Effectiveness of Mama’s Club ASK intervention strategies
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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### ABBREVIATIONS AND ACRONYMS

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<th>Description</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<tr>
<td>ANC</td>
<td>Antenatal Care</td>
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<td>ART</td>
<td>Anti-Retroviral Therapy</td>
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<td>ASK</td>
<td>Access, Services and Knowledge</td>
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<td>AVSI</td>
<td>International Service Volunteers Association</td>
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<td>CEDAW</td>
<td>Convention on the Elimination of all forms of Discrimination against Women</td>
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<td>DHO</td>
<td>Director of Health Officer</td>
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<td>EID</td>
<td>Early Infant Diagnosis</td>
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<td>EMTCT</td>
<td>Elimination of Mother to Child Transmission</td>
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<td>FGDS</td>
<td>Focus Group Discussions</td>
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<td>FP</td>
<td>Family Planning</td>
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<td>FSG</td>
<td>Family Support Group</td>
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<tr>
<td>HC</td>
<td>Health Centre</td>
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<tr>
<td>HCT</td>
<td>HIV Counselling and Testing</td>
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<tr>
<td>HIV</td>
<td>Human Immune Deficiency Virus</td>
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<tr>
<td>ICPD</td>
<td>International Conference on Population and Development</td>
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<td>IGAs</td>
<td>Income Generating Activities</td>
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<td>KII</td>
<td>Key Informant Interviews</td>
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<tr>
<td>LC</td>
<td>Local Council</td>
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<tr>
<td>LG</td>
<td>Local Government</td>
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<tr>
<td>NGO</td>
<td>Non-governmental Organisation</td>
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<tr>
<td>PCR</td>
<td>Polymerase Chain Reaction</td>
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<td>PHC</td>
<td>Primary Health Care</td>
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<tr>
<td>PHWA</td>
<td>Person Living with AIDS</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
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<td>PNC</td>
<td>Post-Natal Care</td>
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<td>RHU</td>
<td>Reproductive Health Uganda</td>
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<tr>
<td>SRHR</td>
<td>Sexual and Reproductive Health Rights</td>
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<tr>
<td>STD</td>
<td>Sexually Transmitted Diseases</td>
</tr>
<tr>
<td>TOR</td>
<td>Terms of Reference</td>
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<tr>
<td>VHT</td>
<td>Village Health Team</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<td>WLHIV</td>
<td>Women Living with HIV</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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EXECUTIVE SUMMARY

As part of the Access, Services and Knowledge (ASK) programme in Uganda, Mama’s Club contributes to: increasing the number of young HIV+ pregnant women (<25 years) receiving prevention of mother to child transmission (PMTCT) in Northern Uganda, and: increasing the number of young HIV+ pregnant women receiving antenatal care in the targeted health facilities. This is implemented through several activities; including rolling out the Mentor Mothers approach and providing support for and oversight on SRH and HIV care of young women living with HIV. Mama’s Club also builds the capacity of service providers to improve the quality of HIV and SRH services and address cases of stigma and rights violations. These activities are designed to integrate prevention of rights violations, in particular violations of the sexual and reproductive health and rights of young women living with HIV in the context of PMTCT and maternal health services.

This study was conducted to document, analyse and evaluate the approaches, processes and practices employed by Mama’s Club in the Access, Services and Knowledge (ASK) programme that contribute successfully to identifying, addressing, and preventing rights violations of the sexual and reproductive health and rights (SRHR) of young women living with HIV (<25 years) in Northern Uganda, to enable replication and inform future programming developments.

Information gathering involved a global desk review of the related literature, field Data Collection was done in the targeted districts of Gulu, Kitgum and Amuru. This involved conducting Focus Group Discussions with 78 beneficiaries and Key Informants Interviews with 29 service providers and 2 district health officers. From the study, the following findings were revealed;

1. Mama’s Club’s activities have helped beneficiaries to identify several SRHR; but the challenge still remains in addressing these violations. The major violations identified included:
   - Health facility-based SRHR violations such as shortage of condoms, denial of access to health care by the health workers, lack of confidentiality and failure to respect human rights by the health workers.
   - Community-Based SRHR Violations such as stigma and discrimination in existence in the community - This was the most prevalent form of SRHR violation faced by the HIV positive young women, limited access to safe sexual intercourse by the spouses/husbands, violation of the right to decide on the number of children one should have, domestic violence - especially among discordant couples, and divorce and separation of spouses due to fear of taking responsibility for their positive status.

2. Mama’s Club integrates SRHR into its activities. The activities and approaches are based on the identified needs of HIV positive youths; who are in their reproductive age, sexually active, and would like to bear children. These approaches include;
   - Facilitating and building the capacity of mentor mother/father to help in coordinating PMTCT, SRHR and FSG activities at health facilities and in communities;
• Conducting monthly Family Support Group (FSG) meetings for HIV positive young mothers;
• Organising youth Corners and Days;
• Facilitating mentor mothers to conduct referrals and home visits;
• Engaging men (spouses) to participate in FSG activities; and,
• Guided the beneficiaries to establish Savings Schemes.

3. Reports from the health workers at the health facility indicate Mama’s Club has been influential in changing the attitudes, beliefs and practices of HIV positive young mothers in attending to PMTCT and ANC services and as a result there has been an increased consumption of HCT and EMTCT services amongst the HIV positive mothers. Available data from the health facilities surveyed indicated that there has been an increased consumption of PMTCT services amongst the HIV positive young mothers by 1.7% between 2013 and 2014 (1,066 to 1,800 clients) in the health facilities where Mama’s Club operates. It also shows a 2.9% increase in family planning consultations and a 3% increase in STI screening in one year. This is partly attributed to the sensitisation of the young mothers by Mama’s Club. Health workers also indicated that the increased uptake of PMTCT services is also partly attributed to the positive reception accorded by the health workers and Village Health Teams (VHTs) towards the mothers.

The project implementation has however met some challenges. These include: inadequate health workers to handle the activities of the FSGs and their daily routine at the health facility – to which Mama’s Club has little or no influence at all; high poverty levels amongst the beneficiaries which sometimes makes them unable to transport themselves to the health facility for the FSG activities; men are not yet actively engaged and thus do not support their HIV positives wives to acquire psychosocial support.

The study recommends that in order to achieve the targets and for future replication of the project, Mama’s Club and its partners should;

a) Economically empower these HIV positive mothers;
b) Engage men to participate in FSG and other PMTCT activities;
c) Conduct more counselling;
d) Increase engagement of health officials and service providers;
e) Provide seed funds into the groups’ savings schemes;
f) Link health services to legal aid and paralegal service providers; and,
g) Provide transport means such as bicycles and increased monthly incentives to mentor mothers.
SECTION 1: INTRODUCTION

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). The Access, Services and Knowledge (ASK) programme 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!, 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 II and Akuma Label HC III in Kitgum; and, Pabo HC III, Labo HC III, Atiak HC IV and Kaladina 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 antenatal 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 with service providers to improve the quality of HIV and SRH services and address cases of stigma and rights violations. It 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 forum for follow-up of the EMTCT services to the HIV positive young mothers.
SECTION 2: CONTEXT AND BACKGROUND

The linking of HIV with SRHR was already done by the Programme of Action of the landmark International Conference on Population and Development (ICPD) in Cairo in 1994. This is one of the pillars of Dutch International Cooperation, and the focus of various high-level political commitments and health systems’ strengthening efforts.

It should be noted that 90% of HIV infections are sexually transmitted (WHO, 2006). Sexually Transmitted Infections (STIs) increase the risk of acquiring or transmitting HIV, and lack of sexual and reproductive well-being and HIV share root causes. Significant progress has been achieved in the HIV response world over. Between 2001 and 2011, prevalence of HIV fell by nearly 27% among young people aged 15-24. Nevertheless, today, young people account for 40% of new infections among adults. Nearly half of those in need of HIV care and treatment are in low income-countries, and they still lack access to antiretroviral drugs, and programs for the prevention of vertical transmission of HIV. In Uganda, overall, 3.7% of young women and men age 15-24 are HIV-positive.\(^1\) HIV prevalence among young women is markedly higher than among young men, except for youth age 15-17 where there is nearly no difference in HIV prevalence between women and men.

Linking HIV and Sexual and Reproductive Health (SRH)\(^2\) refers to joint work in the HIV and SRH sectors at various levels, including policy, advocacy, programming and operations.\(^3\) The integration of HIV and SRH activities has tremendous benefits ranging from efficiency and effective use of the limited health resources to improve health service delivery to increased uptake, follow-up and retention of clients in the HIV and AIDS treatment programmes.

2.1 Aim and Objectives of the Study

The major aim of this study is to document, analyse and evaluate the approaches, processes and practices employed by Mama’s Club in the ASK programme that contribute successfully to identifying, addressing, and preventing rights violations of the sexual and reproductive health and rights (SRHR) of young women living with HIV (<25 years) in Northern Uganda, to enable replication and inform future programming developments.

The specific objectives of the assignment are as follows;

- Documenting in explicit detail the approaches, processes, and practices that contribute to identifying, addressing and/or preventing rights violations of the sexual and reproductive health and rights of young women living with HIV (<25 years) in Northern Uganda;
- Document the successes and challenges and their accompanying remedies to achieving the desired outcomes;

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\(^1\) Uganda AIDS Indicator Survey (UAIS), 2011

\(^2\) SRH programmes and policies include, but are not restricted to, services for family planning; infertility services; maternal and newborn health; prevention of unsafe abortion and post-abortion care; prevention of mother-to-child transmission of HIV; sexually transmitted infections, including infection from HIV, reproductive tract infections, cervical cancer and other gynaecological morbidities; promotion of sexual health, including sexuality counselling, and prevention and management of gender-based violence. See [www.srhhivlinkages.org/uploads/docs/articles/linkagesdefinitions_2010_en.pdf](http://www.srhhivlinkages.org/uploads/docs/articles/linkagesdefinitions_2010_en.pdf)

\(^3\) Intensify linkages between HIV and sexual and reproductive health and rights for maximum impact: Stop AIDS Alliance policy position July 2012.
• Relate approaches, processes, and practices to the works that have been done by others to identify, address, and/or prevent successfully SRHR violations of young women living with SRHR in Northern Uganda;
• Relate the approaches, processes, and practices to changes in uptake or demand of ANC and PMTCT especially EMTCT services; and,
• Identify if and how the successful approaches, processes and practice can be replicated by others.

2.2 Study Area
The assignment was carried out within eight (8) purposively sampled out of the 16 health facilities, in the three districts of Northern Uganda (Gulu, Kitgum and Amuru), where the ASK Programme is currently being implemented by Mama’s Club. These facilities are Atiak HC IV and Pabbo HC III in Amuru district; Patiko HC III, Bobi HC III and Layibi-Techo HC III in Gulu district; and, Namukora HC III, Kitgum-Matidi HC III and Omia-Anyima HC III in Kitgum district.

2.2.1 Background Characteristics of 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).

a) Amuru
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 IIIIs, 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, simum, beans, peas and sunflower as the major traditional food crops (Amuru District Council Score-Card Report 2011/2012).

b) 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.

c) Kitgum
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 Non-Government Organizations. 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).

2.3 Limitations of the Study

The major limitation to the study was the language barrier especially in the FGDs where the participants would only speak in their local language – Acholi, to which the researcher was very pitiable. However, in such circumstances, the researcher sought assistance from mentor mothers and fathers, who would comprehend what is asked in English, interpret it to the respondents and provide the feedback.
SECTION 3: STUDY METHODOLOGY AND APPROACH

a) Document Review
The study involved in conducting a global desk review of the related literature to collect data and information on existing successful approaches, processes and practices for identifying, addressing and/or preventing SRHR violations of women living with HIV. This also involved reviewing Mama’s Club documents on ASK-specific activities and related current activities. This initial review of literature helped further in understanding the ASK programme, designing and updating the study framework, and refining the data collection tools.

b) Data Collection
The Researcher, with the help of the Mama’s Club Field staff, sampled out the health facilities in the three (3) districts from which field data collection was conducted. These field-based consultations helped to understand the process of implementing the ASK programme, key success factors, challenges and remedies, lessons learned and recommendations for future adoption and replication. Information was gathered through Key Informants Interviews and Focus Group Discussions (FGDs) with 109 respondents (see annex 6 and section 4.1 for an overview of the respondents). The Key Informants included the district health officers, the health workers at the health facilities (these included only those who are actively involved in Mama’s Clubs’ activities), and Mentor Mothers/Fathers. The FGDs comprised of 8 to 10 members from the project beneficiaries, and one FGD was conducted at every health facility, making a total of eight (8) FGDs in all. These interviews were guided by topic guides (see annex 2).

c) Data Analysis and Report Writing
The qualitative responses collected were complemented by the literature and treated as follows:

i) Textual data was explored using content analysis. It was read and re-read by the research analyst in order to identify emerging themes from the responses;
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 also selected and included in this report 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.

The above actions on data helped in conducting a confirmatory factor analysis to determine if there is a relationship between the approaches, processes, and practices by Mama’s Club under the ASK programme to the changes in uptake or demand of PMTCT services in the targeted health facilities; relate the identified approaches, processes and practices to the works that have been done by other stakeholders in identifying, addressing and/or successfully preventing SRHR violations of young women living with HIV; and, Identify if the successful approaches, processes and practice can be replicated in new and emerging environments. This report presents the findings from the research and identifies key operational considerations to guide Mama’s Club and partners in the ASK alliance for better programming in line with the ASK project goal.
SECTION 4: FINDINGS AND ANALYSIS

4.1 Categorisation of Respondents

The respondents were categorised to portray their representation and status in this study. In this category, 38% of the respondents were from Kitgum, 37% from Gulu and Amuru was less represented with only 25%. This was particularly because only two health facilities were sampled from Amuru, whereas the rest of the districts each had three health facilities sampled. Women were represented most with 72% as compared to men at 28%. This is particularly because men are few in the FSG as compared to women, an indication of lack of male involvement in issues of health in the home. Amongst the respondents the FSG members, since were the major targets, represented a large section of the respondents (over 72 percent), and followed by the mentor mothers at 8%. This is mainly because at the health centres and in the communities, it’s mainly the mentors who are Mama’s Club contact persons, and therefore are more knowledgeable about the programme, than any other service provider. They do mobilisation, organise, and conduct continuous follow up on the HIV positive young mothers in the communities (see Annex 6).

4.3 Knowledge about the ASK Programme

The study evoked the respondents’ knowledge and understanding of the ASK programme. It was found out that the programme which is popularly known as Mama’s Club is generally known to the beneficiaries, the health staffs and the district health officials. The project beneficiaries, unlike the health staffs and district officials, don’t have particular knowledge about the ASK programme but are aware of Mama’s Club and the activities the organisations is engaged in. Respondents were asked to give their own understanding of the programme, and some of the sampled out responses included;

“Mama’s Club targets a group of young mothers living with HIV of ages 18-23 years. These used to live in fear of coming to the Health Centre but after the intervention by Mama’s Club in October 2013 and mass sensitisation, the group has grown to a large number and mobilisation is continuous” Nursing Assistant, Layibi-Techo HC III, Gulu district

“Mama’s Club is an organisation involving HIV positive young mothers and fathers between the ages of 18-28 years”. Woman, Focus Group Discussion, Namokora HC III, Kitgum district

“Mama’s Club is a psychosocial support group for young mothers living with HIV below 25 years.” –Mentor mother, Layibi-Techo HC III, Gulu district

“Mama’s Club is an NGO partnering with government and its area of concern is HIV positive young mothers. These mothers are educated on Reproductive Health issues and also given psychosocial support.”– Health Worker, Atiak HC III, Gulu district

“An organisation supporting the activities of the health centre especially Family Support Groups for young mothers between 14-25 years, pregnant mothers and breast feeding mothers who are HIV positive.”–Midwife Namokora HC III, Kitgum district
“Mama’s Club is an organisation that deals with HIV positive mothers from 15-25 years. The mothers can be pregnant, lactating alongside their spouses and the children.” She went on to say that “Some are not pregnant but are HIV positive.” She revealed that, “these ages were selected because they fear to disclose their sero-status and yet they need a lot of counselling and guidance and yet they are at a high risk of contracting the HIV virus and passing on to their babies.” – Nursing Assistant, Kitgum-Matidi HC III, Kitgum district

The above responses indicate the people’s knowledge and understanding of Mama’s Club. Mama’s Club has succeeded in creating awareness amongst the beneficiaries about who they are and what they do. The beneficiaries are aware of the kind of people targeted, though they are all not sure of the exact targeted age, their roles and responsibilities in the programme. Under the ASK program, Mama’s Club targets HIV positive mothers who are 24 years and below. It was because of this age misinterpretation that sometimes mothers above 24 years join the group. This was also partly attributed to lack of particular kind of services for them in their communities. They are yearning and thirsty for the similar services and information but they cannot get them. And therefore they seize the available opportunity of joining the young mothers’ groups.

It should be noted, that Mama’s Club operations in this area is only under the ASK programme. The respondents were therefore not in position to compare it with the previous activities of Mama’s Club – that have never existed in their communities.

4.4 Knowledge about the Violations of SRHR

Reproductive Rights are human rights recognised by the International Conference on Population and Development – ICPD – (Cairo, 1994) and the Fourth World Conference on Women (Beijing, 1995). The UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) recognises that rights to reproductive and sexual health include the right to life, liberty and security; the right to health care and information, and the right to non-discrimination in the allocation of resources to health services and in their availability and accessibility.

In this study SRHR is understood as a concept of human rights applied to Sexuality and Reproduction. It is a combination of four fields that in some contexts are more or less distinct from each other, but less so or not at all in other contexts. These four fields are sexual health, sexual rights, reproductive health and reproductive rights. In the concept of SRHR, these four fields are treated as separate but inherently intertwined.

According to World Health Organisation (WHO), Sexual Health is defined as a state of physical, mental and social well-being in relation to sexuality. It includes healthy sexual development, equitable and responsible relationships and sexual fulfilment, freedom from illness, disease, disability, violence and other harmful practices related to sexuality. Sexual rights are defined as the rights of all people to decide freely and responsibly on all aspects of their sexuality, including protecting and promoting their sexual health, be free from discrimination, coercion or violence in their sexual lives and in all sexual decisions, expect and demand equality, full consent, and mutual respect and shared responsibility in sexual relationships. It also includes the right to say ‘no’ to sex if one does not want it.
Reproductive health is defined as the complete physical, mental and social well-being in all matters related to the reproductive system including a satisfying and safe sex life, capacity to have children and, freedom to decide if, when and how often to do so. Reproductive rights is defined here as the rights of couples and individuals to decide freely and responsibly the number and spacing of their children, to have the information, education and means to do so, attain the highest standards of sexual and reproductive health and, make decisions about reproduction free of discrimination, coercion and violence.

For one to protect his/her SRHR, one must be aware of what he/she is exactly protecting. The research therefore went ahead and tested the knowledge of the respondents of their SRHR and the existence of the violations of these rights within their communities in Northern Uganda. Based on the findings, it appears respondents were well informed about the issues surrounding SRHR. However the problem lays in the inability to exercise those rights.

One HIV positive lady in a FGD in Namokora HC III illustrates the challenges they faced when attempting to assert their right to safe sex;

“Yes, we know our right to safe sex. But with our husbands, we are not able to deny them sexual intercourse, even if you feel you don’t want to engage into the act. Even if you are tired or sick, your husband can insist.” Woman, Focus Group Discussion, Namokora HC III, Kitgum

The Respondents went to reveal several violations of SRHR that exist within their Respective communities. These have no specific locations, but were equally mentioned in all districts. These districts were affected by the Kony rebels in the 1990’s and therefore they have similar social, economic and political characteristics and challenges. These included;

a) Stigma and discrimination is in existence in the community. This was the most prevalent form of SRHR violation faced by the HIV positive young women in all the three districts. This is apparent with people who haven’t received enough sensitisation, counselling and guidance by competent health workers. This was revealed as the main reason for the low attendance to HCT services at the health centre. People still fear to be noticed picking ARVs or frequenting treatment points because they will be considered to be HIV positive and hence stigmatised.

“The community breeds stigma by pointing fingers and judging the HIV positive people and blaming them for their infection.” Woman, 22, FGD participant at Patiko HC III, Gulu

Another FGD participant at Kitgum-Matidi lamented that;

“Once the member of the community members realises that you’re HIV positive, they can’t allow you to get involved sexually with any other man in the community. If they realised that there is a relationship going on, they have to make sure that you breakup.” Woman, Namokora HC III, Kitgum
In an FGD at Bobi HC III, women revealed that HIV positive people are branded names like ‘Lye Mawoto’ which means ‘Walking Coffin’ or ‘Dead Alive’ due to their HIV status. Some community members see the HIV positive people as almost dead ones.

Even though sexual and reproductive health services for people with HIV may exist at the health facilities, stigma and discrimination in the communities may discourage people with HIV from using them (EngenderHealth, et. al (2009).

b) **Limited access to safe sexual intercourse:** With the absence of female condoms in the area, young women to fear picking male condoms instead, because they won’t be able to convince their husbands/spouses to use them, and also risk being pointed at as being sexual perverts. Women also revealed that their husbands discourage them from using other contraceptives such as pills, even though they are available at the facilities. They noted that their husbands base their argument on the associated side effects and the desire for more children.

One FGD participant revealed that,

“*My husband cannot accept to use condoms because I am his married wife.*”

Another woman revealed that;

“*Most husbands will insist on not using condoms because we are their wives. They also don’t want one to use Pills or any other birth control method. We end up producing so many children who are poorly spaced, and moreover not well catered for.*” - HIV positive at Namokora HC III, Focus Group Discussion.

High-quality programmes and services that positively address sexuality and promote the sexual health of women living with HIV/AIDS are essential for women living with HIV/AIDS to have responsible, safe and satisfying sexual lives, especially in countries severely affected by HIV (WHO, 2006). Interventions to address the public health crisis stemming from unsafe sexual behaviour must be based on fundamental values and principles grounded in human rights; incorporate emotional, psychological and cultural factors; and address both the pleasure and safety aspects of sexuality and sexual health.

c) **Divorce and separation of spouses, and fear to take responsibilities due to HIV infection.**

“*My husband dropped his responsibilities after realising that he was HIV positive. He does no longer take care of me and our children. He spends his money now on drinking and other women, with a saying that ‘I have to infect other people since I didn’t infect myself’. *” A 24 year old HIV positive mother of four (4), Bobi HC III.

HIV positive people living with HIV need psychological and social support to make informed decisions about their health and to tackle stigma and discrimination. From a sexual and reproductive health perspective, such support might address pressure from families and communities to have, or not to have, children; violence and fear of violence; rights violations such as widow inheritance; negotiation of safer sex; and worries around disclosure of HIV status to partners, family members, and the wider community (EngenderHealth, et. al (2009). The separation of couples implies the denial to such support from the partner, yet programmes
rarely address these needs effectively. Several programmes look at psychosocial support as a ‘soft’ and low-priority service, or because health care workers lack the training and support they need to provide unbiased, non-judgmental advice (EngenderHealth, et. al (2009)). Also Gender-based violence makes women and girls vulnerable to HIV infection in the first place, and perceived and actual threats of abuse may prevent women from using contraceptives and condoms or from accessing health care and counselling services. Women living with HIV are at even greater risk of violence, which can also result in unwanted pregnancies and prevent women from using VCT and health care services (Duvvury, N., Prasad, N. & Kishore N. (2006)).

d) **Violation of the right to decide on the number of children** one should have. Sometimes husbands reject the use of Family Planning on grounds that they have not yet produced a boy child. In the African tradition, which is still much entrenched in Northern Uganda ethnicities, a boy child is considered as the future leader and heir to the family fortunes, who will be able to take it forward. Married women who have given birth to only female children found it hard to make a choice on when to stop producing and how to manage child spacing.

A midwife at Bobi Health Centre III revealed that,

“Sometimes women come here and they have produced over five children, and if these children are all girls, the mother’s facial expression is always disconsolate when she is told that her sixth child is a girl too. One time here the woman had given up on breastfeeding her newly-born baby girl. She wanted to starve the baby to death because of the fear from wrath of the husband who always wanted a boy, instead. She suspected that the husband would force her to have more children, yet to her she had given birth to six and they were enough. So it is still a big problem, in the communities here women cannot choose on when to stop producing.” Mid-wife, Bobi Health Centre III, Gulu district

People living with HIV may want to avoid pregnancy for a variety of reasons: They may fear that the child will become infected with HIV, already have the number of children they desire, want to avoid infection with another strain of HIV, or need to focus their resources on maintaining the health and wellbeing of themselves and their families. However, they may also be forced to cope with community and family pressures to have children, partner opposition to contraceptive use, and stigma associated with condom use (EngenderHealth, et. al (2009)).

e) **Denial of access to health care and failure to respect human rights by the health workers**: This has been common in Kitgum district, especially in two health centres. The HIV positive young mothers complained of the failure by the health workers to provide them with the required information on family planning; such as a range of contraceptive services that are available and their side-effects to a person living with HIV and on ARVs. When asked what these mothers think would be the reason, their thought was that perhaps the health workers think that since they are HIV positive, they are no longer interested in conceiving and producing children.
The young mothers also complained of the uncaring attitudes of the health workers, and sometimes not given the treatment they require. This was common in rural health centres that are characterised with huge number of clients. One woman, an FGD member revealed that,

“During the birth of my second child in 2012, at Pajimo HC III, I went to the facility while I was feeling labour pains and I was assigned to specific midwife who started abusing me. When she read over my maternity card and found out that I was HIV positive, she even went on to shout louder to whoever was there to listen, ‘why are you giving birth if you know your status’ I was pissed off and if I wasn’t in pain at the moment, I would have fought her for insulting me in the public. I hated that health facility that I have never gone back to that facility since then.”

Woman at Omiya-Anyima HC III, (FGD)

When contacted, the health workers attributed this to the high ratio of medical workers to patients. For instance, in Kitgum district, Omiya Anyima HC III, a medical worker noted that, on a specific clinic day, one health worker in this HIV section may have to attend to over 50 clients. By the end of the day, one is exhausted to adequately attend to all the patients. The health workers also mentioned the stock out of drugs, especially ARVs, and some occupational hazards and risks that may be involved that may deter them from providing necessary treatment.

Although the occupational hazards and risk of HIV infection is low, health care workers and staff may resist providing services to people living with HIV out of fear of infection. Some workers perceive procedures like Intra-Uterine Device (IUD) insertion, vaginal examination, delivery, and examination of ulcerative STIs to be very risky, even with gloves on (EngenderHealth, et. al (2009). They sometimes deny labour assistance to pregnant women with HIV, test pregnant women and people suspected of risk behaviours without consent, give test results to family members rather than to people with HIV themselves, otherwise violate privacy and confidentiality, pressure HIV-positive women to undergo sterilisation or abortion, or fail to inform women living with HIV about all their options regarding contraceptives or infant feeding (EngenderHealth, et. al (2009). This calls for concerted efforts with the MoH to educate or remind the health workers about the National Policy for Occupational Safety and Health for the Health Services Sector (2007) and its accompanying operationalisation guidelines (2008). These give a comprehensive coverage on the management of HIV and AIDS as a workplace hazard within the health sector as well as some other common hazards such as tuberculosis, hepatitis and viral haemorrhagic fevers.

4.5 Best Approaches, processes, and practices that contribute to identifying, addressing and or preventing rights violations of the SRHR of young women living with HIV

The Respondents were able to reveal several approaches, processes and practices applied by Mamas Club to ensure that they identify, address and/or prevent rights violations of SRHR in the community. With the use of these unique approaches, Mama’s Club links SRHR into its activities in order to ensure the protection of the rights of the HIV positive young mothers. These best practices and approaches are linked to specific SRHR violations that are identified above. These approaches, processes and practices include;
1) **Facilitating and building the capacity of mentor mother/father to help in managing PMTCT and SRHR activities at health facilities**

The shortage of doctors and nurses in local health centres makes it difficult for women, children, and families to access the medical care they need. These health workers often do not have the time or practical experiences to adequately counsel young mothers on preventing transmission of HIV to infants and address issues of SRHR. This necessitated the need to identify HIV positive young mothers who have successfully gone through the PMTCT and SRH experience to voluntarily support health education of pregnant women; conduct follow-up of HIV+ pregnant and lactating mothers, their babies and partners; support intra- and inter-facility linkages and referrals.

These Mentor mothers therefore, do not provide direct medical care or treatment, nor do they replace the roles and responsibilities of clinical staff. They just play a task-shifting role to enhance the education and psychosocial support component of PMTCT and SRHR. They provide essential health education and psychosocial support to HIV positive pregnant young women and new mothers on how they can prevent the transmission of HIV to their babies and stay healthy. Mentor mothers also provide emotional and psychosocial support to their clients’ partners and children and give the families an opportunity to speak openly, receive information and help to ensure that both mother and child are healthy.

Mentor mothers’ ties to the community and first-hand knowledge of HIV and SRHR makes them highly effective FSG facilitators. Young mothers are more likely to trust other mothers in their community who are of similar HIV status and have gone through quite similar experiences. Deploying them as frontline healthcare workers creates stronger health systems and linkages between the health facilities and the communities.

Mama’s Club trains and supports young mothers and fathers living with HIV to be mentor mothers/fathers. The organisation trained 45 mentors (34 mothers and 11 fathers) in 2014 and 90 mentors (72 mothers and 18 fathers) in 2013. They are trained upon recruitment and given continuous support by Mama’s Club field officers. These trainings are on several topics such as conducting the whole process of referrals and home visits, including filling the referral forms; mobilising and coordinating FSG members for FSG meetings; giving support to the health workers during the ART days; and PMTCT and SRHR topics, among others. The organisation also facilitates them with tools to act as a liaison to the health system and to health care providers and provide information on maternal health, PMTCT, Infant care, and SRHR. They also advised on how to encourage expectant mothers to attend antenatal clinics and services for the PMTCT. This has helped to improve on access to health care services by the clients, but also reduce the number of clients that have to be attended to by the health care worker, since the mentor mother/father provides some of the information that may be required by the client. Consequently,
the mentor mothers/fathers help to curb down on the violation of denial of access to services by the health care workers by the clients.

Working together with the mentor mothers/fathers and Village Health Teams (VHTs), Mama’s Club has been very effective in identifying and reducing violations against SRHR. The Mentor Mothers are able to identify people whose rights are violated, talk to them and refer the cases either to the health facilities or to the responsible authorities. All this is under strict confidentiality, which gives the victim the self-confidence to seek for redress and countering the violence. They are therefore able to help the victims of SRHR violations exercise their rights. During the process, mentor mothers engage in in-depth interactions and discussions on a range of PMTCT and SRHR topics and services such as disclosure, ARVs for prophylaxis, PMTCT-EID testing services, family planning and appropriate infant feeding options, Sexual and Reproductive Rights, stigma and discrimination among others.

2) Engagement of health Service Providers to provide SRHR services

Mama’s Club also works with service providers to improve the quality of HIV and SRH services and address cases of stigma and rights violations. Mama’s club held a dialogue session and an orientation workshop with health care providers in every health centre on services and quality of care during the project inception. At every health centre, there is at least one health worker who acts the focal point person for Mama’s Club activities. But also through the field officer and routine visits by Mama’s Club Staff from the headquarters, in every district of operation, the organisation carries out backstopping activities to always refresh service providers’ understanding and implementation of the project within the health centres and communities. The organisation targets to involve 96 service providers in the three implementation districts of Amuru, Gulu and Kitgum. The service providers help to provide youth-friendly service to the youths in groups and individual basis; train mentor mothers on the provision of SRHR and EID services to the group members; and also dialogue with the youths.

According to the responses from the FGD and Key Informants Interviews the ASK programme adopted the use of health facilities’ approach of the FSGs and adjusted it to meet the objectives of the programme. Because of the engagement from Mama’s Club, the health workers have been able to identify the young mothers that come for ANC and enrolled into the PMTCT-EID strengthening process (including enrolment into pre-ART care), and then refer all young women that have tested HIV positive to the Mentor Mothers for on-going psychosocial support. During this time the young mother is engaged by the Mentor Mothers in in-depth interactions and discussions on a range of PMTCT and SRHR topics and services such as disclosure, ARVs for prophylaxis, PMTCT-EID testing services, family planning and appropriate infant feeding options.

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4 The VHTs are the first contact persons in the village or rural area on matters of health. They advise and refer patients to the health centres. They work as volunteers and move on bicycles but carry no medicine.
During this process client consent, contact information and needs for community follow-ups are obtained. The Mentor Mother then introduces the young mother to the benefits of being a dedicated member to a Family Support Group which includes members of the community with whom they share the sero-status and age range (14-25 years). In these groups the service providers arrange forums where young mothers and their partners receive psychosocial support, and share experiences and challenges with colleagues. In order to minimize transport costs, Mama’s Club engaged health workers to synchronize these meetings with the ART clinic days so as to ensure maximum health care benefits for the clients.

3) Conducting Family Support Group Meetings for HIV positive young mothers

Under this approach, the beneficiaries are organised into the Family Support Group (FSG) meetings. The general concept of the FSG group was adopted by the Ministry of Health to bring together all HIV positive people, encourage disclosure, share experiences and provides psychosocial support to the members. Through these FSGs, HIV positive pregnant mothers are supported to cope with their status and disclosure to their spouses and children. Mama’s Club picked the concept and modified it to accommodate and give special attention to the HIV positive young mothers and their spouses. It was revealed that under Mama’s Club, the FSG is however arranged in a unique way, it has an age boundary, for only HIV positive mothers between the ages 14-25 years. These mothers include breastfeeding/lactating mothers, their children and spouses, and pregnant/expectant mothers also with their spouses. In these FSG meeting, Mama’s Club links HIV and SRHR sensitisations and awareness to promote the SRHR of the youths. In the FSG, spouses to the HIV positive young mothers are also encouraged to engage in HIV and SRHR promotion, and all members are fully informed and able to make their own health-related decisions.

One health worker noted that,

“The age was limited to 24 years. This was because in the general FSG meeting, these youths are usually not comfortable with revealing their experiences with older people, they prefer to meet among themselves and discuss their challenges. This is a unique idea and it helps us handle them more easily than it was before, they are free with us and generally with the health centre.”

Health worker, Layibi Techo HCIII, Gulu

Observations from the general attendance registers for the members at the health facilities indicate that the groups have between 25 – 70 members and on a particular meeting day more than two-thirds of the members do attend. These meetings are usually carried out once a month. It was however noted that this time frequency for the group meetings is actually inadequate for one to receive all the support and the sensitisation required of an HIV positive person.

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5 Offers peers support to help HIV positive pregnant/lactating mothers and their families cope better with the impact of HIV/AIDS on their lives through utilization of PMTCT and EID interventions.
The respondents also revealed that on top of the information and comfort they receive from their colleagues when they come for the meetings, the cash allowance and refreshments that are given to each participant who has attends that particular day, worth shs. 2000, is an incentive to the members to regularly attend. In Gulu district (Bobi HC III and Layibi Techo HC III) though, this amount was cited to being inadequate in covering the transport costs met to reach the health facility.

An HIV positive mother of four at Bobi HC III in Gulu district revealed that;

“When we come here, we are given refreshments; we are also trained about positive living and breast feeding to our babies by Mama’s Club Liaison Officer, Mentor Mothers and Health Workers. Also mothers give testimonies during these meetings to encourage, engage, and share experiences amongst the participants. This has strengthened us so much, we are like sisters now; we always encourage one another and give care for the sick. We also mobilise those who are not yet members to join the group.” Woman, FGD, Bobi HC III, Gulu district

National Implementation guidelines for the FSG for EMTCT (MoH, 2011) indicate that these groups aim at;
(i) Creating support, strength and confidence through disclosure to each other, friends, relatives and partners;
(ii) Creating awareness about SRHR, existing violations and ways of addressing them;
(iii) To learn to accept and understand one’s sero status and how to live life positively;
(iv) To encourage HIV positive pregnant mothers to access Antenatal Care (ANC), take their drugs(niverapine), deliver from the health facility, breast feeding and Postnatal care (PNC) and Family Planning (FP);
(v) To sensitisate the members on how to access Anti-Retroviral Therapy (ART) and help those on ART to adhere to the treatment; and,
(vi) Start-up Income Generating Activities (IGAs), so as to improve members’ incomes and welfare.

FSGs provide an avenue through which young people living with HIV are able to accept the HIV status, decrease depression, become more knowledgeable about HIV/AIDS that translates into reduction in stigmatisation and discrimination, increases disclosure of one’s sero-status, and become more knowledgeable about other SRHR and their violations. The groups provide a forum for sharing experiences and challenges, discussing family planning issues, and create an easy way for health providers to follow up for HIV positive mothers and or couples. In these FSGs, topics such as child protection and breastfeeding are integrated into the teachings.

It is also through FSGs that members decided to come up with proposal of integrating Income Generating Activities (IGAs) into the approaches used. The IGAs will be of importance in improving the welfare and incomes of members. The respondents revealed that they have identified several IGAs through which Mama’s Club can help and facilitate them. They
identified areas where Mama’s Club can help like skills training in soap and bread making; provision of agricultural seeds and training, and training in making of African Crafts, among others.

4) Organising Youth Corners and Days

Mama’s Club established a youth corner at every health facility where operations are taking place. It’s within these corners, that the youth get access to information and services such as guidance and counselling concerning HIV and SRHR. The approach was arranged in such a way that as they are waiting to engage with the health worker in counselling and guidance sessions, they can as well be engaged in some sports and games activities. Mama’s Club provided the health facilities with sports equipment for games and sports like Football, Netball, Darts, and Draft. These activities are an all-inclusive approach engaged in by all the youth irrespective of their sero-status.

Under these corners, the youth are sensitised by the health workers as a group and individually about HIV/AIDS and SRHR. They also share challenges and experiences during sensitisation sessions and through role plays arranged by their leaders such as Mentor Mothers and Fathers and youth leaders in the community. In some centres, the youth corners have television sets on which they watch films/videos about HIV/AIDS and SRHR. These videos are provided by the health facilities in conjunction with other organisations such as Reproductive Health Uganda (RHU). In the corners, the walls are pinned with several reading materials and posters on HIV and SRHR for whoever comes in to read. Some of these posters are pictorial form that are attractive and cater for those who can’t read. For those who can read, the posters and all the reading materials are both in English and local languages (Acholi) to make it easier for understanding and comprehension to all the youths at different levels of literacy. These materials are also provided in form of brochures and leaflets which are given to the youths to read from their homes and share with those who did not attend.

Apart from the knowledge, guidance and counselling services, youth also have access to cervical cancer testing and treatment, free condoms, HIV testing, and information on Reproductive Health. This is again done in partnership with RHU.

In Bobi HCIII, the group members have gone ahead to get involved in Music, Dance and Drama activities. The group is well organised to an extent that sometimes it’s hired to entertain guests at different functions. The earnings form these activities are shared amongst members which also contributes to their families’ welfare.

The Head, ART Unit, Layibi Techo HC III, noted that,
“Mama’s club came up with the integration of sports activities in the youth corner as a new approach in the fight against HIV. They provided sports facilities for sports activities such as netball, volleyball, chess, darts, draft and football. During sports, they integrate in other practices such as condom distribution, HIV screening among others. I have to tell you that before the introduction of these initiatives, the youths tended to fear to come for the health services such as condoms, HIV testing and counselling and sometimes refill for those who were positive. But now, when they come for the sports activities, they always also go on to ask for the services from the health staff. So once sports activities are going on, we are always on alert for any youth whom we spot searching for help and we provide it under strict confidentiality.”

One HIV positive father of three (3), who has been encouraged to join the group by the health worker after testing positive revealed that;

“The sports activity, makes us physically fit, relaxed and opens up the minds of the participant to take up HCT services, encourages others to share experiences, and creates unity amongst the HIV positive persons. Some youths who fear to come up for HIV test are also encouraged to test during the sports activities.” Man, FGD, Atiak HC III, Amuru district

According to a Health Worker at Pabbo HC III, the approach of integrating Sports activities into the HIV and SRHR activities has been influential in identifying and preventing the violations of SRHR. Once the youths come together, they freely share their challenges and experiences and identify solutions. He noted that;

“When they come here for the sports activities, we also give them information and education of sexual reproductive health. And when you talk to them about issues of Sexual Reproductive health, they are very attentive and willing to listen.” Nursing Assistant, Pabbo HC III

Under similar arrangements, Mama’s club also organises youth days on which the health workers alongside the Mama’s Club staff and other stakeholders provide treatment services and information on PMTCT of HIV; sexually transmitted infections, including infection from HIV, reproductive tract infections, cervical cancer and other gynaecological morbidities; promotion of sexual health, including sexuality counselling, and prevention and management of gender-based violence under Youth Friendly arrangements. Also on such days, participants engage in sports activities that were introduced by Mama’s Club at the health centres.

5) Facilitating mentor mothers/fathers to conduct referrals and home visits

Mentor mothers/fathers have the responsibility of Tracing defaulters and Conducting Referrals. In 2013, the mentor mothers/fathers were facilitated and referred 700 clients to the health facilities (698 females and 2 males). These increased to 1,664 clients (1,652 females and 12 males) referred in 2014. The mentors also conducted 155 and 217 home visits in 2013 and 2014 respectively. They were facilitated with referral forms that were designed by the ministry of health in which they keep records of clients who are on treatment. In these forms, Mentor
Mothers record client contact information, including: Full name, including any nicknames used at home, Phone number and alternate phone number, Village/residence and physical landmark. They follow up priority HIV, PMTCT and SRH clients who have dropped out of care at key points along the cascade. This exercise commences with a phone call or an SMS; if not successful a home visit is then undertaken by the Mentor Mother.

If the client is identified as a defaulter and mentor mother is unable to lure him/her back to the health facility for care through counselling and sharing experiences, the Mentor Mothers then pass over the clients’ contact information to the health facility, which health facility assigns one health worker to make a home visit to the household of the defaulted client. This health worker provides generic message encouraging client to visit the health centre. At this point, the Mentor Mother documents each case, noting whether the client attended, was not traced, declined further support, is deceased or has relocated. She also inquires from the client the reasons for the default which she documents, and communicates them with the health facility administration, to be resolved, if the cause of default is health facility-related. This helps to improve service delivery.

The most identified health facility-related reasons for default that revolved around the long waiting times at the health facility, sub-optimal interactions between the health workers and the clients; and the uncaring attitudes, harsh and lack of respect for the client by the health workers. The major cause for these reasons is the inadequacy in the numbers of health workers at the facility to attend to all the needs of the huge numbers of clients that assemble at the centres on the ART Clinic days. To some of these challenges, the facilities have direct control and mitigation measures such as continuous sensitisation of the health workers to how to handle, especially HIV/AIDS clients. However, challenges that are brought about by the understaffing of the health facilities, these facilities have little or no control over them. To mitigate defaulting cases, the facility usually gives them special attention once they accept to return to the health facility until when they are duly integrated back into the health care system.

6) Engaging men (spouses) to participate in FSG activities

Some violations especially the family-related violations have been mainly instigated by men over their wives. The inclusion of men in the groups has been a right prescription to address the issues of violations of SRHR. In 2014, 179 men/spouses participated in the FSG activities. This is however still low when compared to 2,682 female participants. It is important in supporting and addressing the on-going psychological and social problems of HIV infected individuals. The spouses (men) need the knowledge to provide support to their wives in coping better with the virus. Their inclusion meant that they will need special treatment. This necessitated the need for Mentor fathers to handle the issues in the male domain. Thus all groups have both the mentor mothers and fathers. However in all groups, men are still few and deeper engagement would suffice.
Male partner involvement in PMTCT and SRHR programmes is important because; as sole bearers of money in most communities in Northern Uganda, men influence their partners’ decision-making including the use of health-related services. Targeting men influences their sexual behaviours thus prevent STDs, HIV/AIDS inclusive. It is also promotes disclosure of HIV sero-status, prevent sexual, reproductive, and domestic violence.

7) **Guiding the beneficiaries to establish savings schemes**

As a way of improving the group’s members Savings culture, provide an easier way of accessing ‘simple’ credit services, creating ownership and sustainability of the group, the groups have started up Savings schemes. All groups have this scheme and all members of the group automatically are members of the savings group scheme. In all the savings schemes members are able to borrow at a 20 percent interest rate per month. However, this rate seems to be high compared to interest rates at other financial and lending institutions in the country, which lend at an average of 23 percent per annum. On the light note however, the members are able to borrow without a collateral security, but with reference from the members. This however, also seem to be an obstacle to the growth of this scheme. Once one defaults, it becomes difficult to force him/her to pay since the group has no security to be used to repay.

The FGD members at Atiak HC III, explained,

“The club members also started a savings scheme – locally known as ‘Gwoke Pe Yot’ which literally means ‘Taking Care of Yourself is not Easy’. The scheme started in 4 months ago and has a total of 30 members, where every member saves between shs. 1000-5000 a week, depending on one’s financial capacity.” Woman, FGD, Patiko HC III, Gulu district

When asked how much the group has saved so far. Another member went on to explained that,

“……we have been able to save between shs. 400,000- 500,000. Members are free to borrow from the group at an interest rate of 20 percent. At the end of each year, the profits are shared amongst the members depending on the amount of deposits one has with the scheme.” Woman, FGD, Patiko HC III, Gulu district

When asked about the main reasons given by people who apply for credit, one member responded that,

“People buy to conduct small business trade such as dealing in soap, making cassava chips and ‘Rujoro’ (Alcohol).” Man, FGD, Patiko HC III, Gulu district.

At Bobi HC III, the Mama’s Club group has a savings scheme popularly known as ‘Bed Kingen’ literally meaning ‘Have Hope’. The Bed Kingen has two main arms- the Welfare arm, to which every member contributes shs 200 per week; and the Credit and Savings Scheme to which every
member saves according to his/her financial capacity. It is from the credit and savings scheme which members borrow. The amount collected in the Welfare scheme is used to help members whenever they have sudden challenges like in death of loved ones or sickness. Money given to the member from this basket is in form a grant. Borrowing however from the Credit and Savings Scheme attracts an interest of 20 percent per month. The Bed Kingen has been in existence since November, 2013, and the group has been able to save shs. 280,000. It has helped to create ownership of the group and sustainability.

4.6 Attributions to Mama’s club Activities in Preventing and /or Addressing Violations of SRHR

When asked whether the approaches of Mama’s Club have helped to prevent or address violations of SRHR. Information from health workers, beneficiaries, mentor mothers, and routine data collected by Mama’s Club indicates that Mama’s Club activities have generally had a positive influence on reducing cases of violations. They however noted that there are still some challenges, since the majority of the community members are not involved in the activities or don’t even get sensitised.

One respondent noted that,

*HIV positive people are no longer bothered at people pointing at them, they are confident and stronger because to the counselling and health talk they get from the FSG meetings.*” – Health Worker, Kitgum-Matidi HC III.

Another health worker revealed that,

*Stigma has tremendously reduced due to sensitisation by the mentor mothers and Mama’s Club field staff. We have observed an increase in the uptake of youth friendly services recently. Many youths come freely for HIV Counselling and Testing, treatment and also do attend FSG meetings to discuss these Violations. We can now witness HIV positive pregnant mothers living positively and this is seen in the way they boldly come to pick the drugs, talk about their status with fellow HIV positive mothers, mentor mothers and their counsellors.*” Health Worker, Patiko HC III, Gulu district.

Information from Mama’s Club shows consistency with annual data collected by Mama’s Club. The data shows a 1.7% increase in the number of people that have received information on SRHR and SRHR service through E&M channels from 2013 to 2014.

Also annual data collected by Mama’s Club from the facilities of operations shows a 2.3% increase in number of HIV positive young mothers accessing to counselling services. In Kitgum, one health worker noted that,

*“Previously, people feared to enter the counselling room because whoever would enter there was considered to be HIV positive, but with education and counselling now, through Mama’s Club,*
people freely enter, get their counselling and the required treatment without fear of being seen by others around.” Health Worker, Omiya Anyima HC III, Kitgum district

“With the on-going counselling, there has been an improvement in acceptance and even those who are discordant come back for re-testing to be sure of their status.” Nursing Assistant, Pabbo Health Worker, Amuru District

“There are reduced cases of SRHR violation such as fighting by the discordant couples and couples in the club live in peace due to sensitisations and service provision such as condom distribution by Mama’s Club. Partners can now discuss and live positively when found HIV positive.” Mentor Mother, Pabbo HC III, Amuru district.

“The Mentor Mothers and Fathers trained by Mama’s Club conduct home visits, in which they sensitise the family members on stigma. This has led to a reduction stigmatisation in the community with more HIV positive young mothers and their spouses able to freely disclose their status to the most significant ones and the friend, and remain not castigated.” Women, FGD, Atiak HC IV, Amuru district

One FGD member revealed that, “I used to be mistreated by my mother-in-law, but when the mentor talked to her, she stopped and we are now good friends.” Woman, FGD, Patiko HC III

The responses above indicate the role of Mama’s Club in reducing violations of SRHR in Northern Uganda. The respondents indicate that violations such as stigma and discrimination, denial of access to SRH services among others has reduced. According to the HIV positive respondents, before, it was difficult to get information on Family planning services available at the health facilities, information on the right to choose the number of children to produce, information on the right to say ‘no’ to sex, even with usual sexual partners. These services and information would sometimes be available at the health facility but the youths did not know how to access them. This was because the youths didn’t know that the services were available, were not aware about the services, or the health workers were not willing to give them time and attention to explain the available services. With involvement in Mama’s Club activities that have brought about the improved interactions and relations between the youths and the health workers, the youths are now able to access this information and reproductive services such as family planning services and condoms.

Stigma and discrimination were feared and experienced largely in the community. This led many women to struggle to disclose their HIV diagnosis to even their partners for fear of negative repercussions that reflected pervasive societal stigma. Where women were encouraged to bring along their partners for HIV testing, it created nervousness among them. But after the interventions through counselling by the mentor mothers, and through oneness created by the sports activities, the fear for stigma within the health care setting has generally reduced. Health
care workers in Layibi Techo HC III (Gulu) and Atiak HC IV (Amuru) indicated that more men, especially those whose wives belong to the FSG groups are now accompanying their wives for care and treatment. Male partners’ level of support and involvement positively or negatively affects women’s uptake of services. However, it should be noted that Mama’s Club only targets young mothers and their spouses; this implies that the largest group of the population is left out sensitisation and education created by Mama’s Club. This partly explains the violations that still exist in the communities in Northern Uganda.

In addition to the extensive levels of SRHR violations, stigma and discrimination, it was widely found that young HIV positive mothers did not know where to go for redress or feared seeking assistance. Though the mentor mothers and fathers are available to provide assistance to the victims, they are (mentor mothers/fathers) only 135 (by 2014) and they can’t adequately cover the vast geographical areas to provide the required assistance to the victims. Among those who sought redress got it from the health workers. However many are still unable to get the required assistance and are unsatisfied with the level of services in their community. Also respondents indicated severe limitations in the ability of the health workers to adequately address cases of rape, marriage dissolution, forced unprotected sex and medication being denied to young people living with HIV. This was particularly in all the three districts of the study. Health workers have skills in treating victims of physical or sexual assault, but can hardly give a whole package that would equally involve counselling and rehabilitation. There is therefore a need to focus more on capacity building of health workers to address these cases, or train more mentor mothers and fathers who can deal with these issues.

4.7 Relationship between the approaches, processes, and practices done by others to identify, address and/or prevent successfully SRHR violations of young women living with HIV in SRH settings

There are several organisations (see Annex 1 for an overview) either working in partnership or in isolation with Mama’s Club to identify, address and/or prevent violations of SRHR of young women living with HIV in SRH settings. These organisations were found to apply similar approaches and practices to what Mama’s Club is applying. Approaches like the use of Family Support Group, use of VHTs in the communities, Counselling and Guidance of the affected individuals, and engagement of service providers were found to be cutting across and yielding similar results.

However, the approaches, processes and practices have several differences to what Mama’s Club is offering under the ASK programme. These may include activities such as having no age limit and provide other products like paying school fees for children whose parents are HIV positive or orphans whose parents succumbed to the virus, providing food supplements to the HIV positive people and ARVs. However, integrating SRHR with sports activities and emphasizing a
particular age group (10-24 years) of HIV positive pregnant/lactating young mothers are new approaches and unique to Mama’s Club.

In areas where Mama’s Club has no expertise, it has been however collaborating with other organisations in the area to provide these services. These organisations include Ministry of Health, that provides guidelines for scaling up FSG activities, PMTCT and delivery services; AMREF for E&M Health Information; Reproductive Health Uganda (RHU) for STI screening during outreaches, and SRHR services especially Family Planning; CHAI for the provision of condoms; Straight Talk Foundation for the young talk Newsletter provided to the youths in the youth corners; Young Positives Uganda for the mobilisation of sex workers for the moonlight activities; Young Alive Uganda for Testing and Counselling during outreaches; and other private individuals who act as volunteers.

There is also potential for collaboration with other several organisations in the region to improve service provision to the communities. These include the International Service Volunteers Association (AVSI). This can be in form of sharing knowledge and experiences on the process of implementation and coordination of FSG activities, Health education, SRHR and ANC/PMTCT activities. The organisation can also collaborate with other organisations such as Health Alert Uganda on issues of health education and counselling; among others.

4.8 Relationship between the approaches, processes, and practices of Mama’s Club to changes in uptake or demand for PMTCT

During the FSG meetings, Mama’s Club mentor mothers, liaison officers and the health workers always mobilise and conduct sensitisation and encourage the HIV positive mothers to take PMTCT especially the EMTCT services that are available at the health facilities. With increased sensitisation and education of the HIV positive couples by Mama’s Club, health workers have observed that couples who are benefiting from the PMTCT service seem happier in their relationship and have a more positive attitude towards their status even if both may have tested positive. They are supportive of each other’s responsibilities. These couples are more likely couples to access services together and support each other. In most cases men are the sole bearers of household requirement like food, decision making, sexuality and reproduction, so when they are involved, cordial discussions are held around sharing resources and couple dialogue which promote happy and positive living which essentially prolongs life for those who are infected, making way for the coming baby to enter a happy home.

Where both couples are involved, taking of Niverapine and eventually ARV becomes easy in that the couple reminds one another, and once in the group, it becomes like a larger part of the family where home visits to those who may be too ill to participate in meetings are carried out to find out reasons for abstention. It also increases the levels of adherence to treatment and refills. The group members always encourage each other to take up the treatment, especially in
circumstances where the member is detected to be trying not to adhere to treatment. The group members revealed that they help to pick up neighbouring friends to pick up drugs at the health facility.

An HIV positive couple and parents of a newly born-baby found at Kitgum-Matidi, revealed that, "When my wife came for Antenatal services, she was tested for HIV and found positive, with advice from the Health worker, I was invited to also get tested, I also tested positive, and advised to join Mama’s Club. It was at first difficult for me, but later alone I accepted. My wife and I have found life easier with this group, the members have been supportive and they have always encouraged us to take PMTCT services, which we now embrace because our life is far much better than we were when we had just tested positive.” Father of two baby boys, FGD, Kitgum-Matidi, Kitgum district

4.9 Attribution of Mama’s Club to the uptake of PMTCT and ANC on the young women living with HIV

The role of the Mama’s Club in changing the people’s attitudes and behaviours cannot be underestimated. Mentor mothers and VHTs who are facilitated by Mama’s Club do mobilise the youths and refer them to the different health facilities to access medical services like PMTCT. They also give community counselling and guidance especially on condom usage in discordant couples who usually respond to the advice.

Routine data collected by Mama’s Club from the health facility indicate that there has been an increased consumption of PMTCT services amongst the HIV positive young mothers by 1.7% between 2013 and 2014 (1,066 to 1,800 clients) in the health facilities where Mama’s Club operates. It also shows a 2.9% increase in family planning consultations and a 3% increase in STI screening in one year. This is partly attributed to the sensitisation of the youths by Mama’s Club especially the Mentor Mothers. Health workers also indicated that the increased uptake of PMTCT services is also attributed to the positive reception by the health workers and VHTs towards the mothers. This has encouraged them to continuously visit health facilities for medical attention.

Mama’s Club also adopted the use of Mentor Mothers and Fathers to mobilise, counsel, guide and make follow up on the HIV positive young people. These have been influential in encouraging pregnant mothers attend PMTCT and ANC services. A respondent noted that;

“...Because they have a mentor mother, and she is their age mate, they feel free to share with her and she refers them here. We can see now that the demand and uptake of services like PMTCT, ANC, and HIV testing have all increased. In case they don’t come for the treatment, the mentor mother knows them personally and she makes a follow up.” Mid-wife at Namokora HC III
“With the health education that we’ve received from Mama’s Club, we are happy that we can now even produce HIV negative children even though we are positive.” HIV positive Woman, Focus Group Discussion, Namokora HC III, Kitgum

Another member noted that,

“We also receive training and encouragement on how to access PMTCT services, for instance, we are always sensitized on to take option B+ for pregnant mothers, breast feeding for the infants and family planning.” Woman, Focus Group Discussion, Bobi HC III.

### 4.10 Challenges faced by Mama’s Club in Implementing the ASK Programme in Northern Uganda

There are several challenges identified that infringe on Mama Club’s ability to implement the ASK Programme in Northern Uganda. These include:

- Information dissemination and access is still low to all people at the grassroots. This is mainly attributed to the transport challenges and the long distances involved in reaching out to all people in their remote settings. Most of the youth friendly services are at the health facility and not all youths are able to reach these facilities. Most of these youths are the out-of-school older youths, who dropped out of school during the rebel insurgencies in the region in the 1990’s. These are mainly the boys, for the girls, they are in the reproductive age and very often access this information at the health facilities. This is common in all the 3 districts.

- Inadequate Human Resources (health workers) to attend to all the FSG activities. Health facilities do have few health workers; and cannot all be involved in the activities of the FSG. The activities are mainly managed by one Focal person, who is at times overwhelmed by work and cannot attend to all the activities. “Usually time doesn’t allow us to join the youth in the sports activities in the evening. We are supposed to leave work at 5:00 pm and sometimes we are so tired and overwhelmed by the day’s duties.” Nursing Assistant, Layibi Techo HC III, Gulu.

- Some of the mentor mothers and fathers lack the required capacity to mobilise and organise the club meetings. The issues that are handled here concern the lives of people and require high level of confidentiality, this is however still lacking in some of the mentor mothers. Where the beneficiaries sense that their lives are not handled well, they tend to withdraw from the group.

- Insufficient Remunerations: According to the Mid-wife at Namokora HC III, the beneficiaries are money-minded because the previous organisations corrupted their minds with cash bonuses. Mama’s Club gives them refreshments worth shs. 2000; to which they think is very little and cannot enable them finish their personal financial challenges. This lowers their morale to engage in Mama’s Club activities.
• Meeting frequency. The FSG meets only once a month and this is little. According to the health workers, the impact created by this meeting can be easily wallop ed away before the next meeting is held. It is vital that more frequent meetings are held in a month.

• Poor transport facilitation to mentor mothers and health workers to move deep into the villages. It is inevitable that mentor mothers have traverse large areas to reach out to all beneficiaries, if they are to do mobilisation and follow ups. Lack of easier modes of transport makes it difficult for the mentor mothers to reach out to all the beneficiaries.

• High poverty levels in the region. The region is the poorest in the country with poverty rates of 40% being much higher than the national poverty rates at 19.4% (UBOS 2014). This makes it difficult for the beneficiaries to access some of the services they require. Even where the services are freely provided, like in the public health facilities, the inability to access transport funds to the nearby health centre may hinder one from accessing these services.

• Attendance of FSGs by HIV positive mothers who are above the project targeted age: It has been observed that some of the members in the FSG are over and above the targeted ages (10-24 years). This is mainly attributed to lack of similar services that are provided to people who are beyond 24 years. Since they also need the services, they take advantage of lack of proper data and deceive about their ages during FSG entry points. This is common in all FSGs. Mama’s Club has been working to ensure that all mothers who have reached 25 years exit the group. It occasionally organises a function to pass out the mothers by providing them with simple gifts such as basins, soap, etc. However, many have not exited and since they have no similar services provided for HIV positive women who are 25 years and above. This has rendered the organisation to serving people beyond the target age. This violates the principle of serving the youths who were timid in engaging in the general FSG that caters for all HIV positive people irrespective of their age at the facility, but it offers less services.

• Lack of minimum facilitation to link all the targeted beneficiaries to the health centres. It was observed that there some young mothers who still don’t attend or deliver from the health facilities as required. This is because they lack the minimum requirements such as Mama Kits to deliver in the hands of the trained health care worker. Such young mothers are sometimes left out of the service provision by Mama’s Club, since it has no specific activities to target such mothers.

It should be noted that every woman who wants to deliver at the health centre needs to bring her own Mama Kit. The kit would consist of a two metre piece of plastic sheet for the pregnant woman to lie on during labour and delivery, half a metre of plastic sheet to provide a clean surface for placing the items being used, two pairs of surgical gloves; a
piece of soap for washing hands, a roll of cotton wool for cleaning the vulva, a new razor blade for cutting the cord, two pieces of thread or tape for tying the cord, two packs of gauze for cleaning the baby’s eyes, and a packet of sanitary pads for the mother.
4.11 Success Stories

Success story 1

One FGD participant, a woman from Amuru district, 21, revealed that;

“I used to fall sick very often, and when I was pregnant, I came to Pabbo HC III for ANC services, I tested for HIV and the results came out positive. I hated myself, my children and even my husband. I didn’t blame my husband but rather I just wanted to the best for my family. When I disclosed to him, he was bitter accusing me of infidelity and having brought the virus into the home, yet I have always been a faithful wife.” “He stopped me from going back to the health centre, even though I tried to explain to him the benefits, including preventing my baby from contracting the virus.”

The husband would batter her whenever he was drunk and the children started to hate their parents because of the continued fighting. The community also started isolating her as well the children getting isolated at the school.

“When I gave birth to this child, I felt sad and refused to breast feed my child, I knew he was already sick and would not last for long, and I couldn’t stop blaming myself for my failure to save her from contracting the virus.”

According to the midwife at Pabbo HC III, this lady had not gone through proper PMTCT procedures and her child was exposed to the virus. After six (6) months, the 1st DNA PCR was conducted and the results came out positive.

“But one day when I came for Post-Natal Care, I was advised by the health worker to join Mama’s Club; ever since I joined, I felt comfortable and willing to carry on with life, I was taught on the proper ways of breastfeeding my child, and now you can see she is enjoying the breast milk. I also encouraged my husband to join, we were counselled and we realised that we were not the only couple with HIV. He now regularly attends the FSG meetings, he no longer fights and quarrels and we have peace in the home. My children are happy with me and their sister so much.” She thanks Mama’s Club for rescuing her life.
Success story 2

“My names are Lakaraber Winnie, am 23 years old and a single mother of three (3) boys. I was married in 2008. I had my first boy the same year when I was 17, in 2010 I delivered my second boy and in September, 2011, I delivered my third boy.

I separated with my husband in December 2013. It was with my last kid, when I realised that I was HIV positive. I went for ANC at Layibi Techo HC III, and tested HIV positive. He was away in South Sudan for work. When I tested, I also enrolled in option B+; Mama’s Club was already there at the Health Centre, but I wasn’t really sure about it. So the health workers started giving those treatments and everything.

After realising that I was positive, life was very horrible because I couldn’t believe that I was positive, after all I had lived with only one man, I felt bad but I couldn’t wallow into sadness, am a strong woman as you can see. Then I went back home it was also very difficult for me to comprehend, but after some counselling from the midwife who was also working on me and the sisters in the FSG, I regained courage. I disclosed to my husband immediately he came back and it was a shock to him, but he had to believe it was the truth, he also went for the testing and also found himself positive and he as well started on the treatment.

We both made accusations of each other, he accused me and I accused him; but all in all he was wrong because I had never slept with any other man and he was travelling in many places and he must have got it from those places. I should not actually have accused him, but it was because out of the anger that I had. When I was counselled through Mama’s Club, I understood, but for him he couldn’t understand.

My kid was six weeks when I brought him for the first DBR test that is when I heard about Mama’s Club. It was the midwife, who told me that I should come back for the meeting on the 16th June, 2013. That is when Mama’s Club officially came to the health centre. They told us about the organisation, I was among those people who joined and I was then selected as the mentor mother at the health centre.

My husband didn’t join Mama’s Club because he is a little selfish and fears being exposed. He doesn’t want people to know about it. Even getting his own drugs is very difficult for him; he just buys from the Pharmacies. He only went for the first time to be tested and stopped that day.

When I joined Mama’s Club, at first we used to have two (2) FSGs at the facility in a month, because we used to have quite a number of members (between 60 and 70 mothers). I could mobilise the first FSG in the first Friday of the month and then second lot in the Friday of the month. Because of the stigma, some disappeared, but I tried to convince some to come back.
Some of them you saw are the pioneers, and now they no longer mind about the stigma. They are used and now stress free. They stuck on up to now and we have now like 50 old members and some few mothers enrolled from antenatal.

Separating with my husband started the day we were to have a dialogue meeting with the Mama’s Club Staff. We were informed to go to the health facility very early in the morning and I left home without cooking, we waited the whole day long and the guest came very late in the evening. We actually didn’t have the dialogue meeting, we just exchanged overtures and I went back home to prepare a meal with that allowance they had given. He never wanted me to join the Club, I found him drunk and he fought me; and from that day on he changed and became jealous. He would quarrel at every phone call I would get from a man. And being a mentor mother, I am approached by all kinds of people, and that would make him quarrel and fight.

He was no longer working and I was the one to take care of the family, feed my children and him, yet he had started becoming obscene. He was using abusive language to me and to my mother. And I decided that on the sickness I had I could add on another kind of stress that would lead to my early death. I decided to quit.

Mama’s Club has given me the courage to live on with confidence. I can now live by myself without being abused and there are so many years to come. I now know that am not the only one with it and it is not so bad that I have the virus. I have learnt to take care of myself and mitigate the sickness that would attack and endanger my life as a result of the HIV virus. At first, when I had discovered that I was HIV positive, I was very sad, but when I joined this group, I became free and strong. I was always worried for my children, thinking that I was soon dying and leave them young, but am now strong, confident and looking forward to take care of my children until when they grow up.
SECTION 5: RECOMMENDATIONS

Based on findings derived from this study, it is apparent that the ASK programme must address the following recommendations if it is to fully realise its outcomes. It should be noted that the same issues should be into consideration if ASK Programme is to be replicated in other areas.

(i) Need for Economic Empowerment for HIV positive young mothers

Results from the study clearly indicate that youth in the FSG groups are demanding means for economic empowerment. Meeting the needs of HIV positive young mothers requires economic autonomy which will be central to truly achieving the project’s objectives of protecting and promoting their SRHR. The current state of economic dependency young women face exacerbates their vulnerability to violations as they are unable to assert their rights without severe consequences to their economic well-being. Reports from the respondents indicate that these groups have already identified Income Generating Activities (IGAs) such as soap making, bread making, African crafts, access to agricultural and others. However, these projects are yet to be implemented and members require being skilled so that they can produce quality and marketable products. If these groups are to assert their SRHR, their economic circumstances must be addressed. It is imperative that Mama’s Club develop strategies for skilling the group members to improve their wellbeing.

In a context where group leaders do not have enhanced financial management skills, they need training in the operation of the Village Group Savings and loan schemes. The programme should add a component of business skills training to ensure that funds borrowed by members are well used i.e. build financial management capacity at individual level.

(ii) Engagement of Men to participate in FSG and other PMTCT activities

As men often are the ones making decisions regarding sexual and reproductive health issues, and most often the perpetrators of sexual and domestic violence, it is essential to include them in order to change behaviour patterns. The ASK Programme has a provision for admission of men, but men are still very few in these groups. The project should incorporate couples as SRHR promoter to advocate for SRHR within their families and encourage other couples to do the same. This approach will ensure male involvement in the promotion of SRHR amongst HIV positive young people. Trainings and counselling, integrating men through couples may serve as the beginning to addressing the power imbalances between genders, which facilitates SRHR violations.

(iii) Individual Level Trainings and Counselling

The gaps in the knowledge appear to stem from not knowing the relevant institutions to engage in instances of SRHR violations. In response, trainings and counselling provided through the ASK Programme should deliver information on how to access relevant organizations and legal
networks in the community. Yet given the weak system of redress that was evidenced, the young women living with HIV should be trained in political advocacy to be able to enact changes in policy and programs available to them at the community and district level. This could potentially be achieved through building the capacity of the groups to engage in and initiate public debates, district and community campaigns, meetings and Participatory Radio Campaigns (PRCs). Though there appears to be widespread knowledge surrounding the rights of PLHIV, further educating the women and men on their SRHR and relevant laws and policies may assist in strengthening the success of above efforts and their ability to assert their SRHR.

(iv) *Exchange Programmes and Sports Competitions*

The programme should consider exchange programmes for Family Support Group members to give them an opportunity to visit other groups in the districts or other districts to acquire new strategies for managing stigma, discrimination and support programmes for the PLHIV, Adherence to treatment, and acquire new ideas on investment. Since it integrated the idea of sports activities, Mama’s Club should consider organising tournaments for the groups which they can engage in on Youth Days. These could be an opportunity for sharing experiences and challenges and learning from one another.

(v) *The need for more Frequent Group Meetings*

Information from the FSG registers indicated that on a particular meeting day more than two-thirds of the members do attend. Groups have between 25 – 70 members, and these meetings are usually carried out once a month. It was however noted that this time frequency for the group meetings is actually inadequate for one to receive all the support and the sensitisation required of an HIV positive person. There is need to create resources and time such that these meetings are more frequent for all the targeted young mothers to fully be sensitised about HIV and their rights.

(vi) *Transport Assistance to the Mentor Mothers and Fathers in form of Bicycles and increase on the monthly incentives they receive*

Mama’s Club should consider providing transport facilitation for the mentor mothers/fathers and youth councillors. These should be provided with transport facilitation in the form of bicycles. These are easy to maintain and easily traverse rural roads. This will also ease their work of mobilization and follow ups of the beneficiaries.

(vii) *Seed funds into the Savings Schemes*

Encourages savings to assure sustainability and ownership of the ASK programme amongst the members. Mama’s Club should lobby for donor funds to be provided as seed money to the group’s savings schemes. This will motivate the members to join and also save with the scheme.
in anticipation that they will share from the interest at the end of the year. The groups have started savings schemes for the group members such as the Bed Kingen at Bobi HC III, Members borrow from the group at an interest and it has helped to create ownership amongst the group members, however, the scheme requires more capital to improve its capacity to lend its members and improve their welfare.

(viii) **Linking Health and Legal Services as a Potential Strategy**

Due to weak referral systems or lack of awareness on where to go, linking health services to legal aid and paralegal service providers may improve issues of access. In Tanzania, the Centre for Comprehensive Community Based Rehabilitation joined forces with the Tanzanian District Health Authorities to create the Holistic HIV/AIDS Related Program (HARP) which provides legal aid services in addition to providing voluntary counselling and testing, home-based care and ARV treatment. The HARP program has been successful in targeting the legal needs of WLHIV while simultaneously providing medical care. Previous suggestions have already been made to implement similar initiatives in Malawi (Mgbako et al., 2007). In Uganda the ASK Alliance Partners should work together to ensure that they advocate for such linkage that will help in tracking down violations of SRHR.

(ix) **Linking Mama’s Club Activities to the Communities**

It was generally noticed that most of Mama’s Club activities are conducted at the health centres, yet there are a number of HIV positive young mothers who fear or don’t have the facilitation to come to the health centres to receive the health services. Several young mothers fear disclosing or knowing their HIV status, and aware that once they come to the health facilities, they will forcefully tested. Such women resort to delivering through the use of Traditional Birth Attendants. Others don’t have the minimum requirements such as Mama Kits, which are demanded at the health centres. Some of these women are left out of the project, yet they are some of the targets. Mama’s Club should therefore venture into ways of meeting these mothers from their communities, instead of waiting for them to come to the health facilities.

**Research Gaps**

To achieve the objectives of increasing demand, uptake and continued use of PMTCT services in particular EMTCT and SRHR services in the area, a number of challenges have to be handled. There is also need to conduct research to inform the activities that are geared towards eliminating these challenges. Some areas that were identified for possible further research include;

(i) Causes of Low Male involvement in the EMTCT and SRHR activities and possible solutions;

(ii) Feasible economic empowerment options that available and affordable for the HIV positive young mothers; and,
(iii) The effects of domestic violence on the demand, uptake and continued use of EMTCT and SRHR services.
ANNEXES

Annex 1: Mapping of Organisations providing Related Services in Northern Uganda

|-------------------------------------|--------------------------------------------|----------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|
| AMREF                               | Patiko HC III; Kitgum-Matidi; Namokora HC III; Pabbo HC III; | - Reproductive health, counselling and guidance, and mobilisation of HIV positive youths.  
- Others services include condom distribution and Family Planning services such as Pilplan | - AMREF also carries out insecticide spraying for mosquitoes to reduce the prevalence of Malaria  
- Capacity building of Health Workers to handle SRHR                                                                 |
| AVSI (International Service Volunteers Association) | Patiko HC III; Bobi HC III; Namokora HC III; Kitgum-Matidi HC III; | - It provides support to contribute to the reduction of maternal and child mortality and to improve quality of life of children and women in the Acholi region  
- AVSI is also supporting the FSG activities with facilitation of shs. 5000/= to members every day of the meeting and support to the savings group.  
- It also conducts Health education to the communities | - It provides support to district health department teams empowering them to effectively coordinate and lead the processes of planning, management, implementation, monitoring and evaluation of maternal and child health, ANC/PMTCT+, nutrition, and health services |
| Comboni Samaritans                  | Layibi Techo HC III;                         | - These usually provide health education, counselling and refer suspected HIV positive people to the health unit for HCT. They also carryout counselling and guidance to the HIV positive people. | - They provide activities to the general population; have no specific programme for the youths |
| Health Alert Uganda                 | Layibi Techo HC III;                         | - These usually provide health education, counselling and refer suspected HIV positive people to the health unit for HCT. They also carryout counselling and guidance to the HIV positive people. | - They provide activities to the general population; have no specific programme for the youths |
| World Vision                        | Layibi Techo HC III;                         | - Usually are in the community and don’t concentrate at the health facility                                 | - They provide activities to the general population; have no specific programme for the youths |
| Nu-Hites                            | Layibi Techo HC III; Namokora HC III;        | - Used to cater for the ART Clinic;  
- Provide Home-based utensils  
- Conduct Health education | - They provide activities to the general population; have no specific programme for the youths |
| Straight Talk Foundation            | Layibi Techo HC III                          | - They provide youth friendly services                                                                  | - They no specific programme for the HIV positive young mothers |
| Reproductive Health Uganda          | Layibi Techo HC III                          | - Cancer screening and treatment and reproductive health services                                       | - They provide activities to the general population; have no specific programme for the youths |
| Marie Stopes Uganda                 | Layibi Techo HC III; Pabo HC III;            | - Mainly in Family Planning                                                                           | - They provide activities to the general population; have no specific programme for the youths |
| Save the Children                   | Atiak HC III                                 | - Provide HCT                                                                                          | - They provide activities to the general population; have no specific programme for the youths |


Annex 2: Terms of Reference for Applied Research

1. Summary of Assignment

| Assignment | Evaluation of the processes, practices and effects of the activities of Mama’s Club and WOFAK’s activities within the Access, Services Knowledge Programme |
| Location | Uganda and Kenya |
| Duration | Tbd |
| Budget | Tbd |

2. Introduction

About ASK and STOP AIDS NOW!

The Access, Services and Knowledge (ASK) programme is being implemented from 2013 to 2015 in seven countries: Ethiopia, Ghana, Kenya, Senegal, Uganda, Indonesia and Pakistan. ASK is led by the Youth Empowerment Alliance (YEA), consisting of Rutgers WPF (lead agency), AMREF Flying Doctors, CHOICE for Youth and Sexuality, dance4life, IPPF, Simavi and STOP AIDS NOW! The overall aim of the Programme is to improve the SRHR of young people (10-24 years) by increasing their uptake of SRH services by taking a comprehensive and inclusive approach to removing the barriers young people face in taking up SRH services. ASK targets young people in the age group 10-24 years, including underserved groups.

ASK focuses on youth participation and the participation of selected underserved groups, YPLHIV, LGBTIQ youth, young mothers, disabled youth, hard-to-reach youth in remote areas and young people in the age group 10-16 years. The ASK programme also focuses on enabling young people to make safe choices by directly receiving or seeking information or services, without the need of intermediaries, such as peer educators or teachers. To that end, ASK makes use of text messaging, mobile phone applications, web-based information platforms, chat and telephone help lines and non-traditional offline campaigns to build young people’s knowledge. ASK also seeks to improve the quality of youth-friendly services and referral systems. ASK makes specific efforts to enhance access to RH commodities, including ARVs and contraceptives, as well as safe abortion.

STOP AIDS NOW! is an independent and partnership-driven organization, founded in 2000 by Aids Fonds and four Dutch development organisations: Cordaid, Hivos, ICCO, and Oxfam Novib. Our aim is to expand and enhance the quality of the Dutch contribution to the AIDS response in developing countries. STOP AIDS NOW! operates at the crossroads of fighting poverty, eliminating exclusion, and responding to the AIDS epidemic in countries with a generalized epidemic. We particularly focus on women, youth, and children. STOP AIDS NOW! supports projects using learning by doing approach, sharing knowledge and expertise and by using local level results to influence international policies and government.

As a member of the YEA, STOP AIDS NOW!’s role in ASK is as follows. STOP AIDS NOW! Supports the overall programme in all countries by providing technical support to the other Alliance members and selected partner organisations in Kenya and Uganda on strengthening youth friendliness and SRHR and HIV integration in services addressing of rights violation and increasing access to ARVs and other commodities (supply chain management national government)

- Developing integrated, comprehensive HIV-prevention and SRHR programmes and building capacity to measure effects at outcome level;
- Increasing access to ARVs and other RH commodities (supply chain management with the national governments);
- Strengthening youth-friendliness and SRHR and HIV integration in services;
- addressing the needs of young people living with HIV by supporting them in advocacy and gathering evidence to articulate their needs;
- Increasing political commitment to improve sexual health outcomes for young people; and
- Addressing rights-violations of HIV+ young pregnant women in the context of SRH activities related to the prevention of mother to child transmission of HIV (PMTCT) and antenatal care.

The area of work listed last is the focus of the applied research project to be rolled out under these terms of reference.

**About Mama’s Club and WOFAK**

**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 has 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 them 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.

Mama’s Club also works with service providers to improve the quality of HIV and SRH services and address cases of stigma and rights violations. Mentor Mothers are a liaison to the formal health system and to health care providers. Mama’s club holds regular dialogue sessions and orientation workshops with health care providers on services and the quality of care.

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). Activities centre on rolling out the Mentor Mothers approach (up-scaled to new districts) and providing support for and oversight on SRH and HIV care of young women living with HIV. Mama’s Club also builds the capacity of service providers to improve the quality of HIV and SRH services and address cases of stigma and rights violations. These activities are designed to integrate prevention of rights violations, in particular violations of the sexual and reproductive health and rights of young women living with HIV in the context of PMTCT and maternal health services.

**WOFAK**
Women Fighting AIDS in Kenya (WOFAK) was founded in Kenya in 1994 by a group of women who had tested positive for HIV. WOFAK provides comprehensive care, counselling, and support services to women, youth and children living with and affected by HIV and AIDS. WOFAK operates in 13 centres throughout Kenya.
WOFAK provides medical services through referrals and close collaboration with public and private hospitals and facilities. WOFAK also provides counselling and support services, including nutritional care, vocational training, and income generating activities. In addition, WOFAK takes up peer-education based Behaviour Change Communication (BCC) for HIV prevention and to mobilize communities to take up antiretroviral treatment.

Within ASK in Kenya, WOFAK\(^6\) contributes to increasing the number of HIV+ pregnant women receiving PMTCT (in the targeted areas) and antenatal care (in the targeted health facilities in targeted areas). WOFAK also contributes to increasing acceptance/support of young people’s rights to access SRH services at community/local level. WOFAK achieves these results by improving the quality of HIV and SRHR health care services for young women living with HIV, in particular with regard to rights-related issues.

WOFAK works on improving the quality of HIV and SRHR health care services by running Youth Friendly Service (YFS) desks and maternal health and PMTCT desks at health facilities. Both types of desks consist of a WOFAK counsellor assigned to a government health facility to provide information, encourage clients to be proactive in seeking services, support couples’ counselling, and record and follow up on alleged rights violations. Both types of desks are supported through group counselling and community-based activities.

Activities for ASK including: providing peer-led refresher training to YFS and Maternal Health & PMTCT desk officers, respectively, to strengthen their capacity to support the HIV and SRHR needs of young pregnant women living with HIV; integrating the YFS and maternal health and PMTCT desk models to form Young Mother desks (at eight facilities); and running dialogue sessions (three per year) at health facilities between young positive mothers and health providers on the quality of HIV and SRH services.

3. Aim and objectives of the applied research

The aim of the applied research is to document, analyse and evaluate the approaches (focus on content), processes and practices Mama’s Club and WOFAK employed in their activities in ASK that contribute to successfully identifying, addressing and preventing rights violations of the sexual and reproductive health and rights (SRHR) of (young) women living with HIV (<25 years) in SRH settings (especially PMTCT and antenatal care (ANC)).

The specific objectives of the applied research are as follows:

- Document in explicit detail the approaches, processes, and practices that contribute to identifying, addressing and/or preventing rights violations of the sexual and reproductive health and rights of young women living with HIV (<25 years.) in SRH settings. Document successes and challenges to achieving these outcomes.
- Relate these approaches, processes, and practices to work that has been done by others to identify, address and/or prevent successfully SRHR violations of young women living with HIV in SRH settings (see for example work by ICW, GNP+, OSI).
- Relate the approaches, processes and practices to changes in uptake or demand for PMTCT and ANC services.
- Identify if and how the successful approaches, processes and practices can be replicated by other stakeholders.

\(^6\)WOFAK contributes to result area 3: Public and private clinics provide better sexual and reproductive healthcare services, which more and more people are using; and result area 4: Greater respect for the sexual and reproductive rights of people to whom these rights are denied.
4. Questions to be addressed by the research

- What are the current approaches, processes, and practices of Mama’s Club and WOFAK—part of the ASK programme—and how do they quantitatively and qualitatively differ from each other?
- How do these approaches, processes, and practices differ in relation to what Mama’s Club and WOFAK did before the ASK programme? Did they develop new (for them) activities especially for ASK?
- Did Mama’s Club and WOFAK adapt their respective activities during the ASK programme? If so, how and why?
- Do the respective approaches, processes, and practices of Mama’s Club and WOFAK contribute to identifying, addressing and/or preventing violations of the sexual and reproductive health and rights of young women living with HIV in SRH settings (<25 years)? If so, how so? If not, why not?
- Can we be sure the contribution to identifying, addressing and/or preventing SRHR violations is due to their ASK activities? If so, how so? Which ones contributed the most? Which ones contributed the least?
- Which conditions or factors have hindered Mama’s Club and WOFAK’s respective abilities to identify, address and/or prevent SRHR violations? Why?
- Did Mama’s Club and WOFAK succeed in increasing significantly the uptake of PMTCT and ANC on the part of young women living with HIV? If there is a significant increase, can it be attributed to their ASK activities? Link to M&E.
- How do WOFAK and Mama’s Club’s approaches, processes and practices for identifying, addressing and/or preventing SRHR violations differ from those projects or organisations known to have been successful?

5. Proposed elements of the research method (to be finalized with the researchers)

- Global desk review to collect data and information on existing successful approaches, processes and practices for identifying, addressing and/or preventing SRHR violations of women living with HIV in SRH settings.
- Desk review of WOFAK and Mama’s Club’s ASK-specific activities and related current activities, respectively.
- Interviews with key informants (to be determined) from WOFAK and Mama’s Club to obtain additional data and information.
- Focus groups discussions with the target group.
- Observation in the clinics.
- Confirmatory factor analysis to determine if there is indeed a positive relationship between increased uptake or demand for PMTCT and/or ANC services on the part of young women living with HIV and WOFAK and Mama’s Club’s ASK-specific activities

Deliverables

- Research proposal with description of protocol
- Data collection tools: interview, FGD and observation guides
- Research report
6. Intended use of the research findings

WOFAK will work with STOP AIDS NOW! and Mama’s Club in Uganda to develop a tool articulating the most successful methods to allow for replication of their most effective methods. Through a regional training meeting of partner organisations in ASK and distance learning-e-learning and e-coaching—WOFAK will collaborate with Mama’s Club and STOP AIDS NOW! to support other partner organizations that are part of the ASK programme to implement the tool.
Annex 3: References


3. Alexandra Muller and Hayley Macgregor (2014), sexual and reproductive health rights of women living with HIV in South Africa, sexuality, poverty and law


10. Intensify linkages between HIV and sexual and reproductive health and rights for maximum impact: Stop AIDS Alliance policy position


Annex 4: List of Key Informants

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<thead>
<tr>
<th>No.</th>
<th>Title</th>
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<tbody>
<tr>
<td>1.</td>
<td>Assistant District Health Officer, Gulu District</td>
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<tr>
<td>2.</td>
<td>Assistant District Health Officer, Kitgum District</td>
</tr>
<tr>
<td>3.</td>
<td>Nursing Assistant, Atiak HC IV, Amuru District</td>
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<tr>
<td>4.</td>
<td>Mentor Father, Atiak HC IV, Amuru District</td>
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<td>Nursing Assistant, Pabbo HC III, Amuru District</td>
</tr>
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<td>7.</td>
<td>Mid-wife, Patiko HC III, Gulu District</td>
</tr>
<tr>
<td>8.</td>
<td>Mentor Father, Patiko HC III, Gulu District</td>
</tr>
<tr>
<td>9.</td>
<td>Head, ART Unit, Layibi Techo, HC III, Gulu District</td>
</tr>
<tr>
<td>10.</td>
<td>Mid-wife, Layibi Techo, HC III, Gulu District</td>
</tr>
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<td>14.</td>
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<td>Nursing Assistant, Omiya Anyima HC III, Kitgum District</td>
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<td>26.</td>
<td>Midwife, Pabbo HC III, Amuru District</td>
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Annex 5: Photographs of some of the Beneficiaries in FSGs

Beneficiaries at Kitgum-Matidi Health Centre III, Gulu District in an FSG

Beneficiaries at Omia Anyima Health Centre III, Kitgum District in an FSG
Beneficiaries at Bobi Health Centre III, Gulu District in an FSG

Some of the Reading materials at youth corners
Medical worker sensitising the youths about SRHR and HIV at Kitgum-Matidi HC III
Annex 6: Categorization of Respondents

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