Barriers faced by HIV Positive Women to return their HIV-Exposed and Infected Infants and Children for HIV/AIDS services
Final Report
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The Access, Services and Knowledge (ASK) programme is a three-year programme (from 2013 to 2015) funded by the Dutch Ministry of Foreign Affairs with the aim of improving the SRHR of young people (10 – 24 yrs.), including underserved groups. The programme which is a joint effort of eight organizations comprising of Rutgers (lead), Simavi, Amref Flying Doctors, CHOICE for Youth and Sexuality, dance4life, Stop AIDS Now!, the International Planned Parenthood Federation (IPPF), and Child Helpline International (CHI) is implemented in 7 countries, namely Ethiopia, Ghana, Indonesia, Kenya, Pakistan, Senegal, and Uganda. Operations research (OR) was identified as an integral part of activities in the ASK programme. The aim was to enhance the performance of the program, improve outcomes, assess feasibility of new strategies and/or assess or improve the programme Theory of Change.
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Barriers faced by HIV Positive Women and/or partners to return their Exposed Infants to access HIV/AIDS services in Northern Uganda

Acronyms

AIDS  Acquired Immune-Deficiency Syndrome
ANC  Ante-Natal Care
ART  Anti-retroviral Therapy
ARVs  Antiretroviral Drugs
ASK  Access, Services, Knowledge
AVSI  Access, Services and Knowledge
AZT  Zidovudine
DBS  Dry Blood Spot
DHO  District Health Officer
DNA  Deoxyribonucleic acid
CBC  Complete Blood Count
CD4  Cluster of Differentiation 4
EID  Early Infant Diagnosis
EMTCT  Elimination of Mother-to-Child Transmission of HIV
FP  Family Planning
FSG  Family Support Group
FGD  Focus Group Discussion
HC  Health Centre
HIV  Human Immunodeficiency Virus
HCT  HIV Counselling and Testing
HMIS  Health Management Information System
HRH  Human Resources for Health
HTC  HIV Testing and Counselling
IATT  Inter-Agency Task Team on EMTCT
KII  Key Informants Interview
KMCC  Knowledge Management and Communication Capacity Initiative
LRA  Lord’s Resistance Army
M&E  Monitoring and Evaluation
MDGs  Millennium Development Goals
MoH  Ministry of Health
MSM  Men who have Sex with Men
MTCT  Mother-to-Child Transmission
NAADS  National Agricultural Advisory Services
NGO  Non-Government Organisation
NMS  National Medical Stores
NUSAF  Northern Uganda Social Action Fund
NVP  Nevirapine
OI  Opportunistic Infection
OPD  Outpatient Department
PCR  Polymerase Chain Reaction
PMTCT  Prevention of Mother-to-Child Transmission of HIV
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>PNC</td>
<td>Post Natal Care</td>
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<tr>
<td>SRH</td>
<td>Sexual and Reproductive Health</td>
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<td>SRHR</td>
<td>Sexual and Reproductive Health Rights</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<tr>
<td>RRH</td>
<td>Regional Referral Hospital</td>
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<tr>
<td>TASO</td>
<td>The AIDS Support Organisation</td>
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<td>TAT</td>
<td>Turnaround Time</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<td>TBA</td>
<td>Traditional Birth Attendants</td>
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<td>UAIS</td>
<td>Uganda AIDS Indicator Survey</td>
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<td>UDHS</td>
<td>Uganda Demographic Health Survey</td>
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<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<td>UNICEF</td>
<td>United Nations Children’s’ Fund</td>
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<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<td>VHTs</td>
<td>Village Health Teams</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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<td>WOFAK</td>
<td>Women Fighting AIDS in Kenya</td>
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<td>YEA</td>
<td>Youth Empowerment Alliance</td>
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Acknowledgements

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Finally, I would like to extend our special thanks to Nienke Westerhof, the Advisor SRHR and Gender, and all the STOP AIDS NOW! Team for your support, both financially and technically towards the completion of this study and the ASK project in general.
Executive Summary

There are renewed global commitments to ending the vertical transmission of HIV in the world. Despite the availability of plans and commitments to achieve this target, uptake of Early Infant Diagnosis (EID) services and infant Anti-retroviral Therapy (ART) coverage rates remain low in low income countries. Modelling shows that, with all efforts and investment realised, there will be a 87% decline in the number of new child infections by 2015 in Uganda. However, the virtual realisation of this target still faces substantial challenges especially in hard-to-reach areas. This is no different in Northern Uganda, the ASK (Access, Services, Knowledge) project implementation areas, where it has been observed that mothers don't return their HIV exposed Infants to access EID services.

This study was conducted to identify the factors that lead to the loss of the HIV exposed babies in Northern Uganda and come up with recommendations for their retention in the continuum of care and treatment services. It was carried out in twelve (12) purposively sampled health facilities out of a total of 16 health facilities, in the three districts in Northern Uganda (Gulu, Kitgum and Amuru) where the ASK (Access, Services, Knowledge) Programme is being implemented by Mama’s Club. The respondents included young mothers (<25 years), their partners, mentor mothers and fathers and the health service providers. It involved document reviews and analysis, primary data collection that included individual interviews; key informant interviews (KIIs) and focus group discussions (FGDs); and the use of a health facility checklist.

This study revealed that there are a number of Elimination of Mother to Child Transmission (EMTCT) services that are provided to both the mothers and the HIV exposed babies and children at the health facilities that participated in the study; and that the major entry into the EID service provision is at health centres during antenatal care (ANC). The health workers unanimously agreed with the available literature that the major loss of infants occurs after the first DNA PCR tests, especially when the results show that baby is HIV negative. The respondents were aware of how babies become infected. They were also aware of how to prevent HIV transmission from the mother to the baby. However they acknowledge that sometimes they are reluctant to stop breastfeeding at an early age due to poverty and lack of the proper alternative feeding requirements and food supplements for the babies. Results also indicated that 80% of the young mothers in the study are aware that infant testing is the major way of identifying that a baby is HIV positive. Knowledge gaps were however exhibited amongst some mothers who thought that the first DNA PCR test is definitive and that there is no need to repeat the test 6 weeks after cessation of breast feeding in the HIV exposed infants. They were also found to be aware of how and when they can access drugs.

It was generally found that the mothers have a positive attitude towards EID care and treatment, but are unable sometimes to practise whatever they are taught because they are curtailed by several challenges and beliefs. The respondents therefore revealed several reasons for the loss of HIV exposed babies and lack of adherence to appointments, which are both population-based and health facility related. The population-based factors included low knowledge levels on EID service provision by HIV positive young mothers; long distances to the health facilities that provide such services; lack of psychosocial support from the partners/spouses and parents; non-disclosure of the HIV status between couples and to the family members; domestic violence; stigmatisation, and; agricultural seasonal changes.
The health facility-based factors included stock out of dry blood spot (DBS) materials and testing kits in health centres and lack of equipments, particularly CD4 Count Machines; delays in the return of DBS results; long waiting hours at the health facility due to low staffing levels; unprofessionalism amongst health workers exhibited in failure to keep the clients’ results confidential, late reporting to work and constant absenteeism; lack of facilitation to conduct follow ups; and lack of hands-on experience and training in implementing the provision of EID services; among others.

To ensure increased uptake, retention and follow up of the HIV exposed infants in the continuum of EID care and treatment, the following recommendations were generated and categorized into government health facilities’ and by Mama’s Club and partners’ recommendations. As a NGO, Mama’s Club should ensure that all young mothers attending EMTCT be actively engaged in FSGs to acquire more knowledge and psychosocial support to access these services. This should be done by advocating for male involvement, engaging community leaders, facilitating follow ups, empowering HIV positive mothers economically, among others. The health facility and the government should ensure that health workers’ capacity is built to provide EID services; pregnant mothers are given incentives to attract them to deliver from health centres; Scale down the provision of EID services to Health Centre II; and, Establish consistent Logistics and Supplies Management Systems to avoid drug stock outs among others. The health workers should also adapt with increased demand on the time of service, acquire and sustain EID skills and knowledge while maintaining optimal attitudes and practice towards caring of HIV exposed infants.
1.0 INTRODUCTION

Paediatric HIV care and treatment is increasingly being prioritized in the global response to the HIV epidemic. Early infant diagnosis (EID) programs offer diagnosis of HIV infection from 0-18 months of age, which facilitates provision of life-saving care and treatment to infants infected with HIV. Morbidity and mortality can be greatly reduced through EID of HIV and timely initiation of antiretroviral therapy (ART). Despite global efforts to scale-up of EID and infant ART, uptake of these services remains low, especially in low income countries UN General Assembly (2011).

HIV-infected babies are at high risk of serious illness and death. Until recently, the prospect for HIV-exposed infants was bleak, with 52% of perinatally infected children dying by two years of age, and a significantly higher morbidity and mortality even among those uninfected (Newell et al., 2004; Obimbo et al., 2004). The development of EID services (ability to diagnose HIV at age six weeks by Polymerase Chain Reaction (PCR) and demonstration that antiretroviral treatment (ART) reduces infant mortality by 76%) has brought some salvation on the lives of HIV-exposed infants.

In Uganda, there has been a remarkable reduction in new infections among children in recent past, from 29,500 in 2009, 27,660 in 2011, 15,411 in 2012, and 9,629 in 2013. The elimination of Mother-to-Child Transmission (eMTCT) Option B+ approach was scaled up country-wide. It reached 1,726,177 mothers of known and documented HIV sero-status; 123,754 of them (7.2 percent) HIV positive. While 71.7 percent of the positive mothers received ARVs for eMTCT; only 36.7 percent of the exposed infants received ARVs for eMTCT (2013 Uganda HIV and AIDS Country Progress report). The country has 22,000 sites offering EID out of which only 8% in hard to reach areas. This makes access to EID services very difficult for people in such areas. In general, the prevalence of HIV infection is estimated at 7.3% in adults aged 15–49 years and 1.7% in children less than 5 years (MoH 2012, HIV/AIDS Indicator Survey). Available information indicates that if all interventions are scaled up and planned targets achieved there would be 3,900 new child infections in 2015 - an 87% decline (from 29,500) in the number of new child infections between 2009 and 2015 (UNAIDS, Unpublished estimates on PMTCT country targets, 2010).

Despite the availability of plans and commitments, uptake of EID services and infant ART coverage rates in Uganda is still low. According to UNICEF (2010), if there is no systematic follow up and plan for early testing at 6 weeks, about 85% of HIV-exposed infants are lost. The loss to follow up of HIV-exposed infants in the cascade of EID is caused by poor linkage of PMTCT program after delivery; the lack of coordination between reproductive and child health clinic, outpatients, inpatients wards and maternity wards (Gamaliel, J. (2012)). It should also be noted that some health facilities focus on infants of known maternal HIV status while missing the opportunity to test those whose mother's statuses are unknown.

In Northern Uganda, especially in Gulu, Amuru and Kitgum districts, the ASK (Access, Services, Knowledge) Project implementation areas, it has been observed that mothers of HIV-Exposed babies, after birth, don’t return exposed babies to access HIV/AIDS services. Mama’s Club’s activities are charged with increasing maternal uptake of ARVs and follow up of HIV-exposed infants to reduce the
percentage of HIV positive children. However, the EMTCT activities i.e. lost to follow up activities, home visits, EID, and Family Support Group (FSG) activities have been hampered with several implementation challenges; that need to be investigated and exposed to inform the future EID and ART programming. It is against this background that this research study was conducted, to identify the factors that lead to the loss of HIV-exposed babies in Northern Uganda and come up with recommendations for their retention in care and treatment.

1.1 Background of this Research

1.1.1 The ASK Programme

In 2012, the Dutch Ministry of Foreign Affairs called for proposals for large impact actions for achieving Millennium Development Goals 5 and 6 (to further reduce maternal mortality and create universal access to reproductive health and to halt the spread of HIV, respectively). Access, Services and Knowledge (ASK) received funding through this call.

ASK is a three year (2013-2015) programme to improve the Sexual Reproductive Health Rights (SRHR) of young people (aged 10-24 years) by increasing their uptake of SRH services. It is implemented by the Youth Empowerment Alliance (YEA) in Kenya, Uganda, Ethiopia, Ghana, Senegal, Pakistan and Indonesia. In Uganda and Kenya, the programme is implemented by STOP AIDS NOW!1 in partnership with Mama’s Club and WOFAK respectively.

In Uganda, the programme targets hard to reach young people, especially those in marginalized areas, living with HIV, and young mothers living with HIV (aged 10-24). It is currently implemented in 16 health facilities in the three districts of Northern Uganda. These facilities are Patiko HC III, Odek HC III, Layibi HC III and Bobi HC III in Gulu district; Namukora HC III, Kitgum-Matidi HC III, Omia Anyima HC III, Pajimo HC III, Muchin HC III, Okidi HC III, Orom HC III and Akuma Label HC III in Kitgum; and, Pabbo HC III, Labo HC III, Atiak HC IV and Kaladima HC III in Amuru district.

Under the ASK programme, Mama’s Club integrates prevention of rights violations, in particular, the violations of the sexual and reproductive health and rights of young women living with HIV, in the context of EMTCT and maternal health services. This is done in order to;

i) Increase demand, uptake and continued use of PMTCT services in particular EMTCT on the part of young women living with HIV;

ii) Increase antennal coverage in the targeted health facilities;

iii) Increase access to and utilization of quality HIV and SRHR services among HIV positive young mothers; and,

iv) Enhance capacity of service providers to address cases of stigma and rights violation.

In its operations, Mama’s Club works through the concept of Mentor mothers, who support other mothers living with HIV and act as a liaison to the formal health system and to health care providers. Mentor mothers are already established at the health facilities through the FSG strategy, to provide a

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1 STOP AIDS NOW! operates at the crossroads of fighting poverty, eliminating exclusion, and responding to the AIDS epidemic in countries with a generalized epidemic.

2 Barriers faced by HIV Positive Women and/or partners to return their Exposed Infants to access HIV/AIDS services in Northern Uganda
forum for follow-up of the EMTCT services to the HIV positive young mothers. This operational research aims to identify barriers faced by HIV Positive Women to return their Exposed Infants to access HIV/AIDS services in Northern Uganda.

1.1.2 About Mama’s Club

Mama’s Club Uganda was founded in 2004 as a local community based organization to provide psychosocial support to HIV positive mothers and their families. Mama’s Club’s network of HIV positive mothers operates in twenty five districts. Clubs have 50-70 members, and most of them are under 24 years of age.

Mama’s Club trains and supports young mothers living with HIV to be “Mentor Mothers”. Mentor Mothers provide information on maternal health, prevention of mother to child transmission of HIV, infant care, family planning, and sexual and reproductive health and rights. They encourage HIV positive young mothers to attend antenatal clinics and services for the prevention of mother to child transmission of HIV (PMTCT). In addition, they help strengthen their life and parenting skills, and provide them with psychosocial support. Once trained by Mentor Mothers, trainees become Mentor Mothers as well. Furthermore, Mama’s Club works with men to engage them in antenatal care and maternal health. These men are the partners to the HIV positive young mothers in the FSG, and they are also trained to work as mentor fathers to support the EMTCT cascade.

As part of ASK in Uganda, Mama’s Club contributes to increasing the number of young HIV+ pregnant women receiving PMTCT (in the targeted areas) and to increasing the number of young (<25 years) HIV+ pregnant women receiving antenatal care (in the targeted health facilities in targeted areas). This also involves ensuring that the HIV exposed infants along with their mother get access to treatment and care. Mama’s Club also builds the capacity of service providers to improve the quality of HIV treatment and care provided to young mothers and their children. These activities are designed to increase access to health care among young women living with HIV in the context of PMTCT and maternal health services.

1.2 Aim and objectives of this research

The study aimed at identifying the factors that lead to the loss of HIV-Exposed babies in Northern Uganda and come up with recommendations for their retention in the continuum of care and treatment services.

Specifically, the study objectives were to:

- Understand the knowledge and practices of HIV-positive young mothers and partners with HIV-exposed babies towards EID and Infants ART regimens;
- Identify the barriers affecting HIV-positive young mothers and partners to return their HIV-exposed babies for HIV care and treatment;
- Identify the challenges that health workers face in ensuring maternal uptake/follow-up and retention of HIV-exposed babies in the continuum of HIV care and treatment;
- Identify possible solutions to the barriers affecting HIV-positive mothers and partners to return their HIV-exposed babies to access HIV care and treatment services;
• Identify possible solutions to the challenges faced by health workers in ensuring maternal uptake/follow up and retention of HIV-exposed babies in the continuum of care and treatment services

1.3 Questions addressed by this research
• What exactly is the current situation; how many exposed infants are not accessing services and in what stage of the continuum of care are they lost?
• What are the young mothers and fathers’ knowledge, attitudes and practices towards EID and Infant ART regimens?
• What barriers do HIV-positive young mothers face that prevent them from returning their HIV-exposed babies to access HIV/AIDS services?
• What are the possible solutions to the barriers that prevent HIV-positive young mothers from returning their HIV-exposed babies to access HIV/AIDS services?
• What are the challenges that Service providers face in ensuring EID and Infants ART uptake, follow up and retention of HIV-exposed babies in continuum of care and treatment services?
• What are the possible solutions to the challenges faced by service providers in ensuring uptake, follow up and retention of HIV exposed babies in continuum of care and treatment services?

1.4 Contextual Background of the study area

Northern Uganda is recovering from the consequences of a 20-year conflict and has remained relatively stable and secure since 2006. Regarding the essential health indicators, the Northern Region—due to its insecurity and, consequently, its unreliable services—has lagged behind other regions, though the recent stability has led to considerable improvement in some regional statistics. The proportion of institutional delivery in the region is generally low, especially in rural areas. The Uganda Demographic & Health Survey (UDHS) 2011 preliminary report stated that in the Northern Region, 52% of deliveries occurred in a health centre and 54% were attended by a skilled provider, compared with the national average of 57% and 59%, respectively. From the same report, the contraceptive prevalence rate is at 24% (national average 30%) while full immunization coverage stands at 49%, slightly lower than the national average of 52%.

In 2011, the Uganda AIDS Indicators Survey (UAIS) was conducted by the MOH to measure national and regional estimates of HIV prevalence and other relevant indicators about knowledge, attitudes, and behaviour related to HIV. The report indicated a reduction of HIV prevalence in Northern Uganda from 8.2% in 2005 to 6.9% (8.5% among women and 5.1% among men), close to the national average of 6.7%. Among other indicators, knowledge of modalities of mother-to-child transmission of HIV greatly improved and a notable reduction in the number of sexual partners was also found among respondents from the region.

The three districts in the study (Amuru, Gulu and Kitgum) are located in the Mid-Northern Region of Uganda. The incidence of poverty in the Mid-North region (36%) is much higher than the national average of 19.7 percent. The major economic activity carried out in the sub region is agriculture. The percentage of the population employed is 13.1%. In the rural areas, most of the men and women are involved in
agriculture while in urban areas; most men are involved in professional associate work and trade while most of the women are social service workers.

The 2012/13 National Household Survey results showed that 65 percent of the population in the region is literate. More males were literate (84 percent) compared to females (47 percent). This is still below the national average which stands at 68% (males 79 percent and females 59 percent). The net enrolment rate in primary schools in the mid-north is 83.1 (84.3 percent males and 81.8 percent females).

**Amuru district**

Amuru District was created by an act of Parliament in July 2006. It initially comprised two counties of Kilak and Nwoya, formerly of Gulu District. However, in July 2010, Nwoya County was also awarded district status. The 2014 National Housing and Population Census revealed the population of Amuru at 190,000 inhabitants (92,502 males and 98,014 females). Its annual population growth rate is 2.83, just below that national rate at 3.03%.

Amuru District has only one HC IV (Atiak), seven HC IIIs, and 23 HC IIs. The district is still grappling with several challenges such as staff absenteeism, and late opening of health centres making access to health services a big challenge. Sixty-one per cent (61%) of the population reside within 5km radius of the health centres and deliveries at the health centre stands at 34% while ANC 4th visit is at 20%. The Infant Mortality rate is at 172/1000 (Amuru District Council Score-Card Report 2011/2012).

The primary school enrolment stands at 40,859, and the district has a high pupil-teacher ratio (75:1) compared to the 51:1 national average and pupil-classroom ratio (112:1). At least 50.2% of the population of Amuru has access to safe water, latrine coverage is only 58.22%, and hand washing facilities are at 23.66%, while bath shelters serve only 52.94% of the population. Nearly 98% of the district’s population thrives on agriculture as their major economic activity, with food crops like maize, finger millet, sorghum, sweet potato, cassava, groundnut, simsim, beans, peas and sunflower as the major traditional food crops (Amuru District Council Score-Card Report 2011/2012).

**Gulu district**

Gulu District is located in Northern Uganda bordered by Amuru District in the West, Lamwo District in the North East, Pader District in the East, Lira District in the South East, Oyam District in the South and Nwoya District in the South West. In the 2014 National population Census, Gulu district had a total population of 443,733 people with 215,610 males and 228,123 females. The district population growth rate stands at 3.30% slightly higher than the national population growth rates at 3.03%.

In Gulu district alone, out of 83,109 pupils expected to enrol in primary school in 2012, 74,986 enrolled, giving 89.8 percent of the school going age, implying that 11.2 percent are not going to school. Access to health services still remains poor in the whole district. Over 26.2 percent of the population still moves a distance of more than 5 km in search of health services and only 73.8 percent are within 5 km radius. HIV/AIDS still remains a big development challenge in the district.
Kitgum district

Kitgum is one of the districts in the Northern region of Uganda. It is bordered by Gulu district in the Northwest, Lamwo in the North, Agago District in the South East, Pader District in the South, Republic of Southern Sudan in the Northeast and Kotido District in the East. In the 2014 National population Census, Kitgum district had a total population of 204,012 people with 98,438 males and 105,574 females. The district population growth rate stands at 1.67% much lower than the national population growth rates at 3.03%.

Kitgum district is predominantly engaged in small scale agriculture, animal husbandry and produce buying. Over 90% of the farmers are engaged in crop production as their major activity and a small percentage in livestock rearing, bee keeping and fishing farming on small family holdings using family labour and rudimentary hand tools such as hoes mostly for home consumption.

Kitgum district has 25 Health Units of different categories. Some of them are government hospitals while others are owned by NGOs. The distribution is fair, but some of them lack the basic equipment to offer reasonable services. Many rural units require rehabilitation and equipping. Besides diseases, poor nutrition has contributed to worrying situation. Because of the cross cutting nature of health issues, there is need for an integrated approach to health. There are various NGOs both Local and International that are involved in AIDS prevention and control in the district. They provide services such as blood screening and counselling, medical treatment, home care, pastoral education, health education, AIDS research and orphan support (Kitgum district Statistical Abstract 2012/2013). The fertility rate for Kitgum district is 6.3 (2013) compared to 6.2 (UDHS 2011) at national level.

Safe water coverage for the district is at 66.5 percent slightly higher than the national level of 65 percent. The percentage of population with sustainable access to an improved water source in rural area is 66.5 percent while for urban setting range between 80-90%. Total primary school enrolment stands at 64,054 pupils (31,710 males and 32,344 females) (Kitgum district Statistical Abstract 2012/2013).
2.0 APPROACH AND METHODOLOGY

This section outlines the approach and methodology that guided the achievement of the study objectives.

2.1 Study Setting

The study was carried out within twelve (12) purposively sampled health facilities out of a total of 16 health facilities, in the three districts in Northern Uganda (Gulu, Kitgum and Amuru) where the ASK Programme is being implemented by Mama’s Club. This translates into four (4) health facilities (HC III) per district. These are the facilities where PMTCT services are provided, including the provision of Option B+ to mothers and cotrimoxazole prophylaxis for all the HIV-exposed babies until after their cessation of breastfeeding. These facilities are Patiko HC III, Bobi HC III, Layibi Techo HC III & Odek HC III (Gulu district); Atiak HC IV, Kaladima HC III, Labongogali HC III & Pabbo HC III (Amuru district); and, Kitgum Matidi HC III, Omiya Anyima HC III, Namokora HC III & Pajimo HC III (Kitgum district).

2.2 Study Participants

The study participants included young mothers (<25 years), their partners, mentor mothers and fathers and the health service providers at the health facilities that were sampled. To increase the likelihood of capturing a variety of experiences, young mothers were purposively sampled out in four different categories; (i) HIV positive young mothers whose babies tested positive for HIV; (ii) HIV-positive young mothers of babies who tested negative for HIV; (iii) HIV positive young mothers in the first months after delivery, prior to the six week EID visit; and, (iv) HIV positive pregnant young women/mothers. Since the study concentrated around HIV positive young mothers and their babies, more mothers were recruited to participate in the exercise than any other category of respondents. More midwives also participated because at the health centres, the comprehensive EMTCT cascade largely relies on the

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2 Uganda’s healthcare system works on a referral basis; if a level II facility cannot handle a case; it refers to a unit the next level up. The structure of Uganda’s health system is detailed below:

a) Village health teams/community medicine distributors

The first contact for someone living in a rural area would be a medicine distributor or a member of a village health team (VHT). Each village is supposed to have these volunteers using bicycles to reach out to the community. They still have no medicine, but they can advise patients and refer them to health centres.

b) Health Centre II

According to the Ugandan government’s health policy, every parish is supposed to have one of these centres. A health centre II facility, serving a few thousand people, should be able to treat common diseases like malaria. It is supposed to be led by an enrolled nurse, working with a midwife, two nursing assistants and a health assistant. It runs an out-patient clinic, treating common diseases and offering antenatal care.

c) Health Centre III

A health centre III facility should be found in every sub-county in Uganda. These centres should have about 18 staff, led by a senior clinical officer, who runs a general outpatient clinic and a maternity ward. It should also have a functioning laboratory.

d) Health Centre IV/ District Hospital

A health centre IV is a mini hospital. It should have the kind of services found at health centre III, but it should have wards for men, women, and children and should be able to admit patients. It should have a senior medical officer and another doctor as well as a theatre for carrying out emergency operations.

e) Regional Referral Hospital (RRH)

There are 10 RRH which should have all the services offered at a health Centre IV, plus specialized clinics –such as those for mental health and dentistry—and consultant physicians.

f) National Referral and Teaching Hospital

At the top of the healthcare chain is the national referral hospital, located at Mulago in the capital Kampala. This is where some of the best medical brains can be found, often working part-time at private clinics to supplement their meagre government salaries.
midwives as the interface between the pregnant woman and the health system. The table 1 below summarises the composition of the study participants. See section 3.2 for more details on the study participants.

Table 1: Respondents Categorisation

<table>
<thead>
<tr>
<th>No.</th>
<th>Respondent Category</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nursing Assistants</td>
<td>4</td>
<td>2.0</td>
</tr>
<tr>
<td>2</td>
<td>Midwives</td>
<td>10</td>
<td>4.9</td>
</tr>
<tr>
<td>3</td>
<td>Lab Technicians</td>
<td>2</td>
<td>1.0</td>
</tr>
<tr>
<td>4</td>
<td>Mentor Mothers</td>
<td>8</td>
<td>3.9</td>
</tr>
<tr>
<td>5</td>
<td>Mentor Fathers</td>
<td>3</td>
<td>1.5</td>
</tr>
<tr>
<td>6</td>
<td>HIV Positive Young Mothers</td>
<td>170</td>
<td>83.7</td>
</tr>
<tr>
<td>7</td>
<td>Spouses/Husbands to HIV positive young Mothers</td>
<td>6</td>
<td>3.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>203</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

2.3 Data Collection Tools and Questionnaires

The interview guides were developed from themes guided by the literature. The developed tools (Questionnaires, KII and Focus Group Discussion (FGD) Guides and checklist) were shared with Mama’s Club and STOP AIDS NOW! for review and making relevant changes to inform and guide the study.

2.4 Data Collection and Analysis

2.4.1 Document Review

The study employed a qualitative approach that involved a global review of literature and documents on the loss of HIV-exposed babies. This review enabled in the understanding and appreciating the subject matter and guided the development of the study tools and questionnaire. The review also informed the triangulation with the study findings to enable the generation of strategic conclusions and recommendations.

2.4.2 Primary Data Collection

The study involved the collection of primary data that complemented the secondary data from review of documents. The following approaches and tools were used to collect primary data;

a) In-depth Structured Interviews

All young mothers of HIV-exposed babies, who were sampled, were interviewed using a standardized questionnaire. In-depth interviews were employed at this stage, where the interviewer asked the participant series of questions in a one-on-one session. This was a good means for capturing the attitudes and knowledge of young mothers on EID and Infants ART programmes. It allowed probing and posing of follow-up questions by the interviewer. This face-to-face interview process also allowed the interviewer to get information from both verbal and non-verbal cues which are relevant to the purpose of the study.
b) Key Informants Interviews

Qualitative semi-structured interviews to key informants included key service providers at the health centre, especially the health workers working in EMTCT, ANC, Laboratory and Maternity clinics. These were conducted to explore participants' views of key themes identified from the literature. These interviews consisted of open-ended questions to explore perceived barriers to EID and Infants ART by HIV-positive young mothers.

All interviews took place in private/isolated settings where other people were not able to hear the respondents' answers. For interviews with young mothers, a local trained counsellor or health worker would assist with translation and interpretation of questions. Interviews were recorded and transcribed in English.

c) Focus Group Discussion

The consultant also conducted FGDs to explore further the HIV-positive young mothers' opinions and understanding of the EID and infant ART regimens, reasons for failure to return the HIV-exposed infants for EID and Infant ART services and possible solutions in a group. The FGD participants included HIV positive young mothers and their partners who were handled separately to ensure safe space to talk and to have open and honest discussions. These included both the young mothers who are members of the FSGs supported by Mama’s Club and the FSG non-members. Each FGD comprised of 8-10 members to enable easy control and management by the interviewer. In case of language challenges, a local counsellor or mentor mother was used as an interpreter between the members and the interviewer. All responses recorded verbatim and transcribed later for analysis and reporting. One FGD was conducted at every health facility and in total 12 FGDs; 11 for women and 1 for men.

d) Observation Checklist on utilization of the EID at the health facilities

The observation checklist was also used to capture information on the available ART & EID services and resources. This helped to generate information on the current utilization of ART & EID services at the health facility.

e) Questionnaires and Tool Pre-testing

Due to time constraint, it was not be possible to pre-test the tools. Instead, the data collectors shared their experiences and lessons after the first day of data collection to allow for review of the tools. There was however no need for changes and adaptions on the tools.

2.4.3 Data Analysis and Triangulation

Analysis of the collected data from in-depth-structured interviews, semi-structured interviews, FGDs and observations, complemented by literature review, was done as follows:

i) Textual data was explored using content analysis while recorded data was transcribed to get the first hand information and relevant quotes to the study. Data was read and re-read by the
analysts in order to identify emerging themes from the responses, related to the study objectives and any other emerging issues;

ii) All relevant data to each theme was identified and examined using the process of constant comparison, in which each item was checked or compared with the rest of the data in order to establish the analytical theme;

iii) Typical quotes were selected and included in the reports in order to emphasize the response given without losing the original context of the meaning;

iv) Triangulation of responses with the Literature was conducted to ensure consistency and reliability of the information gathered.
3.0 PRESENTATION OF RESULTS

3.1 Introduction
This study aimed at identifying the factors that lead to the loss of the HIV-Exposed babies towards the continued uptake, follow up and retention in the continuum of EID care. This section presents the findings from the data collected in the three districts of Amuru, Gulu and Kitgum, in Northern Uganda.

3.2 Demographic Characteristics of Respondents
A total of 61 HIV positive young women were recruited and participated in the individual interviews. All but one of them were between 20-24 years (98%). Most of these women were also married (54%). Majority had at least gone to primary school (47%), though also a relatively large number (34%) had never gone to school at all. This has been found to have a ripple effect to read and interpret the appointment days and sometimes forget the appointments. It was reported that some mothers may at times fail to read these appointments, and hence miss out of appointment days.

The majority of these respondents were unemployed (95%), and this partly explains the high poverty levels in the area. These people mainly survived on peasant farming. The poverty level in the area and amongst these HIV positive young mothers has an effect on their access to the EID services. They face challenges on meeting the required costs such as transport to the health facilities and buying the required food nutrients for their breastfeeding infants. Results also indicate that 93 percent of the respondents had received EMTCT care and service, an indication that they were the targeted beneficiaries of the Option B+ program, and 84% experienced the PMTCT treatments (Table 2).

Table 2: Demographic Characteristics of HIV positive young mothers that participated in the Individual Interviews (n = 61)

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of the Mother</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 – 19</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>20 – 24</td>
<td>60</td>
<td>98.4</td>
</tr>
<tr>
<td>Marital Status of the Mother</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11</td>
<td>18.0</td>
</tr>
<tr>
<td>Married</td>
<td>33</td>
<td>54.1</td>
</tr>
<tr>
<td>Cohabiting/Staying together</td>
<td>11</td>
<td>18.0</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>3</td>
<td>4.9</td>
</tr>
<tr>
<td>Widow</td>
<td>3</td>
<td>4.9</td>
</tr>
<tr>
<td>Education Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never went to School</td>
<td>21</td>
<td>34.4</td>
</tr>
<tr>
<td>Primary</td>
<td>29</td>
<td>47.5</td>
</tr>
<tr>
<td>Secondary</td>
<td>10</td>
<td>16.4</td>
</tr>
<tr>
<td>Above Secondary</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>58</td>
<td>95.1</td>
</tr>
<tr>
<td>Employed</td>
<td>3</td>
<td>4.9</td>
</tr>
<tr>
<td>Received EMTCT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>57</td>
<td>93.4</td>
</tr>
<tr>
<td>No</td>
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<td>6.6</td>
</tr>
</tbody>
</table>

Barriers faced by HIV Positive Women and/or partners to return their Exposed Infants to access HIV/AIDS services in Northern Uganda
<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>51</th>
<th>83.6</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>10</td>
<td></td>
<td>16.4</td>
</tr>
</tbody>
</table>

**District**

<table>
<thead>
<tr>
<th></th>
<th>Amuru</th>
<th>23</th>
<th>37.7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gulu</td>
<td>21</td>
<td>34.4</td>
<td></td>
</tr>
<tr>
<td>Kitgum</td>
<td>17</td>
<td>27.9</td>
<td></td>
</tr>
</tbody>
</table>

### 3.3 Major Option B+ Services Provided at the Health Centres

There are a number of EMTCT services that are provided to both the mothers and the HIV exposed babies and children at the health facilities that participated in the study. Where the required services do not exist at a given facility, the client is always referred to a unit the next level up that provides such a service. These services included; provision of Antenatal Care Services including health education on issues like hygiene, proper nutrition; HIV testing, and Clean and Safe delivery. The facilities also provide Nevirapine Syrup to HIV exposed babies and enrol them as exposed infants. These health facilities also provide breast feeding advice to the HIV positive young mothers; provide Post-Natal Care including Monitoring Child Growth & weight; Diagnose opportunistic Infections such as diarrhoea, sores of the mouth and on the body, fever, malaria, cough etc.; and Routine care for new born. These services are provided by all facilities at level III.

According to the health workers, DNA PCR test is conducted to confirm the HIV status in infants and children less than 18 months of age. The HIV exposed Infant is subjected to the first DNA PCR at 6 weeks of age or the earliest opportunity thereafter. If the child is HIV positive, it’s referred to ART clinic and started on ARVs. However a repeat test is taken on the day a child is started on ART. If the first test is negative and the child is breastfeeding or has breastfed in the 6 weeks before testing, the test is not definitive, therefore a 2nd PCR test is taken immediately, even when breastfeeding. If the 2nd test in still negative, a 3rd test is taken 6 weeks after cessation of breastfeeding. Mothers are always advised to completely stop breastfeed at one year. The child is also put on Cotrimoxazole prophylaxis from 6 weeks of age until when it graduates (confirmed HIV negative), after the third test.

Ayot Cecilia, a Nursing Assistant, attached to Maternity Ward at Patiko HC III, Gulu, when asked about the services she provides and how she guides young mothers and their babies, revealed that,

> “I always meet these mothers when they come for ANC, usually when they are four months into pregnancy. Here I test them to establish HIV status, and if found HIV positive, we start to give them counselling and treatment and we advise them to come for the drugs every months. We also advise them not to deliver at home, but at the health facility. When they deliver from here, we give treatment to both the mother and the baby. To the baby we give Nevirapine Syrup and after six weeks we conduct the first DNA PCR test on the baby, and if the baby is negative we advise the mother on how to breastfeed. We conduct such tests three times before the baby is two years. And if the baby is positive we refer the baby to the ART Clinic.” Ayot Cecilia, a Nursing Assistant, attached to Maternity Ward at Patiko HC III, Gulu
**Testing Algorithm for HIV Exposed Infants**

**What is the Mother's HIV Status?**

1. **Negative**
   - Child is HIV-negative
   - Manage as HIV-negative
2. **Unknown**
   - DO HIV rapid test
   - Set another or intend to determine infant’s exposure status
3. **Positive**
   - Child is exposed
   - DO 1st DNA PCR
     - Child is negative:ART clinic
     - Child is positive:ART clinic
4. **Unknown**
   - DO HIV rapid test
   - Set another or intend to determine infant’s exposure status
5. **Positive**
   - Child is HIV-positive
   - Manage as HIV-positive

- If infant with negative 1st PCR is symptomatic, take off a 2nd PCR immediately even when still breastfeeding.
- If the 2nd PCR is negative, still take a 3rd PCR 5 weeks after stopping breastfeeding.

---

**3.4 Entry point for the EID and Infant ART**

The entry point for the HIV mothers and their HIV exposed infants to the health facility is mainly at ANC. There are however other entry points such as the OPD, Outreaches, ART clinic days, Post-Natal Clinic Days and Mother-Baby Pair Care Point which also have their own specific clinic day. At the mother-baby-care point, the mothers and their HIV exposed infants are given same appointments for the drug refill to ease the mothers’ role in coming to pick the drugs and that of the baby. This saves the mothers from coming twice at the health centre for both herself and the babies. The mother and the baby can now get their refills at once and at one point. This is a common practice initiated by the MoH in Uganda.

**3.5 Stage of the Continuum of Care HIV Exposed Infants are Lost**

The general agreement amongst the health care workers was that most babies and infants are lost after the first DNA PCR test turns negative (Annex 5). Usually when the test is negative, mothers take it for granted that the child has already escaped the virus and therefore there is no need to return to the health facility. This resonates with national statistics that show that the biggest loss (60 percent) of the total HIV exposed infants that are lost in the continuum of care occurs between the first and second tests. The loss at six weeks is estimated to be at 25% (2013 Uganda HIV and AIDS Country Progress report).

One healthcare worker noted that;
“Mothers are informed of all the tests that an HIV exposed baby is supposed to undergo, but once the first DNA PCR test is done and the results are negative, the mothers tend to ignore the remaining tests.” Anek Jennifer, Nursing Assistant, Kitgum-Matidi HC III, Kitgum district

3.6 Respondents’ Knowledge about HIV Transmission in Infants, EID and Infant ART

The knowledge of the mothers about the transmission of HIV to Infants, EID and Infant ART is critical in understanding the barriers to EID uptake, retention and follow up. It was revealed by the health workers that they explain the do's and don'ts of option B+ and the procedures to follow to ensure the exposed baby successively graduates negative. The Mothers’ knowledge was tested on the following aspects;

3.6.1 Knowledge on how the baby is Infected with HIV

All respondents, irrespective of their age or education background, are aware of how babies become infected. They mentioned several ways including; breastfeeding; during unsafe delivery – where the umbilical cord is cut wrongly and the blood mixes with that of an HIV positive mother; and; sharing sharp instruments between the HIV positive mother and the HIV exposed Infants. Unsafe delivery was reported to usually happen when someone delivers at the home instead of the health centre,

However, the less educated mothers compared to those who had at least reached secondary level education expressed little knowledge on how breastfeeding can be a risk factor in transmitting an HIV infection. One respondent noted that, “when the baby has wounds in the mouth and the mothers breasts (nipples) have wounds or are damaged, the blood of the two can easily mix.” Less educated mothers also expressed more knowledge gaps by mentioning ways like kissing between a mother and the baby.

3.6.2 Knowledge of HIV prevention in Children

HIV positive young women also expressed knowledge on HIV prevention among the infants. They were aware of the importance of pregnant mothers attending ANC and observance of the counsellor’s advice on issues such as breastfeeding – though they were vague on exactly when one should stop breast feeding. Some would argue that it’s one year and others six months, when the baby starts teething and able to feed properly. They argued that some are reluctant to stop breastfeeding at an early age due to poverty and lack of the proper alternative feeding requirements and food supplements for the babies. This partly explains why some HIV positive young mothers sometimes breastfeed beyond the recommended 1 year, which puts the life of the exposed baby at a risk of contracting the virus. The males who would provide support in terms of providing the food supplements; while discussing this issue in an FGD, they acknowledged their ignorance about breastfeeding practices for an HIV exposed Infant.

Mothers of all categories and ages are well aware of the importance of adherence to appointments and drug refills for both their children and themselves, risks involved in sharing sharp objects with the baby, proper hygiene for the mother and the baby and HIV testing for the mother during ANC visits. Though the mothers are aware of these risk factors, practising and guarding themselves against these factors is still a challenge. The less educated HIV positive young mothers expressed disappointment with some of the service providers who refuse to explain to them whatever is written in the appointment books. They sometime miss out on appointments because they can’t read and understand their next appointments. It was also a challenge for those who are not fully supported by their spouses or husbands and at the same
time not employed to regularly meet their appointments. They sometimes lack the necessary facilitation such as transport to always go to health facilities at least once a month. This case is worsened by the long distances to the Health Centre III, where they receive the EID services from.

3.6.3 Knowledge of the Effects of HIV Infection in Babies
All the respondents were well versed with the effects of HIV infection in babies. They cited examples like general bodily weaknesses; frequent illnesses caused by opportunistic infections such as diarrhoea, fever, malaria, cough etc.; bodily wounds/sores; and eventually death.

3.6.4 Knowledge on how to Identify HIV positive Baby
Results also indicated that 80% of respondents are aware that infant testing is the major way of identifying that a baby is HIV positive. Knowledge gaps were however exhibited amongst some mothers who thought that the first DNA PCR test is definitive and that there is no need to repeat the test 6 weeks after cessation of breast feeding in the HIV exposed infants. They also referred so much to opportunistic infections as the other ways of identifying an HIV positive baby. They are not aware that though these may be signs and symptoms of an HIV infection in the babies, they are not conclusive enough for the child to be HIV positive. Some of the mentioned signs of HIV included weak and pale babies’ structures, low body weight, loss of appetite for food, swollen body, bodily wounds/sores, loss of hair and stunted growth.

3.6.5 Knowledge of when the baby should be diagnosed
Both the illiterate and literate young mothers are aware of the existence of the DNA PCR diagnosis for their babies. They are also aware of the importance of conducting these tests, but however, they exhibited mixed reaction on the exact dates when the babies should be diagnosed of HIV. Such divergent understanding on when the diagnosis should be conducted may partly explain lack of adherence to appointments or even loss of the HIV exposed from EID care and treatment. Some of the respondents indicated that;

“The baby should be diagnosed at 6 weeks for the first test and after one year for the second test.” stated by a 22 year old HIV positive mother of a one year old HIV exposed baby boy at Pajimo HC III.

“The child should diagnosed at 6 weeks for the first test and then after 6 months for the second test, and one year for the third test.” Woman Respondent, at Patiko HC III

Results also indicated that 60% of the respondents were aware that an HIV negative baby at the age of six weeks can still get infected later alone, through breastfeeding or if no proper care is taken later in that child’s life. All the mothers indicated their desire to protect their baby from contracting the HIV virus, and that this motivates them to always come back to the facility and seek EID services.

“If tested negative at the six weeks, the child can easily turn positive later, if no good care is provided, and this can be disturbing and leads to child’s death. That’s why we always come back here to get more services.” Respondent, Patiko HC III, Gulu district

The men respondents were however found to be extremely unaware of HIV diagnosis for children. 90% of men didn’t know when HIV infection in children should be diagnosed. Results also indicated that 40% of the
men were not sure whether the Infant can still get infected with HIV in future after testing negative at 6 weeks.

It was however noted that more literate mothers are more aware when ART should be commenced in children, compared to their semi or illiterate counterparts. They were asked when the ART should be commenced in children and why, and these are some of their responses;

“When the baby is tested positive, it’s automatically enrolled to start receiving the medication and appointments are fixed to start receiving the treatment from the ART Clinic.” Respondent, Patiko HC III, Gulu district

“The provision of ARVs to the HIV positive child should never stop, because when you stop, the child is at risk of dying.” FGD Participant, Odek HC III

“…..immediately after the mother tests positive during ANC.” HIV positive illiterate mother of three, Labongogali HC III

3.6.6 Knowledge of the source of EID and Infant ART

All the HIV positive young mothers are aware of the major sources of EID services; they mentioned the available health centres and outreach centres by TASO, on a specific TASO day that is held once a month. When asked about the major sources of information on EID and Infant ART, the young mothers mentioned several sources including, Health Centres, Visual aids pined at the health centres, FSG meetings, Health talks on Radios, and through VHTs and Mentor Mothers.

“We get these services from our health centre here at Odek, others go to TASO. TASO comes at the community centre once a month and gives out treatment to those who are on appointment.” Akello Lucy, HIV positive young mother at Odek HC III, Gulu district

3.6.7 Knowledge on how one accesses the drugs

Over 90% of the young mothers were also found to be aware of how and when they access drugs. They are aware of the specific clinic days at particular health facilities and the procedures they go through to access the required treatment. They revealed that they bring the babies along with an ‘exercise book’, the child monitoring book and a Child Health Card which they present to the health workers, who then prescribes the necessary treatment and provides the drugs. Some respondents revealed that;

“One is tested first and then given a card indicating appointment dates and also follows the time of taking the drugs strictly.” Respondent, Odek HC III, Gulu district

Respondents also revealed that TASO clients have a meeting place within the communities with group leaders who mobilise them to access the drugs. Others receive treatment from private clinics in Gulu town.

3.7 Attitudes and Practices of HIV positive Mothers towards EID and Infant ART

The attitude of the HIV positive young mothers can be a determinant to the HIV exposed baby’s adherence and loss from the continuum of EID care and treatment. This study therefore explored the mothers’ attitudes and practices towards EID and Infant ART. It was generally found out that the mothers have a
positive attitude towards EID care and treatment. These mothers would like to see their babies having an HIV negative status and surviving the virus at the end of the EID treatment process. They are positive towards HIV testing for their babies and are willing to pick results, and prescribed drugs.

One HIV positive mother revealed that,

“…I was worried to take my child for testing, but I was happy that the results came out negative. It is also gratifying to know that even when they are positive, the babies have drugs that can help them sustain their lives for longer period.” Respondent, Patiko HC III, Gulu district

“I took my child for the test and I was very terrified and disappointed because my baby had turned positive, yet he was born negative, I am still worried and blamed myself because I was careless.” Respondents Labongogali HC III

“In October 2010, I was pregnant and went for ANC, I had TB and during birth, I lost a lot of blood. I thought that my child would be HIV positive, but to my amusement, the first PCR test showed that the child was negative. I followed all the advice that was given to me by the health worker. After 18 months, a Rapid test was conducted, the child tested negative and I was very happy.” HIV positive mother of three, Odek HC III, Gulu district

Concerning practising whatever they are taught by the health workers, the HIV positive young mothers argue that they want to practice whatever they are taught, but they curtailed by several challenges and beliefs. For instance, traditionally mothers are taught to breastfeed the infants at least up to two years of age. However Option B+ recommends breastfeeding up to 1 year. This coupled with the lack of the recommended proper nutrition supplements, and high levels of poverty in the area, the mothers find it difficult to stop breastfeeding at the recommended one year.

One health worker confirmed that;

“Many mothers are not following the right prescriptions as concerns breastfeeding. They breast feed past the recommended one year, because sometimes they don’t have the necessary food requirements to feed the babies on. So they risk infecting their children. We always advise them, but because we can’t stay with them all the time, when they go back home they continue breastfeeding.” Health Worker, Pajimo HC III, Kitgum

There were also some negative attitudes among parents, thinking that the child would be soon dying and there is no need to take it for care and treatment. This frustration exists especially when the baby is positive; they feel like it’s a waste of time. This shows greater need for better information dissemination and support to these HIV positive mothers. This was claimed by both the service providers and some of the mothers, who gave as one of the reasons why such mothers are lost in the continuum of care.

“Some mothers once their HIV positive status is disclosed to them, they are devastated, and eventually give up on even coming back for treatment, even returning their HIV exposed Infants.” Midwife, Layibi Techo HC III
3.8 Community Knowledge towards EID and Infant ART

Community Knowledge on EID and Infant ART is crucial in organising and mobilising HIV positive mothers to seek for EID services for the HIV exposed babies. It also has a ripple effect to the fight against stigma and discrimination of people living with HIV. Analysis from the focus groups discussions indicated that the community is not well versed with EID. This is because they don’t always attend public sensitisations and outreach programmes about HIV prevention and treatment, which are usually organised by TASO and other organisations. It was also revealed that most of the public sensitisations organised by TASO and other organisation are generally of HIV, not specifically on EID and Option B+. This implies that there is little or no community sensitisation programmes specifically of Option B+. Although the Mentor Mothers and VHTs are doing a good job in mobilising and passing on knowledge about EID and Infant ART and generally HIV, they are however limited by their knowledge inadequacies on EID, and the inadequate facilitation to sufficiently inform the whole community about the availability and importance of the services.

“A few of the community members are aware that the HIV exposed children can survive but the majority still believe that once the mother is affected, the baby cannot escape getting infected and therefore need no any support because they are going to die soon.” Respondent, Namokora HC III, Kitgum district

3.9 Community Attitudes and Practices towards EID and Infant ART

Like knowledge, community attitudes and practices are important in shaping the uptake, retention and follow up of EID and Infant ART. Community Stigma is still very prevalent – to an extent that some community members would prohibit their children from playing with the children of HIV positive parents, who are presumed to be automatically HIV positive. Some HIV positive community members fear taking their children for HIV care and treatment for fear of learning about their (babies) HIV status. Others fear delivering from the health facilities and prefer to deliver from home, because the health facility will first subject them to HIV testing, and if positive, they will be stigmatised by the community.

Because of stigma, respondents reported that they are pointed at, abused, not listened to, don’t get jobs, and others cannot associate with them to an extent of not even drinking together in a bar. For some of the elderly mothers who are still in denial, even after seeing the symptoms of HIV in the babies they take care of prefer taking the babies to the traditional healers instead of going for treatment in health centres. This is mainly in rural areas.

Several respondents noted that;

“There is too much stigma in the community and this makes people not to disclose their HIV status. For the men, because of fear to disclose and have no one to talk to, they resort to drinking; and for the children, if born to a known HIV positive couple, they are not allowed to interact with other children in the community.” Midwife, Labongogali HC III, Amuru district

“Community considers the HIV positive mothers to be prostitutes and others refer to us as walking corpses.” FGD Participant and a mother of two (2), Atiak HC IV, Amuru district
Because of fear to be disassociated by the community members, couples also fear to take their children for treatment because once the community members sees them frequenting the ART clinic; they are associated with HIV, a thing they hate to hear.

It was also reported that there is still stigma subjected to discordant couples. If it’s the wife who is positive, she is blamed and branded all sorts of names and insults by the community. The husband’s family stigmatises the wife and she always meets a lot of resistance from them. However, if the husband is the one positive, the community and the families are lenient on them and are not blamed for having brought the virus.

All that said and done, it should be noted that the organisations that have been operating in the field of HIV in these community have done tremendous job to reduce the prevalence of stigma and attitudinal change amongst the people. Though stigma still exists, it has reduced to an extent that some HIV positive people are willing to disclose their status and the leaders are able to encourage the known HIV positive people to seek medical care for themselves or their children. Some respondents revealed that;

“With sensitisations from a number of NGOs the community has also learnt to be positive with the children; they now know that babies can come out with a negative status, so they even encourage the HIV positive mothers to take their babies to the health facility.” FGD Participant, Patiko HC III, Gulu district

“At first I was heavily stigmatised by the community, people were not willing to associate with me, but when I continued to take my medication, and they have seen me living with the virus for now 10 years, their attitude towards me has changed. They see me healthier than even some of them and have learnt to live positively with me.” Respondent, Patiko HC III, Gulu district

“My community is very supportive and encourages couples to test together, and also advises those on drugs to continue taking the drugs.” Mentor mother, Labongagali HC III, Amuru District

There is therefore a clear indication that community stigma towards people living with HIV including the children is still prevalent. There is still need to do a lot of sensitisation work through outreaches and with the use of community leaders. The community leaders and members need to understand the importance and operationalisation of EID such that they are in position to mobilise or support the mobilisation of the HIV mothers to access the EID services.

3.10 Effects of Psychosocial Support on Utilisation of EID and Infant ART

Family members, beyond spouses and partners, are important in assisting HIV positive young mothers with decision-making on care and treatment. Even though Clinic support is critical, the financial, material, instrumental and emotional support provided by family is also essential to maintain high adherence levels (Khamarko, K. et. al. (2013). Even one key supportive family member helps with adherence and overall
wellbeing of the HIV positive mother and the exposed Infant. HIV positive young women reported to be receiving psychosocial support from family members, including their husbands, parents and the most significant ones. They also reported receiving support from the health facilities and non-government organisations especially Mama’s Club and Associazione Volontari per il Servizio Internazionale (AVSI) that supports the FSG meetings.

An HIV positive mother with a HIV negative husband commented that,

*My husband has been an encouragement to me though he is HIV negative, he encourages me to take drugs as they are recommended by the health workers and also advises me not to think negatively about myself and that I can live for a longer life even when am HIV positive.*

Respondent Patiko HC III

“The baby’s father is very understanding and supportive; he very supportive and understanding and we take the drugs together, as a couple living together.” Respondent Labongogali HC III

Grandparents were found to be very supportive, they take the children to health facilities to receive the drugs, in case the mothers are sick, dead or frustrated and the husbands are not supportive. Some mothers also reported not receiving psychosocial or any other form of support from the husband/spouses and/or family members. These mothers found it hard to cope with pressing needs of the family and at the same time take care of the exposed babies. This prompted some of them to either miss appointments or worse still drop out of the EID and Infant ART cascade.

“My husband is not very supportive, even though he is also HIV positive, he even refused to take the drugs, he does no longer give us transport to come for the treatment or even financially support the family, and he just drinks. I think he is frustrated and needs you people to counsel him.” FGD participant, Bobi HC III, Gulu

“I one day heard my father calling me a moving skeleton, that I cannot dig or even give him good advice because I was about to die.” FGD participant, Bobi HC III

### 3.11 Effects of Disclosure on utilisation of EID and Infant ART

Health workers (55%) and the mothers (40%) revealed that there are couples in the communities that failed to disclose their status to each other and even to their most significant ones and close family members for fear of stigmatisation and rejection. This has left them at a risk of losing out on receiving the required psychosocial and clinical support. The mothers reported that some of the HIV positive mothers have not been able to access the services simply because they have not disclosed their status to their husbands. They therefore have no reason to regularly convince their husbands to let them go to health centres for the EID and Infant ART services.

Over 90% of young mothers who were interviewed and are married or have sexual partners, reported to have disclosed their HIV status to their partners soon after receiving their HIV diagnosis. However, they reported that their husbands seem to be adamant to disclose their status to their wives, especially if they (husbands) get to know their status first. This also risks the woman to delay starting on treatment. If such a
woman delivered at the home, rather than at the health facility, the HIV exposed infant also misses out on treatment at an earlier stage.

“By the time I learnt that I was positive and disclosed to my husband, he already knew his status. He already knew his status and didn’t want to disclose to me. I later learnt that that he has been on drugs for the last three years. HIV positive woman, 23, Labongogali HC III

“My husband didn’t want me to reveal our status, but with advice and encouragement from the health care worker we were able to disclose and leave freely.” Respondent, Kitgum-Matidi HC III

The women who did not disclose to their partners spoke about fear of abandonment or violence as the main reasons behind.

“I fear disclosing to my husband because I know if he gets to know that I am HIV positive, he will blame me for having brought the virus into the family and he chase me out of the home.” Respondent, Omiya Anyima HC III, Kitgum

Nearly all 90% of women in the study had disclosed to at least a member of their family, often their mother, whom they trust can keep their secrets.

“I disclosed to the family members including my mother, father and in-laws, because they were very close to me. For my husband, it was easier because he was the first to test and already knew that he HIV positive, but my mother broke down in tears.” Respondent, Patiko HC III, Gulu district

“I disclosed to my cousin because he is the only relative am left with, my parents and other siblings were killed by the Kony (LRA) rebels, and I was abducted for 18 years. My cousin felt very bad and he cried. The baby’s father disappeared after learning that I was HIV positive and he even refused to seek for counselling and testing.” Respondent, Patiko HC III, Gulu district

“In early 2014, I felt dizzy, fainted and rushed to the hospital, I was tested for pregnancy and the results were positive. I also tested for HIV and still the results came out positive. I was devastated and I couldn’t accept what I saw. I disclosed my status to my parents, and instead ‘killed’ them. Because of the attachment they had with me, it was disastrous for them to learn of my status. My elder committed suicide, my mother too attempted to commit suicide but was rescued and survived, and suddenly my father collapsed and died on his way to hospital. Its only one brother who was strong enough to accept my status, my mother has now recuperated and she is gradually learning to accept my status. With the help of the nurse here (Ataik HC IV), my baby boy (8 months) is fortunately HIV negative and am doing everything the nurse tells me to enable him graduate negatively. To my amusement, the father is not bothered; I later learnt that he knew that he was HIV positive before I even got married to him.” HIV positive respondent, Kaladima HC III, Amuru district
Few women disclosed their status to friends or others outside their families, except the health workers. It was reported that women usually disclose to only health workers they are familiar with and women friends with whom they usually pick the drugs or attend family support group meetings together.

“I only disclosed to the people I always come with to pick the drugs because I already know their status and they can’t laugh at me. When I disclose to other friends in the community, they will just disassociate from me.” Respondent at Labongogali HC III, Amuru district

Where there is no HIV disclosure about the child’s status to the father and the caregiver other than mothers, it leads to poor understanding of the importance of follow up of HIV exposed infants for EID (Emily K. et. al. (2014). Fear of stigma of having a child tested in public, fear or rejection by the family, fears regarding confidentiality, and fears regarding the potential forced disclosure of their infant’s and their own status, can all impede uptake of EID (as extracted from (Emily K. et. al.(2014)).

3.12 Autonomy and Decision Making in the Home and its effect on EID Care and Treatment

Most women who are married reported that their husbands make most of the decision in the home including on issues related to health. Most of the women do peasant farming to provide food for the family and sell the remainder to gain some income, though sometimes this money is also taken away by the husbands. Very few women had financial autonomy, as they were unable to obtain a source of independent income.

It was found that male involvement in Option B+ care and treatment is still very low. In all the health centres visited, observations indicated that more than three quarters of the consumers of the services are entirely by women and their children. This is particularly due to tradition, where women are meant to take care of the babies, but also due to design of some programs at the health centre, like the Mother-Baby-Pairs and the Mother-Baby Care Point, where even the mere mentioning of the words creates a perception that it’s exclusively meant for mothers and their babies. The men argue that the arena for testing, the antenatal clinic, has been defined as a typical female domain where men are out of place (Falnes EF, 2011). The lack of male involvement in sexual and reproductive health services (SRH) is a known constraint and should be of no surprise, since comprehensive EMTCT programmes primarily target women in reproductive age groups (WHO, 2010).

“And for the husbands, they believe it’s the duty of the wife to take the baby to the health centre for treatment.” FGD Participant, Odek HC III

Most women did not feel that their husband would directly refuse them to seek care for themselves or their children. However men may indirectly refuse them by denying facilitation like transport. Health workers reported that men who stop their wives and children to seek for medical attention do so in fear that the women will be asked to come with husband/spouse for testing, yet they (men) don’t want to test for HIV. It was also noted that for most mothers who are single or abandoned, decision making on health-related issues is solely theirs. However they are sometimes constrained by financial difficulties’ and frustrations of abandonment by their husbands. Some don’t go or take their children for treatment for fear identified in the
community as being HIV positive, yet they would like to get engaged or re-married with other men to help them financially.

4.0 BARRIERS TO UPTAKE, RETENTION AND FOLLOW-UP OF HIV-EXPOSED BABIES IN THE CONTINUUM OF HIV CARE AND TREATMENT

EID of HIV infection provides an opportunity for identification of HIV Exposed Infants, DBS collection, growth monitoring and development, provision of co-trimoxazole to prevent opportunistic infections (OI), proper feeding options, final HIV status determination and referral to care and treatment of HIV infected infants and young children. Proper implementation of the EID services results into increased access to these services by the targeted beneficiaries. However access to these services has been hampered by loss and lack of adherence to appointments. Observations have shown that HIV-exposed babies are not returned to access the services after the first diagnoses. This section therefore presents the distinct barriers faced by HIV positive young mothers to return their HIV exposed babies for HIV care and treatment. It also presents the challenges that are faced by the service providers in ensuring uptake, follow up and retention of these babies in the continuum of care and treatment services.

4.1 Barriers Affecting HIV Positive Mothers and/or Partners to Return their HIV Exposed Infants for HIV Treatment and Care

The following barriers were revealed mainly by respondents as impediments to returning HIV exposed infants for treatment;

i) The Long Distances to the health facilities
Some health facilities are in a distance of more than 10 kilometres. This makes it difficult for the positive mothers to walk to and from the health facility to access EID services. Caretakers are sometimes grandparents who are aged and cannot travel long distances to pick the required treatment for the babies. Sometimes it requires the mother to come and sleep over at a nearby place to be able to meet the next days’ appointment. This was mentioned mainly in Amuru and Kitgum districts. For instance in Kitgum, out of the 33,000 households, over 13,000 households (over 25.3 percent) live in a distance of more than 5 kilometres to the nearest health facility (Kitgum district statistical abstract, 2013). In Gulu over 26.2 percent of the population still moves a distance of more than 5 km in search of health services and only 73.8 percent are within 5 km radius, (Gulu district statistical abstract, 2013). This is a national problem. A study conducted by Sonia Boender et al. (2012) in Kampala, Mbale and Fort Portal in Uganda, revealed that having to travel long distances to reach the clinic makes it difficult for people to leave and return home within one day, especially when no or limited public transport is available. Others drop out of treatment continuum or miss appointments in the process.

“Because of the distance, some mothers deliver on the way and fear to bring their children to the health centre because the health workers will be annoyed with them.” Mentor mother, Patiko Health centre III

ii) Poor Public Transportation System
Poor transport systems cause high transport costs that are unaffordable for many mothers. Coupled with the long distances and lack of or limited public transport means, makes it prohibitively difficult to afford. The
public means of transport, like *boda bodas* (motorcycles), don’t reach deep in the villages. It therefore becomes costly for the impoverished HIV positive mother to meet the transport costs; especially when they are divorced/separated or are not supported by their husbands/spouses. Sometimes people would prioritise to buy food other than spending the money on transport to take the baby for treatment and care. This is consonant with a study conducted in Uganda by Sonia Boender *et al.* (2012) which indicated that transportation costs are prohibitively high when considered in comparison to the need for food.

**iii) Low Knowledge levels on EID service provision**

Mothers lack comprehensive knowledge about EID services, the schedules of diagnosing the HIV exposed babies and infants, the recommended breastfeeding for an exposed Infant, and the proper feeding options recommended. Some mothers show negative attitudinal thinking that if an Infant is already positive, it’s bound to die soon and there is therefore no need to provide them with EID services. Mothers sometimes lack proper information and guidance on Option B+, since some of the service providers and mentor mothers are not well trained and skilled in EID service provision. This partly explains the unintended loss of the HIV Exposed Infants.

The Clients’ low level of PMTCT knowledge is frequently cited as a barrier to retention, Gourlay, J., *et al.* (2008). Knowledge is further impeded by unequal power dynamics between health providers and clients. Women do not feel sufficiently empowered to ask questions during counseling sessions as they view healthcare professionals as authority figures, Larsson, E., *et al.* (2012). EID is highly stressful and it cannot be taken for granted that all mothers (or parents, caregivers) understand that it is a pathway for treatment for the infant, Donahue M., *et al.* (2012) Not all women are aware of this service and may not be guided there by health workers, Sprague, C., *et al.* (2011).

**iv) Lack of psychosocial support from spouses especially amongst discordant couples**

Lack of psychosocial support is very noticeable with discordant couples, especially when the wife is HIV positive and the husband is negative. In such families, mothers have reported that separation and divorce tend to occur. This leads to frustrations of the mothers and they give up on returning the HIV exposed infants for treatment at the health facilities.

Some of these HIV positive young mothers noted that;

“In October 2010, I went with my husband to the health centre to test for HIV and the results showed that we were a discordant couple. He was negative and I was positive. He was annoyed, quarrelled and accused me of infidelity that I brought the virus into the family and he even left me at the facility. We separated since then.” Respondent Patiko HC III

**v) Non-Disclosure of the HIV status by the parents of the Exposed Infants**

In families where there has been denial of the status, parents tend not to take their HIV exposed Infant to seek medical care at the health facilities. The parents fear to discover the child’s status, especially if the child is exposed and this has left the baby at risk of contracting the virus.
“My father has been very encouraging and advised me to start taking the drugs, but my husband refused to accept his status, even though he tested positive. He has even refused to take the drugs, which worries me so much.” Respondent, Patiko HC III, Gulu district

Poor HIV disclosure among partners, non-maternal caregivers have been linked to underutilization of EID as awareness of infants exposure status may not be known hence lack opportunity to serve these kids (Ciaranello et al., 2011). If there is no HIV disclosure to fathers and caregivers other than mothers, this can lead to poor understanding of the importance of follow up of HIV exposed infants for EID.

vi) Domestic Violence
It has been reported that violence is one of the looming challenges to the implementation of Option B+ in the area. If it is discovered that the couples are HIV positive, men start accusing their wives of infidelity. They beat up their wives and at times resort to drinking. Women become frustrated, stressed and less caring mothers towards their HIV exposed babies. This frustrates the women and they give up on even the lives of their children, exposing them to the risk of contracting the virus.

One respondent revealed that;

“I disclosed to my husband, when I told him to go and have the test done on him, he refused and I suspected that may be he already knew his status, and never disclosed to me. When I interrogated him to tell whether, he beat me badly to an extent that I was admitted, this later led us to part ways.” Respondent Omiya Anyima HC III, Kitgum

Domestic Violence has been identified by several studies as a strong predictor to HIV testing and return visits. Many women do not disclose their status to their partners for fear of violence, which causes difficulties adhering to EID and ART. This is because women may have to hide their status and that of their babies, resulting in missed doses and refill appointments. Women in a Malawian study reported that domestic violence at the hands of their partners and the fear of such violence had a negative impact on their ability to start and continue using ARVs, Gourlay, J., et al. (2008).

vii) Divorce or Separation of the parents
Divorce and/or separation of partners, leaving the mother to single-handedly take care of the baby, is a barrier to adhere to services. It was reported that some of the divorced mothers relocate to new areas, abandoning all the treatment they were undergoing at the previous centre. Others once divorced, and relocated, re-marry and fear to disclose their HIV status and that of their babies to their new partners. This can lead to them giving up on returning the babies for treatment in order to save their new marriages.

viii) Personal stigmatisation
Personal stigmatisation has an eventual negative effect on the uptake, retention and follow-up of Option B+ by the HIV positive young mothers. These mothers tend to feel sorry about themselves and give up their lives together with the lives of their babies. When asked what they feel or felt being HIV positive and pregnant, some of the respondents noted that;

“I feel sad about my life and I think that probably God hates me.” 18 year old HIV positive pregnant respondent, Patiko HC III, Gulu
“When I tested positive, I was pregnant and only 17 years, I was devastated, I felt like aborting. I regret the anger I exhibited that time and even after producing. It is out this anger that I neglected my child and she turned positive. If it wasn’t that anger, my child would be negative now because the health workers used to tell what to do and I just neglected, because I felt tired and gave up on life.” Respondent Namokora HC III, Kitgum

ix) Agricultural Seasonal changes
Agricultural Seasonal changes can lead to temporary migrations, affecting adherence to appointments and sometime loss of babies. Both the health workers and the mother agreed that during the planting and harvesting periods i.e. June/July and November/December respectively, a lot of babies and their mothers are lost. In such periods, they are in the gardens and can’t find time to go the health facilities for EID services. In some cases some cross over to far away areas where they do casual labour in plantations. In such cases babies and children are lost from the continuum of care. This was mainly mentioned in Amuru, were such migrations are common. The health workers however noted that in such cases, some mothers do report their upcoming movements to other areas. If the mother reports, where possible, the health workers give drugs for three months instead of one-month, such that by the time the drugs are over, the season too has ended and the mother is able to come back to the facility. However, this is difficult for the mothers who don’t report and just disappear without notice, in such a case the appointments are lost.

More engagement in agricultural activities especially poor communities may have less access to education and hence poor health seeking behaviour (Keen E. & Karfakis J., 2014). In Malawi, less educated mothers and those from farming communities are less likely to attend HIV exposed infants follow up clinic for EID of HIV (Loannidis et al., 1999).

4.2 Challenges faced by Service Providers in ensuring Uptake, Retention and Follow-Up of HIV Exposed Babies in the Continuum of HIV Care and Treatment
All the facilities that participated in the study had a system of identifying HIV-exposed infants on Child Health Card, where the HIV exposure status of the child is recorded. Eight out of the twelve (67%) health facilities had Job Aids i.e. guidelines, posters, etc. on EID services and they were put to use. All the facilities that were visited had proper documentation of results, follow up and growth monitoring for babies. However the health workers identified several the following challenges that they face in a bid to ensure uptake, follow up and retention of the HIV exposed infants in the continuum of care and treatment services:

(i) Stock out of DBS materials and HIV testing kits at the facilities
All the facilities in the study regularly have DBS materials and cotrimoxazole drugs available in stock, with the exception of two (2) health facilities in Kitgum – Namokora and Omiya Anyima HC III. This was particularly attributed to delays in making requisitions by the relevant authorities and delivery by National Medical Stores (NMS). The health workers reported that in such a case, they borrow from the nearby facilities. All the facilities also reported regular collection of DBS samples. All facilities reported to have a clear transportation system of the DBS samples under the hub3 system and the samples are transported at

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3 The Hub system involves setting up local networks centered around regional hospitals, district hospitals and health centers called hubs. Each hub is given a motorbike and a bike rider with facilitation. The transporter visits 25-35 health facilities within 20-40km radius around the hub, bringing all referred samples from each facility and delivers results on a weekly basis. The hub would then further refer highly specialized tests like DNA PCR tests. In area of study the Hub are at
least once a week to the National Laboratory in Entebbe. A well connected transportation system of DBS samples reduces the turnaround (TAT) time for results and hence timely availability of HIV DNA PCR results. Delay of results makes mother-infant-pair default from follow up. Inconsistencies in the availability of test kits for testing all women attending antenatal services makes it difficult for the identification of exposed infants. The irregularities in the availability of EID test kits and commodities also make eligible infants who come to the clinic to miss out on an HIV test.

(ii) Lack of the Requisite Laboratory Equipments
Lack of equipments required at the Health facilities, especially in laboratories such as the CD4 count machine (Complete Blood Count – CBC machine), rendering the clients to be referred to far way centres. In the health facilities that were visited, only two (2) had a CBC machine – Ataik HC III and Labongogali, which had just acquired one. In all the other facilities, when there is need for the CD4 count to prescribe proper treatment, the client has to be referred to another facility that has the machine. This sometimes discourages the clients, who at times don’t have the transport fees to reach such centres rendering them to give up.

One health worker noted that,
“You may for instance refer the person for CD4 count, but because they are far, the clients end up not going for it. There was one organisation that used to come here for the reagents to conduct the CD4 count, but they ceased at one point ……” Midwife at Odek HC III.

(iii) Delays in Return of the DBS results
DBS results take between 2 weeks to 1 month to return to the health facility. All facilities reported to explain to the mothers the next appointment and the importance of adhering to this appointment. However, some mothers take long without returning for the results, to an extent that some don’t turn up at all. The health workers reported that in case the results came back positive, the affected child is called upon immediately and another test is taken to confirm the results. Mothers attributed this to the delays in the return of the results, which makes them to give up on coming back for them. If results are not available after traveling to the health centre, and this happens more than once, mothers and caregivers are unlikely to return again for results. Though this turnaround time is still high, it’s however within the national recommended averages.

According to Kiyaga C. et al. (2013), the EID program handled the issue of time lost at the laboratory by setting up an efficient EID centralized laboratory, which reduced the laboratory turnaround time 28 days nationally. Turnaround time is measured as the time from collection of a sample to receipt of the results. The EID program embarked on the transit time by setting up the sample transport network around the country that has helped to reduce the turnaround time from unacceptable 60 days to 28 days.

(iv) Long Waiting Hours at the Health Facility
The number of health workers compared to the number of HIV positive mothers and HIV exposed Infants met on a particular clinic day is usually high. This sometimes leads to long waiting hours at the health facility. They are at times advised to come back the following day. This at times frustrates the clients, who
usually don’t come back or keep appointments. On average, three health workers provide EID health care services at the facilities and each attend to an average of 60 clients on a particular clinic day.

“On a given Clinic Day, I meet around 30 mothers, and if each mother comes with a baby that means that I have to meet like 60 clients.” Health worker, Patiko HC III

(v) Inadequate and lack of well-trained health workers in the provision of EID Services
All the facilities that participated in this study had commodities for EID, 11 out of 12 (92%) health facilities had at least a trained human resource in EID service provision, with the exception of Labongogali HC III, which did not have even a single health worker trained in EID service provision at all. This health centre had just been upgraded to level III, at which level the facility qualifies to provide Option B+ services. It was found out that there are a number of health workers that provide EID services but were not trained. They sometimes lack the necessary knowledge on how to handle the HIV exposed Infants.

One untrained health worker that provides Option B+ revealed that;

“I always contact the midwife if she is around, if she is not, I refer the client to another day and attend to her when I have already consulted. We need on-job training in provision of Option B+ and continuous mentoring from the experts.” Health worker, Kitgum-Matidi Health Centre III

The same challenge was also found with mentor mothers that sometimes provide misleading EID information to the clients and the community, exposing the provision of EID services to risks of failure. This was realised when one HIV positive mother of four (4) was asked why she was still breastfeeding her HIV exposed baby at 15 months. She claimed to having been advised by the mentor mother to continue breastfeeding since the child was diagnosed HIV negative for the first and second DNA PCR test. That the child was now safe and can contract the virus anymore and therefore she should breastfeed even beyond the recommended one year.

Shortage of staff, inadequate skills and knowledge, inappropriate perception and overwhelmed are human resource factors which affect provision of health services. These will be manifested as poor motivation and regular absenteeism. Health care providers should be motivated by formal trainings, mentorship and regular supportive supervision (Gamaliel, J. 2012)

(vi) Different Clinic Days between the HIV positive mother and HIV Exposed baby
Five facilities reported to provide EID services five (5) days a week, while the rest of the facilities have special clinic days they provide EID services. They however would also provide these services to the mothers in case on need on any other day. It was noted in some cases that the mothers and their HIV exposed infants have different clinic days. This was reported mainly by respondents in Odek HC III, Gulu and in Namukora HC III, Kitgum. This poses a challenge to the mother who has to come to the facility at least twice a month to collect treatment for herself and the child. Given the transport challenges involved and the long distances, the mother may sometimes fail to turn up on one of the two appointments.

(vii) Unprofessionalism from some health workers
Several young mothers reported unprofessional behaviour among health workers. Examples are: failure to keep the client’s status confidential, subjecting the client to more community stigma and prompting some clients to seek treatment from far away health facilities where they are not known; Segregation amongst the
HIV positive mothers by the health workers, who tend to pick and work first on their relatives or those who have paid them; Late coming and Early departure from duty by the health workers providing little time to the mothers; Refer the clients to private clinics for the drugs for pay, yet they are meant to receive them for free in public health centres; and, Negative health workers’ attitudes and handling of the HIV positive mothers and their exposed Infants.

Negative staff attitudes are frequently cited as a barrier to returning to facilities, and women have experienced or fear scolding from staff for home deliveries when returning with their baby for neviripine administration, or were otherwise stigmatized (Levy, J. (2009).

(viii) Lack of facilitation for follow up by the health workers
The health workers reported difficulties in making follow ups and outreaches on the lost HIV exposed babies and infants. This is particularly due to lack of facilitation in terms of transports and daily allowances, loss of address and contacts of the clients, and long distances involved. The referral system is also reported as a challenge for follow up: when a mother and her child are referred, a coupon from the referral form is supposed to be plucked off by the recipient health facility, filled and returned to the sending facility. However, it was found out these coupons are not returned by the client, and therefore it is difficult to trace whether the client received the treatment.

“Some clients change places of residencies and don’t even ask for referrals; others don’t have telephone numbers that you can always contact them; others don’t know the names of the parishes or sub counties from which they come from. All this makes it difficult to follow them up, once they are lost.” Nursing Assistant, Kaladima HC III, Amuru district

The health workers also reported that due to high levels of stigmatisation in the community, some of the HIV positive patients don’t want to be identified with the health workers and mentor mothers/fathers. Some of the clients don’t want to be visited in their homes, and hence they disappear once they see the health workers and mentor/fathers heading to their homes. This at times has demoralised the health workers from carrying out follow ups.

(ix) Patient-Client attachment
FGD respondents in Atiak HC IV noted that usually HIV positive young mothers are freer with a health worker who conducted the first diagnosis. Once that health worker is unavailable, the client feels uncomfortable to disclose or be attended to by another health worker available at the facility. The FGD participants claimed that this sometimes leads one to self-transfer herself to another facility where she is treated as ‘new’ client.

4.3 Possible Solutions to the Challenges affecting HIV positive mothers return their HIV exposed babies and Service Providers to ensure Uptake, Retention and Follow-Up in the Continuum of HIV Care and Treatment services
To ensure increased utilization of EID and consistent uptake, retention and follow up of the HIV exposed infants in the continuum of care in Gulu, Amuru and Kitgum, the above concerns have to be addressed. To address them, a number of recommendations were generated. These have been categorized into
recommendations for the government health systems and recommendations for Mama’s Club and other Implementing Partners.

a) **Recommendations for Mama’s Club and Partners**

1) **Facilitation to conduct follow ups and outreach programs**: Where possible Mama’s Club and other organisations should facilitate the health workers and mentor mothers or expert clients to conduct follow ups, outreach programs and home visits, so that services are taken nearer to the people. Facilitation could be in the form of transport-and daily allowances. Mentor mothers can be provided with cheap and affordable means of transport like bicycles, to enable them to reach the villages. Mothers in one locality can be grouped together in one outreach centre in the community, to provide them with affordable EID services, especially where the mothers or caregivers are unable to reach the health facilities. There is still need to do a lot of sensitisation on stigma and discrimination through outreaches and with the use of community leaders.

2) **Advocate for male involvement**: Mobilisation and sensitisation of men/spouses to participate in EID care and treatment would be important in increasing uptake, follow up and retention of HIV exposed Infants in the continuum of EID care. Men are most often the decision makers in the home on health and financial issues. Men as supportive partners can influence the family’s social environment to help make it more conducive to seeking treatment, retaining in care, and adhering to medication. Men’s involvement also positively impacts infant feeding practices. Men were found out to be willing to participate in these activities, but lack adequate engagement to link them up to the health facilities. Health workers also recommended involving men more actively in ANC, in order to improve the uptake of EMTCT measures and enrolment of HIV exposed children in paediatric HIV care.

   There are some excellent outcomes to male involvement that have been documented. For example, a Kenyan study that found that male ANC attendance reduced risk of vertical transmission and infant mortality by up to 40% (Alusio, A. et. al 2011). A study in Malawi found that male partner accompaniment to clinic was significantly associated with hospital delivery, completion of follow-up in the programme and condom use (Kalembo, F. et al. 2013). Couple counselling and testing has been shown to improve adherence to treatment and breastfeeding protocols, and to also increase the odds of having a facility-based delivery (Farquhar, C., et al. 2004).

3) **Engaging community leaders**: Mama’s Club should actively engage community leaders during mobilization and sensitization of community members on EID care and treatment. In Malawi, traditional leaders have regularly been engaged and reports indicate that this has been an effective tactic in reducing stigma and discrimination in the community and increase community support for PMTCT and HIV services (UNAIDS 2012). Very few organizations explicitly seek out and engage faith-based leaders for community outreach and mobilization for Option B+ services. This is a

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4 Male involvement is defined as an umbrella term that can encompass couples counselling and testing, men’s HIV testing, facilitation of disclosure between partners, accompaniment to health facility visits, and outreach and education of men on EMTCT and gender equality.
promising practice promoted by UNAIDS because of faith leaders' potential for influencing opinions and activating communities, and appears to hold potential for mobilizing couples and motivating men to be involved in EMTCT and EID services. Enlisting leaders to mobilize support for EMTCT will help in identifying ‘Champions’ of EMTCT.

4) **Economic Empowerment of the HIV positive mothers:** HIV positive mothers sometimes are financially constrained to go to the health facilities for their own treatment and that of the babies. This is common with mothers who are either divorced or are financially abandoned by their husbands. The organisation should support these women with Income Generating Activities (IGAs) like providing them with agricultural inputs such as seedlings and equipments, training them in modern agricultural practices in livestock farming among others. Alternatively, these women can be linked to other organisations who provide livelihood support. There are a number government programs and social support groups to which these mothers can be linked to provide such support. This includes programs such as National Agricultural Advisory Services (NAADS), NUSAf, Send a Cow Uganda, among others. These organisations are very experienced in offering agricultural support to such groups. It would also be an opportunity for Mama's Club to collaborate with such an organisation.

5) **Fight against domestic violence:** Domestic violence is one of the impediments to continued uptake, retention and follow up of EID care and Infant treatment. This puts the HIV positive mother on stress and can lead to a mother giving up on the baby’s life. It is therefore important, that a component tackling domestic violence should be involved in ASK program, such that the concern is eventually handled. Many of the domestic violent cases are not reported and therefore it’s difficult to have actual figures at the police or health centre, however, several young mothers revealed that they have on several occasions been victims to domestic violent acts.

6) **Organise and conduct HIV awareness campaigns and days:** where HIV positive young mothers with HIV negative graduated babies, can give inspiring testimonies at public gatherings. This would inspire those who have not disclosed and also taken their babies for HCT to go for the services at the nearby health facilities or outreach centres. There are some mothers who are willing to give inspiring testimonies, like this respondent;

> I graduated an HIV negative baby and this is the greatest joy of my life. I use her as an example to other pregnant mothers to encourage them to attend ANC, deliver at the health facilities, and stop breastfeeding before teething. I always tell them that it's possible to have an HIV negative baby, when the mother is HIV positive.” Respondents Labongogali HC III, Amuru

7) **Design tools to specifically collect data for Mama’s Club:** In all the health centres visited, it was very difficult to find up to date data on EID services. The health centres have so many tools for data collection, which requires a lot of time, motivation and skills for the health workers that may not be available. At the time of the study, all the tools were not up to date and some even had information gaps of up to three months. The M&E Officer at Mama’s Club should identify indicators
that the organisation is interested in, and design tools to capture data on these indicators. These tools should also have guidelines and protocols to be followed while being filled. These should be given to Mama’s Club Focal Person, who is at every health centre, to fill at the end of every month. M&E Officer can then with the help of the programmes manager, generate reports at every quarter to present to partners and stakeholders, and gauge performance against targets.

8) **Continuously Conduct Community Sensitisations and Education on EID Services:** Mama Club and implementing partners should liaise with the health facilities to conduct continuous sensitisation and encouragement to the HIV positive mothers and the communities on Option B+ and EID service provision. This should in form of regular health education sessions on different topics like drug adherence, positive living, nutrition, Infant and babies feeding, disclosure & family planning.

b) **Recommendations for the health facilities**

(1) **Conduct Capacity Building programmes to health workers and mentor mothers:** Provide Capacity Building programmes to health workers to enhance their knowledge and skills in option B+. Health workers should also be provided with client/customer care training in healthcare and mentor mothers should be given orientation in Option B+. The government health systems should provide effective EMTCT package to the service providers to facilitate their awareness, understanding and prioritisation of EID service provision. Capacity building programmes should not only stop in training, but also in infrastructure, staffing and incentive provision to the service providers. The government should consider improving the incentives given to the service providers working in hard to reach areas like Northern Uganda to increase their motivation and desire to provide the services.

(2) **Give Incentives to HIV positive Pregnant Mothers to attract them to deliver from Health Centres:** The government should start considering giving incentives in form of Nutritional supplements and reimbursement for transportation costs and Mama Kits to HIV positive mothers for giving birth at the health facility. It was found out that one of the reasons mothers may end up giving birth in their homes without the help of a skilled health personnel is because of the transport challenges and a requirement of Mama kits by the health workers to whoever mother is to give birth. Giving them these incentives would definitely attract them to health facility. It would also be an addition for HIV positive mothers to get nutritional supplements for their HIV exposed infants. Several mothers complained of lack of the necessary nutritional foods to feed their HIV exposed babies once they cease breastfeeding. It would therefore be an incentive for them to cease breastfeeding at the required age, once they are assured of ready-to-use therapeutic food products (i.e. *Plumpy’nut*). This should not only stop in North Uganda, the programme should be scaled up nationally, especially in marginalised communities.

A study in Zambia found that nutritional support to food-insecure individuals led to better adherence and high medication pick-up compared to the control group (Cantrell, R., et al. 2008).
Though this was not associated with retention in care, it is thought that it has an incentivizing effect on treatment dose adherence among those retained in care.

(3) **Scale down the provision of EID services to Health Centre II:** This will particularly take the services closer to people and help to curb down the challenge of transport. These health centres are located at the parish level, and are nearer to people than Health Centre III’s. It should also be noted that in the MoH Stakeholders Status Report 2014, better ANC retention was realised at HC II because it’s nearer to the people; and also out of the 86% expectant mothers who attend ANC services, 20% attend from HC II. This implies that HC II is a good catchment ground for the EID service provision. If the services are scaled down, it would be easier to increase uptake, retention and follow up in the continuum of care.

(4) **Establish consistent Logistics and Supplies Management Systems to avoid drug stock outs:** It was found that some centres usually lack necessary regimens for the infants and the mothers. Also, only two centres in the study had CD4 Count Machines, which all affects the provision of EID services. Lack of point of care CD4 testing could result in loss to follow-up of mothers. Shortage of HIV test kits was also reported to still occur in some centres. All these logistical challenges interrupt the provision of EID services. The government should therefore devise ways to ensure that at least all HC III’s have CD4 testing machine, and constant supply of the required regimens and testing kits at the health centres.
5.0 CONCLUSION AND DISCUSSION

Loss of HIV exposed infants from the continuum of EID care and treatment and lack of adherence to EID procedures was found to be prevalent in Northern Uganda. This study was conducted at 12 health facilities in Amuru, Gulu and Kitgum districts. These facilities provide various EMTCT services including the provision of ANC, health education and safe delivery. These facilities also integrate EID services in the provision of ANC by enrolling the HIV positive mothers on ART and HIV exposed infants into the EID care and treatment.

The HIV exposed infants are subjected to DNA PCR test at 6 weeks and those who are found HIV positive are referred the ART Clinic to be started of ARVs. Those who are HIV negative are subjected to two more tests to confirm their status until they are graduated at 18 months. The loss of HIV exposed infants from the EID continuum of care and treatment exist in the community. The infants are mainly lost after the first DNA PCR test. This is mainly due to attitude and knowledge of the mothers and caregivers about EID treatment and care. It may also be caused by several others personal or health facility-related challenges.

The mothers are also aware of the transmission of HIV to infants and its effects, the EID and Infants ART services that are provided. The health workers are instrumental in explaining the do’s and don’ts of Option B+ and the necessary procedures to ensure that the HIV exposed baby graduates successively. 80% of the respondents knew that testing is the major way of identifying the status of the HIV exposed baby. They are also aware of the sources and how to access the drugs and treatment. There was also positive attitude amongst the respondents towards EID and Infant treatment. However the major challenges were in practising what they knew. The general community is however not versed with EID services and Infants treatment. This has caused a challenge in mobilising HIV positive young mothers and the general community to embrace EID care and treatment. This general lack of awareness also affects the community attitudes and practices; hence community stigma towards people living with HIV, including children is still prevalent.

Although 90% of the mothers interviewed revealed to have disclosed their status to their partners and family members, they however reported that most of the husbands are hesitant to reveal their status to their wives and the community members. They also reported a number of women, especially those delivering from the communities that are also hesitant to reveal their HIV status. Those who have disclosed their status have done so because they are in family support groups and have received support and encouragement from fellow group members and health workers. Failure to disclose ones status leads to poor understanding of the importance of EID and denial of psychosocial support from the husband and family members.

In the study, several reasons for the loss of HIV exposed Infants in the continuum of care and treatments were identified. These are in two categories; a) those that affect mothers to return their HIV exposed Infants to the health facilities to receive treatment and care; and, b) health facility-related challenges. These challenges combined, they affect uptake, retention and follow up HIV exposed infants in the continuum of EID care and treatment services. On the first category, several barriers were identified including the long distances to the health facilities, with an average of 25% of the population still live in a distance of over 5
kilometres to the nearest health facility; low knowledge levels of the mothers and the community about the EID services; domestic violence; poor public transport system; community stigma and changes in agricultural seasons that lead to temporary migrations. In the second category several challenges were identified such as the high turnaround time of the DBS test results; lack of facilitation to conduct follow ups and outreaches, stock outs of drugs, HIV test kits and other laboratory equipments, inadequate human resources, and unprofessionalism among the health workers.

Providing a solution to these challenges will be a huge step towards reducing loss of infants in the continuum of care. The study identified several recommendations to help improve the uptake, retention and follow up on EID care and treatment for both the government, such as providing capacity to the health workers to provide EID treatment and care, giving incentives to pregnant mother to deliver at health facilities, streamlining the system of delivery of drugs and logistics, among others.

On part Mama’s Club and partners, it should be noted that, although the organisation is very influential in mobilising, educating and informing young mothers to access EID and SRH services at the health centres, there is still lack of proper knowledge on these services. It should therefore ensure that all young mothers attending EMTCT be actively engaged in FSGs to acquire more knowledge and psychosocial support to access these services. This should be done by advocating for male involvement, engaging community leaders, facilitating follow ups, empowering HIV positive mothers economically, among others. The health centres should also take an integral part of scaling up access to EID services in the communities. Health workers must adapt with increased demand on the time of service, acquire and sustain EID skills and knowledge while maintaining optimal attitudes and practice towards caring of HIV exposed infants.

5.1 Research Gaps
A number of potential areas that would require further research have been identified and these areas are;

1) The low involvement of men (spouses) in the Option B+ programmes. It has been observed that few men (spouses) participate in Option B+, and the wives would like their husbands to participate. Male participation is likely to have a positive influence on uptake, retention and follow ups in the EID care and treatment. There is a need therefore to find out the causes for the low turn up and their possible solutions.

2) The effects of domestic violence on the uptake, retention, and follow up in the EID care and treatment and the possible ways to curb it down. It has been reported that domestic violence is rampant in the community and has significant effects to the EID care and treatment. There is need to find out the extent and damage caused by this challenge and the probable solutions.

3) The effects of Non-Disclosure or Disclosure on the uptake, retention and follow up in the HIV Care and treatment of HIV positive young mothers and Children. Non-disclosure was found to be one of the challenges in EID care and treatment, but it was also found to be a significant SRH challenge. There is a need to find out its causes and effects among HIV positive young mothers and their babies especially amongst couples, the motivators and predictors to disclosure and generate recommendations for its improvement.
6.0 REFERENCES


34. T. Sonia Boender et al. (2012) Barriers to Initiation of Paediatric HIV Treatment in Uganda: A Mixed-Method Study

35. UN General Assembly (2011) Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS. UNAIDS.


7.0 APPENDICES

Appendix 1: Interviews Guides (Questionnaires) for HIV Positive young Mothers

Introduction:
Good morning/ afternoon, my name is ................. I am conducting a research on the barriers faced by HIV Positive Women to return their Exposed Babies to access HIV/AIDS services in Northern Uganda.

This interview is administered for the purpose of collecting data on the barriers faced by HIV-positive young women to return their Exposed Babies to access HIV/AIDS services in Northern Uganda. The findings from this research will be used to inform and adapt our programmes and services for mothers living with HIV and their exposed babies, to increase the access to and quality of these services. Participation of the mothers living with HIV is therefore highly valued and there are no good or wrong answers.

Participation is voluntary and you have the right at any moment to quit the interview. Any information volunteered by you will be held in confidence and not used for any other purpose apart from the one stated. Mama’s Club will take the initiative to inform you about the findings of the study. Are you willing to participate in this study?

Yes……………………………… No……………………………………..

A. Demographic Characteristics

1. Age of the mother and the child
2. Number of children alive and dead
3. Marital status of the mother
4. Level of education
5. Employment status
6. Received EMTCT (Option B+)
7. Previously experienced PMTCT

B. Knowledge

1. Talk about what you know about how babies become infected.
2. How can HIV infection in children be prevented? How well do these methods work?
3. What could be the effect of HIV infection in children if not treated early?
4. How can we know that a baby is having HIV infection?
5. When should HIV infection in children be diagnosed and why?
6. If a baby has a negative HIV test at 6 weeks, can they still get infected? How?
7. When should anti-retroviral drugs be commenced in children and why?
8. When should anti-retroviral drugs be stopped in children and why?
9. Where do you get information about EID and Infant ART?
10. From where can one access EID and Infant ART services in this community?
11. How can one access these services?

C. Attitudes and Practices

1. Have ever taken your child (ren) for an HIV test? If yes, what where your experiences?
2. If no, have you ever thought about taking your child to the Health Centre for HIV test? If no, why?
   Are you willing to do HIV test on your child now? Why? If you took your child for an HIV test today,
   what would be your expectations while waiting for the HIV result of your baby?
3. Are you willing to return for the result of your baby's HIV test? Why?
4. In your opinion, do you think HIV exposed children attending immunization days at six weeks
   should undergo mandatory testing for HIV? Why?

D. Psychosocial Support
   1. Describe any social support you receive as a person living with HIV.
   2. Describe the support you receive from the baby’s father (financial, emotional, care of the baby)
   3. Do you have people who encourage you to take care of yourself, take your medicine and your
      children? How do you describe their support?
   4. Do you have people talk to you when you feel sad? How do you describe their support?
   5. Is there any community organisation that provides you with psycho-social support? How do you
      describe their support?

E. Disclosure
   1. When did you first test HIV positive and how did you feel about it?
   2. Describe how you feel being HIV-positive and pregnant.
   3. Have ever disclosed your status with anyone?
   4. If yes, whom did you disclose your status to? Why that person? What was that person’s reaction?
   5. Describe the reaction of the baby's father, other family members and friends.

F. Community Stigma
   1. What do people in your community say about HIV infected young women?
   2. What do people in your community say about HIV-infected men?
   3. What do people in your community say about HIV-infected children?
   4. What do you think about yourself as an HIV positive person?

G. Autonomy
   1. How do you make decision regarding health-related issues for yourself and your baby?
   2. Who is involved in the decision making process?
   3. What happens if there is a disagreement about what should be done? Who makes the final
      decision?

H. Challenges Young Mothers Face
   1. What makes it difficult for mothers to return their babies to access HIV testing and testing?
      Hint
      - Health facility related challenges such as handling from the health workers, availability of
        medicines, etc.
      - Accessibility challenges, such as distance to the Health Centre’s.
      - Any other.
   2. What would help mothers to return their babies in for testing and/or treatment?
   3. Why might some mothers not want their babies to be tested?
   4. Do you have any other experiences or stories that you would like to share with us?

THANK YOU!
Appendix 2: Key Informants Interview Guide for Service Providers

Introduction:
Good morning/afternoon, my name is ............... I am conducting a research on the barriers faced by HIV Positive Women to return their Exposed Babies to access HIV/AIDS services in Northern Uganda.

This interview is administered for the purpose of collecting data on the barriers faced by HIV-positive young women to return their Exposed Babies to access HIV/AIDS services in Northern Uganda. The findings from this research will be used to inform and adapt our programmes and services for mothers living with HIV and their exposed babies, to increase the access to and quality of these services. Participation of the mothers living with HIV is therefore highly valued and there are no good or wrong answers.

Participation is voluntary and you have the right at any moment to quit the interview. Any information volunteered by you will be held in confidence and not used for any other purpose apart from the one stated. Mama’s Club will take the initiative to inform you about the findings of the study.

1. What is your position and role in providing services for young mothers living with HIV and their exposed babies? Can you describe what services you provide and how you guide the young mothers and their babies, e.g. how many young mothers and babies do you see each day, when do you first see them, how often do you see them, when are they referred to other services and how do you follow up?

2. Talk about the young mothers’ and/or fathers’ of HIV-exposed babies, knowledge, attitudes and practices towards Early Infant Diagnosis and Infant ART regimens?

3. Talk about their response towards the uptake, follow up and retention of EID and Infant ART?

4. What barriers do HIV-positive young mothers face that prevent them from returning their HIV-exposed babies to access HIV/AIDS services?

5. What are the possible solutions to the barriers that prevent HIV-positive young mothers from returning their HIV-exposed babies to access HIV/AIDS services?

6. What are the challenges that Service providers face in ensuring EID and Infants ART uptake, follow up and retention of HIV-exposed babies in continuum of care and treatment services?

7. What are the possible solutions to the challenges faced by service providers in ensuring uptake, follow up and retention of HIV-exposed babies in continuum of care and treatment services?

8. Can you share one example of a mother and her baby you have supported, which shows either the challenge or success of uptake, follow up and retention of EID and Infant ART?

THANK YOU!
Appendix 3: Focus Group Discussion Guide

Introduction:
Good morning/ afternoon, my name is …………….. I am conducting a research on the on the barriers faced by HIV Positive Women to return their Exposed Babies to access HIV/AIDS services in Northern Uganda.

This interview is administered for the purpose of collecting data on the barriers faced by HIV-positive young women to return their Exposed Babies to access HIV/AIDS services in Northern Uganda. The findings from this research will be used to inform and adapt our programmes and services for mothers living with HIV and their exposed babies, to increase the access to and quality of these services. Participation of the mothers living with HIV is therefore highly valued and there are no good or wrong answers.

Participation is voluntary and you have the right at any moment to quit the interview. Any information volunteered by you will be held in confidence and not used for any other purpose apart from the one stated. Mama’s Club will take the initiative to inform you about the findings of the study.

1. Explore the group Knowledge in the following areas.
   - How babies become infected.
   - How to prevent HIV infection in children.
   - The effect of HIV infection in children if not treated early.
   - How can we know that a baby is having HIV infection?
   - When should HIV infection in children be diagnosed and why?
   - If a baby has a negative HIV test at 6 weeks, can they still get infected?
   - When should anti-retroviral drugs be commenced in children and why?
   - From where can one access EID and Infant ART services in this community?
   - How can one access these services?

2. What are the young mothers’ and/or fathers’ of HIV-exposed babies, knowledge, attitudes and practices towards Early Infant Diagnosis and Infant ART regimens?
3. What are knowledge, attitudes and practices towards EID and Infant ART regimens within the community and family of the young mothers and/or fathers?
4. What barriers do HIV-positive young mothers face that prevent them from returning their HIV-exposed babies to access HIV/AIDS services in this community?
5. Suggest the possible solutions to the barriers that prevent HIV-positive young mothers from returning their HIV-exposed babies to access HIV/AIDS services?

THANK YOU!
## Appendix 4: Health Facility Checklist

<table>
<thead>
<tr>
<th>No.</th>
<th>Question</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Are EID services available? What do these services consist of (e.g. contact moments, information provided, etc.)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Are there Trained Health Workers on EID services?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Number of female HCW trained at the health facility</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Number of Male HCW trained at the health facility</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Number of HCWs performing EID at the health facility</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Number of Days per week EID Clinic is conducted</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Facility have Child Record Cards</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Is the Exposure status of children recorded in the Child Record Cards</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Number of exposed babies currently accessing EID and Infant ART services</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Number of Exposed infants enrolled for the last 18 months</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Number of exposed infants lost in the continuum of care for the last 18 months</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Availability of Job Aids i.e. guidelines, posters, etc. on EID services</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Are these Job aids in use</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Availability of Dry Blood Samples (DBS) materials, cotrimoxazole drugs</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Are the DBS materials Regularly in stock</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Regular collection of DBS samples</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Documentation of results, follow up and growth monitoring for babies</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Are parents given &amp; explained the next appointment</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Does the facility has transportation system for the DBS Samples to the laboratories</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Is the sample transported in a weekly basis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>How many times in a week is the sample transported</td>
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</tr>
<tr>
<td>15</td>
<td>How long does it take to return the DBS results to the health facility</td>
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</tr>
<tr>
<td>16</td>
<td>Do mothers come back for the DBS results</td>
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</tr>
<tr>
<td>17</td>
<td>Are there any psychosocial support group for HIV positive young mothers?</td>
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## Appendix 5: Health Facility Data

<table>
<thead>
<tr>
<th>No.</th>
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<th>Kitgum District</th>
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<td>Patiko HC III</td>
<td>Bobi HC III</td>
<td>Odek HC III</td>
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<tr>
<td>1</td>
<td>Availability of EID Services</td>
<td>Yes</td>
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<tr>
<td>2</td>
<td>Availability of Trained Health Workers on EID Services</td>
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<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Number of female HCW trained in EID</td>
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<td>4</td>
</tr>
<tr>
<td></td>
<td>Number of Male HCW trained in EID</td>
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<td>2</td>
</tr>
<tr>
<td>3</td>
<td>Number of HCWs performing EID</td>
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<td>3</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>Number of Days per week EID Clinic is conducted</td>
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<td>5</td>
</tr>
<tr>
<td>5</td>
<td>Facility have Child Record Cards</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>6</td>
<td>Is the Exposure status of children recorded in Child Record Cards</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>7</td>
<td>Number of exposed babies currently accessing EID*</td>
<td>86</td>
<td>120</td>
<td>36</td>
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<td></td>
<td>Number of Exposed infants enrolled for the last 18 months*</td>
<td>72</td>
<td>162</td>
<td>38</td>
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<tr>
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<td>Number of exposed infants lost in the continuum of care for the last 18 months*</td>
<td>1</td>
<td>1</td>
<td>0</td>
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<tr>
<td></td>
<td>Number of HIV exposed babies referred to ART in the last 18 months*</td>
<td>8</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Number of exposed babies discharged in the last 18 months*</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>8</td>
<td>Availability of Job Aids i.e. guidelines, posters, etc. on EID**</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Are these Job aids in use**</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Availability of Dry Blood Samples (DBS) materials</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>10</td>
<td>Regular availability of DBS materials in stock</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
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<td></td>
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<td>---</td>
<td>---</td>
</tr>
<tr>
<td>11</td>
<td>Documentation of results, follow up and growth monitoring</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>12</td>
<td>Are parents given &amp; explained the next appointment</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>13</td>
<td>Availability of transportation system for the DBS Samples</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>14</td>
<td>Is the sample transported in a weekly basis</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>How many times in a week is the sample transported*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 month</td>
<td>1 month</td>
<td>2 weeks</td>
<td>1 month</td>
</tr>
<tr>
<td>15</td>
<td>Time it takes to return the DBS results to the health facility**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 month</td>
<td>1 month</td>
<td>2 weeks</td>
<td>1 month</td>
</tr>
<tr>
<td>16</td>
<td>Do mothers come back for the DBS results</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>17</td>
<td>Are there any psychosocial support groups for HIV positive young mothers?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

* In all health centres visited, HIV Exposed Infants registers' were not updated, there is likelihood that the data generated was inaccurate
**Results are presented as reported by the respective health workers at the facilities

Barriers faced by HIV Positive Women and/or partners to return their Exposed Infants to access HIV/AIDS services in Northern Uganda
Appendix 6: Field Photographs

Some of the Charts with Information On Option B+ pinned in different Health facilities
Barriers faced by HIV Positive Women and/or partners to return their Exposed Infants to access HIV/AIDS services in Northern Uganda
Feeding Algorithm for HIV-Exposed Infants

HIV-Positive Mother

What is the infant's HIV status?
- Positive
- Negative
- Unknown
- Unborn

HIV-Negative or Unknown or Unborn

How old is the baby?

< 6 months or unborn

Replacement feeding
- Counsel on use of infant formula & fresh animal milk
- Do NOT mixed feed
- If mother is currently breastfeeding, she should wean (Early Weaning)

If AFASS

HIV Positive

Breastfeed up to 1 year or more
- Exclusive breastfeeding until 6 months
- Breastfeeding and complementary feeding after 6 months
- Explain that breastfeeding protects baby from other infections

6 months or older

Exclusive breastfeeding
- Counsel on exclusive breastfeeding until 6 months
- Do NOT mixed feed
- If mother is currently breastfeeding, consider re-lactating

If not AFASS

Accelerated Weaning
- Counsel to wean from breastfeeding over the course of 2 weeks
- Give at least 2 cups of animal milk & introduce complementary foods

Late weaning
- Counsel to continue breastfeeding but also introduce nutritional complementary foods

AFASS Criteria for Replacement Feeding

Acceptable
- Mother does not have significant cultural or social barriers to replacement feeding

Feasible
- Mother has adequate knowledge, skills, resources, and support to correctly mix formula or milk, and feed the infant up to 12 times in 24 hours

Affordable
- Mother and family can pay the costs of replacement feeding (fuel, clean water, and all ingredients) without compromising the health and nutrition of the family

Sustainable
- Mother has access to a continuous and uninterrupted supply of all ingredients needed for safe replacement feeding as long as the infant needs it

Safe
- Replacement feeds are correctly and hygienically stored, prepared, and fed in nutritionally adequate amounts. Infant is fed by clean hands and preferably by cup

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HIV positive young mothers Interviewed

A pregnant HIV positive young mother interviewed
Male participants in a FGD at Labongogali HC III, Amuru district
Happy mother with her recently graduated HIV negative child