, peers, family members, religious leaders, cultural leaders, etc.)
- How does each of the mentioned categories of influencers influence these decisions?

Treatment

- Are all women/girls living with HIV in your community on anti-retro viral treatment?
- How consistently do women/girls who are on treatment take their medication?
 - To what extent do they adhere to the recommended drug intake instructions?
 - In cases where there is no adherence, what are the reasons for non-adherence?
- What are the reasons why some women/girls are not on treatment?
- How do you, as partners, support treatment seeking and adherence to treatment by women and girls living with HIV?
- Are there some male partners who discourage treatment seeking and adherence to treatment by women and girls living with HIV? Are there things they should do, which they do not do to support care seeking by their female partners?

Care

- What care services are available to women and girls living with HIV in your community?
- Are all women/girls living with HIV in your community receiving the care they need?
- What are the reasons why some women/girls are not accessing care?
- What role do you play in providing care or supporting access to care for women and girls living with HIV?
- In what ways do male partners play in discouraging (or do not do to support) care for women and girls living with HIV?

Thank you

International Community of women living with HIV Eastern Africa (ICWEA)

Documenting cultural and other social gender related barriers that hinder WGLHIV effective participation in HIV prevention, treatment and care services in Uganda

Interview Guide for Key Informants – District and Sub-county Officials

Record Position and name of Informant

Overview

- What HIV related services are available in the district? How are they distributed/located? Who provides them?
- What is the situation of women and girls living with HIV in this district/sub-county?
 - Are they practicing HIV prevention?
 - Are they getting treatment with ART?
 - Are they getting care and support services?

HIV Prevention

- Are women/girls living with HIV in sexual relationships? How do they negotiate these?
- How do women/girls living with HIV in your community prevent further infection or infecting their partners?
 - How do you know that this is happening?
- What HIV prevention services or methods do you promote/provide for people living with HIV?
- Are there some women/girls living with HIV who do not use protective measures against HIV infection?
- Under what circumstances may women/girls living with HIV not protect themselves or their partners from HIV infection?
- What specific challenges or barriers stop women/girls living with HIV from protecting themselves from re-infection or their partners from HIV infection?
 - If not mentioned, probe on issues of legal environment, stigma and discrimination, etc.
- What can be done to address these barriers?
- What kind of people influence women and girl's decisions to practice HIV prevention?
- How does each of the mentioned categories of influencers influence these decisions?
- What have you done as a district to promote HIV prevention among people living with HIV?

Treatment

- Are all women/girls living with HIV in your community on anti-retro viral treatment?
- What are the reasons why some women/girls are not on treatment?
- What specific barriers make it difficult for women living with HIV to enroll on treatment?
 - If not mentioned, probe on issues of gender, legal environment, stigma and discrimination, etc.
- For the women/girls who are on treatment, how consistently/regularly do they take their medication?

- To what extent do they adhere to the recommended drug intake instructions?
 - In cases where there is no adherence, what are the reasons for non-adherence?
- What interventions has the district implemented to ensure treatment for people living with HIV?
- How have gender aspects in access to treatment been addressed?

Care

- What care services are available to women and girls living with HIV in your community?
- Are all women/girls living with HIV in your community receiving the care they need?
- What are the reasons why some women/girls are not accessing care?
- What specific barriers make it difficult for women living with HIV to enroll on treatment?
 - If not mentioned, probe on issues of gender, legal environment, stigma and discrimination, etc.
- What has the district done to improve care and support services for people living with HIV?
- What more should be done to increase the participation of women and girls living with HIV in prevention, treatment and care services?

Thank you

International Community of women living with HIV Eastern Africa (ICWEA)
Documenting cultural and other social gender related barriers that hinder WGLHIV effective participation in HIV prevention, treatment and care services in Uganda

Interview Guide for Key Informants – Community-based Informants (Expert Clients, Peer Workers, Local Leaders)

Record Position and name of Informant

Overview

- What is the situation of women and girls living with HIV in this district/sub-county?
 - Are they practicing HIV prevention?
 - Are they getting treatment with ART?
 - Are they getting care and support services?
- Are HIV services available? Where? What services? Who provides them?

HIV Prevention

- To what extent are women/girls living with HIV in your catchment area preventing further infection or infecting their partners?
 - How do you know that this is happening?
- Are there some women/girls living with HIV who do not use protective measures against HIV infection?
- Under what circumstances may women/girls living with HIV not protect themselves or their partners from HIV infection?
- What specific challenges or barriers stop women/girls living with HIV from protecting themselves from re-infection or their partners from HIV infection?
 - Probe for social, cultural, religious challenges/barriers, etc.
- How can these barriers be addressed?
- What support do you provide to women and girls in HIV prevention?
 - Where else do they get support from?
- What challenges do you face in promoting HIV prevention for people living with HIV?

Treatment

- Are all women/girls living with HIV in your catchment area on anti-retro viral treatment?
- What are the reasons why some women/girls are not on treatment?
- For the women/girls who are on treatment, how consistently/regularly do they take their medication?
 - To what extent do they adhere to the recommended drug intake instructions?
 - In cases where there is no adherence, what are the reasons for non-adherence?
- What support do you provide to women and girls in terms of treatment?
 - Where else do they get support from?

Care

- What care services are available to women and girls living with HIV in this community?
- Are all women/girls living with HIV in your community receiving the care they need?
- What are the reasons for some women/girls not accessing care?
- What roles have you played in promoting HIV prevention, treatment and care for people living with HIV?
- What more should be done to increase the participation of women and girls living with HIV in prevention, treatment and care services?

Thank you

International Community of women living with HIV Eastern Africa (ICWEA)

Documenting cultural and other social gender related barriers that hinder WGLHIV effective participation in HIV prevention, treatment and care services in Uganda

Case Documentation Guide

Interviewer: *You do not have to ask all the questions here. Please concentrate only on those questions which will elicit an important story from the respondent.*

1. Tell me about yourself
 - a) How old are you?
 - b) Are you married? Are you currently in a relationship?
 - c) Do you have children? [How many?]
 - d) Whom do you live with in your family? [How many people altogether?]
2. Tell me your journey living with HIV
 - a. In which year did you get to know/were you first diagnosed to have HIV?
 - b. Which people came to know first about your HIV status?
 - c. At what stage did you tell the other people?
 - d. When did you become open about your HIV status?
 - e. Are you on treatment?
3. Tell me about your treatment
 - a) When did you start treatment?
 - b) What was your first source of treatment (name place/hospital/organization and its location)?
 - c) Are you still getting treatment from the same source?
 - d) Have you ever dropped out of treatment, i.e. stopped taking treatment?
 - e) At what point did you stop taking treatment?
 - f) What were the reasons for stopping treatment?
 - g) Did you discuss with anybody before you stopped treatment? Who did you discuss with? What did this person/people say to you? Did they encourage you to stop treatment or they wanted you to continue on treatment?

- h) (If the interviewee later on got back on treatment) Please tell me how you got back on treatment.
- i) (Those who are on treatment) – What helps you / encourages you/ motivates you to continue with treatment?
- j) What challenges do you find in trying to continue with treatment?
- k) Tell me how the following influence your decision to take your treatment:
 - a. Your partner/ spouse;
 - b. Your other family members;
 - c. Your friends / and women with the same condition;
 - d. Health workers;
 - e. Your religion/religious leaders/ church/ mosque;
 - f. Your culture/cultural beliefs and norms; and
 - g. The community / society's beliefs about women (gender issues)?
- l) What needs to be done to enable you and other women/girls in the same position like you to continue treatment?

Prevention

- 4. Are you doing anything to protect yourself / are you using any of the ways of HIV protection?
- 5. What are you doing?
- 6. Why are you doing that? Why is it important?
- 7. Whose decision is it to use those protection measures?
- 8. Who influences your decision about whether to use protection or not?
- 9. Since the time you discovered you had HIV, are there times when you have failed to use protection?
- 10. What were / are the circumstances under which you do not use protection? What makes it difficult to use protection?
- 11. How can those challenges that prevent you from using protection be addressed?

Care

- 12. Are you receiving other forms of care (e.g. counseling, social, nutritional, and/or legal support if needed)?
- 13. Tell me when you started receiving HIV care and support and how it has been over time.
 - a. When did you start receiving such support?
 - b. Have you continuously received this support or there are times when you stopped?

- c. If the support stopped, at point did you stop?
 - d. What were the reasons for stopping it?
 - e. Did you discuss with anybody before you stopped treatment? Who did you discuss with? What did this person/people say to you? Did they encourage you to stop treatment or they wanted you to continue on treatment?
 - f. (If re-joined) Then, how did you rejoin to continue receiving support?
14. (Those on care and support) – What helps you / encourages you/ motivates you to continue seeking care and support?
15. What challenges do you find in trying to continue with care services?
16. Tell me how the following influence your decision to seek care:
- a. Your partner/ spouse;
 - b. Your other family members;
 - c. Your friends / and women with the same condition;
 - d. Health workers;
 - e. Your religion/religious leaders/ church/ mosque;
 - f. Your culture/cultural beliefs and norms; and
 - g. The community/society's beliefs about women (gender issues).
17. What needs to be done to enable you and other women/girls in the same position like you to continue treatment?
18. What have you learnt about living with HIV and managing the condition over this period?
- a. What has been the greatest support for you to attain positive living?
 - b. What has been the greatest difficulty for you to attain positive living?

Thank you.



CONTACT US



Physical Address: Plot 1106 Ssenge Road - Wakiso District



Postal Address: P.O.Box 32252 Kampala, Uganda



Tel: +256 414 531 913



Fax: +256 414 533 341



admin@icwea.org



www.icwea.org



@ICWEastAfrica



ICW Eastern Africa

March 2017



International Community
of Women Living with HIV
Eastern Africa (ICWEA)

with support from



United Nations Entity for Gender Equality
and the Empowerment of Women