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## **University of Alberta**

Breastfeeding practices of HIV-positive and HIV-negative women in Kabarole District, Uganda

Suggested short title: Breastfeeding and HIV in Kabarole, Uganda

by

Esmé Lanktree



A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of

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## **Dedication**

I dedicate this study to the memory of Silvanos Otieno (1972-2007), a great friend and teacher who introduced me to the natural beauty of the land and the peoples of East Africa.

#### Abstract

Ugandan policy, for HIV-positive mothers, if feasible, is replacement feeding; otherwise exclusive breastfeeding (EBF) for three months is advised (six months if still unfeasible). HIV-negative mothers should follow six month EBF. The study objective was to explore maternal HIV status and breastfeeding practices in Kabarole, Uganda. Questionnaires were administered to 182 women (44 HIV+ and 138 HIV-) residing in Kabarole three months post-delivery, to assess infant feeding practices. Participant medical charts were reviewed. Focus groups conducted with healthcare workers involved in infant feeding education in Kabarole found that advice given corresponds to WHO and National guidelines. Multivariate analyses showed a negative association between child illness and urban residence and exclusive breastfeeding but no statistically significant association with maternal HIV status. More research is needed to determine the direction of association between child illness and exclusive breastfeeding. This region-specific information on breastfeeding practice determinants is relevant to MTCT programs.

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#### **List of Definitions**

AFASS (see acronyms): There is no social, economic, cultural or health-related

barrier or perceived barrier to replacement feeding.

Cessation of breastfeeding: A complete end to any form of breastfeeding (Linkages

2004)

Complementary food: Any food (solid or liquid) used to supplement or

complement an infant's breastmilk or alternative diet (ie.

Millet porridge, gripe water...) (Linkages 2004)

Exclusive Breastfeeding: Mode of infant feeding whereby the infant receives

mother's breastmilk only. The only exceptions are

vitamins, minerals, vaccines or medicines (WHO 2006).

HIV-negative: Refers to an individual, or group of people, who is/are

known to be HIV-negative, after a confirmed HIV test.

HIV-positive: Refers to an individual, or group of people, who is/are

known to be HIV-positive, after a confirmed HIV test.

Known HIV status: There is a record of the individual's HIV test results in

hospital records/medical files and the individual is aware of

his/her HIV status.

Mixed Feeding: Mode of infant feeding whereby the infant receives

mother's breastmilk and other liquids or solid foods

(Linkages 2004)

Replacement Feeding:

Mode of infant feeding whereby the infant receives a complete diet without any breastmilk (Linkages 2004; WHO 2006)

#### List of Acronyms

AFASS: Acceptable, feasible, affordable, sustainable and safe (the criteria for

replacement feeding in the context of HIV, according to the WHO)

AIDS: Acquired Immune Deficiency Syndrome

ART: Antiretroviral Therapy

ARV: Antiretroviral

DHMT: District Health Management Team

EBF: Exclusive breastfeeding

FPRRH: Fort Portal Regional Referral Hospital (Buhinga Hospital)

GI: Gastrointestinal illness

GTZ: Deutsche Gesellschaft für Technische Zusammenarbeit (German Agency

for Technical Cooperation)

HAART: Highly Active Antiretroviral Therapy

HC: Health Cente

HIV: Human Immunodeficiency Virus

IEC: Information, Education, Communication

JCRC: Joint Clinical Research Centre

MTCT: Mother to Child Transmission (of HIV)

MoH: Ministry of Health, Uganda

NGO: Non-Governmental Organization

PHS: Public Health Sciences

PLWHAs: Persons Living with HIV/AIDS

PMTCT: Prevention of Mother to Child Transmission

RTI: Respiratory tract infections

SRH: Sexual and Reproductive Health

SSA: Sub-Saharan Africa

STI: Sexually Transmitted Infection

TASO: The AIDS Support Organization

UNAIDS: Joint United Nations Programme on HIV/AIDS

UNCST: Uganda National Council of Science and Technology

UNICEF: United Nations Children's Fund

U of A: University of Alberta

VCT: Voluntary Counseling and Testing

WHO: World Health Organization

#### **Chapter 1: Introduction**

HIV/AIDS is a global epidemic but Sub-Saharan Africa has been the hardest hit region.

Uganda has widely been regarded as a success story in progress towards increasing awareness and decreasing transmission of the disease. Despite this success incidence has now stabilized, which, for a growing population, means increasing new cases each year (UNAIDS & WHO 2008).

Breastfeeding is seen as an important public health practice since it confers protective maternal antibodies to newborns, protecting them from common childhood diseases. However, up to 40% of pediatric HIV cases in Sub-Saharan Africa can be attributed to breastfeeding (Phillips 2007). Therefore, for HIV-positive mothers in developing countries, breastfeeding is only recommended when they do not have access to an appropriate, feasible, affordable, sustainable and safe substitute (AFASS) (WHO/UNICEF/UNFPA/UNAIDS 2003a). In this case, the World Health Organization (WHO) recommends exclusive breastfeeding (EBF) for a short period followed by an abrupt cessation, since exclusive breastfeeding entails a reduced risk of transmission compared to mixed feeding (Piwoz et al. 2006). The short EBF period is up to six months (WHO HIV and Infant Feeding Technical Consultation 2007). The national Policy for Reduction of the Mother-to-Child Transmission (MTCT) of HIV in Uganda states that if social or economic factors force an HIV-positive mother to breastfeed "then exclusive breast-feeding for about three months is recommended" (Ministry of Health, Uganda

2003). Six month exclusive breastfeeding is recommended if it is still unfeasible to stop breastfeeding at three months.

Research on determinants of breastfeeding in HIV-positive mothers is still limited. A study conducted in South Africa demonstrated that it is primarily mothers who are the decision-makers regarding their newborn's nutrition, but some mothers consult with health workers or grandmothers (Bland et al. 2002). In addition, a study suggested that, in Uganda, fathers and their relatives made decisions about weaning time (Pool et al. 2001). This demonstrates the importance of knowing which practices are common in this region of Uganda in order to address the causes and identify appropriate interventions to reduce mother-to-child transmission via breastfeeding.

The number of children born to HIV-positive women is approximately 1.6 million annually (WHO Secretariat 2002). While drugs to decrease MTCT are available, work must be done to ensure their accessibility to mothers even in remote locations. After birth, appropriate infant feeding choices can further limit the number of children who acquire the virus through this route. Successful ART treatment of pregnant and lactating mothers can minimize the risk of MTCT (Volmink et al., 2008). Reducing mother-to-child transmission of HIV is not only essential to decreasing morbidity and mortality in the vulnerable under-five age group, but it is also an investment in the health and future of the next generation.

#### **Chapter 2: Literature Review**

The literature review was conducted using the following databases: Medline, EMBASE, Global Health, Scopus and the Cochrane database of systematic reviews. Key words included: breastfeeding, breast feeding, breastfed, bottle feeding, HIV infections, Human Immunodeficiency Virus Infection, HIV, HIV seronegativity, HIV seropositivity, HIV-1, AIDS, Acquired Immune Deficiency Syndrome, Africa South of the Sahara, subsaharan Africa, HAART, ARV, antiretroviral, treatment, outcome, Africa, Uganda, Developing country, World Health Organization, WHO, UN, adherance, compliance, guidelines, policy, recommendations, consensus, randomized controlled trial, cohort analysis, prospective study, longitudinal, observational study, mother's milk, breastmilk. Articles not relevant for the literature review were excluded by title and abstract, leaving 37 sources. Searches were also conducted on the World Health Organization and Uganda Ministry of Health webpages, and additional literature review materials were provided by Ugandan colleagues.

#### 2.1: HIV in Sub Saharan Africa

#### Epidemiology

In 2007, the WHO announced that global prevalence of HIV had stabilized and incidence had decreased (UNAIDS & WHO, 2008). However, in 2007 the worldwide prevalence of HIV, according to the 2007 AIDS epidemic update, the joint UNAIDS and WHO report on the global status of the AIDS epidemic, was still estimated at 33.2 million people. The

incidence was estimated at 2.5 million people acquiring the virus per year. Deaths during 2007 totaled approximately 2.1 million (UNAIDS & WHO, 2008). For the population under 15 years of age, the estimates for annual prevalence, incidence and deaths were 2.1 million, 420 000 and 290 000 children, respectively (UNAIDS & WHO, 2008).

The largest portion of the HIV/AIDS burden rests on Sub-Saharan Africa, which in 2007 had a prevalence of 5%, an incidence of 1.7 million, and 1.6 million deaths (UNAIDS & WHO, 2007). Although these numbers had declined since 2001, the HIV burden on the continent is still huge, with 11.4 million orphans and 22.5 million PLWHAs (Persons Living with HIV/AIDS) in 2007 (UNAIDS & WHO, 2007). The majority (61%) of HIV-positive individuals in Sub-Saharan Africa are women (UNAIDS & WHO 2007).

Southern Africa has been the hardest hit with new infections and deaths due to HIV/AIDS representing 32% of the global figures in 2007 (UNAIDS & WHO 2008). In general, East African countries have seen decreasing prevalence rates, both due to mortality and behaviour modification (UNAIDS & WHO 2008), but HIV incidence has been raising again in recent years (personal communication Heiner Grosskurth, Director, MRC Uganda).

### Public Health Approach for MTCT

In a pooled analysis of Ugandan, Tanzanian and Malawian studies, Zaba et al. (2005) demonstrate a hazard ratio of 2.9 for infant death with an HIV-positive mother, compared

to a reference group of children born to HIV-negative mothers. A Ugandan study, based in Rakai, showed a lower hazard ratio of 2.0. (Brahmhatt et al. 2006). The hazard increased to 3.8 if the child is HIV-positive (Brahmhatt et al. 2006).

Mother-to-child transmission can be reduced during pregnancy (using antiretroviral therapy to decrease viral load), during labour (by safe hospital delivery and administration of short-course antiretrovirals such as Nevirapine to the mother and the newborn) and during the first months of life (appropriate feeding practices and antiretroviral treatment of the mother). MTCT rates increase with longer duration of breastfeeding but the first weeks are especially crucial (Magoni et al. 2005). Depending on the choice of infant feeding method, transmission rates can approach zero with replacement feeding, are higher with exclusive breastfeeding, and highest with mixed feeding. A Ugandan study demonstrated six month transmission rates of 3.7%, 16.0% and 20.4% for formula-fed, exclusively breastfed and mixed fed infants, respectively, compared to 3.4%, 11.2% and 17.1%, respectively at six weeks post-partum (Magoni et al., 2005). Despite the low risk of transmission from formula feeding, the disadvantages, discussed in the following section, outweigh the benefits for most women and their children in the developing world (Coutsoudis et al., 2008). Exclusive breastfeeding during the first 6 months followed by cessation of breastfeeding and introduction of replacement feed is currently the best practice for low-income countries (Coutsoudis et al., 2008).

The knowledge, role and perspectives of healthcare workers are essential to understand in order to implement appropriate public health interventions. Healthcare workers are key to the delivery of health services. However, they often operate in a "context of secrecy" due to stigma surrounding HIV, and the influence of cultural norms and authority figures, based on a study in southern African countries (Buskens et al, 2007).

Suryavanshi et al. (2003) conducted a prospective cohort study on 101 HIV-positive women antenatally, immediately post-delivery and two or more weeks post-natal. The same proportions of women were intending to breastfeed and to use replacement feed using diluted animal milk. Feeding choices were informed and influenced by the hospital counselor. Immediate post-delivery re-counseling was found to decrease mixed feeding. Factors contributing to choice of breastfeeding were financial reasons, hygiene and social stigma (Suryavanshi et al., 2003).

The BAN (Breastfeeding, Antiretroviral, and Nutrition) trial in Malawi conducted a qualitative study with healthcare workers and determined that some healthcare workers' perspectives differed from WHO guidelines (Piwoz et al., 2006). Conflicting professional and personal beliefs were cited as challenges to exclusive breastfeeding. In general, experienced healthcare workers were able to properly counsel HIV-positive women (Piwoz et al., 2006).

#### 2.2: Breastfeeding

#### Sub-Saharan African studies

Bland et al. (2002) conducted a longitudinal study of 130 women in South Africa and determined through interviews that exclusive breastfeeding was not common. Only about half of infants were exclusively breastfed during the first 48 hours post-delivery and less than 10% were exclusively breastfed by week 16. Mothers supplemented their infants' diets with formula, porridge, other solids or glucose water since breastmilk was seen as insufficient. The three principal infant feeding advice-givers were the women themselves (43%), health staff (22%) and grandmothers (16%). Bland et al. (2002) also conducted a cross-sectional study of 394 mothers. Mothers in the cross-sectional study recalled higher exclusive breastfeeding rates (47%, 40% and 33%, at 2, 6 and 12 weeks respectively) than in the longitudinal study (17%, 10% and 7%, respectively) (Bland et al. 2002).

De Paoli et al. (2001) conducted a cross-sectional study in Tanzania's Kilimanjaro region. Only fifty-four percent of the 309 multigravidas interviewed had exclusively breastfed in the first few days after birth. Focus group discussions identified causes of early introduction of complementary foods: the belief that an infant's thirst will not be satisfied by only breastmilk and the absence of the mother when she returns to work. Breastfeeding practices did not depend on the mother's knowledge of postnatal transmission of HIV through breastfeeding. Following focus group results, authors

reported that women perceived EBF advice as conflicting with their knowledge that HIV can be present in breastmilk, and were skeptical that mixed feeding could be a greater risk than EBF.

Lunney et al. (2008) showed a positive correlation between a mother's knowledge of HIV transmission, family support and disclosure of status with early breastfeeding cessation, through interviews with HIV-positive mothers in Zimbabwe. Early breastfeeding cessation was seen by mothers as important to minimize mother-to-child transmission of HIV (Lunney et al. 2008).

Shah et al. (2005) conducted a cross-sectional survey of 71 healthcare workers in Kwa-Zulu Natal, South Africa. They noted that healthcare workers' knowledge of breastfeeding (especially that of community health workers) did not mesh with the World Health Organization's guidelines. Although all doctors were aware HIV transmission could occur from breastfeeding, only 60% of professional nurses, 37% of staff nurses and 50% of community health workers recognized this mode of transmission. No community health worker identified all three MTCT modes (during pregnancy, at delivery, during breastfeeding), while only 4% of professional nurses, 62% of staff nurses, and 36% of doctors identified all three (Shah et al. 2005), which shows an important deficiency in knowledge.

A study on infant feeding practices assessed the average breastfeeding duration of women in western Uganda (including Kabarole district) to be 18 months (Poggensee et al. 2004).

Exclusive breastfeeding prevalence was 45.9% at four months and factors which were significantly associated with cessation of exclusive breastfeeding before the age of six months were residence (rural/urban/semi-urban), age group, occupation and ethnic group (Poggensee et al. 2004). The most common fluid introduced by mothers in western Uganda was milk (66%) and 70% of these women supplemented with milk only. Causes of early cessation of exclusive breastfeeding were identified as having insufficient milk, lack of time and health reasons (Poggensee et al. 2004).

#### Feasibility of best practice

Breastfeeding provides ideal nutrition to an infant (WHO Secretariat 2001) and is considered the best diet for newborns, as "only under exceptional circumstances can a mother's milk be considered unsuitable for her infant"

(WHO/UNICEF/UNFPA/UNAIDS 2003b). Since it is also widely accepted as the infant feeding norm throughout Sub-Saharan Africa, it is culturally accepted. It is also the economic choice, since no alternatives need to be purchased. Therefore theoretically, there should be few problems to adherence to six months exclusive breastfeeding. However, there are some cultural practices which involve supplementing a breastmilk diet and beliefs that breastmilk is insufficient. Improper latching techniques can also hinder proper breastfeeding and lead to complementary feeding at an early age. In the context of HIV, complementary feeding should be avoided; therefore these beliefs can cause problems for exclusive breast feeding (EBF) adherence. Before the HIV era, mothers in Kabarole were taught, by healthcare workers, to breastfeed exclusively for

four months followed by the gradual addition of solid food (personal communication Walter Kipp, professor, University of Alberta).

It may be possible to increase adherence to the international infant feeding guidelines due to the growing numbers of PLWHA on HAART (Highly Active Antiretroviral Therapy) therapy. According to the Consensus Statement of the WHO HIV and Infant Feeding Technical Consultation (2007), post-delivery MTCT may be reduced with HAART for treatment-eligible mothers.

According to the WHO HIV and Infant Feeding Technical Consultation (2007), "inaccurate, insufficient, or non-existent infant feeding counselling has led to inappropriate feeding choices by both HIV-infected and HIV-uninfected women." It is therefore essential to determine if infant feeding counseling is taking place and what information is being transmitted during counseling sessions in order to better understand local feeding practices and to address avenues for improvement. Best practice can only be achieved if infant feeding counseling is adequate to inform women of their options.

With the increasing commitment of governments and international organizations to the provision of HAART therapy to treatment-eligible persons, as well as the strengthening of already existing healthcare systems and additional training of community healthcare workers to improve counseling services, it is conceivable to bolster the implementation of best practice, which can translate to decreased postnatal transmission in the near future. However, this must involve the joint efforts of governments, communities, health

workers and international organizations since "no single intervention or group can succeed in meeting the challenge" (WHO Secretariat 2002).

#### Exclusive breastfeeding determinants

Factors affecting exclusive breastfeeding (EBF) have been demonstrated by various studies. Ssenyonga *et al.* (2004) demonstrated a positive correlation with health centre delivery and standard vaginal delivery, as well as a negative association with children over the age of three months and male gender of infant. This cross-sectional study took place in Rakai district in Uganda and involved a questionnaire administered to women with a child six months of age or younger. In this study exclusive breastfeeding was notably not affected by the mother's knowledge of her HIV status (Ssenyonga et al. 2004).

A difference in EBF during the first week post-partum was observed between HIV-positive and HIV-negative women, with HIV-positive women having higher EBF rates (Kamau-Mbuthia et al. 2008). They also noted the positive association between younger women and EBF at six weeks and that between higher birth weight and EBF at the tenth week mark (Kamau-Mbuthia et al. 2008).

Coutsoudis (2005) reported several risk factors for mother-to-child transmission of HIV through breastfeeding, including a strong positive association with advanced disease (low CD4 count), high plasma viral load, breast pathology, new HIV infection, HIV re-

infection and long breastfeeding duration, as well as a limited positive association with mixed feeding, high viral loads in breastmilk, maternal subclinical mastitis, infant oral candidiasis, low maternal vitamin levels (B, C and E).

Chisenga et al. (2005), in a Zambian study of both HIV-positive and HIV-negative women, reported a negative correlation between short EBF duration and first-time mothers, infant length by age at six weeks and positive correlation with women with systemic illness. There was a negative trend between socio-economic status and EBF duration, but it was not statistically significant (Chisenga et al., 2005).

#### Guidelines (description and critique)

The World Health Organization (WHO), UNICEF, UNFPA and UNAIDS have published recommendations for breastfeeding for both HIV-positive and HIV-negative mothers. According to these guidelines, for HIV-negative mothers, six months of exclusive breastfeeding should be practiced and subsequently, complementary nutritious foods should be added to the infant's diet. Mixed feeding (feeding both breastmilk and complementary food) can continue for two years or longer (WHO/UNICEF/UNFPA/UNAIDS 2003a). For HIV-positive mothers, avoidance of all breastfeeding is recommended. However, where this is not "acceptable, feasible, affordable, sustainable and safe" (AFASS), as is the case for the majority of women in the developing world, exclusive breastfeeding was recommended for the first six months (WHO/UNICEF/UNFPA/UNAIDS 2003a). Once stopped, breastfeeding should cease

completely. If these five criteria are still not met at six months, introduction of complementary foods can begin with ongoing breastfeeding until a safe and nutritious breastmilk alternative can be substituted (WHO HIV and Infant Feeding Technical Consultation 2007). There are also additional options such as heat-treating expressed breastmilk, or using breastmilk from another person (i.e. wet nursing or using breastmilk banks).

HIV-positive mothers should receive counseling while making, or reconsidering, their infant feeding choice, so that they can adopt a mode of breastfeeding or replacement feeding which is best suited for their circumstances. (WHO/UNICEF/UNFPA/UNAIDS 2003a; WHO HIV and Infant Feeding Technical Consultation 2007). Known HIV-positive infants should continue to breastfeed (with timely introduction of complementary solid foods), since there is no concern for acquiring HIV and they can benefit from the nutrition and antibodies in breastmilk (WHO HIV and Infant Feeding Technical Consultation 2007). Counseling should not just be for the HIV-positive mothers, since prevention of HIV acquisition of a breastfeeding HIV-negative mother is essential to the breastfeeding infant's HIV-free survival. This is important since transmission rates are higher when the mother is newly infected.

The rationale behind these guidelines is for optimal health of the mother and infant. Specifically in the context of HIV, a balance is required between the risk of HIV transmission to the child of an HIV-infected mother and the risk of mortality of a child who does not benefit from its mother's breastmilk (WHO Secretariat 2002). Breastmilk

provides antibodies, which are especially important in an environment where diarrhoeal disease and other common infectious causes of morbidity and mortality are very common. Replacement feeding, despite virtually eliminating the post-delivery risk of HIV acquisition, can increase infant mortality due to the risk of contamination. Current research supports six months exclusive breastfeeding for HIV-positive mothers in resource-poor settings, according to Coovadia and Kindra (2008).

With current knowledge on transmission and breastfeeding these guidelines seem appropriate. However, locally specific circumstances must be taken into consideration when determining infant feeding, especially in the context of HIV. Social and cultural norms may affect the adoption of these recommendations and may create the need for counselors to adopt feasibility and harm reduction strategies, counseling each woman individually or creating regional specific guidelines from the international recommendations.

#### 2.3: Uganda

The state of HIV/AIDS in Uganda with respect to MTCT

Uganda has been a success story in progress towards increasing awareness and decreasing transmission of HIV, with President Museveni acknowledging the epidemic in 1986, and subsequent work through the Uganda AIDS Commission and other partners (Kilian 2002). In 1995, a decrease in HIV prevalence was shown and in 2000, a decrease in annual deaths was demonstrated (Kilian 2002). But there is cause for concern

following evidence that incidence is on the rise (Uganda AIDS Commission 2007; Uganda HIV/AIDS Partnership Committee & Uganda AIDS Commission, 2007). Women's condom use with non-regular partners has increased but women's age at first sexual experience has decreased, and sex with non-regular partners had risen in both men and women (UNAIDS & WHO, 2007), indicating a change in behaviour towards higher risk practices. Prevalence is currently at 6.4% (Uganda HIV/AIDS Partnership & Uganda AIDS Commission, 2007). Prevalence is higher in urban (10%) compared to rural areas (6%), especially for women and peak prevalence is reached in women in the 30-34 age group and in men in the 35-44 age group (Uganda HIV/AIDS Partnership & Uganda AIDS Commission, 2007).

There were approximately 67,000 babies born to HIV-infected mothers in Uganda per year, based on 2003 estimates, 20,000 of whom will acquire the virus (Ministry of Health 2003). Estimates from 2005 are that 25,000 infants will have acquired HIV from their mothers (Uganda AIDS Commission 2007). While heterosexual contact is the primary route of infection at 76%, mother-to-child transmission rates in Uganda are estimated at 22%, according to The National HIV & AIDS Strategic Plan: 2007/8 – 2011/12 (Uganda AIDS Commission 2007). In order to halve the rate of vertical transmission, Uganda's Ministry of Health (2003) recommends a 200mg Nevirapine oral dose for the delivering mother followed by a Nevirapine syrup dose (2mg/kg) administered in the first three days of the infant's life; or 300mg Zidovudine taken by the mother twice daily from 36 weeks pregnant to labour onset, three times hourly until delivery, twice daily for a weekpost-delivery, and by the baby (Zidovudine syrup 4mg/kg) twice daily for one week; or the

Zidovudine regimen with the addition of 150mg Lamivudine twice daily from 36 weeks pregnant to one week post-delivery and 600mg Zidovudine at labour onset, and by the baby (Lamivudine syrup 2mg/kg) twice daily for one week).

According to the Uganda HIV/AIDS Sero-Behavioural Survey 2004-2005, awareness of AIDS is extremely high (99% in 15-49 year olds) although comprehensive knowledge is much lower at 28.3% and 35.8% for 15-49 year old women and men, respectively (Uganda AIDS Commission, 2006). Over half of respondents listed the radio as their primary information source. The main messages learned were the components of the ABC strategy (abstaining, being faithful, and using condoms), listed by 75.2% whereas prevention of mother-to-child transmission was only cited by 0.3% of respondents (Uganda AIDS Commission, 2006). Awareness of MTCT has increased by 12% in both female and male respondent groups since 2000-2001, and in 2004-2005 stood at 58% and 55%, respectively (Uganda AIDS Commission, 2006).

Despite awareness and attendance during antenatal sessions, reasons most women (both HIV-positive and HIV-negative) do not deliver in health facilities (see following section) include stigma, service quality and limited male involvement in antenatal care (Uganda HIV/AIDS Partnership & Uganda AIDS Commission 2007). During an assessment of MTCT knowledge by the Gesellschaft für Technische Zusammenarbeit (GTZ), which included health centers in Kabarole district, 67.1% of women and 78.3% of men knew HIV could be acquired by an infant during pregnancy or delivery, while more women

than men (59.4% vs. 40.8%) knew that HIV could be transmitted during breastfeeding (Harms et al. 2003).

The Mid-term Review Report on the National Strategic Framework for HIV/AIDS Activities in Uganda: 2000/1 – 2005/6 noted the limited access to PMTCT services (2% of mothers) and suggested scaling up in more health centers as well as involving males (Konde-Lule 2003). Healthcare workers' knowledge of PMTCT was assessed by GTZ in 2003 and Ugandan results showed that in response to an open question to name PMTCT methods, safe delivery practices (65%) was the most common answer, followed by no breastfeeding (26%), however, when asked directly, 81% knew transmission would be reduced by no breastfeeding (Harms et al. 2003).

The National HIV & AIDS Strategic Plan's second objective is to reduce MTCT by 50% by 2012 and proposes the following actions:

- "Integrate SRH services, especially family planning and HIV/AIDS service delivery targeting both women and men;
- Roll out PMTCT programme to all HC-IIIs;
- Explore innovative approaches to increase administration and uptake of PMTCT services including Nevirapine or ART combination prophylaxis and developing a homebased PMTCT program;
- Link mothers, fathers and babies to other prevention, care and treatment services;

- Enhance targeted communication for PMTCT highlighting roles and benefits to girls, pregnant women and their partners, parents and communities as well as facilitating engagement of male partners to provide appropriate support;
- Strengthen integration of food and nutrition support in PMTCT and maternal and child health programmes." (Uganda AIDS Commission 2007)

According to the Policy for Reduction of the Mother-to-Child HIV Transmission in Uganda, mothers who are HIV-positive should replacement feed, or exclusively breastfeed for three months if replacement feeding is not feasible (Ministry of Health, 2003). If replacement feeding after three month EBF is not feasible, then the EBF duration is extended to six months (personal communication Arthur Ssebuko, physician, FPRRH). The Ministry of Health (2003) also calls for breastfeeding and infant feeding counseling for HIV-positive women to enable an educated decision.

#### Kabarole District

#### Description of district

Kabarole district has an area just over 1800 square kilometers (Uganda Communication Commission, 2003). It is situated in Western Uganda and bordered by Kyenjojo district to the East, Kasese district to the South, Bundibugyo district to the North and West, and Kibale in the North-East (see Appendix A). The district is fertile with lush vegetation, 137,802 hectares of forest (Uganda Communication Commission, 2003), and is characterized by two rainy seasons per year. There are three hospitals in Kabarole

district: Kabarole hospital, Virika hospital and Fort Portal Regional Referral Hospital (Buhinga Hospital). All are located in Fort Portal Municipality. Virika hospital is a private, not-for-profit hospital, while Buhinga is a government hospital, and Kabarole is privately run by the Church of Uganda. The district also has two Health Centre IVs (Kibiito and Bukuuku) which are government-run. There are 16 Health Centre IIIs and 29 Health Centre IIs in Kabarole; of which 28 are government health centres, five are private, for-profit, and 12 are private, not-for-profit. Health Centre IVs represent the highest level of care for health facilities after the hospitals, followed by Health Centre IIIs and then Health Centre IIs. There is also an unknown number of unlicensed private clinics, often owned and run by government health care workers (personal communication, Walter Kipp, professor, University of Alberta). According to Kabarole district's current website, the HIV prevalence rate is 11.6% and 39% of deliveries are supervised. Seventy five percent of the population lives within a five kilometer radius of a health centre (Uganda Communication Commission, 2003).

Description of Fort Portal Regional Referral Hospital (FPRRH) maternity services

The FPRRH (Buhinga Hospital) is equipped with a labour ward and a maternity ward, as well as an antenatal clinic. The antenatal clinic (ANC) is located in a separate building from the labour and maternity wards and operates with its own specialized staff. The ANC staff comprises an in charge nurse and four other nursing officers, two of whom are specialized in PMTCT. The labour ward and maternity staff have approximately 15

healthcare workers, 13 nursing officers and two midwives (as of November 2007), as well as an obstetrics/gynecology surgeon.

## HIV testing and intervention

Kabarole district's population is aware of the presence of HIV/AIDS. The prevalence is relatively high (11.6%) (Uganda Communication Commission 2003) and there have been ongoing educational programs and scientific studies, including the University of Alberta's Community-based Antiretroviral (CB-ARV) study based in the Rwimi subcounty. The GTZ, in collaboration with the Ministry of Health, initiated a PMTCT project with Nevirapine in 2001 (Kilian, 2002). The Joint Clinical Research Centre (JCRC) provides laboratory services and ARV treatment to PLWHA and is situated in a building adjoining FPRRH (Buhinga Hospital). The Ugandan government provides HIV test kits and Nevirapine (to prevent mother-to-child transmission of HIV during delivery) free of charge to health facilities within the district. These are delivered to the District Health Office in Fort Portal, but there are still challenges in timely distribution to the health centers (personal communication, Arthur Ssebuko, physician, FPRRH). Therefore, prior to project recruitment, women presenting to deliver were not routinely being screened for HIV. Women are encouraged to attend antenatal sessions, and testing may take place during antenatal counseling.

#### PMTCT (especially via breastfeeding)

There is a lack of research on breastfeeding practices of HIV-positive mothers in Kabarole district. The Prevention of Mother-to-Child Transmission (PMTCT) program

initiated by Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ) was phased out in 2004. GTZ had been providing HIV-positive mothers with free formula and since the end of the program it was unclear what methods of infant feeding women were using and what counseling they were given regarding infant feeding. Nurses at the FPRRH (Buhinga Hospital) are instructed to recommend exclusive breastfeeding to HIV-positive mothers for either three or six months when mothers have no alternative option (personal communication Arthur Ssebuko, physician, FPRRH). PMTCT programs are run in health facilities throughout the district. However, services offered vary from basic counseling at some village level health centers to HIV testing and individual sessions at hospitals (personal communication Mathias Tumwebaze, Kabarole District Health Headquarters).

## **Chapter 3: Objectives**

The overall objective of this study is to explore the association between maternal HIV status and breastfeeding practices in Western Uganda. In addition, the congruency between the information transmitted to women through health system-based educational programs on infant feeding and actual infant feeding practices is assessed.

The following specific questions will be addressed:

- 1) At three months post-partum, are there differences in breastfeeding practices between HIV-positive and HIV-negative women?
- 2) What factors determine exclusive breastfeeding practices at three months?
- What information are HIV-positive and HIV-negative pregnant women and new mothers given regarding infant feeding?

## **Chapter 4: Methods**

## 4.1 – Study area:

The study was undertaken in the Kabarole district of Uganda. Although the participants were recruited from the FPRRH (Buhinga Hospital), the study involves mothers residing throughout the district.

## 4.2 - Study design:

This study has both a quantitative and a qualitative component. The first two research questions were addressed through interviews with mothers and medical chart reviews in a prospective cohort study, while two focus group studies of healthcare workers addressed the third question.

# 4.3.1 - Study Population – quantitative study:

The study population is comprised of a cohort of mothers, aged sixteen years and over, who delivered a live singleton baby at the Fort Portal Referral Hospital (Buhinga Hospital), in the Kabarole district of Uganda between June 20 and September 21, 2007.

# 4.3.2 – Study Population – qualitative study:

The study population is comprised of healthcare workers involved in antenatal or delivery care services and infant feeding education in Kabarole district.

## 4.4 - Sample size estimation – quantitative study

Sample size estimation was based on the proportions of exclusive breastfeeding in HIVpositive and HIV-negative women from the published literature and from discussions with local and Canadian physicians. It was expected that with a power of 90% and a 0.05 alpha, 44 HIV-positive and 132 HIV-negative (1:3 ratio) mothers were required to detect a difference if 90% of HIV-positive mothers and 70% of HIV-negative mothers exclusively breastfed for 3 months (personal communication Walter Kipp, professor, University of Alberta) (STATA 9.1 2005) (see Appendix E). Actual study power was 0.18 (see Appendix E). We would expect that the majority of the participants had received some infant feeding education, since these are women who deliver at a health facility and have an HIV test. HIV-positive mothers would be expected to exclusively breastfeed more than HIV-negative women since they would be informed of the importance of EBF versus mixed feeding for PMTCT (no participant chose to replacement feeding at delivery). Based on a conservative estimate of 8% for HIV prevalence and 700 deliveries in a 3 month period (personal communication Walter Kipp, professor, University of Alberta), 56 HIV+ mothers could potentially be recruited. This would allow the sample size to be attained even if the proportion of loss-to-follow-up reached 20%.

# 4.5.1 – Recruitment – quantitative study

Women who delivered at the Fort Portal Referral Hospital (Buhinga) during the study period were offered HIV testing and their contact information was recorded in order to locate them for interviews at a later date. The mothers were given information about the

nature of the study and asked for consent to be contacted at a later date. Stage 1 written consent or thumbprint if the woman could not provide written consent, was obtained at this time.

Currently, although the national guidelines stipulate HIV testing for women who present to deliver, HIV testing was not routinely provided at the time the study was conducted due to logistical problems in (personal communication Dr. Arthur Ssebuko, physician, FPRRH). Therefore financial incentives were given to nurses (the equivalent of just under one Canadian dollar per woman), and provisions were made for HIV test kits to be made available, if required, in order to ensure that testing was done during the study period. Nurses were encouraged to provide Nevirapine (as per national guidelines) to women and their newborns, to decrease the probability of mother-to-child transmission.

Sixty-one HIV-positive women delivered at FPRRH (Buhinga Hospital) within the study period. To obtain a one to three ratio of HIV-positive to HIV-negative women, 183 HIV-negative women were selected. Three HIV-negative women, who delivered on the same day as each HIV-positive woman, were to be chosen. This was not possible given the distribution of deliveries. Therefore, two HIV-negative women were chosen within 3 days for each HIV-positive woman where this was possible (56 women) and one HIV-negative woman closest in delivery date to the respective HIV-positive woman. The remaining five women were matched based on delivery date with one HIV-negative woman within 3 days of delivery date, and two additional HIV-negative women closest in

delivery date to the respective HIV-positive woman. The process used (minimax) minimized the delivery date discrepancy in the worst match.

A list of addresses and dates of delivery of these women was compiled and used to schedule visits taking into account the baby's age and logistical considerations. Kabarole district is a mountainous region with rainy seasons, one of which fell during the months of data collection. This made finding participants challenging. Kabarole district is divided into three counties (Fort Portal Municipality, Burahya and Bunyangabu). These are divided into a total of 14 subcounties, which each are sub-divided into parishes, which are groups of villages. There are 581 villages, according to the latest district records (personal communication Mathias Tumwebaze, Kabarole District Health Headquarters). Contact information obtained during Stage 1 recruitment included the names of the county, subcounty, parish and village of residence. The participant was also asked for a cellular phone number if she had one, or had access to one (so that the research assistant could call for directions), as well as the name of the village chairperson and directions to her house (i.e. which route to take from a known location, or who to ask for who could give directions). Many homes could only be reached by *boda boda* (small motorcycle) and when the rain formed streams over the roads, passengers had to disembark and find a way to cross. This limited the number of participants who could be found in any one day. Due to the project's time component, a schedule was made by grouping participants with similar delivery dates who lived in the same subcounties (or neighbouring subcounties). At about three months post-delivery, a research assistant visited the selected participants in their homes (or at a different location if more convenient or comfortable for the

participant). The research assistant (RA) ensured that the woman she found had delivered a baby three months prior at FPRRH (Buhinga Hospital). She also confirmed that the woman she found had the same name as the woman who was recruited during Stage 1 consent, in order to verify her identity. Each participant was read an information letter about the study and written consent to participate was obtained at this time. This was Stage 2 of the consent process. If the participant was not able to sign, a thumb print was used for consent (if an ink pad was not available, oral consent was obtained).

# 4.5.2 – Recruitment – qualitative study

# Focus Group 1:

All participants were selected from the Fort Portal Regional Referral Hospital (Buhinga Hospital). Four participants were randomly selected from the labour ward staff, of the 14 who were available to participate, and four were randomly selected from the five antenatal clinic staff who were available to participate.

### Focus Group 2:

Two Health Centre IIs and two Health Centre IIIs were randomly selected from the 29 Health Centre IIs and 16 Health Centre IIIs in the district. The two Health Centre IVs and the two other hospitals in the district (besides Buhinga Hospital) were also selected. A staff member involved in infant feeding education was randomly selected from each of these health facilities and invited to participate in a focus group session. Participants were informed that their transportation expenses would be reimbursed at the time of the focus group.

# 4.6 - Inclusion and Exclusion criteria – quantitative study

#### Inclusion criteria:

#### Mothers who:

- delivered a live singleton infant between June 20 and September 21, 2007 at FPRRH (Buhinga Hospital).
- have a known HIV status (previous HIV-positive confirmed test or current test result in their medical chart)
- reside in Kabarole district
- are 16 years of age or older
- have provided informed consent

#### Exclusion criteria:

#### Mothers whose:

- medical condition prohibits them from breastfeeding (based on documentation from hospital charts) – however no one was excluded for this criterion.
- infant has a medical condition which prohibits breastfeeding (i.e. cleft pallet)

  (based on documentation from hospital charts) however no one was excluded for this criterion.

# 4.7 - Data collection and entry

This study involved semi-structured interviews, medical chart reviews and focus groups, each with specific data collection and entry methods.

1) Structured questionnaires were administered to participating women between October 3, 2007 and January 8, 2008. The questionnaires, constructed in English, are based on Modules 2 and 6 of the Breastfeeding and Replacement Feeding Practices in the Context of Mother-to-Child Transmission of HIV (WHO 2006) (Appendices T-W). The questionnaires consist of both closed and open-ended questions. They were translated into Rutooro and then back translated into English by a different translator to verify accuracy. Modifications were done when inconsistencies were identified, but only minor modifications were necessary. The questionnaires were pre-tested in two sub-counties within Kabarole district to ensure proper interpretation of the questions and cultural appropriateness with three participants. Any changes to questions would have resulted in repetition of the translation procedure followed by another pre-test. However, no changes were necessary. Two interviewers were trained before the pre-test using role-play techniques and the principal investigator was present during the pre-test. One additional interviewer was hired after data collection had begun, but the same role play techniques were employed.

Each woman was interviewed once, about three months after delivery (from 91 days to 121 days post-delivery). Mean time to questionnaire administration was 95.8 days in the HIV-positive group and 97.4 days in the HIV-negative group. Fifteen women were randomly selected from the cohort and 13 of these were re-interviewed approximately one week following the first interview, as a reliability check. The other two women could not be found for the initial interview, so they were removed from the re-test group. The interviews were conducted by local research assistants in Rutooro. The principal

investigator checked the questionnaires for completeness on the day of the interview, except for questionnaires which were administered after departure of the principal investigator from the study area (due to the Ebola outbreak in Western Uganda). The research assistant was in regular contact with the principal investigator during this time and the hard copies of these questionnaires were checked upon receipt up to two weeks later. The research assistants who administered questionnaires were blinded to HIV status (unless HIV status was revealed to them by the study participant voluntarily during questionnaire administration). Questionnaire data were double entered into a Microsoft Access database to increase accuracy of data entry.

- 2) Medical chart reviews were conducted by the primary investigator, in order to maintain confidentiality. These data were double entered and combined with the questionnaire data. Medical chart data which was used in this study included delivery method, parity, and gestational age and birth weight of the newborn.
- 3) Two focus group sessions were conducted in English with healthcare professionals involved in antenatal care and breastfeeding education. Eight healthcare workers, all female, were invited to participate per session. One session was conducted by a local focus group expert with four hospital delivery staff and four antenatal clinic staff at FPRRH (Buhinga Hospital). The second was conducted by the principal investigator with nurses and midwives from seven different healthcare facilities (two HC IIs, two HC IIIs, two HC IVs and one hospital) at the District Health headquarters. Focus group sessions

were tape recorded and transcribed by the primary investigator and two research assistants.

#### 4.8 - Analyses

Quantitative analyses: Analyses included descriptive frequency distributions for all variables, chi-squared tests for categorical variables, t-tests for continuous variables and multivariate analyses (logistic regression using exclusive breastfeeding status at three months as the grouping variable) using Stata statistical software (STATA 9.1 2005). In order to verify the responses to the question on type of breastfeeding (to obtain a reliable representation of exclusive breastfeeding status), subsequent questions were asked on complementary feeding. Nine respondents had answers in the verification questions which differed from their inital response to the type of breastfeeding question. Of these one had reported exclusive breastfeeding when she had actually begun mixed feeding at two months post-partum. She was classified as not exclusively breastfeeding at three months post-partum. The remaining eight had reported non-exclusive breastfeeding when they had actually been exclusively breastfeeding until the infant was at least three months of age. These were classified in the exclusive breastfeeding status at three months.

For the logistic regression analyses, the dependent variable was exclusive breastfeeding status at around three months. The main independent variable of interest was HIV status (positive or negative) of the mother, while other independent variables were age of mother, delivery method and variables obtained from the questionnaires and medical charts found to have a p-value of 0.2 or lower on bi-variate analyses (illness of the child

between birth and three months, residence with cement floors) (see Table 5). The original model included exclusive breastfeeding status at three months and HIV status. Variables were added to this model individually. The model was checked for effect modification and confounding of all combinations of the variables in the model, by including them in the model and assessing by the changes in odds ratios of variables previously included in the model, whether effect modification or confounding took place. Overall model fit was tested using the Likelihood Ratio test (STATA 9.1 2005). The same procedures were followed for the bi-variate and multivariate analyses in the sensitivity analysis, where groups of individuals are excluded from the sample.

Qualitative analyses: Thematic analysis techniques were applied to the transcribed focus group data by the principal investigator. Subthemes, of patterns in breastfeeding teaching, for example, were grouped under major themes of interest, which generally corresponded to the question guide (Appendix Z). Each focus group was analyzed separately and the analyses were then combined.

#### 4.9 – Ethics approval

Ethical approval for this project was obtained by the Health Research Ethics Board of the University of Alberta (Appendix B) and the UNCST (Uganda National Council of Science and Technology) Uganda (Appendix C). Approval for the study was also given by the Director of Health (DHO) of Kabarole District (Appendix G).

### **Chapter 5: Results**

# **Quantitative findings:**

During the study period 336 women were identified as potential study participants. All were offered HIV tests and only three refused. The reason for refusal was not documented. The number of women from this group initially deemed eligible to participate (meeting the inclusion criteria) was 276. Of this sample, 61 were identified as HIV-positive. The sampling procedure was applied using minimax (see Chapter 4) to obtain a sample of 244 women (61 HIV-positive and 183 HIV-negative women). All 244 of these women agreed to be contacted at 3 months post-delivery. Of these, 182 (74.6%) completed the interview questionnaires. The reasons for the 62 women not completing the interviews were:

- Refusal to consent (1 or 1.6%)
- Safety concerns during the Ebola outbreak in Western Uganda (1 or 1.6%)
- Study participant gave wrong contact information during Stage 1 recruitment (18 or 29.0%)
- Study participant could not be found within four months post-delivery (7 or 11.3%)
- Relocation between Stage 1 and Stage 2 recruitment (9 or 14.5%)
- Did not meet inclusion criteria during questionnaire administration (10 or 19.3%)
- Information not obtained before commencement of data analysis (7 or 11.3%)

 Child died before questionnaire administration (7 or 11.3%). These women completed modified questionnaires but their information was not included in the final tables.

Of the 62 excluded women, 15 (24.2%) were HIV-positive and 47 (75.8%) were HIV-negative. The proportion of HIV-positive women is equivalent to that of the remaining participants in the study. The HIV status of participants was verified using multiple sources following selection of participants (since the principal investigator was blinded to HIV status during selection) and it was discovered that two women thought to be HIV-positive were in fact HIV-negative. Therefore the correct HIV prevalence in the study population recruited during Stage 1 was 21.4%. The characteristics of the 182 study participants are shown in Table 1 as a whole and by HIV status. At three months past-partum 117 (64.3%) of women were breastfeeding exclusively. One hundred eighty women (98.9%) were still breastfeeding at three months. The mean number of day and night feeds for these women were 6.1 and 3.6, respectively, with respective standard deviations of 2.6 and 1.6. Table 2 shows these characteristics by exclusive breastfeeding status at three months post-partum.

Table 1: Characteristics of the study population by HIV status in Kabarole district, Uganda, 2007 (n=182, unless indicated (n= n for HIV+; n for HIV-) )

|                                     | Mean ± SD or n (%) |                  |          |              |           |                  |         |
|-------------------------------------|--------------------|------------------|----------|--------------|-----------|------------------|---------|
| Variables                           | All                |                  | HIV+     |              | HIV-      |                  | p-value |
|                                     | (n                 | = 182)           | (1       | n=44)        | <u>(r</u> | ı=138)           |         |
|                                     |                    |                  |          |              |           |                  |         |
| Age in years                        | 24.1               | ± 5.8            | 24.1     | $\pm 5.3$    | 24.1      | $\pm 6.0$        | 0.992   |
| Tribe (ns=154;35; 119) <sup>a</sup> |                    |                  |          |              |           |                  |         |
| Batooro                             | 129                | (83.8)           | 30       | (68.2)       | 99        | (71.7)           | 0.722   |
| Religion (n=164;40; 124)            |                    |                  |          |              |           |                  |         |
| Christian                           | 159                | (97.0)           | 40       | (100.0)      | 119       | (96.0)           | 0.197   |
| Other                               | 5                  | (3.1)            |          |              |           |                  |         |
| Marital Status                      |                    |                  |          |              |           |                  |         |
| Married/Living w partner            | 121                | (66.5)           | 32       | (72.7)       | 89        | (64.5)           | 0.314   |
|                                     |                    | •                |          |              |           |                  |         |
| County                              | 4.4                | (24.2)           | 1.0      | (40.0)       | 26        | (10.0)           | 0.007   |
| Fort Portal Municipal.              | 112                | (24.2)<br>(61.5) | 18<br>23 | (40.9)       | 26<br>89  | (18.8)<br>(64.5) |         |
| Burahya<br>Bunyangabu               | 26                 | (01.3) $(14.3)$  | 3        | (52.3) (6.8) | 23        | (16.7)           |         |
| Builyunguou                         | 20                 | (11.5)           |          | (0.0)        | 23        | (10.7)           |         |
| Education                           |                    |                  |          |              |           |                  | 0.671   |
| No formal education                 | 14                 | (7.7)            | 3        | (6.8)        | 11        | (8.0)            |         |
| Some elementary                     | 102                | (56.0)           | 28       | (63.6)       | 74        | (53.6)           |         |
| Completed elementary                | 29                 | (15.9)           | 5        | (11.4)       | 24        | (17.4)           |         |
| More than elementary                | 37                 | (20.3)           | 8        | (18.2)       | 29        | (21.0)           |         |
| Employment                          |                    |                  |          |              |           |                  | 0.813   |
| Employed at home                    | 147                | (80.8)           | 35       | (79.6)       | 112       | (81.2)           |         |
| Partner employment                  |                    |                  |          |              |           |                  | 0.427   |
| (n=176;44; 132)                     |                    |                  |          |              |           |                  |         |
| Employed at home                    | 73                 | (41.5)           | 16       | (36.4)       | 57        | (43.2)           |         |
| Electricity - Yes                   | 11                 | (6.0)            | 2        | (4.6)        | 9         | (6.5)            | 0.632   |
| Household possessions <sup>b</sup>  |                    |                  |          |              |           |                  |         |
| Radio                               | 85                 | (46.7)           | 24       | (54.6)       | 61        | (44.2)           | 0.231   |
| Telephone                           | 36                 | (19.8)           | 6        | (13.6)       | 30        | (21.7)           | 0.240   |
| Lantern                             | 39                 | (21.4)           | 10       | (22.7)       | 29        | (21.0)           | 0.809   |
| Bicycle                             | 41                 | (22.5)           | 8        | (18.2)       | 33        | (23.9)           | 0.428   |

|  | Mean ± SD or n (%) |        |           |       |               |         |
|--|--------------------|--------|-----------|-------|---------------|---------|
| Variables                              | All                |        | HIV+      | ]     | HIV-          | p-value |
|  | (n=18)             | 2)     | (n=44)    | (n    | <b>=138</b> ) |         |
| Cupboards                              | 28 (15             | .4)    | 3 (6.8)   | 25    | (18.1)        | 0.071   |
| Fuel                                   |                    |        |           |       |               | 0.682   |
| Only firewood                          | 155 (85            | .6) 30 | 6 (83.7)  | 119   | (86.2)        |         |
| Other than firewood                    | 26 (14             | .4)    | 7 (16.3)  | 19    | (13.8)        |         |
| House composition                      |                    |        |           |       |               |         |
| Cement floor                           | 40 (22             | .0)    | 5 (11.4)  | 35    | (25.4)        | 0.051   |
| Iron sheet roof                        | 168 (92            | .3) 42 | 2 (95.5)  | 126   | (91.3)        | 0.368   |
| Brick wall                             | 40 (22             | •      | 6 (13.6)  |       | (24.6)        | 0.125   |
| Number of household occupants          | $4.2 \pm 1.9$      | . 3.7  | ' ± 1.4   | 4.4 ± | ± 2.0         | 0.020   |
| Gender of child                        |                    |        |           |       |               |         |
| Female                                 | 109 (59            | .9) 28 | 8 (63.6)  | 81    | (58.7)        | 0.560   |
| Mothers who have had children who died | 6 (3               | 3)     | 1 (2.3)   | 5     | (3.6)         | 0.662   |
| Child Sickness <sup>b</sup>            |                    |        |           |       |               |         |
| Sick since birth                       | 108 (59.           | 3) 24  | 4 (54.6)  | 84    | (60.9)        | 0.457   |
| RTI                                    | 81 (44.            | ,      | , ,       |       | (46.4)        | 0.368   |
| Fever                                  | 35 (19.            | ,      | ` /       |       | (18.1)        | 0.499   |
| GI                                     | 7 (3.              | *      | 2 (4.6)   | 5     | (3.6)         | 0.782   |
| Other/unknown                          | 9 (5.              |        | 4 (9.1)   | 5     | (3.6)         | 0.145   |
| Immunizations <sup>b</sup>             |                    |        |           |       |               |         |
| Visit 1                                | 180 (98.           | 9) 44  | 4 (100.0) | 136   | (98.6)        | 0.422   |
| Visit 2                                | 166 (91.           |        | (93.2)    |       |               |         |
| Visit 3                                | 71 (39.            |        | 9 (43.2)  |       |               |         |
| Antenatal session                      |                    |        |           |       |               |         |
| attendance                             | 181 (99.           | 5)     |           |       |               |         |
| Number of antenatal                    | $3.5 \pm 1.4$      | 3.7    | $\pm 1.8$ | 3.5 ± | = 1.3         | 0.407   |
| visits (n=179;43; 136)                 |                    |        |           |       |               |         |
| Knowledge of HIV                       |                    |        |           |       |               |         |
| transmission through                   |                    |        |           |       |               |         |
| breastfeeding                          |                    |        |           |       |               | 0.295   |
| Yes                                    | 163 (89.           | 6) 38  | 8 (86.4)  | 125   | (90.6)        |         |
| No                                     |                    |        | (2.3)     |       | (4.4)         |         |
| Don't know                             | 12 (6.             | 6) 5   | 5 (11.4)  | 7     | (5.1)         |         |

|  | Me            |                |                |         |
|--|---------------|----------------|----------------|---------|
| Variables                                | All           | HIV+           | HIV-           | p-value |
| ·  | (n= 182)      | (n=44)         | (n=138)        |         |
| Source of breastfeeding                  |               |                |                |         |
| advice                                   | 440 (04.0)    |                | 444 (00.1)     | 0.799   |
| HCW                                      | 148 (81.3)    | 37 (84.1)      | 111 (80.4)     |         |
| Grandmother                              | 12 (6.6)      | 2 (4.6)        | 10 (7.3)       |         |
| Other                                    | 22 (12.1)     | 5 (11.4)       | 17 (12.3)      |         |
| Preferred EBF at 3 months                | 123 (67.6)    | 29 (65.9)      | 94 (68.1)      | 0.785   |
| 3 mos EBF                                | 117 (64.3)    | 25 (56.8)      | 92 (66.7)      | 0.235   |
| Support of family (n=181;43; 138)<br>Yes | 175 (96.7)    | 41 (95.4)      | 134 (97.1)     | 0.575   |
| Delivery method<br>Vaginal delivery      | 160 (87.9)    | 36 (81.8)      | 124 (89.9)     | 0.154   |
| Gestational age (n=162;41; 121)          | 37.2 ± 1.3    | $36.8 \pm 1.7$ | $37.3 \pm 1.2$ | 0.026   |
| Parity (n=178;44; 134)<br>Primigravida   | 61 (34.3)     | 18 (40.9)      | 43 (32.1)      | 0.285   |
| Weight (n=175;42; 133)                   | $3.2 \pm 0.4$ | $3.1 \pm 0.4$  | $3.2 \pm 0.4$  | 0.130   |

 $<sup>^{</sup>a}$ ns = total n ; n for HIV-positive ; n for HIV-negative  $^{b}$ not mutually exclusive

Table 2: Characteristics of the study population in Kabarole district, Uganda, by exclusive breastfeeding status at three months post-partum

|  | Mean ± SD or n (%)  |        |      |                        |         |  |
|--|---------------------|--------|------|------------------------|---------|--|
| Variables  | EBF at 3 mo (n=117) |        | Not  | EBF at 3<br>ths (n=65) | p-value |  |
| HIV  |                     |        |      |                        |         |  |
| Positive   | 25                  | (21.4) | 19   | (29.2)                 | 0.235   |  |
| Age in years                                     | 24.3                | ± 5.9  | 23.7 | ± 5.7                  | 0.509   |  |
| Tribe (n=154;98; 56)<br>Batooro                  | 81                  | (82.7) | 48   | (85.7)                 | 0.620   |  |
| Religion (n=164;104; 60)<br>Christian            | 101                 | (97.1) | 58   | (96.7)                 | 0.872   |  |
| Marital Status<br>Married/Living with<br>partner | 80                  | (68.4) | 41   | (63.1)                 | 0.468   |  |
| County   |                     |        |      |                        | 0.031   |  |
| Fort Portal Municipality                         |                     | (17.9) |      | (35.4)                 |         |  |
| Burahya  | 78                  | (66.7) | 34   | (52.3)                 |         |  |
| Bunyangabu                                       | 18                  | (15.4) | 8    | (12.3)                 |         |  |
| Education  |                     |        |      |                        | 0.366   |  |
| No formal education                              | 12                  | (10.3) | 2    | (3.1)                  |         |  |
| Some elementary                                  |                     | (53.9) |      | (60.0)                 |         |  |
| Completed elementary                             |                     | (16.2) | 10   | (15.4)                 |         |  |
| More than elementary                             | 23                  | (19.7) | 14   | (21.5)                 |         |  |
| Employed at home                                 | 94                  | (80.3) | 53   | (81.5)                 | 0.844   |  |
| Partner employed at home (n=176;113; 63)         | 48                  | (42.5) | 25   | (39.7)                 | 0.718   |  |
| Electricity                                      | 8                   | (6.8)  | 3    | (4.6)                  | 0.547   |  |
| Household possessions                            |                     |        |      |                        |         |  |
| Radio  | 53                  | (45.3) | 32   | (49.2)                 | 0.610   |  |
| Telephone  | 25                  | (21.4) | 11   | (16.9)                 | 0.471   |  |
| Lantern  | 25                  | ,      | 14   | (21.5)                 | 0.979   |  |
| Bicycle  | 27                  | (23.1) | 14   | (21.5)                 | 0.812   |  |
| Cupboards  | 17                  | (14.5) | 11   | (16.9)                 | 0.668   |  |

|                               | Mean ± SD or n (%) |               |         |  |  |
|-------------------------------|--------------------|---------------|---------|--|--|
| Variables                     | EBF at 3 months    | Not EBF at 3  | p-value |  |  |
| ,                             | (n=117)            | months (n=65) | P /     |  |  |
|                               |                    |               |         |  |  |
| Fuel (n=181;117; 64)          |                    |               | 0.932   |  |  |
| Only firewood                 | 100 (85.5)         | 55 (85.9)     |         |  |  |
| Other than firewood           | 17 (14.5)          | 9 (14.1)      |         |  |  |
| House composition             |                    |               |         |  |  |
| Cement floor                  | 22 (18.8)          | 18 (27.7)     | 0.165   |  |  |
| Iron sheet roof               | 109 (93.2)         | 59 (90.8)     | 0.562   |  |  |
| Brick wall                    | 25 (21.4)          | 15 (23.1)     | 0.790   |  |  |
| DITOR WAIL                    | 25 (21.1)          | 15 (23.1)     | 0.750   |  |  |
| Number of household occupants | $4.3 \pm 1.9$      | $4.1 \pm 1.8$ | 0.605   |  |  |
|                               |                    |               |         |  |  |
| Gender of child               |                    |               |         |  |  |
| Female                        | 67 (57.3)          | 42 (64.6)     | 0.332   |  |  |
| Mothers who have had          | 5 (4.3)            | 1 (1.5)       | 0.322   |  |  |
| children who died             |                    |               |         |  |  |
| Child Sickness                |                    |               |         |  |  |
| Sick since birth              | 61 (52.1)          | 47 (72.3)     | 0.008   |  |  |
| RTI                           | 46 (39.3)          | 35 (53.8)     | 0.059   |  |  |
| Fever                         | 19 (16.2)          | 16 (24.6)     | 0.169   |  |  |
| GI                            | 2 (1.7)            | 5 (7.7)       | 0.044   |  |  |
| Other/unknown                 | 6 (5.1)            | 3 (4.6)       | 0.878   |  |  |
|                               | , ,                | ,             |         |  |  |
| Immunizations                 |                    |               |         |  |  |
| Visit 1                       | 116 (99.2)         | 64 (98.5)     | 0.672   |  |  |
| Visit 2                       | 109 (93.2)         | 57 (87.7)     | 0.212   |  |  |
| Visit 3                       | 42 (35.9)          | 29 (44.6)     | 0.248   |  |  |
| Number of antenatal visits    | $3.5 \pm 1.5$      | $3.5 \pm 1.2$ | 0.718   |  |  |
| (n=179;115; 64)               |                    |               |         |  |  |
| Knowledge of HIV              |                    |               |         |  |  |
| transmission through          |                    |               |         |  |  |
| breastfeeding                 |                    |               | 0.843   |  |  |
| Yes                           | 105 (89.7)         | 58 (89.2)     |         |  |  |
| No                            | 5 (4.3)            | 2 (3.1)       |         |  |  |
| Don't know                    | 7 (6.0)            | 5 (7.7)       |         |  |  |

|                                 | Mean ± SD       |                  |         |
|---------------------------------|-----------------|------------------|---------|
| Variables                       | EBF at 3 months | Not EBF at 3     | p-value |
| D (C 1)                         | (n=117)         | months (n=65)    | 0.246   |
| Breastfeeding advice            | 0.7 (0.4.7)     | <b>50</b> (04 5) | 0.246   |
| HCW                             | 95 (81.2)       | 53 (81.5)        |         |
| Grandmother                     | 10 (8.6)        | 2 (3.1)          |         |
| Other                           | 12 (10.3)       | 10 (15.4)        |         |
| Preferred EBF at 3 months       | 108 (92.3)      | 15 (23.1)        | < 0.001 |
| Support of family               |                 |                  |         |
| (n=181;116; 65)                 | 111 (95.7)      | 64 (98.5)        | 0.318   |
| Delivery method                 |                 |                  |         |
| Vaginal delivery                | 102 (87.2)      | 58 (89.2)        | 0.684   |
| Gestational age (n=162;103; 59) | $37.1 \pm 1.5$  | $37.3 \pm 1.0$   | 0.249   |
| Parity (n=178;114; 64)          |                 |                  |         |
| Primigravida                    | 41 (36.0)       | 20 (31.3)        | 0.525   |
| Weight (n=175;112; 63)          | $3.2 \pm 0.4$   | $3.2 \pm 0.4$    | 0.575   |
|                                 |                 |                  |         |

Bi-variate analyses are presented in Table 3 with odds ratios and the corresponding p-value. Results for exclusive breastfeeding status at three months post-partum are also presented with the sum total of each variable group as the denominator.

Table 3: The association between HIV status and other covariates on exclusive breastfeeding status at 3 months post-partum, Kabarole district, Uganda, 2007 (bi-variate analysis)

| Variables (n=182, unless indicated) | n (%) EBF at<br>3mo | OR (95% CI)      | p-value |
|-------------------------------------|---------------------|------------------|---------|
| HIV                                 |                     |                  |         |
| Positive                            | 25 (56.8)           | 1.00 (Reference) |         |
| Negative                            | 92 (66.7)           | 1.52 (0.76-3.04) | 0.239   |
| Age in years                        |                     | 1.02 (0.97-1.07) | 0.504   |

| Variables (n=182, unless          | n (% | %) EBF at | OR   | (95% CI)    | p-value |
|-----------------------------------|------|-----------|------|-------------|---------|
| indicated)                        | 3mc  | )         |      |             |         |
|                                   |      |           |      |             |         |
| Tribe (n=154)                     |      |           |      |             |         |
| Other                             | 17   | (68.0)    |      | (Reference) |         |
| Batooro                           | 81   | (62.8)    | 0.79 | (0.32-1.98) | 0.618   |
| D !! ! ( 164)                     |      |           |      |             |         |
| Religion (n=164)                  | 2    | (((0,0)   | 1.00 | (D. C. )    |         |
| Other                             | 3    | (60.0)    |      | (Reference) | 0.073   |
| Christian                         | 101  | (63.5)    | 1.16 | (0.19-7.15) | 0.873   |
| Marital Status                    |      |           |      |             |         |
| Married/Living with               | 80   | (66.1)    | 1.00 | (Reference) |         |
| partner                           | 80   | (00.1)    | 1.00 | (Reference) |         |
| Not living with partner           | 37   | (60.7)    | 0.79 | (0.42-1.49) | 0.470   |
| Not hving with partier            | 31   | (00.7)    | 0.77 | (0.42-1.47) | 0.470   |
| County                            |      |           |      |             |         |
| Fort Portal Municipality          | 21   | (47.7)    | 1.00 | (Reference) |         |
| Burahya                           | 78   | (69.6)    |      | (1.23-5.14) | 0.012   |
| Bunyangabu                        | 18   | (69.2)    |      | (0.89-6.84) | 0.084   |
| Dunyangaba                        | 10   | (0).2)    | 2.10 | (0.0) 0.01) | 0,001   |
| Education                         |      |           |      |             |         |
| No formal education               | 12   | (85.7)    | 1.00 | (Reference) |         |
| Some elementary                   | 63   | ` '       |      | (0.06-1.27) | 0.391   |
| Completed elementary              | 19   | (65.5)    |      | (0.06-1.70) | 0.319   |
| More than elementary              | 23   | (62.2)    |      | (0.05-1.41) | 0.492   |
| ·                                 |      | , ,       |      | ,           |         |
| Employed at home                  | 94   | (63.9)    | 0.93 | (0.43-2.01) | 0.844   |
|                                   |      |           |      |             |         |
| Partner employed at home          | 48   | (65.8)    | 1.12 | (0.60-2.10) | 0.718   |
| (n=176)                           |      |           |      |             |         |
|                                   |      |           |      |             |         |
| Electricity                       | 8    | (72.7)    | 0.66 | (0.17-2.58) | 0.539   |
| YT 1 11 '                         |      |           |      |             |         |
| Household possessions             | 52   | (62.4)    | 1 17 | (0 (4 0 15) | 0.611   |
| Radio                             | 53   | (62.4)    |      | (0.64-2.15) | 0.611   |
| Telephone                         |      | ` /       |      | (0.34-1.64) | 0.467   |
| Lantern                           | 25   | ` ,       |      | (0.48-2.11) | 0.979   |
| Bicycle                           | 27   | ,         |      | (0.44-1.90) | 0.811   |
| Cupboards                         | 17   | (60.7)    | 1.20 | (0.52-2.74) | 0.670   |
| Eugl (n=101)                      |      |           |      |             |         |
| Fuel (n=181)                      | 100  | (64.5)    | 1 00 | (Pafaranaa) |         |
| Only firewood Other than firewood | 100  | (64.5)    |      | (Reference) | 0.022   |
| Omer man nrewood                  | 17   | (65.4)    | 1.04 | (0.43-2.49) | 0.932   |
| House composition                 |      |           |      |             |         |

| Variables (n=192 unless    | - (0 | / \ <b>FDF</b> a4 | OD (059/ CI)      | n volue |
|----------------------------|------|-------------------|-------------------|---------|
| Variables (n=182, unless   | 3ma  | %) EBF at         | OR (95% CI)       | p-value |
| indicated) Cement floor    | 22   |                   | 0.60 (0.30-1.24)  | 0.170   |
|                            |      | ` ′               | ` ,               |         |
| Iron sheet roof            | 109  | ` '               | 1.39 (0.46-4.18)  | 0.566   |
| Brick wall                 | 25   | (62.5)            | 0.91 (0.44-1.87)  | 0.790   |
| Number of household        |      |                   | 1.04 (0.89-1.23)  | 0.601   |
| occupants                  |      |                   |                   |         |
| Gender of child            |      |                   |                   |         |
| Female                     | 67   | (61.5)            | 1.00 (Reference)  |         |
| Male                       | 50   | (68.5)            | 1.36 (0.73-2.55)  | 0.331   |
|                            |      | ,                 |                   |         |
| Mothers who have had       | 5    | (83.3)            | 2.86 (0.33-25.00) | 0.294   |
| children who died          |      |                   |                   |         |
| Child Sickness             |      |                   |                   |         |
| Sick since birth           | 61   | (56.5)            | 0.42 (0.22-0.80)  | 0.009   |
| RTI                        | 46   | (56.8)            | 0.56 (0.30-1.02)  | 0.059   |
| Fever                      | 19   | ` ,               | 0.59 (0.28-1.25)  | 0.175   |
| GI                         |      | (28.6)            | 0.21 (0.04-1.11)  | 0.050   |
| Other/unknown              | 6    | ` '               | 1.12 (0.27-4.62)  | 0.878   |
| Other/unknown              | U    | (00.7)            | 1.12 (0.27-4.02)  | 0.676   |
| Immunizations              |      |                   |                   |         |
| Visit 1                    | 116  | (64.4)            | 1.81 (0.11-29.47) | 0.678   |
| Visit 2                    | 109  | (65.7)            | 1.91 (0.68-5.36)  | 0.221   |
| Visit 3                    | 42   | (59.2)            | 0.70 (0.37-1.29)  | 0.249   |
| Number of antenatal visits |      |                   | 1.04 (0.83-1.30)  | 0.715   |
| (n=179)                    |      |                   | 1.01 (0.05 1.50)  | 01,15   |
| Vnowledge of HIV           |      |                   |                   |         |
| Knowledge of HIV           |      |                   |                   |         |
| transmission through       |      |                   |                   |         |
| breastfeeding              | 105  | ((1.4)            | 1.00 (D - f )     |         |
| Yes                        |      | (64.4)            | 1.00 (Reference)  | 0.600   |
| No                         |      | (71.4)            | 1.38 (0.26-7.34)  | 0.688   |
| Don't know                 | 7    | (58.3)            | 0.77 (0.23-2.55)  | 0.285   |
| Breastfeeding advice       |      |                   |                   |         |
| HCW                        | 95   | (64.2)            | 1.00 (Reference)  |         |
| Grandmother                | 10   |                   | 2.79 (0.59-13.21) | 0.423   |
| Other                      | 12   | (54.5)            | 0.67 (0.27-1.65)  | 0.175   |
|                            |      | (**)              | ,                 |         |
| Preferred to EBF at 3 mos  | 108  | (87.8)            | 40 (16.40-97.58)  | < 0.001 |
| Support of family (n=181)  | 111  | (63.4)            | 0.35 (0.04-3.03)  | 0.289   |
| capport of family (ii 101) |      | (55)              | (3.55 (3.5.5.5)   | 0.20)   |

| n (%) EBF at<br>3mo | OR (95% CI)                          | p-value        |
|---------------------|--------------------------------------|----------------|
|                     |                                      |                |
| 15 (68.2)           | 1.00 (Reference)                     |                |
| 102 (63.8)          | 0.82 (0.32-2.13)                     | 0.682          |
|                     | 0.84 (0.63-1.13)                     | 0.222          |
|                     |                                      |                |
| 73 (62.4)           | 1.00 (Reference)                     |                |
| 41 (67.2)           | 1.24 (0.64-2.37)                     | 0.523          |
|                     | 0.81 (0.39-1.68)                     | 0.572          |
|                     | 3mo  15 (68.2) 102 (63.8)  73 (62.4) | 3mo  15 (68.2) |

A multivariate logistic regression was performed, using independent variables thought to be related to the outcome (HIV status, age of mother and delivery method) and variables with p-values of less than 0.2 in the univariate analyses (child not sick since birth and cement floor). The variables RTI (respiratory tract infection), fever and GI (gastrointestinal illness) were not included since they are represented in the model by the variable for child illness. Preference of the mother to exclusively breastfeed was not included in the model. This would overshadow the other variables in the model and therefore is only presented in the previous tables. The original model included HIV status and the final model only differed by the addition of the variable for illness of child (see Table 6). Potential confounders (delivery method, age of mother and type of flooring) were checked but none was identified as significant. The interaction term between HIV status and child illness was tested but did not improve the model, therefore it was not included. Overall model fit was assessed using the Likelihood Ratio test. This test produced a p-value of 0.042 and the Likelihood Ratio chi-squared is 13.19 (STATA 9.1 2005).

Table 4: Determinants of exclusive breastfeeding status at 3 months post-partum, Kabarole district, Uganda, 2007 (multivariate analysis)

| Determinants (n=182)    | OR   | 95% CI      | p-value |
|-------------------------|------|-------------|---------|
| HIV status - negative   | 1.36 | 0.64 - 2.89 | 0.418   |
| Child sick since birth  | 0.40 | 0.21 - 0.79 | 0.008   |
| Residence in Burahya    | 2.43 | 1.15 - 5.13 | 0.020   |
| Residence in Bunyangabu | 2.18 | 0.75 - 6.34 | 0.152   |

### Inconsistencies

Inconsistencies were identified between the information in the questionnaires and the medical charts (four or more years of difference in mother's age and difference in sex of the infant). Therefore, the analyses were redone following the same method as above, but omitting participants with discrepancies. Analyses were conducted with differences in sex alone omitted (Tables 3c and 4c; n=158), differences in age alone omitted (Tables 3b and 4b; n=143), and both sex and age differences omitted (Tables 3a and 4a; n=131). See Appendix AA for tables. In general, similar results were obtained from additional analyses of data where inconsistencies were omitted. No effect modification was found. The multivariate models demonstrated that exclusive breastfeeding status at three months was positively associated with no child illness since birth. Residence in Fort Portal Municipality was negatively associated with exclusive breastfeeding status when all inconsistencies were omitted and also in the model with only infant sex inconsistencies omitted. In the analyses where sex differences were omitted, and where both sex and age differences were omitted, an additional independent variable was included in the model. This was a socio-economic variable (cement flooring was negatively associated with

exclusive breastfeeding) and suggests that socio-economic status may also affect exclusive breastfeeding status at three months post-partum (Appendix AA).

## Mothers with infants who died before questionnaire administration

Of the seven women who were excluded from previous analyses due to the death of their infant before questionnaire administration, four were HIV-positive and three were HIV-negative. Five were exclusively breastfeeding, four of whom planned to continue for six months and one planned to continue exclusive breastfeeding for three months. Two of these children died of unknown causes, and three children died of fever or malaria. Of the remaining mothers, one gave gripe water at birth and the child died of unknown cause within one day. The other gave tinned milk from birth to one week, when the child died. The cause of death given was that the child was underweight. Three of the four HIV-positive mothers had notes in their medical charts indicating that Nevirapine was administered.

#### Introduction of additional food

Of the 65 women who introduced food other than breastmilk into their child's diet before the age of three months, 61 (93.8%) introduced animal milk. One mother introduced tinned milk, five gave millet porridge, one supplemented with soya porridge and one gave water. The average age of introduction was 7 weeks for animal milk (with most, 42 mothers, introducing animal milk at 8 weeks) and 9 weeks for millet porridge. The duration of supplementary feeding was ongoing in all cases, with the exception of one

mother who fed millet porridge to her child for a period of two weeks. The reason for cessation was not ascertained during questionnaire administration.

Table 5: Number and proportion of mothers who introduced different foods before the age of three months with respective mean age at introduction (n=65)

| Food introduced | n (%)     | Mean time of introduction |
|-----------------|-----------|---------------------------|
|                 |           | (weeks)                   |
| Animal milk     | 61 (93.8) | 7                         |
| Millet porridge | 5 (7.7)   | 9                         |
| Tinned milk     | 1 (1.5)   | 10                        |
| Soya porridge   | 1 (1.5)   | 8                         |
| Water           | 1 (1.5)   | 3                         |

# <u>Differences in Preferred and Actual Exclusive Breastfeeding</u>

Fifteen women, whose preferred method of infant feeding was exclusive breastfeeding for at least three months, were not exclusively breastfeeding at three months post-partum. The reasons given for the difference in practice were insufficient breastmilk (9 responses or 60.0%), mother's absence (4 responses or 26.7%) and health of the mother or baby (2 responses or 13.3%).

## Administration of Nevirapine and Breastfeeding counseling at delivery

Nevirapine information was present in the medical charts of 33 study participants (75% of HIV-positive participants). This indicates that for 25% of HIV-positive women, either Nevirapine was not administered, or the healthcare worker present failed to note this in the chart. Breastfeeding information was only present in the medical charts of five study

participants, suggesting that breastfeeding counseling is either rarely practiced at the time of delivery, or that it is not routinely being written in the woman's medical chart.

# Breastfeeding Interruption and Wet Nurses

Only one of the two study participants who interrupted breastfeeding gave a reason for this interruption. She explained that she did not have breastmilk because she was sick.

One woman used a wet nurse, her mother-in-law, since she delivered by caesarian section and was weak from the operation.

## **Qualitative Findings:**

The following results were obtained through two focus group discussions with healthcare workers involved in infant feeding counseling throughout the district.

# Timing and location of breastfeeding counseling

Women may be counseled on breastfeeding pre-delivery, during family planning sessions, HIV voluntary counseling and testing (VCT), antenatal visits and PMTCT clinics. They may also receive breastfeeding counseling during delivery and after delivery during follow-up or post-natal exams and immunizations. This counseling is mainly conducted at the health centres but may also be done during home visits or outreach activities.

#### Number of women counseled

Number of women counseled varies in each health facility with between 25 and 100 women being counseled per month at each health centre, while hospitals counsel between ten and twenty women per day.

## Counseling methods

The method used for counseling depends on the facility and on the HIV status of the woman. Generally there are group education sessions which cater to all women and following HIV testing there are individual counseling sessions for HIV-positive women. The duration of each session also varies and can range from five minutes (usually for individual sessions) to half an hour (for group education sessions).

# Healthcare worker training

The training healthcare workers received was limited to their formal education in midwifery or nursing, except for a few participants who had participated in bi-annual PMTCT sessions.

## Knowledge communicated during counseling

Breastfeeding information transmitted to women during breastfeeding education sessions included how to put baby on the breast. For example: "we always tell the mother to sit upright and have enough time and hold the baby with the nipples being well attached." Women participating in these sessions are also instructed in the benefits and nutritional value of breastmilk. They are also told to stop breastfeeding and to see a healthcare professional if sores develop on baby's mouth or the mother's breast, in the case of HIV-positive mothers, since: "this baby may be delivered when its HIV negative and due to the cracked nipples, she gets the infection in the baby."

#### Breastfeeding recommendations

For HIV-negative mothers, the local healthcare providers recommend exclusive breastfeeding for six months, or four months in certain situations, and to continue breastfeeding while introducing supplementary feeds up until the age or two or three years. Examples from the focus groups illustrate that "after six months, after the introduction of the weaning feeds, we [midwives and nurses] still encourage the mother

to continue feeding her baby up to 24 months" and "when the baby suckles and you think it feels can suckle more then at around 4 [months] you can give [additional food]."

HIV-positive mothers are counselled to exclusively breastfeed for either three or six months. Exclusive breastfeeding is taught: "We tell the mother to breast feed and not give any other thing." But in other cases if "she [the mother] decides not to breast feed, [we advise] not to put her baby on the breast only to give feed only." The duration of exclusive breastfeeding "will depend on positive mothers sometimes it's three months, sometimes it is six months." There was also a belief that "the first 3 months is always acceptable for them to give the baby [...] breastfeeding because it is believed that within the first 3 months the baby still have the antibodies which she got from the mother during the intrauterine life."

#### Weaning

Participants were aware that the start of the proposed weaning time was six months, but that this was not always feasible: "in the learning they say six months, but if you are a working lady, will you start weaning your child at six months? You are even leaving her at home after one month and a half. You can start at two months, it will depend." Guidelines were seen as unclear for the length of the weaning period.

#### Exclusive breastfeeding

The concept of exclusive breastfeeding was well understood: "Here the mother feeds the baby on the breastmilk only, without any other artificial addition feed" but "for the

medication, it's allowed, since you will be treating some other infections that are dangerous to the baby."

The reasons participants encouraged exclusive breastfeeding included promoting the mother-child bond; decreased risk of infections due to less contamination and the transfer of mother's antibodies; and the fact that breastmilk was always readily available, nutritious, easily absorbed and at the right temperature. There was also the belief that the amount of breastmilk consumed decreases with food introduction, so food introduction should be postponed. Participants also noted that supplemental foods may injure the gut and allow entry of HIV virus, if present in the breastmilk.

## Challenges identified

Participants identified many challenges in educating mothers and in promoting adherence to their advice. These challenges included stigma, since neighbours will conclude that a woman is HIV-positive if she stops breastfeeding her child at three months. Women may also be worried about the healthcare worker's intentions and may hide information from them. Mothers may not follow breastfeeding advice due to their specific physical condition. For example, if a mother's breasts hurt, she may continue to breastfeed past her desired weaning time. She may also breastfeed when dehydrated or sick and may therefore think she must supplement the child's diet due to a lack of breastmilk. Financial reasons also influence breastfeeding education, since most mothers cannot afford the cost of formula or other breastmilk substitute. Participants also cited the fact that HIV test kits and drugs such as Nevirapine are not on site in the health facility where women are

treated and counselled. These may be stored in the lab, or at the district health office.

Women become discouraged with the health system if they are not able to access these services and may not return when they are available.

## Suggestions for improvement of services

The participants suggested ways in which to improve the breastfeeding education service delivery. These included training more healthcare workers, which would enable each healthcare worker to have a greater amount of time with each woman she counsels. Refresher courses were also suggested so that practicing healthcare workers can have confidence in their skills and in the information they are transmitting to women. The involvement of men in antenatal and breastfeeding counselling was seen as extremely important, and has already been put into practice in some health centres. Participants felt that when men are informed of the reasons for certain breastfeeding options, and included in the decision-making process, they are more likely to support their partner both socially and financially. Income generating activities were also seen as important since many women are taking care of their children themselves and their infant feeding choices are limited with limited income. The use of locally available resources was also emphasized, so that during counselling women should be encouraged to use millet porridge, for example, if she can afford that as a replacement feed, instead of animal milk or formula. Better nutrition for mothers should also be encouraged. Social support was also regarded as essential and suggested ways to enhance this were the creation of post-test clubs, sensitization of the community, for example through the use of volunteers. Provision of a constant accessible stock of HIV test kits and PMTCT drugs such as Nevirapine could

improve the reputation of the healthcare system and result in more women knowing their status and having access to PMTCT drugs.

## **Chapter 6: Discussion**

## HIV status and exclusive breastfeeding status

HIV status was the main variable of interest but was not shown to significantly affect exclusive breastfeeding status at three months post-partum. However, there is a high percentage (43.2) of HIV-positive mothers mixed feeding at three months post-partum. HIV-positive mothers who were mixed feeding had a mean planned breastfeeding cessation time of 15 months post-partum. This raises a concern that many HIV-positive women are exposing their children to increased risk of acquiring HIV, over an extended period of time. Focus group information shows that infant feeding counselors are aware of the WHO and Government of Uganda recommendations but there are barriers to proper delivery and adherence to advice. The majority of study participants listed healthcare workers as their source of breastfeeding information, and almost all had attended at least one antenatal session, therefore healthcare workers remain a vital source for interventions. Further research is needed to ascertain reasons for non-adherence to breastfeeding guidelines. Breastfeeding education should be strengthened using the suggestions of healthcare workers voiced during the focus group discussions.

Only two variables showed a significant difference between HIV-positive and HIV-negative women. These were gestational age and number of household occupants (see Table 1). HIV-positive women give birth on average half a week earlier than HIV-negative women. For the second variable, being HIV-positive is associated with a lower number of household occupants (see Table 1). This is interesting since the HIV-positive

group had a higher proportion of either married or living with a partner. The difference may be due to mortality of children, or to a family planning choice, for those aware of their HIV status. However more research is needed in this area to determine the reasons within this specific context.

Although not statistically significant, a trend may also be observed in cement flooring, a socio-economic status indicator, since the proportion of HIV-negative women who live in homes with cement floors is more than double that of HIV-positive women. Those with cement floors had lower odds of exclusive breastfeeding. This may also be explained by residence in Fort Portal Municipality, since cement flooring may be more common in urban areas.

## Illness of child and exclusive breastfeeding status

Illness of the child at least once between birth and three months was shown to be significantly negatively correlated with exclusive breastfeeding using a multivariate logistic regression model. However, this is not necessarily a straight-forward relationship, since the association can be interpreted in both directions. Mothers may introduce additional foods when a child is sick, due to beliefs that breastmilk is insufficient for children who are ill. Mothers who introduce additional food before three months for other reasons (i.e. absence of mother, cultural norms, etc), may be at higher risk of having a sick child since other foods have a greater risk of contamination than breastmilk, and the child would be acquiring less antibodies from their mother's breastmilk to assist them in fighting off infection.

Therefore further studies are needed to determine the directionality of this association. Study participants should be asked when the child was ill. Whether illness of the child precedes or follows the introduction of other foods would provide insight into this association. If illness precedes introduction of foods, interventions could be targeted, through healthcare professionals, towards mothers of sick children who visit clinics or hospitals to remind them of the importance of continuing to breastfeed exclusively. If illness follows food introduction, research to document reasons for the introduction of each specific food would enable a greater understanding of cultural norms surrounding infant feeding, and could inform additional interventions.

#### County of residence and exclusive breastfeeding status

Both Burahya and Bunyangabu, the rural counties, were positively associated with exclusive breastfeeding status at three months in the multivariate logistic regression model. This may be due to urban/rural differences. Mothers in urban settings, such as Fort Portal Municipality, may be away from their infants more often than mothers in rural communities, and therefore introduce complementary foods at an earlier age. More research should be focused in the urban areas to determine reasons for exclusive breastfeeding cessation. These results also demonstrate that it may be appropriate to specifically target urban centres for additional infant feeding counselling or PMTCT activities.

#### Breastfeeding education

The focus group discussions provided insight into the information women are being taught regarding infant feeding. The definition of exclusive breastfeeding given by healthcare workers corresponds to that of WHO (2006). Their advice corresponds to both WHO and Uganda guidelines for both HIV-positive and HIV-negative mothers. For HIV-positive mothers, replacement feeding is suggested when feasible, otherwise three month EBF or six month EBF. Although some healthcare workers demonstrated knowledge of the dangers of mixed feeding, it is unclear if this is adequately explained to mothers. This lack of information could explain the lack of adherence to EBF in the first three months of life, especially in the HIV-positive group, since they may want to decrease the amount of breastmilk given to their child in the hopes of decreasing the chance of transmission. Confusion about how abruptly weaning should occur may also lead to differences in breastfeeding education. And since women traditionally wean over a long period, lack of clear teaching about weaning may lead to longer mixed feeding.

#### Limitations due to inconsistent data

Limitations of this study may originate from the recruitment method. When comparing synonymous data from questionnaires and medical charts, discrepancies were found in approximately 28% of cases. These discrepancies were either a difference of four or more years in the mother's reported age (39 participants or 21.4%) or a difference in the sex of the infant (24 participants or 13.2%).

To ascertain the cause of these discrepancies, a sample of 21 study participants with these discrepancies was selected (all participants for whom we had both questionnaire data and medical chart information, at the time) and information on each compiled including the mother's name, her date of delivery at FPRRH (Buhinga Hospital), and her contact information. This information was supplied to a verifier who was not involved in questionnaire administration during the study. The verifier was asked to locate each woman using the information provided and to confirm whether she was the women who gave birth at FPRRH (Buhinga Hospital) on the date of delivery, had given informed Stage 1 consent at the hospital, and had answered the follow-up questionnaire three months later. If the verifier was unable to find the woman using the original contact information supplied by the recruiting nurse, updated contact information supplied by the research assistant who administered the questionnaire would be used.

Following this verification no one cause of the discrepancies was identified.

• In five (23.8%) of the cases, a participant's home was found using the contact information. However, in four cases the verifier was told either by the participant (3) or by a family member (1) that questionnaire administration did not take place. In two of these cases the verifier was told that the research assistant had come but was not able to complete the questionnaire because the participant was not home at the time. In the fifth case, the participant confirmed she had answered a questionnaire, but the questionnaire data differed from the verifier's data for both mother's age and infant sex. For these cases, there are two possibilities: the

questionnaire data may have been fabricated by either the research assistant or the study participant, or the questionnaire was administered at a later time without the person the verifier saw knowing of the subsequent interview.

- In six cases (28.6%) a home with putative study participant was located but the
  participant could not be found. Therefore the discrepancies could not be
  reconciled.
- In nine cases (42.9%) the verifier found a person with the same name at the same address as in the contact information supplied to him. Seven of these woman confirmed delivering at Buhinga Hospital during the study period. However, all but one (who claimed to have delivered at another hospital, and therefore would not have been recruited) of these women denied being enrolled in the study. All denied having had a follow-up interview. Therefore it is surmised that either a) the follow-up interviews were undertaken with the wrong persons (women with similar names, who delivered in the study period but were not enrolled in the study) or b) the verifier identified a non-study participant or c) the data were fabricated.
- In one case (4.8%) the discrepancy was attributed to wrong data in the medical chart (since the follow-up interview and verification data on age of mother were the same but did not match the chart data).

The main research assistant involved in the study was informed of the discrepancies and asked for her insight into possible reasons for these discrepancies. She appeared eager to help figure out the problem. However, it was difficult for her to remember all the

participants in question when described in a telephone conversation. Therefore the information was sent to her by e-mail. Likely due to infrequent access to the internet, and limited internet literacy, she has not yet responded. However, during telephone conversations, she did explain how she sometimes felt certain women were reluctant to be honest, and also that women were not always sure of their exact age.

Research assistants were given the woman's name, date of delivery, name of next of kin (if provided), the county, subcounty, parish and village or residence, and directions to follow to locate the participant's residence. The research assistant was given instructions to confirm that the woman had delivered at FPRRH (Buhinga Hospital) on the delivery date written on the contact information sheet (Appendix S) and had a child approximately three months of age. This was done to minimize the chance of interviewing the wrong woman.

One way to ensure more accurate identification of study participants in similar studies would be to accompany RAs to the field on a daily basis. However, this may also come with certain disadvantages. For example, participants may be more likely to give responses they see as the "right" answers in the presence of the principal investigator. There is also a perception in the district, due to years of HIV/AIDS studies in the area, that a foreigner visiting a house must be doing HIV/AIDS research, and that therefore a member of the family residing in the house has HIV. Logistically, the study would take longer to complete, since only one research assistant could be sent to the field per day, and administer questionnaires in one part of the district.

#### <u>Limitations of study design</u>

Participants were all initially recruited from a hospital. Therefore these participants may not be representative of the general population of Kabarole district. They were able to travel to the city for delivery, which indicates they may have higher socio-economic status or reside closer to the city. The participants included in the study were those who could be found and followed-up by research assistants. Therefore women who moved within three months post-partum were not represented in the study sample.

#### Limitations of study power

The study power was calculated to be 0.18, based on the proportions of HIV-positive and HIV-negative women in the exclusively breastfed and exclusively breastfed or replacement fed categories, respectively (Appendix E). This is much lower than the expected 0.80 power, based on the original sample size calculation, since there was less of a difference between the two proportions. This study was not able to show a significant difference between exclusive breastfeeding practices of HIV-positive and HIV-negative mothers. This may not mean that there is no difference, but that the sample size was not sufficiently large to show a significant difference between the two groups.

#### <u>Limitations of Focus Group Discussion information</u>

Since focus group discussions did not yield as thorough information as expected, additional interviews were scheduled to complement the data. Ethical approval was obtained from the Health Research Ethics Board of the University of Alberta for two in

depth interviews to be conducted with the in charges of the antenatal clinic and the maternity ward of the FPRRH (Buhinga Hospital). However, due to the Ebola outbreak in Western Uganda during the scheduled interview time, these interviews did not take place. Therefore qualitative information reported in this study is limited to the two original focus groups.

#### HIV prevalence

The HIV prevalence in the study population was 21.4%, almost twice the reported prevalence in the district (11.6%) (Uganda Communication Commission 2003). This may indicate a rising incidence, which may be occurring for many reasons (i.e. decreasing fear of HIV due to availability of ARVs, intergenerational relationships, etc). However, it may be explained by women who are HIV-positive being more likely to deliver at the hospital, if they are aware of their status.

#### **Chapter 7: Conclusions**

This study aimed to identify factors determining exclusive breastfeeding practices three months post-partum, to assess differences by HIV status and to ascertain what information is available to women about infant feeding, in Kabarole district, Uganda.

Illness of the child at least once within the first three months of life was identified as a significant factor in this study to be negatively associated, by multivariate modeling, with exclusive breastfeeding status. This provides an important area of further study to determine the direction of association and implement interventions accordingly (such as reminder infant feeding counselling upon presentation at a healthcare facility with a sick child). Residence in Fort Portal Municipality was negatively associated with exclusive breastfeeding status, suggesting a need to target infant feeding activities in urban areas.

In both HIV-positive and HIV-negative women, there is low adherence to exclusive breastfeeding guidelines. This is of special concern for HIV-positive mothers, since non-adherence carries the additional risk of increased potential for HIV transmission to their child. Healthcare workers are important and knowledgeable sources of information regarding infant feeding. Improvements should be made to health education, such as training and involvement of men, as suggested by focus group participants, in order to strengthen and support the current infant feeding education services. Additional research should explore the reasons for non-adherence to recommendations.

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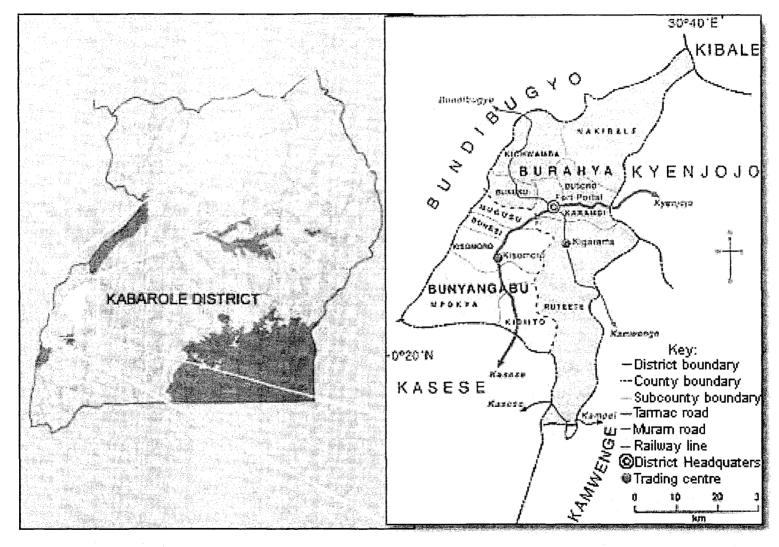
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Appendix A: Map of Kabarole District

http://www.kabarole.go.ug/overview/health.htm 2008

#### Health Research Ethics Board

213 Heritage Medical Research Centre University of Alberta, Edmonton, Alberta T6G 2S2 p.780.492.9724 (Biomedical Panel) p.780.492.0302 (Health Panel) p.780.492.0459 p.780.492.0839 f.780.492.7808

#### HEALTH RESEARCH ETHICS APPROVAL FORM

Date of HREB meeting:

April 13, 2007

Name of Applicant:

Dr. Duncan Saunders

Organization:

U of A

Department:

**Public Health Sciences** 

Project Title:

Breastfeeding practices of HIV positive and HIV negative women in Kabarole District, Uganda

The Health Research Ethics Board (HREB) has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information letter and consent form.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval. Written notification must be sent to the HREB when the project is complete or terminated.

**Special Comments:** 

MAY 3 0 2007

Dr. Glenn Griener, PhD Chair of the Health Research Ethics Board (B: Health Research) Date of Approval Release

File Number: B-040407







#### Appendix C



## Uganda National Council For Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

| Your Ref: |         |
|-----------|---------|
| HS 347    | 01/10/0 |
| Our Ref:  | Date:   |

Ms. Esme Lanktree
<sup>C</sup>/o Institute of Public Health
P O Box 7072
Kampala

Dear Ms. Lanktree,

RE: RESEARCH PROJECT, "BREASTFEEDING PRACTICES IN HIV-POSITIVE AND HIV-NEGATIVE NEW MOTHERS IN KABAROLE DISTRICT, UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on August 30, 2007. The approval will expire on July 30, 2008. If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

The Resident District Commissioner of Kabarole District in which the study will be conducted is informed by copy of this letter, and is kindly requested to give you the necessary assistance to accomplish the study.

Yours sincerely,

Leah Nawegulo
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION/CORRESPONDENCE

Plot 3/5/7, Nasser Roud P.O. Box 6884 KAMPALA, UGANDA. COMMUNICATION

TEL: (256) 414-250499, (256) 414-705500 FAX: (256) 414-234579 E-MAIL: uncst@starcom.co.ug WEBSITE: http://www.uncst.go.ug

#### Appendix D

#### Memorandum of Understanding between the Kabarole District Health

#### Officer and the University of Alberta Research Project on Breastfeeding

#### **Practices in Kabarole District**

#### **Project title**

Breastfeeding practices of HIV-positive and HIV-negative women in Kabarole District, Uganda

#### Preamble

The University of Alberta is conducting a study to explore what factors determine exclusive infant breastfeeding practices in the Kabarole District of Western Uganda and whether mothers feed their infants differently depending on their HIV status. Infant feeding education will also be ascertained by interviewing healthcare professionals. Feeding practices will be determined by surveying mothers who have given birth three months prior to data collection.

#### **Activities for both parties**

The Buhinga Hospital Clinic Maternity Ward will, under the supervision of Dr. Arthur Ssebuko:

- Allow the researchers access to medical chart data (demographic information, HIV status and birth information) for women enrolled in the study and facilitate collection of this information throughout the study period
- Obtain consent from women to be contacted at a later time to participate in the full research study
- Provide the names of women who consented to be in the study to the researchers in order that they may follow up these women
- Facilitate the recruitment of focus group participants (healthcare workers) through support of the research project

The University of Alberta Research Project shall:

- Provide 1000USh to nurses (1000USh per woman who presents to deliver during the study period June 1 to September 15, 2007) for:
  - o collecting detailed contact information (woman's names, date of birth, age, parent names, next of kin, LCI address, and a telephone contact)
  - o obtaining consent from the woman to be contacted
  - o requesting an HIV test and performing the blood test if the woman does not refuse, and noting whether the woman was informed of her HIV status *Note: HIV testing is part of the National Health Policy and not directly part of the research project.*

• Communicate research findings in an aggregate form to the Kabarole District Health Officer.

Ownership of data

All clinical data (patient medical charts) are the property of the healthcare facility and the Kabarole District Health Services. However, demographic information, HIV status and birth information of women enrolled in the study will be shared with the researchers. Data collected for the study during focus group sessions and administration of questionnaires will belong to the researcher (Esmé Lanktree), supervisor (Dr. L. Duncan Saunders), and the University of Alberta.

| Kabarole District Health Officer | University of Alberta Research Project |  |  |  |  |
|----------------------------------|--|--|--|--|--|
| Name                             | Name                                   |  |  |  |  |
| Signature                        | Signature                              |  |  |  |  |
| Date                             | Date                                   |  |  |  |  |

## $\label{eq:Appendix} Appendix \ E \hbox{: Sample size and power calculations}$

using STATA (STATA 9.1 2005)

. sampsi 0.7 0.9, alpha(0.05) power(.80) ratio(3)

Estimated sample size for two-sample comparison of proportions

Test Ho: p1 = p2, where p1 is the proportion in population

and p2 is the proportion in population

2

Assumptions: alpha = 0.0500 (two-sided)

power = 0.8000p1 = 0.7000

p2 = 0.9000n2/n1 = 3.00

Estimated required sample sizes:

n1 = 44

n2 = 132

. sampsi 0.6667 0.5682, alpha(0.05) n1(138) n2(44)

Estimated power for two-sample comparison of proportions

Test Ho: p1 = p2, where p1 is the proportion in population 1

and p2 is the proportion in population

2

Assumptions:

alpha = 0.0500 (two-sided)

p1 = 0.6667

p2 = 0.5682

sample size n1 = 138

n2 = 44

n2/n1 = 0.32

Estimated power: power = 0.1755



## KABAROLE DISTRICT LOCAL GOVERNMENT

Tel: +256 483 22575 - District Health Officer (DHO) Tele-Pax: +256 483 23043 - Secretariat Email: ddfskabaroled@yahno.com Department of Health Services Kabarole District P. O. Box 38 FORT PORTAL

DATE: 40<sup>th</sup> April, 2007

#### TO WHOM IT MAY CONCERN

This is to confirm that the Research Proposal entitled "The breast feeding practices of HIV-positive and HIV-negative women in Kabarole District, Uganda" study by Esme Lanktree, Msc. Global Health student, University of Alberta – Canada, has been reviewed by our team and found to be worthy

The results will contribute to a pool of knowledge which will be beneficial not only to Kabarole, Western region, but to Uganda as a whole.

I highly recommend and approve the study for funding.

Thank You.

Joa Okech Ojóny Br. DISTRICT HEALTH OFFICER/KABAROLE



## KABAROLE DISTRICT LOCAL GOVERNMENT

Office of the District Chairperson Kabarole District P. O. Box 38 FORT PORTAL

Date: 1st November, 2007

#### TO WHOM IT MAY CONCERN

This is to introduce **Esmé Lanktree**, an MSc student from the University of Alberta conducting a study entitled 'Breastfeeding practices of HIV-positive and HIV-negative new mothers in Kabarole District, Uganda.'

The purpose of this study is to look at factors that determine exclusive breastfeeding practices and to see whether mothers feed their infants differently depending on their HIV status. In order to do so we also determine what women in Kabarole District are being taught regarding breastfeeding by conducting focus group sessions with hospital/clinic staff. I would appreciate your assistance with her research Project.

Thank you,

Joa Okeen Ojony Dr. , DISTRICT HEALTH OFFICER/KABAROLE

#### **Information Letter for Nurses**

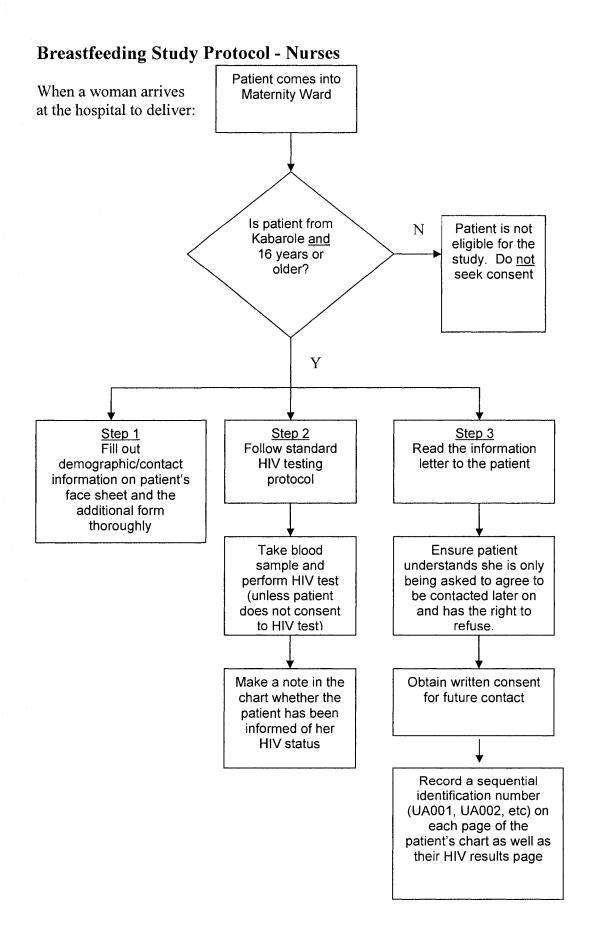
You are being asked to assist in the recruitment of patients for a research project looking at the breastfeeding practices of mothers. This research project will start in September 2007.

Your duties will be to:

- a) Properly and completely fill out the admissions form for the mother
- b) Offer her an HIV test, which she is free to refuse if she does not want the test
- c) Read out the provided information letter asking the mother if she is willing to be contacted later on to participate in a research study
- d) If the mother agrees to be contacted later on by the research project, ask the mother to sign the provided consent form.

This study is only looking at mothers who are over the age of 16 and who live in the Kabarole District. You should only recruit mothers who live in the Kabarole District. For example, mothers living in Kamwenge, Kyenjojo, Kasese and Bundibugyo are <u>not</u> to be recruited.

Dr. Ssebuko will review the patient charts and if you have completed the paperwork properly have offered an HIV test, and have read out the information letter and obtained a consent, you will be paid 1,000 Uganda Shillings per patient. You will be paid even if the mother refuses to take an HIV test.



#### Notes:

- These steps should not interfere with standard labour and delivery care.
- HIV testing should occur before delivery and be followed by the administration of treatment to prevent vertical transmission, if the mother is found to be HIV-positive.
- Completion of contact information and consent forms may be done after delivery but before discharging the patient.
- Do not force the patient to get the HIV test or the first stage study consent if they do not wish to do so. If a woman does not wish to give consent she has the right to refuse.
- Nurses will identify each eligible woman with a sequential identification number (UA0001, UA0002, UA0003...) which should be written on each page of the patient's chart as well as their HIV test results.
- A nurse who completes these steps completely and accurately will be remunerated 1000USh per patient. You will be paid even if the mother refuses to take an HIV test.

## Appendix I

# LOGBOOK:

| Date recruited (day/ month/ year) | Name of recruiting nurse                | Name of<br>pregnant<br>woman | Contact<br>forms<br>completed<br>and put in<br>folder? | HIV<br>test<br>offered? | HIV<br>Test<br>Refused<br>(specify<br>reason) | HIV<br>test<br>done? | HIV test<br>result<br>put in<br>patient's<br>folder? | Was the information letter read to the patient? | Consent<br>form<br>signed,<br>and put<br>in<br>folder?<br>(if not,<br>reason) | Baby's<br>date of<br>birth<br>(day/<br>month/<br>year) | Twins<br>(Yes,<br>No) | Baby's<br>health<br>status<br>(alive,<br>healthy,<br>other) | Baby<br>breastfed<br>in<br>hospital<br>(Yes,<br>No) | Date<br>discharged<br>(day/<br>month/<br>year) |
|-----------------------------------|---|------------------------------|--|-------------------------|---|----------------------|--|---|---|--|-----------------------|---|---|--|
|                                   | *************************************** |                              |  |                         |   | -                    |  |   |   |  |                       |   | ·   |  |
|                                   |   |                              |  |                         |   |                      |  |   |   |  |                       |   |   |  |
|                                   |   |                              |  | :                       |   |                      |  |   |   | :  |                       |   |   |  |
|                                   |   |                              |  |                         |   |                      |  |   |   |  |                       |   |   |  |
|                                   |   |                              |  |                         |   |                      |  |   |   |  |                       |   |   |  |
|                                   |   |                              |  |                         |   |                      |  |   |   |  |                       |   |   |  |
|                                   |   |                              |  | *****                   |   |                      |  |   |   |  |                       |   |   |  |
|                                   |   |                              |  |                         |   |                      |  |   |   |  |                       |   |   |  |



#### Information letter (Stage 1 of consent for mothers)

<u>Project Title</u>: Breastfeeding practices of HIV-positive and HIV-negative women in Kabarole District, Uganda

Esmé Lanktree, Principal Investigator Master of Science student, Global Health School of Public Health University of Alberta, Edmonton, AB

Dr. L. Duncan Saunders, Supervisor Professor School of Public Health University of Alberta, Edmonton, AB

<u>Purpose</u>: The purpose of the study is to describe breastfeeding practices of mothers.

<u>Procedure</u>: We would like to request your permission to contact you in the future to participate in the research study.

<u>Risks and benefits</u>: This stage of consent only permits us to contact you later and therefore there are no risks to you. If in the future you agree to be part of the study, you will add to the knowledge of breastfeeding practices in Kabarole district.

<u>Confidentiality</u>: Your name, and contact information will be kept confidential and will only be shared with the principal researcher.

<u>Free to withdraw</u>: You do not have to agree to be contacted. You can choose not to participate in the study if you do not wish to do so. Your decision will not impact your care.

Questions: To ask any questions about this study or to voice any concern, please contact the researcher at: (to be determined).



#### UNIVERSITY OF ALBERTA

# Ebbaruha Ey'okumanyisa amakuru (Idara eryokubanza hakwikiriza kwabazaire okukaguzibwa )

<u>Ibara lya Project (Omusomo)</u>: Emiringo eyokwonkya abaana omubakazi abaine nabataine kahuka ka Silimu omu Distrikiti ya Kabarole, Uganda

Esmé Lanktree, Omukuru w'okukaguliriza Omweegi wa Msc omu Global Health School of Public Health University of Alberta, Edmonton, AB

Dr. L. Duncan Saunders, Owarukurolerra Professor School of Public Health University of Alberta, Edmonton, AB

<u>Ekigendererwa</u>: Ekigendererwa ekyomusomo gunu kiri okusoborra hamiringo yabazaire bonkezamu abaana.

<u>Ebyokuhondera</u>: Nitukusaba okutwikiriza okukukaguza omubwire obwomumaiso okwetaba omukuseruliriza kunu.

Obuzibu hamu nebirungi ebirumu: Linu idara eryokwikiririzaho niritwikiriza okubazaho naiwe omubiro ebyomumaiso nahabweki busaho buzibu bwoona obusobora okukubaho. Kakuba omubwire obwomumaiso oikiriza okwetaba omumusomo gunu, noija okwongeraho hakwetegereza ebirukukwata hamiringo yokwonkya abaana omu Distrikiti ya Kabarole.

Okulinda ensita: Ibara lyaawe, nebintu ebindi ebirukukukwataho nibija kulindwa nkesita kandi birimanywa iwe nowarukuseruliriza wenka.

Obugabe obwokuleka: Tikiri kyokuhambiriza kukuhikaho hanyuma. Oine obugabe okutetaba omukukaguliriza kunu obworaba otarukugonza. Ekyoracwamu tikirukwija kutalibaniza okujanjabwa kwaawe.

<u>Ebikaguzo</u>: Obu oraba nogonza okukaguza ekintu kyona ekirukukwata hamusomo gunu, ohikeho owarukukaguliriza omukuru ha:

## Appendix L



## Consent form (Stage 1 of consent for mothers)

| Title of Project:   |     |             |  |  |
|---|-----|-------------|--|--|
| Breastfeeding practices of HIV-positive and HIV-negative women in Kabarole District, Uganda |     |             |  |  |
| Part 1: Research information  |     |             |  |  |
| Name of principal investigator: Esmé Lanktree   |     |             |  |  |
| Affiliation: University of Alberta  |     |             |  |  |
| Contact information: 0773045965   |     |             |  |  |
| Name of Supervisor: Dr. L. Duncan Saunders  |     |             |  |  |
| Affiliation: University of Alberta  |     |             |  |  |
| Contact information: 1-780-492-6814   |     |             |  |  |
| Part 2: Consent of Subject  |     |             |  |  |
|   | Yes | No          |  |  |
| Do you understand you have been asked to be contacted in the future                         |     |             |  |  |
| regarding a project on breastfeeding?   |     | <del></del> |  |  |
| Have you read and received a copy of the information sheet?                                 |     |             |  |  |
| Do you know that you can withdraw anytime without an explanation?                           |     |             |  |  |
| You have the right to refuse to participate.  |     |             |  |  |
| Do you understand confidentiality? Do you know who has access to                            |     |             |  |  |
| your personal information?  |     |             |  |  |
| Part 3: Signatures  |     |             |  |  |
| I agree to allow the researcher to contact me:  |     |             |  |  |
| Signature of participant: Date:   |     |             |  |  |
| Printed name:   |     |             |  |  |
| Signature of investigator:  |     |             |  |  |



# Formu eyokwikiriza okukaguzibwa (Idara eryokubanza omukwikiriza okwabazaire okukaguzibwa)

| Omutwe gwa Project:   |                                       |          |
|---|---------------------------------------|----------|
| Omative give 110jeeu.   |                                       |          |
| Emiringo eyokwonkya okwabakazi abaine nabataine akahuka ko      | miinywer                              | erro omu |
| Distrikiti ya Kabarole, Uganda                                  | indity were                           | ono oma  |
| Distrikiti ya Kabarote, Oganda                                  |                                       |          |
|   |                                       |          |
| Ekicweka kyokubanza: Amakuru gabarukuseruliriza                 |                                       |          |
| Ekicweka kyokubanza. Amakuru gabarukuserumiza                   |                                       |          |
| Ibara ly'owarukuseruliriza omukuru: Esmé Lanktree               |                                       |          |
| Narugirra: University of Alberta                                |                                       |          |
|   |                                       |          |
| Nahikibwaho ata (Esimu): 0773045965                             |                                       | 1.000    |
| Ibara ly'owarukurolerra : Dr. L. Duncan Saunders                |                                       |          |
| Narugirra: University of Alberta                                |                                       |          |
| Nahikibwaho ata (Esimu): 1-780-492-6814                         |                                       |          |
|   |                                       |          |
| Ekicweka ekyakabiri: Okwikiriza kwarukukaguzibwa                |                                       |          |
|   |                                       |          |
|   | Ego                                   | Nangwa   |
| Nokimanya ngu osabirwe okukaguzibwa omubwire bwomumaiso         |                                       |          |
| ebirukukwataho ebyokwonkya kwabaana?                            |                                       |          |
|   |                                       |          |
| Otungire kandi wasoma ebbaruha eyokumanyisa amakuru?            |                                       |          |
| Okimanyire ngu nosobora okuleka okwetaba omukuseruliriza obwire |                                       |          |
| bwona otaina nokusoborra kintu kyoona? Oina obugabe okwanga     |                                       |          |
| okwetaba omukuseruliriza kunu.                                  |                                       |          |
| Omanyire okulinda ensita? Omanyire noha asemerire okumanya      |                                       |          |
| ebintu ebirukukukwataho?  |                                       |          |
| Contra Con artarary values.                                     |                                       |          |
| Ekicweka ekyakasatu: Okutaho omukono rundi ekinkumu             |                                       |          |
| EMOWERA OR JANUARAM ORACAMO OMAROMO FAMOR ORACAMA               |                                       |          |
| Ninyikiriza owarukuseruliriza okumpikaho akankaguza:            | <del></del>                           |          |
| Tiniyikiriza owarakaseramiza okampikano akankagaza.             |                                       |          |
| Omukono gw'owayetabire omukuseruliriza: Ebiro byol              | cweezi:                               |          |
| Luito byon  | . WOOZI                               |          |
| IBARA LYAWE OMUNYUGUTA ENKOTO:                                  |                                       |          |
| IDIMOLLIA WE OMONIOGOTA ENWOLO.                                 | · · · · · · · · · · · · · · · · · · · |          |
| Omukono gw'owarukuseruliriza:                                   |                                       |          |
| Omakono 5m omatakaseramiza.                                     |                                       |          |

Appendix N



#### Information letter (Stage 2 of consent for mothers)

Project Title: Breastfeeding practices of HIV-positive and HIV-negative women in Kabarole District, Uganda

Esmé Lanktree, Principal Investigator Master of Science student, Global Health School of Public Health University of Alberta, Edmonton, AB Tel: 0773045965

Dr. L. Duncan Saunders, Supervisor Professor, School of Public Health University of Alberta, Edmonton AB

Tel: 780-492-7814

Purpose: The purpose of this study is to look at factors that determine exclusive breastfeeding practices. We will also see whether mothers feed their infants differently depending on their HIV status.

<u>Procedure</u>: You will be contacted by a research assistant who will interview you. The person interviewing you will not know your HIV status. The interview should take less than one hour to complete. It can be done either at your home or at the hospital, whichever is most convenient for you. Your transportation costs will be paid at the time of your interview. You may be contacted for a second interview. In addition, information from your medical chart (HIV status, demographic and birth information) will be collected after the interview by someone other than the person who interviewed you.

Risks and benefits: There are no risks to you except for possible discomfort in answering interview questions. The benefits are being part of a study which will lead to a better understanding of breastfeeding practices in Kabarole district.

Confidentiality: Your name, personal identifiers and the information from your medical chart will be kept confidential. Your medical chart information will be obtained by nurses working at the Buhinga Hospital. You will not be named in any report of this study. All information we collect will be stored in a locked file for five years, after which they will be destroyed.

Free to withdraw: You do not have to take part in this study. You can leave the study at any time by notifying the researcher. We will immediately stop the interview. You also can choose not to answer any questions without explaining. Your care at the Buhinga Hospital will not be impacted by your decision.

Questions: To ask any questions about this study or to voice any concerns, the principal investigator can be reached at (to be determined).

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Appendix O

#### UNIVERSITY OF ALBERTA

## Ebbaruha ey'okumanyisa amakuru (Idara eryakabiri (Stage 2) hakwikiriza kwabakazi abaine abaana okukaguzibwa)

<u>Ibara lya Project (Omusomo)</u>: **Emiringo eyokwonkya abaana omubakazi** abaine nabataine akahuka ka Silimu omu Distrikiti ya Kabarole, Uganda

Esmé Lanktree, Omukuru w'Okukaguliriza Master of Science student, Global Health School of Public Health University of Alberta, Edmonton, AB

Tel: 0773-045965

Dr. L. Duncan Saunders, Owarukurolerra Professor School of Public Health University of Alberta, Edmonton,

Tel: 780-492-7814

Tom Rubaale, Project Manager, Community-Based ARV Project Tel: 0782-856865 (Rutooro)

**Ekigendererwa**: Ekigendererwa kyomusomo gunu kiri okurora biki ebiretereza abazaire okwonkya abaana batabahaire kyokulya kindi kyoona. Nitwija nokurora obu abakazi baraba baliisa/banywisa abaana omumulingo ogundi kusigikirra obu baraba baine Silimu rundi nangwa.

Ebyokuhondera: Owarukukaguliriza naija okukuhikaho okukukaguza ebikaguzo. Omuntu ogu owarakukaguza naija okuba atamanyire obu oraba oina akahuka ka Silimu rundi otaina. Okukaguzibwa kunu tikurukuhikya nesaaha emu. Nikusobora okukolerwa omuka owaawe rundi hairwarro, rundi ekikaro kyoona ekiraba kikusemeriire. Sente enzendubata ezorakozesa niziija okukugarulirwamu habwire bwokukukaguza. Nibasobora okwongera okukuhikaho okukukaguza habwomurundi ogwakabiri. Ebirukukwataho obwomeezi bwaawe ebiri ha Card, ebirukukwataho oruzaaro hamu nobworaba oine akahuka ka Silimu rundi nangwa, nibiija kumanywa owarukuseruliriza omukuru kandi nibirindwa nkensita.

<u>Obuzibu hamu nebirungi ebirumu</u>: Busaho bizibu byoona ebisobora okukubaho oihireho okutalibanizibwa kukukaguza. Ebirungi ebirumu nukwo okuba omu owayetabire omumusomo ekirukwija okwongera hakwetegereza habirukukwata hamiringo eyokwonkya abaana omu Distrikiti ya Kabarole.

Okulinda ensita: Ibara lyaawe, ebirukukukwataho ebindi kandi namakuru okurugirra ha Card yaawe nigaija okwahura nkesita. Amakuru okurugirra ha Card yaawe gaija okutungwa aba Naasi abarukukora omwirwarro lya Buhinga. Ibara lyaawe tirirukwija okwoleka hantu hoona omukuseruliriza kunu. Amakuru goona agarasorozibwa nigaija okwahurwa okumara akasumi nukwo gahwerekerezebwe.

Obugabe obwokuleka: Tikiri kiragiro ngu oyetaba omumusomo gunu. Nosobora okwerekera okubamu obwire bwoona obu nomanyisa abarukuseruliriza. Itwe nitwija

okuleka okukukaguza aho naho. Nosobora nokucwamu okutagarukamu ebikaguzo otaina nekyosoboroliire muntu weena. Obujanjabi bwaawe tibirukwija okutalibanizibwa omumulingo gwoona omwirwarro lya Buhinga habwencwamu yaawe.

**Ebikaguzo**: Obu oraba nogonza okukaguza ekintu kyoona hamusomo gunu rundi oina ekintu kyoona ekikukwasireho, osobora okuhikaho omukuru owarukuseruliriza hasimu namba **0773-045965 rundi 0782-856865**.



# Appendix P

## Consent form (Stage 2 of consent for mothers)

| Title of Project:   | •  |             |
|---|--|-------------|
| Breastfeeding practices of HIV-positive and HIV-negative women in K Uganda                  | abarole D  | District,   |
| Part 1: Research information  |  |             |
| Name of principal investigator: Esmé Lanktree   |  |             |
| Affiliation: University of Alberta  |  |             |
| Contact information: 0773045965   |  |             |
| Name of Supervisor: Dr. L. Duncan Saunders  | water the same the same to | ****        |
| Affiliation: University of Alberta  |  |             |
| Contact information: 1-780-492-6814   |  |             |
| De 12 Ce agent of Gulliant  |  |             |
| Part 2: Consent of Subject  | Yes  | No          |
| Do you understand you have been asked to participate in a study?                            | 105  | INU         |
| Have you read and received a copy of the information sheet?                                 |  |             |
| Do you know the risks and benefits of participating in the study?                           | -  |             |
| Have you been able to ask questions and discuss the study?                                  |  |             |
| Do you know that you can withdraw anytime without an explanation?                           |  |             |
| You have the right to refuse to participate.  |  |             |
| Do you understand confidentiality? Do you know who has access to your personal information? |  |             |
| Part 3: Signatures  |  |             |
| The study was explained by: Date:   |  | <del></del> |
| I agree to take part in this study:   |  |             |
| Signature of participant: Date:   |  |             |
| Printed name:   |  |             |
| Signature of investigator:  |  |             |



Appendix Q

### UNIVERSITY OF ALBERTA

Formu ey'Okwikiriza okukaguzibwa (Idara lyakabiri (Stage 2) omukwikiriza okwabakazi abaine abaana okukaguzibwa)

| Omutwe gwa Project: Emiringo eyokwonkya abaana omubakazi abaine                                  |             |                        |  |  |  |
|--|-------------|------------------------|--|--|--|
| nabataine akahuka k'Omunywererro omu Distrikiti ya Kabarole, Uganda                              |             |                        |  |  |  |
| Ekicweka kyokubanza: Amakuru gabarukuseruliriza  |             |                        |  |  |  |
| Ibara ly'Owarukuseruliriza omukuru: Esmé Lanktree  |             |                        |  |  |  |
| Narugirra: University of Alberta   |             |                        |  |  |  |
| Nahikibwaho ha simu: 0773045965  |             |                        |  |  |  |
| Ibara ly'Owarukurolerra: Dr. L. Duncan Saunders  |             |                        |  |  |  |
| Narugirra: University of Alberta   |             |                        |  |  |  |
| Nahikibwaho hasimu: 1-780-492-6814   |             |                        |  |  |  |
| Ekicweka kyakabiri: Okwikiriza kwa arukukaguzibwa  |             |                        |  |  |  |
|  | Ego         | Nangwa                 |  |  |  |
| Oyetegeriize ngu osabiirwe okwetaba omumusomo gunu?  |             |                        |  |  |  |
| Osomere kandi otungiirre ebbaruha eyerukumanyisa amakuru?  |             |                        |  |  |  |
| Omanyire ebizibu hamu nebirungi ebirumu habwokwetaba   |             |                        |  |  |  |
| omumusomo gunu?  |             |                        |  |  |  |
| Osoboire okukaguza ebikaguzo kandi nokubazaho omusomo  |             |                        |  |  |  |
| gunu?  | ·           |                        |  |  |  |
| Okimanyire ngu nosobora okwerekera okuba omumusomo gunu  |             |                        |  |  |  |
| obwire bwoona kandi otasoboroire nensonga? Oina obugabe  |             |                        |  |  |  |
| okwanga okwetaba omumusomo gunu.   |             |                        |  |  |  |
| Noyetegereza ebyokulinda ensita? Omanyire nooha  |             |                        |  |  |  |
| owaramanya amakuru agarukukukwataho?   |             |                        |  |  |  |
| Ekicweka ekyakasatu: Okutaho emikono   |             |                        |  |  |  |
| Omusomo nkagusoborolerwa:Ebiro byokweezi:  |             |                        |  |  |  |
| Ninyikiriza okwetaba omumusomo gunu:   |             |                        |  |  |  |
| Milyikiiiza okwetaba oliiuliiusolilo guliu.  |             |                        |  |  |  |
| Omukono ogwogu owayetabire omumusomo: l  | Ebiro b     | yokweezi:              |  |  |  |
| Ibara omunyuguta enkooto:  | AN BATHY TO |                        |  |  |  |
| Omukono gw'Owarukuseruliriza:  |             | _                      |  |  |  |
| Ibara omunyuguta enkooto eryogu owarukurolerra omwaa omumusomo obu araba ali hansi yemyaka ikumi |             | ayetabirre<br>munaana: |  |  |  |

| Omukono gw'Owarukurolerra omwaana:   |  |
|--|--|
| omination by the state of the s | A CONTRACTOR OF THE CONTRACTOR |

## Appendix R

## **RA** information sheet

\*\*Confirm that child is the three month old baby delivered at Buhinga hospital\*\*

Check name with mother before questionnaire administration.

If a child died at three months, or before, confirm if it was the study child or not.

| RA Observations: Did the mother breastfeed the             | child while you were the  | ere? Y      | N                        |
|--|---------------------------|-------------|--------------------------|
| Is the study child present – if r (daycare, with relative) | not, where?               | Y           | N<br>-                   |
| Did the household have:                                    | Electricity               | Y           | N                        |
|  | Radio                     | Y           | N                        |
|  | Television                | Y           | N                        |
|  | Telephone                 | Y           | N                        |
|  | Refrigerator              | Y           | N                        |
|  | Lantern                   | Y           | N                        |
|  | Cupboards                 | Y           | N                        |
|  | Bicycle                   | Y           | N                        |
|  | Vehicle:                  | <del></del> |                          |
| Type of fuel observed:                                     | Electricity               | Y           | N                        |
|  | Natural gas               | Y           | N                        |
|  | Kerosene                  | Y           | N                        |
|  | Charcoal                  | Y           | N                        |
|  | Firewood                  | Y           | N                        |
|  | Dung                      | Y           | N                        |
|  | Other:                    | - <u>-</u>  |                          |
| Floor material:<br>natural, earth/sand, dung, cem          | nent, ceramic)            |             |                          |
| Roof material:   | iles, tin, cement)        |             |                          |
| Wall material:  (thatch, mud and pole, unburn              | bricks, burnt bricks with | h mud/cemen | t, timber, cement, stone |

| Appendix S   |
|--|
| ID number:   |
| Mother's name:   |
| Name of N. O. K.:  |
| Baby's name:   |
| (Study child who was born at Fort Portal Referral Hospital (Buhinga) 3 months ago) |
| Date of delivery:/   |
| Contact information:   |
|  |
|  |
|  |
|  |
| Any additional comments:   |

# Mothers' Questionnaire

| 1.  | How old are you? Date of birth://   |
|-----|---|
|     | Day / Month / Year What is your marital status? □ Single □ Married □ Widowed □ Separated □ Divorced □ Living with partner □ In a relationship but living separately □ Other |
| 3.  | Who currently lives in your household?  |
|     | Husband/Partner   |
|     | Children (sex and age for each): 1 2 3  |
|     | 4 5 6   |
| 4.  | Child deaths (if any) - age, sex, reason: 12  |
| 5.  | Level of education:   |
| 6.  | What is your occupation? your partner's occupation?   |
| *   | **All the following questions refer to your three month old baby []**   |
| 7.  | Is [Name] still alive? □ Yes □ No □ I don't know  |
|     | a. If not, when did he/she die? and why?  |
| 8.  | Since [Name] was born, have you worked outside the home?   Yes  No  |
|     | Type of work and frequency:   |
| 9.  | Since birth has [Name] been sick? □ Yes □ No □ I don't know   |
|     | a. If yes:   Hospitalized  Sick at home  Taken to clinic Reason:  |
| _ \ | What vaccinations has [Name] received? ☐ None ☐ BCG ☐ Polio 0 Vitamin A ☐ Polio 1 ☐ DPT 1 ☐ Polio 2 ☐ DPT 2 ☐ Polio 3 ☐ DPT 3 don't know                                    |
| Эr  | age at time of vaccination visits:  |

| 11. Did you attend antenatal education talks during this pregnancy?              |
|--|
| □ Yes □ No □ I don't know  |
| a. If so, where and how many?  |
| 12. In your opinion, can HIV/AIDS be transmitted by breastfeeding?               |
| □ Yes □ No □ I don't know  |
| 13. From whom did you receive advice about infant feeding?                       |
| □ Counselor/Health worker □ Peer (friend) □ Husband/partner                      |
| □ Family member: □ Other: □  |
| 14. What feeding method would you have preferred to use?                         |
| □ Exclusive Breastfeeding for 3 mths □ Exclusive Breastfeeding for 6 months      |
| □ Mixed feeding □ Wet nursing □ Replacement Feeding (type:)                      |
| Other:   |
| 15. What feeding method are you using now? □ EBF 3 mths □ EBF 6 mths             |
| □ Mixed □ RF (type:) □ Wet nursing Other:  |
| 16. If different from preferred method Why?                                      |
| 17. Has your family been supportive of your feeding choice?                      |
| □ Yes □ No □ I don't know  |
| 18. Since birth, have you breastfed [Name] at any time?□ Yes □ No □ I don't know |
| 19. Is your breast milk the only food/drink [Name] has received?                 |
| □ Yes □ No □ I don't know  |

| Type of food/drink                               | Age at introduction                                   | Duration                      |
|--|---|-------------------------------|
|  |   |                               |
|  |   |                               |
|  | -   |                               |
|  |   |                               |
|  |   |                               |
|  |   |                               |
| 21. Have you ever interrupt                      | ed breastfeeding? □ Yes □                             | No □ I don't know             |
|  | n?  |                               |
|  | ed [Name]?   Yes (Who:                                |                               |
| 23. Are you still breastfeed:                    | ng [Name]? □ Yes                                      | □ No □ I don't know           |
| a. If yes, how often?                            | Daytime feeds: N                                      | ighttime feeds:               |
| b. When do you plan on<br>Other:                 | stopping? By: □ 4 mths □                              | 6 mths □ 1 yr □ 2 yrs         |
| c. <i>If no</i> , when did you c                 | ompletely stop breastfeeding                          | g, every day and every night? |
| d. How long did it take decided until the day [N | you to completely stop breas ame] did not breastfeed) | tfeeding? (from the day you   |
| **Continue to the no                             | ext three questions if the answ                       | wer to 23 was no**            |
| 24. Why did you stop brea                        | astfeeding?   |                               |
| 25 How did you stop bres                         | patfooding?   |                               |

| 26. Did you face any problems? | □ Yes  | □ No | □ I don't know |
|--------------------------------|--------|------|----------------|
| a. If yes, what were these pro | blems? |      |                |
|                                |        |      |                |

\*\*That is the end of the questionnaire. Webale muno.
We appreciate you taking the time to assist in our research.\*\*

# Ebikaguzo hali Abakazi abaine Abaana

| 1.    | Oina emyaka ingaha? Okazarwadi://  |
|-------|--|
|       | Ekiro /Omweezi /Omwaaka  |
| 2.    | Obuswere bwaawe? □ Nyikara nyenka □ Nswirwe □ Ndi mufakati               |
| □ Tuk | hukana nomusaija 🛘 🗆 Tukahukana nomusaija omu Kooti zebiragiro           |
| □ Nyi | ara na munywani wange 🛭 Nyina munywani wange baitu buli omu akaira wenka |
| □ Ebi | li   |
| 3.    | Omuka yaawe haikaramu oha? □ Musaija wange/ Munywani                     |
| □ N   | na nyowe □ Ise nyowe □ Nyinazara nyowe □ Isezara nyowe                   |
| Abaar | (Mwisiki/mwojo hamu nemyaka yabuli omu): 12                              |
|       | 3 4 5 6  |
| Abano | ·  |
|       |  |
| 4.    | Emyaka, mwojo/mwisiki, ensonga habwaki omwaana yafiire:                  |
|       | 1 2  |
| 5.    | Okasoma wahika haidaraki:  |
| 6.    | Okora mulimoki? Omusaija waawe akora mulimoki?                           |
|       | aguzo ebirukwongeraho byoona nibikwataho omwaana waawe owemyeezi<br>]**  |
| 7.    | Omwaana [] akyali mwomeezi? □ Ego □ Nangwa □ Timanyire                   |
| a.    | Obu araaba yafiire, akafadi?kandi habwaki?                               |

| 8. K       | lurugirra [] obu yazairwe, o                                       | rakozire omulimo aheru yeka yaawe?                         |
|------------|--|--|
| □ F        | Ego □ Nangwa   | □ Timanyire  |
| Mulimok    | ki oguwakozire kandi wagukoraga e                                  | emirundi ingaha:   |
| 9. C       | kuruga [] azarwa, ararwair   | reho? □ Ego □ Nangwa □ Timanyire                           |
| a. Obu     | ı eraba eri Ego: 🗆 Bakamuta hakita                                 | ıbu □ Akarwarra muka                                       |
| □ Okamı    | utwara omu Kliniki Ensonga:  |  |
| 10. C      | Omwaana [] bakamugemak   | i? □ Busaho □ TB □ Polio 0                                 |
| □ Bakamu   | ha ekirisa [Vitamin A] □ Polio 1 □                                 | DPT 1 🗆 Polio 2 🗆 DPT 2                                    |
| □ Polio 3  | □ DPT 3 □ Timanyire  |  |
| rundi okan | nutwara kumugemesa nainganaha?                                     |  |
| 11. C      | okagenda omu Kliniki ya'Abakazi b                                  | oenda obu okaba oina enda? □ Ego                           |
|            | Nangwa □ Timanyire   |  |
| a. Obu     | kiriba kiri Ego, okagenda nkaha ka                                 | andi emirundi ingaha?                                      |
|            | omukutekereza kwaawe nogira akah<br>uraba omukwonkya? □ Ego □ Nang | nuka akomunywererro kasobora okutulirwa<br>gwa 🛘 Timanyire |
| 13. C      | kuhaburwa okwokwonkya abaana                                       | abato okabuhebwa oha?                                      |
| □ Omuha    | abuzi/Omukozi webyobwomeezi  | □ Munywani wange   |
| □ Musaij   | a wange/muntu ndukwikara nawe                                      | □ Omuntu womuka:   |
| □ Handi:   |  |  |
| 14. Iv     | we okaba nogonza omwaana waawe                                     | e kumuliisa mumulingoki?                                   |
| □ Kumwor   | nkya kwonka kumara emyeezi esatu                                   | 1  |
| □ Kumwor   | nkya kwonka kumara emyeezi muka                                    | aaga   |
| □ Kumwor   | nkya nokumuha ebyokulya/ebyokur                                    | nywa ebindi  |

|          | Omwaana okwonkebwa omuntu ondi   |
|----------|--|
| <b>.</b> | Kumuha/kumunywisa ebintu bindi (Bintuki:)  |
| Εt       | pindi:   |
|          | 15. Hati nokozesa ndiisaki hamwaana onu?   |
|          | □ Kwonkya kwonka kumara emyeezi esatu  |
|          | □ Kwonkya kwonka kumara emyeezi mukaaga  |
|          | □ Kumwonkya nokumuha ebyokulya/ebyokunywa ebindi   |
|          | □ Omwaana okwonkebwa omuntu ondi   |
|          | □ Kumuhamu ebintu ebindi (Bintuki:)  |
|          | Ebindi:  |
|          | 16. Obu guraba guli gwembaganiza kuruga hagwawe wakugondeze, Habwaki?                          |
|          | 17. Abomuka bakasagika encwamu yaawe eyokuliisa omwaana?                                       |
|          | □ Ego □ Nangwa □ Timanyire   |
|          | 18. Okuruga []azarwa oramwonkezeho obwire bwoona?  |
|          | $\Box Ego$ $\Box$ Nangwa $\Box$ Timanyire  |
|          | 19. Amabere gaawe nugo byokulya/byokunywa byonka ebya []yakatunga?                             |
|          | □ Ego □ Nangwa □ Timanyire   |
|          | 20. Amabere gaawe obu garaba gatali nugo byokulya/byokunywa byoonka [] yakatunga kuruga azarwa |
| H        | Ebyokulya/Ebyokunywa ebindi Emyaka watandikiremu kubimuha Okamara kasumiki                     |
| _        |  |
|          |  |

| 21.            | Haroho obu wayemeriize okwonkya? □ Ego □ Nangwa □ Timanyire   |
|----------------|---|
| a. (           | Obu kiraba kirikwo, nsongaki?   |
| 22.            | Haroho omuntu ondi ayayonkeze []?   |
| ĺ              | □ Ego (Noha:) □ Nangwa □ Timanyire  |
| 23.            | [] nokyamwonkya? 🗆 Ego 🗆 Nangwa 🗆 Timanyire   |
| a. <i>O</i>    | bu eraba eri Ego, mirundi ingaha? Nyamusana: Ekiro:   |
| b. N           | otekereza kumucukuradi? Ha:   myeezi ena   myeezi mukaga  |
| □ m            | waka gumu 🗆 myaka ebiri Rundi:  |
| c. <i>0</i>    | bu eraba eri Nangwa, okalekadi kwonkya, ebe nyamusana rundi ekiro?                                    |
|                | ikakutwarra bwireki okulekera kimu okwonkya? (kurugirra hakiro wacwerira hakiro[] yalekiremu okwonka) |
| Veyon<br>1gwa* | gere habikaguzo ebirukuhonderaho bisatu obu engarukamu ya 23 yaba<br>*                                |
| 24.            | Habwaki wayemeziire kwonkya?  |
| 25.            | Okwonkya okwamereza ota?  |
| 26.            | Okatangatangana ebizibu byoona? □ Ego □ Nangwa □ Timanyire  |
| a.             | Obu eraba eri Ego,bikaba bizibuki?  |
|                |   |

\*\*Ebikaguzo byagarukira hanu. Webale muno.
Nitukusiima muno habwobwire bwaawe okutukonyera omukuseruliriza kwaitu.\*\*

# Appendix V

# Mothers' Questionnaire (for mothers whose infant has died)

| 1. How old are you? Date of birth://   |
|--|
| Day / Month / Year  2. What is your marital status? □ Single □ Married □ Widowed |
| □ Separated □ Divorced □ Living with partner □ In a relationship                 |
| □ Other  |
| 3. Who currently lives in your household?  |
| Husband/Partner   Mother   Father   Mother-in-law   Father-in-law                |
| Children (sex and age for each): 1 2 3   |
| 4 5 6  |
| 4. Age, sex, reason of any child deaths: 1 2                                     |
| 5. Last school grade completed:  |
| 6. What is your occupation? your partner's occupation?                           |
| *All the following questions refer to your three month old baby []**             |
| 7. Is [Name] still alive? □ Yes □ No □ I don't know                              |
| a. If not, when did he/she die? and why?   |
| 8. When [Name] was alive, have you worked outside the home?                      |
| □ Yes □ No □ I don't know  |
| Type of work and frequency:  |
| 9. Since birth had [Name] ever been sick? □ Yes □ No □ I don't know              |
| a. If yes:   Hospitalized  Sick at home  Taken to clinic Reason:                 |
| 10. What vaccinations had [Name] received? □ None □ BCG □ Polio 0                |
| □ Vitamin A □ Polio 1 □ Pentavalent 1 □ Polio 2 □ Pentavalent 2 □ Polio 3        |

| □ Pentavalent 3 □ I don't know  |
|---|
| 11. Did you attend antenatal education talks during this pregnancy?     |
| □ Yes □ No □ I don't know   |
| a. If so, where and how many?   |
| 12. In your opinion, can HIV/AIDS be transmitted by breastfeeding?      |
| □ Yes □ No □ I don't know   |
| 13. From whom did you receive advice about infant feeding?              |
| □ Counselor/Health worker □ Peer (friend) □ Husband/partner             |
| □ Family Other:   |
| 14. What feeding method did you want to use? □ EBF 3 mths □ EBF 6 mths  |
| □ Mixed □ RF (type:) □ Wet nursing Other:                               |
| 15. What feeding method did you actually use? □ EBF 3 mths □ EBF 6 mths |
| □ Mixed □ RF (type:) □ Wet nursing Other:                               |
| 16. If different from intended method Why?                              |
| 17. Was your family supportive of your feeding choice?                  |
| □ Yes □ No □ I don't know   |
| 18. Since birth, had you breastfed [Name] at any time?                  |
| $\Box$ Yes $\Box$ No $\Box$ I don't know                                |
| 19. Was your breast milk the only food/drink [Name] received?           |
| □ Yes □ No □ I don't know   |

| 20. If your breast milk w                            | as <b>NOT</b> the only food | d/drink [N                             | ame] received since birth |  |
|--|-----------------------------|--|---------------------------|--|
| Гуре of food/drink                                   | Age at introduction         | n                                      | Duration                  |  |
|  |                             | <del></del>                            |                           |  |
|  |                             | <del></del>                            |                           |  |
|  |                             |  |                           |  |
| 21. Did you ever interrup                            | ot breastfeeding?   □ Y     | les □ No                               | □ I don't know            |  |
| a. If so, for what reason                            | ?                           |  |                           |  |
| 22. Did anyone else brea                             | stfed [Name]?               |  |                           |  |
| □ Yes (Who:  | ) 🗆 No 🗈                    | I don't kı                             | now                       |  |
| 23. Were you still breastf                           | eeding [Name] when          | he/she die                             | ed?                       |  |
| □ Yes  | □ No □ I                    | don't kno                              | w                         |  |
| a. If yes, how often?                                | Daytime feeds:              | Nig                                    | httime feeds:             |  |
| b. When did you plan on Other:                       | stopping? By: □ 4 m         | ths □6 m                               | ths □ 1 yr □ 2 yrs        |  |
| c. <i>If no</i> , when did you co                    | mpletely stop breastf       | eeding, ev                             | ery day and every night?  |  |
| d. How long did it take ye decided until the day [Na |                             |  |                           |  |
| **Continue to the nex                                | kt three questions if the   | ne answer                              | to 23 was no**            |  |
| 24. Why did you stop bre                             | eastfeeding?                |  |                           |  |
| 25. How did you stop bre                             | astfeeding?                 | ······································ |                           |  |
| 26. Did you face any prol                            | olems? 🗆 Yes                | □ No                                   | □ I don't know            |  |
| a. If yes, what were th                              | ese problems?               |  |                           |  |
|  | the end of the questi       |  |                           |  |

\*\*That is the end of the questionnaire. Webale muno. We appreciate you taking the time to assist in our research.\*\*

# Ebikaguzo hali Abakazi abaine abaana

| 1.         | Oina emyaka ingaha?             | Oka                 | zarwadi:   | /               |             |
|------------|---------------------------------|---------------------|------------|-----------------|-------------|
|            |                                 |                     | Ekir       | o/ Omweezi / (  | Omwaaka     |
| 2.         | Obuswere bwaawe?   □            | Nyikara nyenka □ N  | swirwe     | □ Ndi mufak     | ati         |
| □ <i>′</i> | Гukahukana nomusaija            | □ Tukahukana non    | iusaija or | nu Kooti yebira | agiro       |
| □ <u>]</u> | Nyikara na munywani w           | ange                |            |                 |             |
| _ l        | Nyina omunywani baitu           | buli muntu akaira w | enka □     | Ebindi          |             |
| 3.         | Omuka yaawe haikaran            | nu oha?             |            |                 |             |
| □ M        | usaija wange/Munywani           | □ Nyina nyowe □     | Ise nyow   | e 🗆 Nyinazara 1 | nyowe       |
| □ Ise      | ezara nyowe                     |                     |            |                 |             |
| Aba        | ana (Mwisiki/Mwojo har          | nu nemyaka yabuli   | omu ): 1.  | 2               |             |
| 3.         | 4                               | 5                   | 6          |                 |             |
| At         | pandi:                          |                     |            |                 | <del></del> |
|            |                                 |                     |            |                 |             |
| 4.         | Emyaka, Mwojo/mwisi             | ki, ensonga habwak  | i omwaar   | na yafiire:     |             |
|            | 1                               | 2                   |            |                 |             |
| 5.         | Okasoma wahika haida            | raki:               |            |                 | ····        |
| 6.         | Okora mulimoki?                 | Omusaija waa        | we akora   | mulimoki?       |             |
|            | bikaguzo ebirukwongei<br>u []** | aho byoona nibikv   | vataho oi  | nwaana waaw     | e owemyeezi |
| 7.         | Omwana [                        | .] akyali mwomeezi  | ' □ Ego    | □ Nangwa        | □ Timanyire |
| a.         | Obu araba yafiire, aka          | afa di?             | kand       | li habwaki?     |             |

| 8. Obu [] akaba akyali mwomeezi, okaba orakozireho omulimo gwoona aheru yeka yaawe? □ Ego □ Nangwa □ Timanyire             |
|--|
| Omulingo gwomulimo wakozire kandi wagukoraga emirundi ingaha:  |
| 9. Okuruga obuyazairwe [] akaba ararwaireho?   |
| □ Ego □ Nangwa □ Timanyire   |
| a. Obu eraba eri Ego: 🗆 Bakamuta hakitabu 🗆 Akarwarra omuka  |
| □ Okamutwara mu Klinika Ensonga:   |
| 10. Omwana [] bakamugemaki? □ Busaho □ TB  |
| □ Polio 0 □ Bakamuha ekirisa [Vitamin A] □ Polio 1 □ DPT 1 □ Polio 2   |
| □ DPT 2 □ Polio 3 □ DPT 3 □ Timanyire  |
| rundi okamutwara okumugemesa nainganaha?:  |
| 11. Okagenda omu Kiliniki ya abakazi benda okaba oina enda?  |
| □ Ego □ Nangwa □ Timanyire   |
| a. Obu kiri Ego, okagenda nkaha kandi emirundi ingaha?   |
| 12. Omu kutekereza kwaawe nogira akahuka akomunywererro kasobora okutulirwa okuraba omukwonkya? □ Ego □ Nangwa □ Timanyire |
| 13. Obuhabuzi obwokwonkya abaana abato okabuhebwa oha?   |
| □ Omuhabuzi/Omukozi webyobwomeezi □ Munywani wange   |
| □ Musaija wange/muntu ndukwikara nawe □ Omuntu womuka:   |
| □ Handi:   |
| 14. Iwe okaba nogonza omwaana waawe kumuliisa mumulingoki?   |
| □ Kumwonkya kwonka kumara emyeezi esatu  |
| □ Kumwonkya kwonka kumara emveezi mukaaga  |

| □ Kumwonkya nokumuha eby                          | okulya/ebyokunywa el | oindi                       |
|---|----------------------|-----------------------------|
| □ Omwaana okwonkebwa om                           | untu ondi            |                             |
| □ Kumuha/kumunywisa ebintu                        | ı bindi (Bintuki:    | )                           |
| Ebindi:   |                      |                             |
| 15. Ndiisaki eyorukukozes                         | a hati? 🗆 Kwonkya l  | kwonka kumara emyeezi esatu |
| □ Kwonkya kwonka kumara e                         | myeezi mukaaga       |                             |
| □ Kumwonkya nokumuha eby                          | okulya/ebyokunywa el | pindi                       |
| □ Omwaana okwonkebwa om                           | untu ondi            |                             |
| □ Kumuhamu ebintu ebindi (B                       | Bintuki:             | ) Ebindi:                   |
| 16. Obu guraba guli gwem                          | baganiza kuruga hagu | wakugondeze, habwaki?       |
|   | Timanyire            | vonkezeho obwire bwoona?    |
| 19. Amabere gaawe nibyo                           | byokulya/byokunywa   | [] yatungire byonka?        |
| □ Ego   | □ Nangwa             | □ Timanyire                 |
| 20. Amata gomumabere ob<br>yatungire okuruga azar |                      | yokunywa byonka [           |
| Ebyokulya/ekyokunywa ebindi                       | Emyaka watandikiremu | kubimuha Okamara kasumiki   |
|   |                      |                             |
|   |                      |                             |
|   |                      |                             |

| 21. Okemerezaaho okwonkya? □ Ego □ Nangwa □ Timanyire   |
|---|
| a. Obu eraba eri Ego, habwansongaki?  |
| 22. Haroho omuntu ondi weena ayayonkezeho []?   |
| □ Ego (Noha:) □ Nangwa □ Timanyire  |
| 23. Okaba nokyayonkya [] habwire yaferiiremu?   |
| □ Ego □ Nangwa □ Timanyire  |
| a. Obu eraba eri Ego, mirundi ingaha? Nyamusana : Ekiro:  |
| b. Notekereza omwaana okumucukuradi? Ha: □ Emyeezi ena  |
| □ Emyeezi mukaaga □ mwaka gumu □ emyaka ebiri   |
| Rundi di?:  |
| c. <i>Obu eraba eri Nangwa</i> , okalekadi kwonkya, ebe nyamusana rundi ekiro?  |
| d. Kikakutwarra bwireki okulekera kimu okwonkya? (kurugirra hakiro wacweriremu okuhika hakiro [] yalekiiremu okwonka)**Weyongere habikaguzo ebirukuhonderaho bisatu obu engarukamu ya 23 yabaire Nangwa** |
| 24. Habwaki wayemeriize kwonkya?  |
| 25. Okwonkya okakwemereza ota?  |
| 26. Okatangatangana ebizibu byoona? □ Ego □ Nangwa □ Timanyire  a. Obu eraba eri Ego, bikaba bizibuki?  |
|   |

\*\*Ebikaguzo byagarukira hanu. Webale muno. Nitukusiima muno habwobwire bwaawe okutukonyera omukuseruliriza kwaitu.\*\*

#### Appendix X



#### Information letter for healthcare workers

<u>Project Title</u>: Breastfeeding practices of HIV-positive and HIV-negative women in Kabarole District, Uganda

Esmé Lanktree, Principal Investigator Master of Science student, Global Health School of Public Health University of Alberta, Edmonton, AB

Tel: 780-435-8636

Dr. L. Duncan Saunders, Supervisor Professor School of Public Health University of Alberta, Edmonton AB

Purpose: The purpose of this study is to look at factors that determine exclusive breastfeeding practices. We will also see whether mothers feed their infants differently depending on their HIV status. In order to do so we also determine what women in Kabarole district are being taught regarding breastfeeding by conducting focus group sessions with hospital/clinic staff.

Procedure: You will be invited to participate in a focus group session about breastfeeding education. The session will take up to two hours to complete. It will be done at the hospital/clinic at a convenient time for staff.

Risks and benefits: There are no risks that the researchers are aware of, except possible discomfort in discussing sensitive topics with colleagues. The benefits are being part of a study which will lead to a better understanding of breastfeeding practices in Kabarole district.

Confidentiality: Your name, and any personal identifiers, will be kept confidential. Only codes will be placed on transcripts. You will not be named in any report of this study. All documents will be destroyed after five years in a locked file.

Free to withdraw: You do not have to take part in this study. You can leave the study at any time by notifying the researcher. You also can choose not to answer any questions without explaining.

Questions: To ask any questions about this study or to voice any concerns, the principal investigator can be reached at 0773045965.



### UNIVERSITY OF ALBERTA

## Consent form for healthcare workers

| Title of Project:   |   |      |  |  |
|---|---|------|--|--|
| Breastfeeding practices of HIV-positive and HIV-negative new mothers in Kabarole District, Uganda |   |      |  |  |
|   |   |      |  |  |
| Part 1: Research information  |   |      |  |  |
| Name of principal investigator: Esmé Lanktree   |   |      |  |  |
| Affiliation: University of Alberta  |   |      |  |  |
| Contact information: 0773045965   |   |      |  |  |
| Name of supervisor: Dr. L. Duncan Saunders  |   |      |  |  |
| Affiliation: University of Alberta  |   |      |  |  |
| Contact information: 1-780-492-6814   | ·- ·· · · · · · · · · · · · · · · · · · | ···· |  |  |
| Part 2: Consent of Subject  |   |      |  |  |
| 1 art 2. Consent of Subject   | Yes                                     | No   |  |  |
| Do you understand you have been asked to participate in a study?                                  | 1 00                                    |      |  |  |
| Have you read and received a copy of the information sheet?                                       |   |      |  |  |
| Do you know the risks and benefits of participating in the study?                                 |   |      |  |  |
| Have you been able to ask questions and discuss the study?  |   |      |  |  |
| Do you know that you can withdraw anytime without an explanation?                                 |   |      |  |  |
| You have the right to refuse to participate.  |   |      |  |  |
| Do you understand confidentiality? Do you know who has access to your personal information?       |   |      |  |  |
| Part 3: Signatures  |   |      |  |  |
| The study was explained by: Date:   | 107                                     | ·    |  |  |
| I agree to take part in this study:   |   |      |  |  |
| Signature of participant: Date:   |   |      |  |  |
| Printed name:   |   |      |  |  |
| Signature of investigator:  |   |      |  |  |

#### Appendix Z

#### Focus group discussion guide

- 1. When do you counsel women on breastfeeding (during pregnancy, at delivery, during follow-up visits...)?
- 2. Where is this done (at the woman's home, antenatal clinic, hospital...)?
- 3. What information do you give pregnant women or new mothers regarding infant feeding practices? (National guidelines, WHO guidelines...)
  - a. Does this differ depending on when the women come in?
- 4. Does this information differ depending on HIV status? If so, in what way? (National guidelines, WHO guidelines...)
- 5. Can you explain exclusive breastfeeding? (WHO definition?)
  - a. Why is this recommended?
- 6. Do you counsel women on weaning? If so, how long is the recommended weaning period? Does this change depending on whether the women are HIV+ or HIV-?
- 7. How many women do you counsel per day (per month/week)? How long is an average session? Shortest and longest.
- 8. When/how were you trained about infant feeding practices and antenatal counseling? Where you retrained? When? What did you learn in these sessions? How frequently do you have refresher training sessions? Did you receive any written information?
- 9. What are some of the challenges? (relating to the mother language, resources, HIV test kits, ...)
- 10. What do you think could be improved about antenatal education, specifically pertaining to infant feeding practices?

Appendix AA

Table 3a: The association between HIV status and other covariates on exclusive breastfeeding status at 3 months post-partum, Kabarole district, Uganda, 2007 ALL DISCREPANCIES OMITTED (n=131)

| Variables                            | OR (95% CI)                          | p-value |
|--------------------------------------|--------------------------------------|---------|
| HIV                                  |                                      |         |
| Positive                             | 1.00 (Reference)                     |         |
| Negative                             | 1.54 (0.71-3.33)                     | 0.271   |
| Age in years                         | 1.01 (0.95-1.07)                     | 0.820   |
| Tribe (n=113)                        |                                      |         |
| Other                                | 1.00 (Reference)                     |         |
| Mutooro                              | 0.81 (0.30-2.23)                     | 0.689   |
| Religion (n=118)                     |                                      |         |
| Other                                | 1.00 (Reference)                     |         |
| Christian                            | 0.78 (0.07-8.83)                     | 0.837   |
| Marital Status                       |                                      |         |
| Married/Living with partner          | 1.00 (Reference)                     | 0.54    |
| Not living with partner              | 0.89 (0.43-1.87)                     | 0.764   |
| County                               |                                      |         |
| Fort Portal Municipality             | 1.00 (Reference)                     | 0.010   |
| Burahya                              | 2.96 (1.29-6.77)                     | 0.010   |
| Bunyangabu                           | 2.32 (0.70-7.73)                     | 0.170   |
| Education                            | 1.00 (D.C.)                          |         |
| No formal education                  | 1.00 (Reference)                     | 0.330   |
| Some elementary Completed elementary | 0.44 (0.09-2.20)<br>0.44 (0.07-2.58) | 0.213   |
| More than elementary                 | 0.27 (0.05-1.54)                     | 0.924   |
| whole than elementary                | 0.27 (0.03 1.31)                     | 0.921   |
| Employed at home                     | 0.59 (0.23-1.54)                     | 0.272   |
| Partner employed at home (n=126)     | 1.22 (0.58-2.55)                     | 0.593   |
| Electricity                          | 0.70 (0.17-2.84)                     | 0.609   |
| Household possessions                |                                      |         |
| Radio                                | 0.68 (0.33-1.39)                     | 0.288   |
| Telephone                            | 0.70 (0.29-1.68)                     | 0.417   |
| Lantern                              | 0.65 (0.27-1.57)                     | 0.334   |

| Variables                              | OR (95% CI)       | p-value |
|--|-------------------|---------|
| Bicycle                                | 0.44 (0.18-1.09)  | 0.065   |
| Cupboards                              | 0.68 (0.24-1.90)  | 0.451   |
| Fuel (n=120)                           |                   |         |
| Fuel (n=130) Only firewood             | 1.00 (Reference)  |         |
| Other than firewood                    | 0.94 (0.36-2.47)  | 0.903   |
| Other than firewood                    | 0.94 (0.30-2.47)  | 0.903   |
| House composition                      |                   |         |
| Cement floor                           | 0.43 (0.17-1.05)  | 0.064   |
| Iron sheet roof                        | 1.50 (0.47-4.74)  | 0.497   |
| Brick wall                             | 0.71 (0.29-1.72)  | 0.452   |
| Number of household occupants          | 1.07 (0.89-1.28)  | 0.459   |
| Gender of child                        |                   |         |
| Female                                 | 1.00 (Reference)  |         |
| Male                                   | 1.40 (0.67-2.92)  | 0.364   |
| Maic                                   | 1.10 (0.07 2.72)  | 0.501   |
| Mothers who have had children who died | 1.82 (0.18-18.03) | 0.592   |
| Child Sickness                         |                   |         |
| Sick since birth                       | 0.48 (0.22-1.06)  | 0.069   |
| RTI                                    | 0.67 (0.33-1.36)  | 0.269   |
| Fever                                  | 0.43 (0.17-1.05)  | 0.064   |
| GI                                     | 0.22 (0.04-1.18)  | 0.060   |
| Other/unknown                          | 1.21 (0.29-5.08)  | 0.792   |
| Immunizations                          |                   |         |
| Visit 1                                | 1.69 (0.10-27.60) | 0.715   |
| Visit 1<br>Visit 2                     | 1.77 (0.54-5.82)  | 0.713   |
| Visit 2<br>Visit 3                     | 0.59 (0.28-1.21)  | 0.148   |
| VISIL 3                                | 0.37 (0.28-1.21)  | 0.140   |
| Number of antenatal visits (n=128)     | 1.09 (0.83-1.44)  | 0.525   |
| Knowledge of HIV transmission through  |                   |         |
| breastfeeding                          |                   |         |
| Yes                                    | 1.00 (Reference)  |         |
| No                                     | 3.03 (0.34-26.79) | 0.603   |
| Don't know                             | 0.73 (0.21-2.53)  | 0.124   |
| Breastfeeding advice                   |                   |         |
| HCW                                    | 1.00 (Reference)  | 0.447   |
| Grandmother                            | 4.20 (0.50-35.43) | 0.447   |
| Other                                  | 0.67 (0.25-1.78)  | 0.602   |
|  | 0.07 (0.23-1.70)  | 0.002   |

| OR (95% CI)         | p-value  |
|---------------------|--|
| 31.95 (11.86-86.10) | <0.001   |
| 0.55 (0.06-5.43)    | 0.592  |
|                     |  |
| 1.09 (0.94-1.26)    | 0.252  |
| 0.95 (0.77-1.17)    | 0.618  |
|                     |  |
| 1.00 (Reference)    |  |
| 0.66 (0.22-2.01)    | 0.459  |
| 0.86 (0.61-1.21)    | 0.370  |
|                     |  |
| 1.00 (Reference)    |  |
| 0.99 (0.47-2.10)    | 0.988  |
| 1.09 (0.45-2.66)    | 0.845  |
|                     | 31.95 (11.86-86.10)  0.55 (0.06-5.43)  1.09 (0.94-1.26) 0.95 (0.77-1.17)  1.00 (Reference) 0.66 (0.22-2.01)  0.86 (0.61-1.21)  1.00 (Reference) 0.99 (0.47-2.10) |

Table 3b: The association between HIV status and other covariates on exclusive breastfeeding status at 3 months post-partum, Kabarole district, Uganda, 2007 AGE DISCREPANCIES OMITTED (n=143)

| Variables                        | OR (95% CI)      | p-value |
|----------------------------------|------------------|---------|
| HIV                              |                  |         |
| Positive                         | 1.00 (Reference) |         |
| Negative                         | 1.46 (0.69-3.09) | 0.325   |
| Age in years                     | 1.02 (0.95-1.08) | 0.635   |
| Tribe (n=124)                    |                  |         |
| Other                            | 1.00 (Reference) |         |
| Mutooro                          | 0.72 (0.27-1.93) | 0.513   |
| Religion (n=129)                 |                  |         |
| Other                            | 1.00 (Reference) |         |
| Christian                        | 0.53 (0.05-5.29) | 0.576   |
| Marital Status                   |                  |         |
| Married/Living with partner      | 1.00 (Reference) |         |
| Not living with partner          | 0.84 (0.42-1.69) | 0.627   |
| County                           |                  |         |
| Fort Portal Municipality         | 1.00 (Reference) |         |
| Burahya                          | 2.30 (1.05-5.04) | 0.038   |
| Bunyangabu                       | 1.94 (0.59-6.33) | 0.275   |
| Education                        |                  |         |
| No formal education              | 1.00 (Reference) |         |
| Some elementary                  | 0.34 (0.07-1.65) | 0.182   |
| Completed elementary             | 0.38 (0.07-2.11) | 0.097   |
| More than elementary             | 0.22 (0.04-1.17) | 0.871   |
| Employed at home                 | 0.62 (0.25-1.53) | 0.292   |
| Partner employed at home (n=138) | 1.31 (0.65-2.66) | 0.451   |
| Electricity                      | 0.71 (0.18-2.88) | 0.627   |
| Household possessions            |                  |         |
| Radio                            | 0.72 (0.37-1.43) | 0.352   |
| Telephone                        | 0.72 (0.31-1.66) | 0.436   |
| Lantern                          | 0.76 (0.34-1.72) | 0.512   |
| Bicycle                          | 0.64 (0.29-1.44) | 0.278   |

| Variables                              | OR (95% CI)         | p-value |
|--|---------------------|---------|
| Cupboards                              | 0.82 (0.33-2.08)    | 0.677   |
| Final (n=142)                          |                     |         |
| Fuel (n=142)                           | 1.00 (Reference)    |         |
| Only firewood                          | 1.00 (Reference)    | 0.041   |
| Other than firewood                    | 1.10 (0.43-2.80)    | 0.841   |
| House composition                      |                     |         |
| Cement floor                           | 0.60 (0.27-1.36)    | 0.225   |
| Iron sheet roof                        | 1.51 (0.48-4.77)    | 0.482   |
| Brick wall                             | 0.91 (0.40-2.07)    | 0.831   |
| Number of household occupants          | 1.08 (0.91-1.29)    | 0.391   |
| Gender of child                        |                     |         |
| Female                                 | 1.00 (Reference)    |         |
| Male                                   | 1.36 (0.67-2.75)    | 0.394   |
| 1.1410                                 | 1.50 (0.07 2.75)    | 0.571   |
| Mothers who have had children who died | 1.79 (0.18-17.69)   | 0.602   |
| Child Sickness                         |                     |         |
|  | 0.40 (0.22 1.02)    | 0.055   |
| Sick since birth                       | 0.49 (0.23-1.03)    | 0.055   |
| RTI                                    | 0.63 (0.32-1.25)    | 0.188   |
| Fever                                  | 0.43 (0.18-1.01)    | 0.054   |
| GI                                     | 0.22 (0.04-1.17)    | 0.058   |
| Other/unknown                          | 1.19 (0.29-4.97)    | 0.810   |
| Immunizations                          |                     |         |
| Visit 1                                | 1.71 (0.10-27.94)   | 0.708   |
| Visit 2                                | 1.79 (0.55-5.85)    | 0.340   |
| Visit 3                                | 0.59 (0.29-1.18)    | 0.133   |
| Number of antenatal visits (n=140)     | 1.13 (0.87-1.46)    | 0.352   |
| Knowledge of HIV transmission through  |                     |         |
| breastfeeding                          | 1.00 (Dofo          |         |
| Yes                                    | 1.00 (Reference)    | 0.421   |
| No                                     | 1.46 (0.27-7.81)    | 0.421   |
| Don't know                             | 0.70 (0.20-2.42)    | 0.211   |
| Breastfeeding advice                   |                     |         |
| HCW                                    | 1.00 (Reference)    |         |
| Grandmother                            | 4.78 (0.58-39.52)   | 0.632   |
| Other                                  | 0.66 (0.25-1.76)    | 0.378   |
| Preferred EBF at 3 months              | 34.36 (13.20-89.44) | <0.001  |

| Variables   | OR (95% CI)                          | p-value        |
|---|--------------------------------------|----------------|
| Support of family                                 | 0.56 (0.06-5.50)                     | 0.602          |
| Still breastfeeding (n=138) Day feeds Night feeds | 1.13 (0.97-1.32)<br>0.96 (0.78-1.18) | 0.092<br>0.710 |
| Delivery method C/S SVD                           | 1.00 (Reference)<br>0.62 (0.21-1.84) | 0.374          |
| Gestational age (n=128)                           | 0.81 (0.59-1.13)                     | 0.164          |
| Parity (n=142)<br>MG<br>PG                        | 1.00 (Reference)<br>1.13 (0.55-2.33) | 0.737          |
| Weight (n=137)                                    | 0.88 (0.38-2.03)                     | 0.763          |

Table 3c: The association between HIV status and other covariates on exclusive breastfeeding status at 3 months post-partum, Kabarole district, Uganda, 2007 SEX DISCREPANCIES OMITTED (n=158)

| Variables                        | OR (95% CI)       | p-value |
|----------------------------------|-------------------|---------|
|                                  |                   |         |
| HIV                              |                   |         |
| Positive                         | 1.00 (Reference)  |         |
| Negative                         | 1.60 (0.78-3.31)  | 0.206   |
| Age in years                     | 1.00 (0.95-1.06)  | 0.970   |
| Tribe (n=133)                    |                   |         |
| Other                            | 1.00 (Reference)  |         |
| Mutooro                          | 1.01 (0.39-2.63)  | 0.977   |
| Religion (n=143)                 |                   |         |
| Other                            | 1.00 (Reference)  |         |
| Christian                        | 1.78 (0.24-13.03) | 0.573   |
| Marital Status                   |                   |         |
| Married/Living with partner      | 1.00 (Reference)  |         |
| Not living with partner          | 0.85 (0.43-1.71)  | 0.657   |
| County                           |                   |         |
| Fort Portal Municipality         | 1.00 (Reference)  |         |
| Burahya                          | 2.88 (1.33-6.26)  | 0.008   |
| Bunyangabu                       | 2.08 (0.72-6.06)  | 0.178   |
| Education                        |                   |         |
| No formal education              | 1.00 (Reference)  |         |
| Some elementary                  | 0.40 (0.08-1.98)  | 0.542   |
| Completed elementary             | 0.40 (0.07-2.24)  | 0.436   |
| More than elementary             | 0.37 (0.07-2.01)  | 0.721   |
| Employed at home                 | 0.87 (0.38-2.00)  | 0.738   |
| Partner employed at home (n=153) | 1.20 (0.61-2.38)  | 0.596   |
| Electricity                      | 0.69 (0.17-2.69)  | 0.580   |
| Household possessions            |                   |         |
| Radio                            | 1.07 (0.55-2.06)  | 0.844   |
| Telephone                        | 0.82 (0.36-1.88)  | 0.634   |
| Lantern                          | 0.82 (0.36-1.88)  | 0.634   |

| Variables                              | OR (95% CI)       | p-value |
|--|-------------------|---------|
| Bicycle                                | 0.66 (0.29-1.49)  | 0.307   |
| Cupboards                              | 1.00 (0.39-2.53)  | 0.998   |
| Fuel (n=157)                           |                   | 0.729   |
| Only firewood                          | 1.00 (Reference)  |         |
| Other than firewood                    | 0.85 (0.35-2.10)  |         |
| House composition                      |                   |         |
| Cement floor                           | 0.48 (0.22-1.05)  | 0.068   |
| Iron sheet roof                        | 1.68 (0.54-5.27)  | 0.379   |
| Brick wall                             | 0.73 (0.33-1.62)  | 0.443   |
| Number of household occupants          | 1.00 (0.84-1.18)  | 0.989   |
| Gender of child                        |                   |         |
| Female                                 | 1.00 (Reference)  |         |
| Male                                   | 1.47 (0.75-2.90)  | 0.262   |
| Mothers who have had children who died | 1.62 (0.16-15.95) | 0.668   |
| Child Sickness                         |                   |         |
| Sick since birth                       | 0.38 (0.18-0.80)  | 0.010   |
| RTI                                    | 0.52 (0.27-1.00)  | 0.049   |
| Fever                                  | 0.58 (0.26-1.29)  | 0.183   |
| GI                                     | 0.20 (0.04-1.06)  | 0.043   |
| Other/unknown                          | 1.07 (0.26-4.46)  | 0.924   |
| Immunizations                          |                   |         |
| Visit 1                                | 1.89 (0.12-30.80) | 0.658   |
| Visit 2                                | 1.73 (0.59-5.06)  | 0.320   |
| Visit 3                                | 0.59 (0.30-1.16)  | 0.125   |
| Number of antenatal visits (n=155)     | 1.05 (0.81-1.35)  | 0.719   |
| Knowledge of HIV transmission through  |                   |         |
| breastfeeding                          |                   |         |
| Yes                                    | 1.00 (Reference)  | 0.262   |
| No                                     | 2.69 (0.31-23.70) | 0.938   |
| Don't know                             | 0.75 (0.23-2.50)  | 0.154   |
| Breastfeeding advice                   | 1 00 (D 2         | 0.200   |
| HCW                                    | 1.00 (Reference)  | 0.298   |
| Grandmother                            | 2.33 (0.48-11.27) | 0.586   |
| Other                                  | 0.57 (0.22-1.45)  | 0.407   |

| Variables                 | OR (95% CI)         | p-value |
|---------------------------|---------------------|---------|
| Preferred EBF at 3 months | 38.37 (14.80-99.47) | <0.001  |
| Support of family (n=157) | 0.36 (0.04-3.15)    | 0.308   |
| Still breastfeeding       |                     |         |
| Day feeds (n=154)         | 1.19 (1.02-1.39)    | 0.019   |
| Night feeds (n=153)       | 0.98 (0.80-1.21)    | 0.875   |
| Delivery method           |                     |         |
| C/S                       | 1.00 (Reference)    |         |
| SVD                       | 0.78 (0.28-2.15)    | 0.625   |
| Gestational age (n=142)   | 0.90 (0.65-1.24)    | 0.499   |
| Parity (n=155)            |                     |         |
| MG                        | 1.00 (Reference)    |         |
| PG                        | 1.06 (0.53-2.12)    | 0.858   |
| Weight (n=153)            | 1.05, (0.48-2.30)   | 0.912   |

Table 4a: Determinants of exclusive breastfeeding status at 3 months post-partum, Kabarole district, Uganda, 2007 (multivariate analysis)
ALL DISCREPANCIES OMITTED

| Determinants (n=131)   | OR   | 95% CI      | p-value |
|------------------------|------|-------------|---------|
| HIV status (-)         | 1.56 | 0.65 - 3.75 | 0.316   |
| Child sick since birth | 0.47 | 0.03 = 3.73 | 0.075   |
| Burahya residence      | 2.87 | 1.18 - 6.97 | 0.020   |
| Bunyangabu residence   | 1.82 | 0.51 - 6.48 | 0.353   |
| Cement                 | 0.38 | 0.14 - 0.99 | 0.048   |

Table 4b: Determinants of exclusive breastfeeding status at 3 months post-partum, Kabarole district, Uganda, 2007 (multivariate analysis)
AGE DISCREPANCIES OMITTED

| Determinants (n=143)                  | OR   | 95% CI      | p-value |
|---------------------------------------|------|-------------|---------|
| HIV status (-) Child sick since birth | 1.64 | 0.76 - 3.56 | 0.210   |
|                                       | 0.46 | 0.22 - 0.98 | 0.072   |

Table 4c: Determinants of exclusive breastfeeding status at 3 months post-partum, Kabarole district, Uganda, 2007 (multivariate analysis)
SEX DISCREPANCIES OMITTED

| Determinants (n=158)   | OR   | 95% CI      | p-value |
|------------------------|------|-------------|---------|
| HIV status (-)         | 1.72 | 0.75 - 3.94 | 0.201   |
| Child sick since birth | 0.35 | 0.16 - 0.76 | 0.008   |
| Burahya residence      | 2.89 | 1.25 - 6.69 | 0.013   |
| Bunyangabu residence   | 1.74 | 0.55 - 5.47 | 0.343   |
| Cement floor           | 0.39 | 0.17 - 0.91 | 0.030   |