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# Missed Opportunities: Prevention of Mother-to-Child Transmission of HIV in Uganda

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Photos from Iganga District taken by the author

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## ABSTRACT

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*Background:* Despite the existence of effective interventions such as prophylactic antiretroviral medicines, mother-to-child transmission (MTCT) of HIV is still a major reason for HIV transmission in sub-Saharan Africa. Antenatal care (ANC) facilities are the main location for implementing prevention of MTCT (PMTCT) programmes and HIV testing is the first step in PMTCT.

*Aim:* The overall aim was to determine access to PMTCT services and to identify barriers and facilitators for accessing these services in rural Uganda.

*Methods:* Four studies (I-IV) were carried out 2008-2010 in, or neighbouring, the Iganga/Mayuge Health and Demographic Surveillance Site (HDSS) covering 12,000 households in Iganga and Mayuge districts in eastern Uganda. Semi-structured interviews were conducted with pregnant women to explore their views on HIV testing during ANC (I). Men's views on being HIV tested together with their spouse were explored through in-depth interviews and focus group discussions (II). Questionnaire-based interviews and ANC record reviews were employed to quantify the HIV testing uptake and to determine risk factors (adjusted relative risks; aRR) for not being tested for HIV among 881 pregnant women (III). Population-based data from Study III, known MTCT rates, and health facility- and semi-structured interview data on dropouts from the PMTCT programme were used to estimate the number of HIV-infected children with base-case PMTCT coverage, and for scenarios with an assumed increase in coverage of PMTCT programme components (IV).

*Results:* ANC attendance was 96% but even with existing policies for opt-out and couple HIV testing only 64% of the women were tested for HIV and only 4% had been tested together with their spouse (III). The quality of HIV counselling was generally poor, few attending facilities that lacked HIV testing services received any counselling (I, III), even fewer (6%) were tested elsewhere (III). Living more than 3 kilometres from a health facility with HIV testing services increased the risk for not being tested among the poorest and among the least poor (aRR 1.44 and 1.72), adjusting for age. Women found recruiting their spouses for couple testing (I) to be very challenging (I, II), and men were very negative towards it (II). The estimated MTCT rate with base-case PMTCT coverage was 13% at birth (IV). Increasing HIV testing uptake to 100% would be the single most effective intervention to reduce MTCT, but only combination interventions with perfect adherence would reduce MTCT rates to the target below 5%.

*Conclusions:* Despite near to universal ANC attendance and opt-out HIV testing and couple HIV testing policies in place, less than two-thirds of women were HIV tested and very few tested together with their spouse leading to missed opportunities for PMTCT. The main barriers to PMTCT are health systems-related: lack of HIV testing and referral, poor counselling, and gender-related power dynamics both at the household level and at the point of health service delivery.

*Keywords:* HIV, prevention of mother-to-child transmission (PMTCT), HIV testing, access, Uganda, Health and Demographic Surveillance Site (HDSS)



## LIST OF PUBLICATIONS

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**I. Elin C. Larsson**, Anna Thorson, George Pariyo, Paul Conrad, Moses Arinaitwe, Margaret Kemigisa, Jaran Eriksen, Göran Tomson, and Anna Mia Ekström. Opt-out HIV testing during antenatal care- experiences of pregnant women in rural Uganda. *Health policy and planning*. 2012 Jan; 27(1): 69-75.

**II. Elin C. Larsson**, Anna Thorson, Xavier Nsabagasani, Sarah Namusoko, Rebecca Popenoe and Anna Mia Ekström. Mistrust in marriage- Reasons why men do not accept couple HIV testing during antenatal care- a qualitative study in eastern Uganda. *BMC Public Health*, 2010 Dec 17; 10:769.

**III. Elin C. Larsson**, Anna Ekéus Thorson, George Pariyo, Peter Waiswa, Daniel Kadobera, Gaetano Marrone, Anna Mia Ekström. Missed opportunities: Barriers to HIV testing during pregnancy from a population based cohort study in rural Uganda. (Submitted)

**IV. Elin C. Larsson**, Anna Mia Ekström, George Pariyo, Göran Tomson, Golam Sarowar, Rose Baluka, Edward Galiwango, Anna Ekéus Thorson. Prevention of mother-to-child transmission of HIV in rural Uganda- Estimated effectiveness and potential impact of scaling-up service delivery (Submitted)

Studies will be referred to in the text by their Roman numerals (I-IV).



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## LIST OF ABBREVIATIONS

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<b>3TC</b>	Lamivudine
<b>ANC</b>	Antenatal care
<b>ART</b>	Antiretroviral therapy
<b>ARVMAC</b>	Effects of Antiretrovirals for HIV on African health systems, Maternal and Child Health
<b>ARVs</b>	Antiretroviral medicines
<b>AZT</b>	Zidovudine
<b>FGD</b>	Focus group discussion
<b>HC</b>	Health centre
<b>HDSS</b>	Health and Demographic Surveillance Site
<b>HIV</b>	Human immunodeficiency virus
<b>IDI</b>	In-depth interview
<b>MDG</b>	Millennium development goals
<b>MTCT</b>	Mother-to-child transmission
<b>PEPFAR</b>	The U.S. President's Emergency Plan for AIDS Relief
<b>PMTCT</b>	Prevention of mother-to-child transmission for HIV
<b>SES</b>	Socio-economic status
<b>sd-NVP</b>	Single dose nevirapine
<b>SSA</b>	Sub-Saharan Africa
<b>VCT</b>	Voluntary counselling and testing for HIV
<b>UNAIDS</b>	The Joint United Nations Programme on HIV/AIDS
<b>WHO</b>	The World Health Organization



## OPERATIONAL DEFINITIONS

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*Access to health care* is defined in this thesis as a concept composed of three dimensions; availability, affordability and acceptability. Access is seen as dependent on the interplay between the three dimensions, as well as the interaction between the individual/household/community and the health system for each of these dimensions.

*Universal coverage* is defined as securing access to a certain service or intervention at an affordable cost. Incorporates two complementary dimensions in addition to financial protection, e.g. who is covered and the extent of health service coverage, which is covered. (Carrin, G., I. Mathauer, K. Xu, and D.B. Evans, *Universal coverage of health services: tailoring its implementation. Bull World Health Organ, 2008. 86(11): p. 857-63.*)

*Coverage* and *Uptake* will be used interchangeably in this thesis. They are defined as the percentage of the population reached by a certain service or intervention.

*Health facility with onsite HIV testing* refers to a health facility that has been accredited by the Ugandan Ministry of Health to carry out HIV testing.

*Health facility without onsite HIV testing* refers to health facilities that have not been accredited by the Ugandan Ministry of Health to carry out HIV testing.

*Couple HIV counselling and testing/ couple HIV testing/ couple testing* all these terms are used with the same meaning in this thesis: a woman and a man in a relationship that are counselled and tested for HIV together. Usually this takes place during antenatal care.

*Provider initiated HIV counselling and testing* or *Opt-out HIV testing*, means that HIV testing should be a standard part of medical care for all patients attending health facilities with simplified pre-test information. All patients should be tested as long as they do not actively opt-out.

*Counselling* in this thesis is defined in a broad sense, including information and communication regarding health topics.

*Efficacy* the ability to cause an effect, or the effect an intervention shows in a research setting.

*Effectiveness*, the impact an intervention achieves in the real world, under resource constraints, in the entire population, or sub-population. (Aral, S.O. and T.A. Peterman. *Do we know the effectiveness of behavioural interventions? Lancet, 1998. 351 Suppl 3: p. 33-6.*)

*Low-income country* GNI per capita of US\$1,005 or less (defined by the World Bank (WB)).

*Middle-income country* GNI per capita between US\$1,006 and US\$3,975 (defined by the WB).

*High-income country* GNI above US\$12,276 (defined by the WB).



## PREFACE

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While arriving at a health facility in Iganga, a rural district in Uganda, with the intention of interviewing a midwife, we instead ended up bringing a pregnant woman to the hospital for an acute Caesarean section. The woman had been in labour for several days at home and when she finally made it to the health facility, she found that she could not get the care that she needed there. Why didn't this woman have access to the care that she needed? What made her remain at home for so many days? This, to me, illustrated the importance of studying and understanding access to health care.

During a half-year break from my pharmacy studies in 2003, I volunteered with an environmental project in rural Bushenyi, in Western Uganda. After that time, I decided to focus the rest of my pharmacy studies on global and public health. For my Master's thesis, I returned to Uganda and studied three different delivery models for antiretroviral treatment to HIV patients at St. Francis Nsambya Hospital in Kampala. This made me realize some of the challenges faced by health workers and patients in the provision of HIV care. Later on, during an internship at the WHO/Ministry of Health Uganda, I had the opportunity to work with the logistics of how antiretroviral medicines were supplied to health facilities, and I understood the importance of a well-functioning health system to provide sustainable care and for delivering medicines.

During the fieldwork for my PhD research I have spent one year in Uganda, mostly in Iganga. In order to try to figure out where the women in my study had sought antenatal care, I visited many villages in the district and nearly 50 health facilities, drug-shops and traditional birth attendants. The time spent in the community and at the various health facilities gave me glimpses of what access to health care can mean in real life. What it means when a rural health facility does not have any equipment at all. What it means to travel on rural roads. What it means to wait the whole day at the health facility.

I have enjoyed writing this thesis. While writing and thinking again through what I have done, and why I have done it, I have realized that many of the things that I have experienced and that have taught me the most about global health have not always been the things that were directly related to the (planned) research. The opportunities to spend time observing and living in the field, and in conversations with colleagues and community members, have provided great depth to my experience and have enabled me to understand my research findings and the connections between them, in new ways.

Stockholm 27 March 2012



## BACKGROUND

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### THE HIV EPIDEMIC

For more than 30 years, HIV has been a major global health problem, and was in 2008 the third leading cause of death accounting for almost 8% of all deaths in low-income countries [1]. HIV has, since it was first identified, shifted from being an untreatable disease with, at the most palliative care available, to today being a chronic disease, at least in high-income settings where antiretroviral therapy (ART) is available to the majority of people in need [2].

Worldwide, an estimated 34 million people live with HIV and 3.5 million are children below 15 years. The majority of all infected people, 23 million live in sub-Saharan Africa (SSA) [2]. The HIV prevalence is highest in SSA countries, but important to note is that HIV prevalence between SSA countries differs tenfold.

HIV is transmitted through body fluids and the major routes of transmission are through sexual intercourse, contaminated needles, and transmission from an infected mother to her baby.

In SSA, most of the HIV infections are heterosexually transmitted or transmitted through mother-to-child transmission (MTCT) [3]. The HIV epidemic in SSA is defined as a generalized epidemic, described by the UNAIDS as, 1. “an epidemic that is self-sustaining through heterosexual transmission” and 2. where the HIV prevalence usually exceeds 1% among pregnant women attending antenatal care (ANC) clinics [4]. In other parts of the world the HIV epidemic is defined as a “concentrated epidemic”, i.e. HIV is mostly concentrated to sub-populations, i.e. among injecting drug users, with a prevalence of 5% or above in the sub-populations [4]. HIV is also included in one of the eight United Nations’ Millennium Development Goals (MDG) to be reached by 2015. The MGD’s aim is to increase health and decrease poverty in resource-poor countries. The HIV related goals include to have halted and began to reverse the spread of HIV by 2015 and to reach universal access to ART for all those who need it by 2010 [5].

### HIV treatment

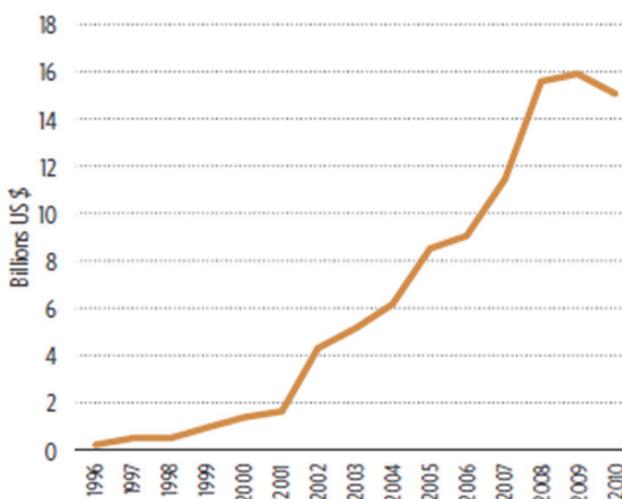
Since the discovery of HIV in the early 1980s, much progress has been made in terms of knowledge about the virus and the development of treatment and prevention strategies [6]. In the early phase of the epidemic, HIV care and treatment was only available in resource-rich countries and these countries were therefore the first to gain experience of treating people living with HIV, the first to develop clinical guidelines, and the first to design and implement HIV service delivery programmes [7]. In 1996 the combination of three antiretroviral medicines (ARVs) into ART was shown to be effective in controlling the HIV infection and shown to have a great impact on morbidity and mortality in HIV-infected people [6, 8]. ART was introduced in high-income countries soon after its discovery. However, due to the fact that most of the early experience of HIV care came from resource-rich settings and the fact that there are huge differences between the HIV care that could be provided in resource-rich and resource-poor settings, just transferring the way HIV care was organized in high-income settings to low-income settings was considered impossible.

Therefore many were pessimistic about the possibility to introduce large scale-ART programmes in low-income settings and there was much resistance towards it [7]. However, the

scale-up of ART to the large population in low-income countries, especially in SSA started with the “3 by 5” initiative, launched by the World Health Organization (WHO), aiming to provide ART to three million people by 2005 [9]. Even though this initiative did not reach its target, this was the start of the scale-up of ART and today 5 million HIV-infected persons have access to ART in SSA, which is nearly 50% of those in need [2].

There has been an unprecedented investment in HIV-care in low- and middle-income countries over the years, especially after the establishment of The Global Fund to Fight AIDS, Tuberculosis and Malaria in 2002, and The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) in 2003 (Figure 1).

Figure 1. Global resources available for HIV programmes in low-and middle-income countries, billions of US dollars, 1996-2010



Although there has been much progress in terms of financial resources available and in terms of access to HIV care, there is still a need for better use of the resources available and in 2010 the UNAIDS launched its new HIV treatment platform for treatment and prevention called, “Treatment 2.0” [10]. The platform seeks to more efficiently reduce new HIV infections by one-third and avert 10 million deaths by 2025 and includes the development of better combination treatment regimens, cheaper and simplified diagnostic tools, and a low-cost community-led approach to delivery.

### HIV prevention

In addition to the scale up of ART and the considerable focus on HIV treatment, in recent years there has been a shift to focusing more on prevention [11]. Prevention efforts are crucial since the number of new infections in 2010 (2.7 million), still outweighed the number of people initiated on ART (1.7 million) [2]. Combination and multi-level prevention interventions have been put forward under the concept “highly active HIV prevention” combining interventions for behavioural change, increased access to ART and treatment for other sexually transmitted infections, and to biomedical (e.g. microbicides, male circumcision) strategies, as well as

increased social justice and human rights to reach more effective preventive measures [11]. Moreover, the UNAIDS has sought to draw more attention to HIV prevention and the fact that there is not one single HIV epidemic but rather various epidemic profiles in different settings and the expression “Know your epidemic, know your response” has been coined [12]. In order to be effective, the preventive response towards HIV should be tailored to fit the epidemic profile in a specific context [13].

Another approach towards preventing HIV is the “test and treat”, or treatment for prevention model, i.e. that people should be tested for HIV on a routine basis and if identified as HIV-infected, receive ART immediately [14]. The justification for the test and treat model is that if people are tested early and receive immediate ART, they would be less infectious, and hence it would prevent them from transmitting the virus to other people.

#### *HIV testing*

Voluntary counselling and testing (VCT) for HIV, client initiated-opt-in-HIV testing where people actively seek to be tested for HIV, has for the last twenty years been part of the HIV prevention efforts.

HIV testing is important both to identify HIV-infected people in need of care and to provide counselling on how to stay uninfected for persons who are tested negative. However, the client-initiated testing model left many HIV-infected people in sub-Saharan Africa unaware of their HIV status, and many HIV-infected people were often diagnosed and received ART very late, with the consequence that many infected died soon after the HIV diagnosis [15].

Consequently, in 2007, the WHO and the UNAIDS launched a new testing strategy; provider-initiated, opt-out HIV testing [16]. With this model the health care provider should initiate HIV testing and counsel all people who seek any type of care, and the strategy has been implemented in most countries with a generalized HIV epidemic [2]. Arguments in favour of the opt-out HIV testing model suggest that it would increase the availability of testing services and reduce HIV-related stigma since it would be part of routine care [17, 18]. A potential risk when moving from the opt-in- to the opt-out testing model might be that patients feel obliged to test without being mentally prepared to receive a positive HIV test result, or even worse, that people would be diagnosed but without medicines being available [19-21]. However, provider-initiated testing has increased HIV testing rates in many SSA countries [22-24].

There are also other approaches employed to increase the number of people tested for HIV such as home-based HIV testing, that has shown testing uptake of 69-94% [25-27] and also resulted in persons with HIV being diagnosed earlier as compared to health-facility based testing [28].

Couple HIV testing is another testing model recommended by the WHO for settings with high HIV prevalence [29, 30]. The policy was formulated in 2002 and suggests that couples should be HIV counselled and tested together, especially during antenatal care (ANC) [31]. The guidelines are based on the assumption that couple testing would help increase spousal support for women to use prevention of mother-to-child transmission (PMTCT) services, create opportunities for secondary prevention by counselling both men and women about HIV, and increase the uptake of testing and identification of HIV-infected persons [31-33]. Studies from SSA and Europe have shown an association between male partner involvement in their wives' ANC, couple HIV testing, and the pregnant women's likelihood of accessing and completing PMTCT services [34-39]. However, the uptake of couple HIV testing during ANC in SSA has

so far been very low, only 5-12% of pregnant women are HIV tested with their spouses [35, 36, 40-42].

## **PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV**

In 2010, an estimated 390 000 children became infected with HIV [2]. More than 90% of children living with HIV have acquired the infection through MTCT, which can occur during pregnancy, labour and delivery and the breastfeeding period. In the absence of any intervention the risk of MTCT is 15-26% peripartum [43-47], with an additional transmission rate of 1.57% or 0.51% per month of breastfeeding, depending on the woman's immune status with CD4 cell count levels below or above 350/mm<sup>3</sup> respectively [48]. However, by using available interventions for PMTCT and assuming that the woman completes all the PMTCT components, the risk of MTCT in high-income countries is about 1-2%.

The PMTCT components are: provision of triple ARV therapy administered to HIV-infected women before, during and after delivery, Caesarean section, and provision of prophylactic ARVs to newborns and replacement infant feeding [49, 50]. Most women in SSA can not provide safe replacement feeding to their infants and are therefore recommended to employ exclusive breastfeeding [49].

Despite the limited access in low-income settings to combination ARV prophylactic regimens and the capacity to provide Caesarean section and replacement feeding, the rate of MTCT can still be reduced to around 5%, provided that women are tested and enrolled in a PMTCT programme [51, 52]. In order to reduce the number of children being infected with HIV, the WHO and the UNAIDS have developed a Plan towards the elimination of new HIV infections among children by 2015, aiming at a reduction of mother-to-child transmission of HIV globally to less than 5% [53].

### **An overview of ARV prophylactic regimens for PMTCT**

To provide a single dose of the ARV nevirapine (sd-NVP) to pregnant women at the onset of labour was in 1999 shown to be effective for PMTCT with a MTCT rate of 19% at six months post-partum [54]. Since then the ARV prophylactic regimens recommended for PMTCT has changed. The WHO guidelines for PMTCT in low- and middle-income countries from 2006, as described in Table 1 below, stated that pregnant HIV-infected women with a WHO staging of 3 or 4, or a CD4 cell count of < 200/mm<sup>3</sup> should receive ART (for WHO staging see Appendix 1). Women who were not eligible for ART should receive dual ARV prophylaxis of zidovudine (AZT) and lamivudine (3TC), as well as sd-NVP (for description of the ARVs, see Appendix 2). Although, in case dual prophylaxis was not available, providing only sd-NVP was also recommended (Table 1).

**Table 1. The 2006 WHO recommendations for ARV prophylaxis for PMTCT. Prophylactic ARV regimens for pregnant women who do not need ART for their own health**

<b>Mother</b>	
Antepartum	AZT starting at 28 weeks of pregnancy or as soon as feasible thereafter
Intrapartum	sd-NVP + AZT/3TC
Postpartum	AZT/3TC for 7 days
<b>Infant</b>	

*Irrespective of mode of infant feeding*

d-NVP within 72 hours after delivery + AZT for 7 days

Reference: *The WHO, Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: towards universal access: recommendations for a public health approach, 2006: Geneva.*

In 2010, the WHO updated the PMTCT guidelines to the current recommendation summarized in Table 2. The major changes from the 2006 policy were the early initiation of ARV prophylaxis (from 14 weeks of gestation), the recommendation to use ARV prophylaxis throughout the breastfeeding period and the change in ART eligibility criteria, starting when the CD 4 cell count  $\leq 350$  cells/mm<sup>3</sup> [49].

For women not eligible for ART for their own health, the WHO recommendations provide two options for ARV prophylaxis:

Option A. AZT from 14 weeks, sd-NVP at onset of labour and AZT+3TC, 7 days postpartum. To breastfeeding infants NVP until one week after exposure to breast milk has ended.

Option B. Triple ARV prophylaxis to the mother until one week after infant exposure to breast milk, infants NVP or AZT until 4-6 weeks.

**Table 2. The 2010 WHO recommendations for ARV prophylaxis for PMTCT. Two options of prophylactic ARV regimens for pregnant women who do not need ART for their own health**

<b>Option A. Maternal AZT + infant ARV prophylaxis</b>		<b>Option B. Maternal triple ARV prophylaxis</b>	
<b>Mother</b>		<b>Mother</b>	
<i>Antepartum</i>	AZT from 14 weeks of gestation and continued during pregnancy	<i>Antepartum</i>	Triple ARV* prophylaxis from 14 weeks of gestation or as soon as feasible thereafter
<i>Intrapartum</i>	Sd-NVP + AZT/3TC	<i>Intrapartum</i>	Triple ARV* prophylaxis
<i>Postpartum</i>	AZT/3TC for 7 days	<i>Postpartum</i>	Triple ARV* prophylaxis continued until 1 week after infant exposure to breast milk has ended.
<b>Infant</b>		<b>Infant</b>	
<i>For breastfeeding infants</i> Daily NVP for a minimum of 4 to 6 weeks, and until 1 week after exposure to breast milk has ended.		<i>Irrespective of mode of infant feeding</i> Daily NVP or twice daily AZT from birth until 4 to 6 weeks of age.	
<i>Infants receiving replacement feeding only</i> Daily NVP or sd-NVP + twice-daily AZT until 4 to 6 weeks of age.			

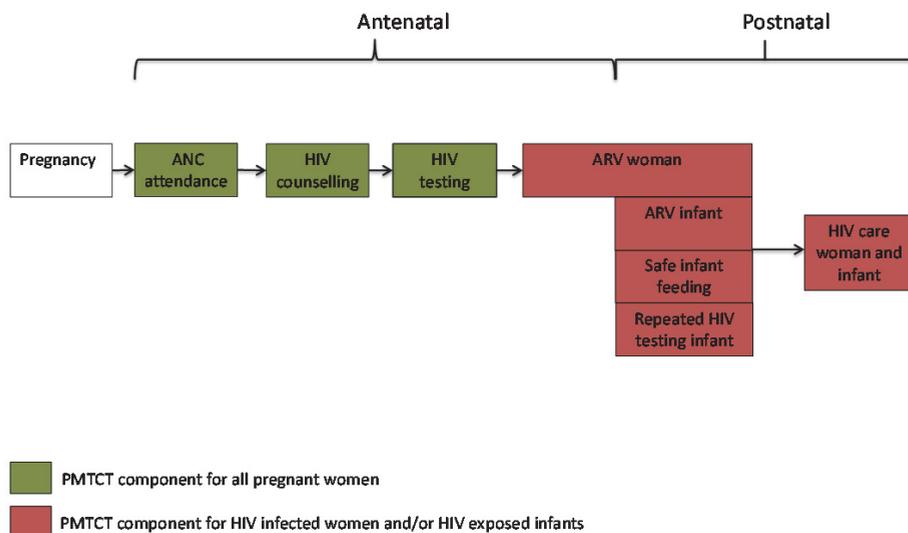
Reference: *The WHO, Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: recommendations for a public health approach, 2010: Geneva.* \*Recommended regimens include: AZT + 3TC + LPV/r or AZT + 3TC + ABC or AZT + 3TC + EFV or TDF + 3TC (or FTC) + EFV

## The PMTCT services

In order for the ARVs to realize their effects, they have to be delivered to, used and adhered to by the pregnant women. The ARV prophylactic regimens included in the PMTCT guidelines described above are based on studies that have shown the ARVs to be effective in prevention of MTCT. This has been shown in trial settings i.e. the *efficacy* of the ARVs has been shown. However, the effectiveness of the ARVs refers to the effect of the ARVs in a real-life situation. The effectiveness of an intervention is: “the impact an intervention achieves in the real world, under resource constraints, in entire population, or sub-population” has been described by Aral 1998 [55].

PMTCT are sequential interventions that should be implemented to reduce MTCT. First of all, it is crucial that all pregnant women receive ANC at health facilities, that they are also being HIV tested during ANC (either alone or couple tested), that they receive the test results, and thereafter, if identified as HIV-infected, receive ARV prophylaxis and are followed up together with the baby until 18 months after delivery. The HIV exposed baby should also receive ARV prophylaxis and be tested for HIV repeatedly until 18 months old (Figure 2).

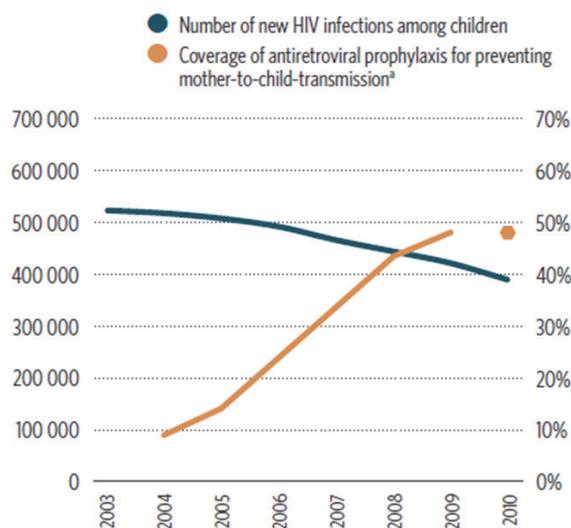
Figure 2. The PMTCT services



Since the PMTCT services should be delivered to pregnant women, the services have been integrated with the regular ANC health services. However, there is a big discrepancy between the coverage of ANC- and PMTCT services in many low- and middle-income countries [56]. HIV testing is the first step in PMTCT, but only 42% of the pregnant women in SSA were tested for HIV in 2010 [2]. Although considerable efforts have been made to expand and integrate PMTCT programmes into ANC clinics [57], studies have shown that even if PMTCT treatment is available in the clinics, the uptake and completion of this intervention is very far from 100% [58, 59]. Moreover, the HIV-infected women should be linked to HIV-care and monitored regularly in order to receive treatment for other infections and ART when eligible [60].

As illustrated in Figure 3, the coverage of ARV prophylaxis for PMTCT i.e. the proportion of pregnant women living with HIV who received prophylactic treatment, was 50% (60% if including sd-NVP) in low- and middle-income countries and only 42% of the HIV exposed infants received ARVs for PMTCT [2].

*Figure 3. Coverage of antiretroviral prophylaxis for prevention of mother-to-child transmission of HIV and the number of new HIV infections among children, low- and middle-income countries, 2003-2010*



<sup>a</sup> Coverage before 2010 includes single-dose nevirapine (sd-NVP), which is no longer recommended by WHO. Coverage in 2010 does not include sd-NVP [2]

From Figure 3 it is evident that despite an increase in coverage from 10% to 60% (if including sd-NVP) between 2004 and 2009, the decrease in number of children infected with HIV for the same period was only from 500 000 to 400 000. The reason for this is the way PMTCT-service coverage is reported. Coverage is often overestimated as it is usually stated as the proportion of woman/baby-pairs that receive ARV prophylaxis [2]. This way of reporting coverage ignores whether the ARVs are taken as prescribed during and after labour and delivery, and whether exclusive breastfeeding is practiced (or alternatively, whether continued ARV during breastfeeding is practiced and adhered to). Since only the first step in the programme is reported, the effectiveness of PMTCT programmes might be significantly lower than reported. Also reporting might sometimes be of inadequate quality, for example, one study for Kenya further showed that routine PMTCT data was double reported and that women already identified as HIV-infected were excluded in the denominator, meaning that the PMTCT programme over-reported its coverage [61].

Most research on the uptake of PMTCT services is from health facility based studies, while actual access to PMTCT services at population level has rarely been assessed [62, 63]. Health-facility data on PMTCT uptake, in contrast to population-level data, do not cover all pregnant women; they do not include those who do not seek ANC at all or those that seek ANC at health facilities without HIV testing services.

## **GENDER AND HIV**

The term gender is often, in feminist theories, defined as a social construct of men and women and acknowledges the power-imbalances both on structural and individual levels. Gender systems are acted and enacted at all levels of society making it crucial to maintain a pluralistic viewpoint when studying gender power relations and their effects. Gender power-relations exist between men and women, between men and men and between women and women. Further, gender structures intersect with other social inequalities such as class and ethnicity that together form a complex web of power-relations that are manifested in structural inequalities in access to social, cultural and legal rights, as well as financial and other resources [64]. Gender is further socially constructed and re-constructed through people's behaviour, and often holds certain characteristics that are (stereo-) typically associated with being a "man" or "woman".

Gender has been illustrated as a social determinant of health in a framework by Sen et al. 2010 [65]. Sen (2010) reveals how factors at the individual and collective levels influence health outcomes differently for men and women. This framework also details the manner in which inequality is generated by gendered structural determinants and intermediary factors. Gendered structural determinants act on a higher level in societies and influence access to health care, for example, through access to education and political power. Intermediate factors influencing health outcomes are: discriminatory norms and behaviours such as stereotyping, influencing men's or women's ability or desire, to seek health care; or gender biased health systems that do not acknowledge gender when, for example, planning and implementing health services [65]. Nearly 60% of people living with HIV in SSA are women [2]. In HIV prevention and care it is necessary to understand how gender dynamics influence men's and women's behaviours and their access to health services. Gender inequality and vulnerability to HIV infection are connected. For example, women are often unable to negotiate condom use with their male partners due to unequal power balance and culturally-prescribed expectations of gendered decision-making within the couple [66, 67]. Moreover, masculine ideals of having multiple sexual partners [68], and the sometimes culturally sanctioned polygamous relationships or unfaithfulness for men, constitute an increased risk of acquiring HIV both for men themselves but also for their sexual partners [69].

Women in SSA are more likely than men to be tested for HIV [2]. In South Africa females accounted for 65% of all testing even when HIV testing during pregnancy was excluded [70]. Hence, in SSA women are often the first in a couple to be tested for HIV and diagnosed with an HIV infection [71]. This means that women risk being perceived as the ones that "bring" HIV into the family and the disclosure of a woman's HIV status to her male partner might lead to abandonment, a severe consequence since the man is most often the breadwinner in the family [71, 72]. The WHO has produced several publications proposing how gender should be acknowledged in HIV programmes and these include taking into account how gender norms influence HIV risk behaviours and access to care [73, 74]. Men on the other hand are often disadvantaged and excluded in HIV programmes [75].

## **HEALTH SYSTEMS AND POLICIES**

The WHO states that: "A health system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health [76]. This includes efforts to influence

determinants of health as well as more direct health-improving activities.” A crucial part of health systems are the health policies that could be defined in various ways but in this thesis a health policy is assumed “to embrace the courses of action that affect the different parts of a health system”, as described by Buse 2005 [77]. In addition, Walt suggests that health policy development should not only focus on the policy content but also on the actors involved in policy reform, the processes required for developing and implementing the policy and the context within which a policy is developed [78]. The major challenge for implementing health policies and tackling health problems in resource-poor countries is not the lack of effective interventions [79]. The reason is rather that services that have shown efficiency are not implemented, or made accessible, i.e. delivered through the health system. In fact, the primary obstacle to achieving many health goals in low and middle-income countries is fragile and fragmented health systems that are unable to deliver the health services [79].

Further, the goal of a health system is to; “improve health and health equity, in ways that are responsive, financially fair, and make the best, or most efficient, use of available resources”. The building blocks of a health system could be divided into; service delivery, human resources, medicines and technologies, governance, information, financing and leadership, placing the people in need of the system in the middle (Figure 4) [76].

Figure 4. The six building blocks of a health system, and the people it aims to serve



Source: *Systems thinking for Health System Strengthening*, WHO 2010.

In order to deliver health care in an effective way, policies are needed and have to be implemented so that good quality service delivery is ensured, and to achieve that strong global and national commitment, adequate financial resources, and intensive technical support are needed [80]. As early as 1978 the Alma Ata declaration emphasized the need for strong health systems in order to deliver health care for all by 2000 [81].

## Health systems and HIV in sub-Saharan African

The large increase in funding for the fight against HIV during the 2000 led to a rapid expansion of HIV care in SSA, and due to a weak health system in most of the highly affected countries, the HIV programmes often has been introduced parallel to the regular health system, i.e. as vertical programmes. A criticism of these vertical programmes has been that they might undermine rather than support national health systems by diverting away for example human resources from the regular health system [79, 82]. It has been argued that if certain conditions are looked at separately and parallel systems are introduced, it would result in, for example, higher costs (e.g. medicines delivered twice to the same place) [79], an internal brain drain, the recruitment of health workers away from their regular work at the health facility to better paid, disease-specific programmes [83], or extra work for the health workers in terms of separate reporting systems for parallel programmes [79]. However, due to weak health systems there is a need to design effective programmes that balance a specific-disease focus with system-based solutions and there has been a debate as to whether HIV care should be provided through the regular health system or delivered vertically to the health system [80].

Based on existing data, the effect of the introduction of HIV care on health systems is not entirely clear. One example of the effect on service provision after introducing HIV care is the quality of ANC that has in some settings been reported as increased [84], and in others decreased, after the PMTCT programmes have been implemented during ANC [85]. Similarly, in facilities with ART provision integrated with other health care services, an increase in workload has been shown [82]. In the light of the situation where there is a critical shortage of health workers in SSA, introducing ART for the millions of people in need requires remarkable efforts for the health systems to adapt [86]. The increase in HIV services has been hampered by the shortage of physicians and nurses and characterized by health workforce innovations such as task shifting, and task sharing [87, 88]. In some countries, for example, nurses and clinical officers can now prescribe and/or order new supplies of antiretroviral medication [89].

Using parallel systems in the scale up of ART has been shown to increase fragmentation and complexity, affecting many areas of the health system [90]. Especially challenging is the governance since many actors, such as external donors are involved and coordination is often lacking [90, 91]. Different funding also makes the provision of ART complex at the health facilities, as several different ART programmes are sometimes run at the same facility [92]. In addition has adherence to treatment been reported to be worse at facilities with several ART programmes at the same time [82].

## **THE UGANDAN CONTEXT**

Uganda is situated in East Africa and has borders with the Democratic Republic of the Congo, Kenya, Rwanda, South Sudan and Tanzania.

The Ugandan population is estimated to 32 million and has, at 3.2%, one of the highest annual growth rates in Africa. The total fertility rate in the rural areas is 6.7 children/woman [93].

The majority of the population, 85%, lives in rural areas. Almost half of the population (49%) are aged 0-14 years and life expectancy at birth (females and males, years) is 56/55 years [1]. Some selected health outcomes in Uganda are presented in Table 3.

**Table 3. Selected health outcomes in Uganda**

Indicator	Measure
ANC attendance at least once/pregnancy <sup>a</sup> (%)	94
Giving birth in a health facility <sup>b</sup> (%)	
Rural	52
Urban	90
Total fertility rate <sup>b</sup> (number of children born/woman)	
Rural	6.7
Urban	3.8
Crude birth rate <sup>a</sup> (number of childbirths per 1000 people per year)	45
Exclusive breastfeeding <sup>b</sup> (%)	
0-1 months	82
2-3 months	67
4-5 months	39
HIV prevalence <sup>c</sup> (%)	
men	8
women	5
Maternal mortality rate <sup>a</sup> (per 100 000 live births)	352
Infant mortality rate <sup>b</sup> (per 1000 live births)	54
Under-five mortality rate <sup>d</sup> (per 1000 live births)	90

<sup>a</sup>UNICEF *Levels & Trends in Child Mortality. UN Inter-agency Group for Child Mortality Estimation. Report 2011*, 2011: New York. <sup>b</sup>Summary of results from Uganda Demographic Health Survey, 2011, Pamela N Kakande, Uganda Bureau of statistics. <sup>c</sup>Ministry of Health and ORC Macro. *Uganda HIV/AIDS Sero-behavioural Survey 2004-2005*. 2006, Calverton, USA.

### The Ugandan Health System

The provision of health services in Uganda is decentralized and health districts and sub-districts are central in the delivery and management of health care provision. The District Local Governments plan, budget and implement health policies and health sector plans [94]. The districts manage general hospitals and provide supervision and monitoring of all health activities (including those in the private sector) in their area.

The public health services in Uganda are delivered through health centres (HCs), ranging from the lowest level HC IIs, to HC IIIs, HC IVs, District Hospitals, Regional Referral Hospitals and the National Referral Hospital. The health sub-districts are responsible for the health services at lower level health centres (II- IV) (Table 4).

**Table 4. Organization of health service delivery in Uganda**

Health facility level	Number of facilities	Services available	Location	Catchment population
National Referral Hospitals	2	Comprehensive specialist services	National	30,000,000
Regional Referral Hospitals	11	Specialist clinical services	National	2,000,000
General Referral Hospitals	98	Maternity, inpatient health services, surgery, blood transfusion, laboratory	District	500,000
Health Centre IV	166	Maternity, in-patient health services, surgery, blood transfusion, laboratory.	County	100,000
Health Centre III	905	Laboratory services for diagnosis, maternity care and first referral level for the sub-county.	Sub-county	20,000
Health Centre II	1887	Outpatient care and community outreach services.	Parish	5,000
Health Centre I /Village Health Team	Unknown	No physical structure, only persons that function as a link between health facilities and the community.	Village	1,000

Source of data; Health Sector Strategic Plan II: 2005/06 – 2009/2010, 2004: Ministry of Health, Kampala, Uganda, and Health Sector Strategic Plan III: 2010/11-2014/15, 2010: Ministry of Health, Kampala, Uganda.

Health-care services should be free of charge in all public health facilities, and user fees were abolished in 2001, except for the hospitals' private wings [94, 95].

ANC should be available at all levels of care and include a physical examination, the provision of necessary medicines, health education, and HIV counselling and testing, or HIV testing referral. The Ugandan national guidelines recommend at least four ANC visits per pregnancy [96].

The private sector plays an important role in the delivery of health services in Uganda covering about 50%. The private health sector comprises of the Private Not for Profit Organisations (PNFPs), Private For Profit Practitioners (PFPs) and the Traditional and Complementary Medicine Practitioners (TCMPs).

The PNFP sector is important in Uganda and more structured and mostly present in rural areas [95]. The PFP is fast growing and most facilities are concentrated in urban areas. TCMPs are present in both at rural and urban areas, even if the services provided vary considerably and range from traditional practices in rural areas to imported alternative medicines, mostly in urban areas. Although 72% of the households in Uganda live within 5km from a health facility (public or PNFP), utilization is limited due to poor infrastructure, lack of medicines and other health supplies, shortage of human resource in the public sector, and other factors that limit access to quality service delivery [94]. The Human Resources for Health Strategic Plan estimates that for maintaining or slightly improving the health worker to population ratio until 2020, the health workforce will need to grow by 66% [97].

## HIV and PMTCT in Uganda

In Uganda HIV was first acknowledged by the Ugandan government in the late 1980s, and large information campaigns about HIV and HIV prevention, including HIV testing, have been carried out at all levels of the society [98]. The overall HIV prevalence in Uganda is estimated at 6%, and the HIV prevalence from the ANC surveillance in 2008/09 was estimated to range from 5–10% [99, 100]. The HIV prevalence is higher in urban areas, especially in Kampala [100]. The epidemic has shifted from the single younger-aged individuals to older individuals aged 30–35 years who are married or in long-term relationships. Multiple concurrent partnerships, extra-marital relationships, discordance and non-disclosure are among the key factors driving the spread of HIV in Uganda [99]. In 2010, an estimated 47% of the HIV infected people in need received ART [2].

The last figures from Uganda show that 1.2 million people are infected with HIV, and 150,000 of them are children below 15 years of age [2]. Of the about 90,000 new infections in 2008, almost 20,000 of them were in children from MTCT [101].

Further, in the same year, of all new infections, 37% were attributable to multiple sexual partnerships including infections of their regular partners. Couples in mutually monogamous partnerships account for 35% of new infections and mother-to-child transmission accounts for 18%. Commercial sex work (including partners of sex, workers, their clients and partners of clients) accounts for 9% of new infections.

Despite a very high ANC-attendance rate of 94% in Uganda, only 10% of women who gave birth in Uganda were tested for HIV in 2003 [102]. Three years later, in 2006, the number of pregnant women receiving HIV counselling (40%) and testing (21%) remained at low levels [103]. However, the WHO and UNAIDS report that in 2011 63% of the pregnant women in Uganda were tested for HIV [2]. Despite an increase in coverage of HIV testing during pregnancy, it remained at rather low levels.

To increase the coverage of HIV testing and PMTCT services, the Ugandan government launched two new policies in 2005 and 2006 respectively, moving from a client-initiated, “opt-in” HIV testing model, to a provider-initiated, “opt-out” model. These policies mean that all patients visiting health care facilities in Uganda, and all pregnant women receiving ANC should be tested for HIV as long as they do not actively opt-out from it [104]. In the Ugandan PMTCT guidelines it is also stated that the pregnant woman’s partner should routinely be offered HIV testing during ANC [105]. If HIV testing services are not available at the ANC health facility where the woman seeks ANC, the woman and any accompanying spouse, should be referred for testing to a nearby health facility with testing equipment [104].

The ARV prophylaxis recommended for PMTCT in Uganda for women not eligible for ART, during 2008–2010, was a dual regimen of AZT and 3TC, given to HIV-infected pregnant women from 28 weeks and until one week after delivery, plus sd-NVP during delivery. However, only sd-NVP was also provided in some cases, especially from the lower level health facilities. The infants born to HIV-infected mothers received either sd-NVP after birth and AZT for one week after delivery, or only sd-NVP. Women were considered to be eligible for ART if their CD4 cell count was  $\leq 350/\text{mm}^3$  or if they were diagnosed to be in WHO staging 3 or 4, irrespective of CD4-count [104].

The PMTCT guidelines were modified in 2010 to the WHO Option B, as described previously. However, since there have been problems with procurement of ART in Uganda, these guidelines have not yet been introduced on a large scale (personal communication, PMTCT officer, Ministry of Health). The estimated uptake of ARV prophylaxis in Uganda was 42% among women (sd-NVP excluded) and 22% among infants [2].

The Ugandan policy states that all pregnant women should receive ANC at least four times per pregnancy. The pregnant women are also encouraged to bring their partner, or a family member to at least one visit. The goals of the ANC visits are to conduct a risk assessment, provide health education, and monitor the progress of the current pregnancy and plan for delivery. Medical, surgical, obstetric and gynaecological history is taken, physical examination and laboratory investigations, and health promotion is carried out, including nutrition, hygiene, pregnancy danger signs malaria prevention, HIV testing and if testing is positive, PMTCT should be offered [96].

## ACCESS TO HEALTH SERVICES

Access to health care can be defined in many different ways and several theoretical models have been developed to explain access to health care services. Some of the models focus on the behavioural aspect, such as the Health Belief Model [106] while others focus more on physical and/or geographical aspects of access.

No particular theoretical model was to guide the design and the development of the studies in this thesis instead the work was guided by the research questions and aims. However, during the course of this PhD work several theoretical models related to access to health care have been reviewed and some will be introduced briefly. One model (McIntyre's) was found to be particularly useful when discussing the results and will be presented more thoroughly.

### A summary of some theoretical models related to access to health care

The Health Belief Model was developed in 1966 to study and promote uptake of health services, and focused on the psychological and behavioural aspect of access to services [107]. The model explains behaviour and uses two kinds of variables; (i) the psychological state of readiness to take a specific action, and (ii) the belief that the action would be beneficial in reducing the threat (disease). Readiness to act depends on the individual's perceived susceptibility and perceived seriousness of a disease, and the perceived benefits and barriers of taking action. For a person to act there is a need for "cues to action". Those cues could be internal, e.g. the bodily state, or external, e.g. media communication. In terms of access to services, this model focuses on the individual perception of taking action and the way that individuals could be influenced to take action.

The first Behavioural Model for access to health care was developed by Andersen in 1960 and the model focuses on the *use of health services* and was created to assist the understanding of why people seek health services [108]. The model has since then been revised several times by Andersen and colleagues. In the model Andersen illustrate how certain population characteristics and health care system characteristics, influence the access to, i.e. the use of health services.

Population characteristics: 1. *Predisposing factors*- socio-demographic factors, e.g. age; social structure, e.g. education; health beliefs, e.g. knowledge about health and health services. 2. *Enabling resources*- e.g. economic resources, 3. *Need*- self decided, or evaluated, based on judgment from medical professionals.

The health care system characteristics: 1. *Policy*- available and implemented. 2. *Resources*- funding, health workers, medicines etc. 3. *Organization*- of the way the care is organized and delivered at the health facilities and the organization of care at higher level.

*Access model by McIntyre, building on the Penchansky model*

Access to health care has been defined by McIntyre et al. 2009 as; the *empowerment* of an individual to use health services [109]. They emphasize the need to take into account the degree of fit, the interaction, between on the one hand the health systems and on the other hand the individuals, households and communities. Each of the three dimensions of access that will be presented in detail below. This definition of access builds on the Access model described by Penchansky et al. 1981 who define access as a concept representing the degree of fit between the clients and the system [110]. The dimensions included in Penchansky's model are: *availability*, *affordability*, *acceptability*, *accommodation* (organization of services e.g. appointment system, opening hours and walk-in facilities) and *accessibility* (the geographical location). The McIntyre model combines Penchansky's definitions of accommodation, accessibility and availability, into the broader definition of availability. However, the main difference between Penchansky's model and the McIntyre one is that the latter focuses on the inter-relationship between the three dimensions. McIntyre et al. further acknowledge the total cost in the dimension affordability and include e.g. transportation cost.

The three dimensions of McIntyre's model of access and the factors that they build on are:

1. *Availability* (physical access): the appropriate health care providers or services, supplied in the right place and at the right time to meet the prevailing needs of the population. This dimension includes issues like: the fit between the quality/type/range of health care services and the extent of health needs among the individuals; the fit between location of health care facilities and the individual's ability to get to that location to receive care; ability/willingness of health care provider to give the services, or the fit between the opening hours and the time the population need the services.
2. *Affordability* (financial access); the degree of fit between full costs (including "under-the-counter" fees, transportation costs, income loss due to waiting time etc.) to the individual of using the services and the individual's ability to secure funds from the household budget and other demands on that budget. The concept of affordability goes beyond "ability to pay".
3. *Acceptability* (cultural access): related to the fit between provider and patient attitudes and expectations of each other. The ability to receive care would depend on the health care provider's attitudes towards the individual's characteristics e.g. gender, age, ethnicity, and the individual's attitudes towards provider characteristics, e.g. type of provider, age gender. Beliefs and perceptions, and past experiences are also part of this dimension.

The definition of access used in this thesis is McIntyre's presented above. This definition was chosen due to the broad definition of access where the interaction between the health system and the individuals are emphasized.

## **RATIONALE FOR THE STUDIES**

Effective interventions are available to prevent children born to HIV-infected women from contracting the virus. Moreover, most pregnant women in Uganda, over 90%, attend ANC services at least once during pregnancy. Hence, the ANC health facilities provide a great opportunity to deliver PMTCT services and an obvious aim should be to reach all women attending ANC with PMTCT services.

However as described in the background to this thesis: the aim is a long way from being achieved. Further, Uganda has one of the highest fertility rates in the world of almost 7 children/women in rural areas. Hence, many women do not access PMTCT services and consequently avoidable HIV infections among children are occurring and HIV-infected women are unidentified and/or untreated.

Very few studies internationally have investigated the actual uptake and completion of PMTCT services at population level. National estimates of coverage are usually based on the enrolment rate of pregnant women into PMTCT at the health facility level, but whether or not the woman completes all steps in the programme is not known [111].

Uganda's HIV preventive policies have been recognised for speaking openly about sexual risk behaviours and for taking action early on in the epidemic. However, many children are still being born with HIV in Uganda. Understanding what factors contribute to access and completion of PMTCT services at population level is therefore crucial.

## **OBJECTIVES**

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### **GENERAL AIM**

The aim is to determine access to Prevention of Mother-to-Child Transmission (PMTCT) services and to identify barriers to and facilitators for accessing these services.

### **SPECIFIC OBJECTIVES**

1. To explore pregnant women's views on routine opt-out HIV testing during antenatal care (Study I)
2. To explore men's views on couple HIV testing during pregnancy (Study II)
3. To assess the population HIV testing coverage during pregnancy, and examine risk factors for not being tested for HIV (Study III)
4. To estimate the number of children infected with HIV with current PMTCT coverage (Study IV)
5. To model the effect on HIV infections among children when increasing the coverage of individual PMTCT programme components (Study IV)



## MATERIALS AND METHODS

### OVERVIEW OF STUDIES

This thesis builds on both qualitative and quantitative research methods, where the method chosen for each study was guided by the specific objectives.

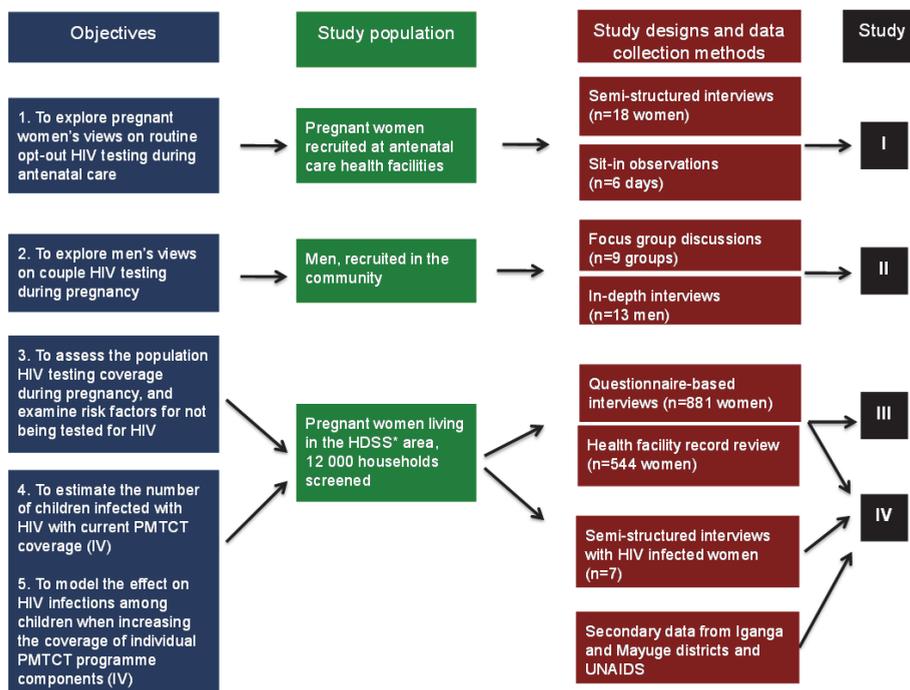
In **Study I**, semi-structured interviews and sit-in observations were used to get an in-depth understanding of the women's perceptions about opt-out HIV testing during pregnancy.

**Study II** explored men's views on couple HIV testing during pregnancy through semi-structured interviews, and focus group discussions.

In **Study III**, questionnaire-based interviews were employed, together with health facility record review, in order to quantify the HIV testing coverage during pregnancy, and to determine risk factors for not being tested for HIV during pregnancy.

**Study IV** employed the same survey and record review data as in Study III. Thereafter the dropout at each step in the PMTCT programme was identified through record reviews and semi-structured interviews and the number of children infected due to the dropout was estimated. The number of HIV-infected children was then estimated for scenarios that assumed an increase in coverage of individual PMTCT components.

Figure 5. Summary of objectives, materials and methods



\*HDSS: health and demographic surveillance site

In addition to the methods described above, field observations during the whole data collection period were conducted together with formal and informal key-informant interviews with local health officers, HIV programme coordinators, health workers and community members. This provided a good understanding of the context in which the studies were conducted and of the results.

#### **This thesis as part of the ARVMAC project**

The research for this thesis were conducted within the project; “Effects of Antiretrovirals for HIV on African health systems, Maternal and Child Health” (ARVMAC), in part supported by the European Community’s FP6 funding 2006-2010. The main objective of the project was to assess the effects of the rapid scale-up of ART on resource-limited health systems, maternal and child morbidity and mortality. The research was carried out in three Health and Demographic Surveillance Sites: Iganga-Mayuge (Uganda), Nouna (Burkina Faso) and Rufiji (Tanzania). Along with the Karolinska Institutet, Sweden, which acted as coordinator, the project partners were Makerere University School of Public Health, Uganda, the Swiss Tropical and Public Health Institute, Switzerland, the Ifakara Health Institute, Tanzania, the Institute of Tropical Medicine, Belgium, University of Heidelberg, Germany, and the Nouna Health Research Centre, Burkina Faso [112].

## **STUDY SETTING**

### **Iganga and Mayuge districts**

All studies in this thesis have been carried out in Iganga and Mayuge districts situated in Eastern Uganda (Map 1). Both districts are mostly rural, except Iganga Town, which is semi-urban, and the major source of income is subsistence farming, along with fishing in Mayuge, which is located on the shores of Lake Victoria. In 2008, Iganga had a population of about 710 000 inhabitants and Mayuge 430 000. In the last district ranking on performance in health management and service delivery, Iganga ranked 53, and Mayuge 61 out of the 80 districts in Uganda [99]. Iganga has 81 health facilities, and Mayuge 38. In Iganga and Mayuge respectively, 30% and 23% of pregnant women deliver at a health facility [99]. The HIV prevalence for the Basoga, the ethnic dominant group in the area, is 5.6% for women 15-49 years and is lower than the Ugandan average for women of reproductive age (7.5%) [100].



## Health system in the study area

Within the HDSS area there is one district hospital, four government HC IIIs, five government HC IIs and three non-governmental organization HC IIs. In addition, there are a number of drug shops, small private clinics, and traditional healers operating in the area.

At the time of the studies, ANC was offered at all health facilities, HIV testing services was available at one third of the facilities and other PMTCT-, and ART services available at around half of the facilities.

The ARV regimen used at lower level health facilities in the two districts was sd-NVP, while the hospital provided either sd-NVP or dual ARV regimen, or triple drug ARV for women eligible for that for their own health (WHO 2006 guidelines).

## STUDY PARTICIPANTS AND DATA COLLECTION

### Qualitative (Study I and II)

#### *Semi-structured interviews and sit-in observations (I)*

In Study I both open-ended semi-structured interviews [116] and sit-in observations were used [117]. Interviews used in qualitative research are usually conducted to get the personal view on a phenomenon [117]. A topic guide was used with areas that the interview should cover, and probes were often posed to follow up on issues that came up during the interviews (Appendix 3). The sit-in observations were conducted to observe the group counselling sessions and to investigate the issues that came up in the interviews [117]. The interviews aimed to investigate pregnant women's experiences of provider-initiated HIV testing [31], and data collection took place between February and March 2008. In total 18 women were interviewed. To get the views of women who sought ANC from different level of care, the respondents were recruited from three purposely-selected health facilities: one district hospital (n=10), one HC III (n=6) and one HC II (n=2). The hospital and the HC III offered HIV testing services during ANC on-site while the HC II was supposed to refer the pregnant women for HIV testing. Purposive sampling was performed in order to obtain the views of both first-time pregnant women (n=4) and women who had been pregnant before (n=14), as well as women with unknown (n=10) and confirmed HIV infection (n=8). The interviews were conducted in a separate room at the health facilities. The interviews were carried out in the local language Lusoga by one of two Ugandan female sociologists who both had previous experience of qualitative- and HIV research, and lasted for about 40 minutes. Interviews were audio-recorded, and thereafter translated and transcribed in English.

The sit-in observations during ANC were performed at all three health facilities to observe the organization of PMTCT services and the content of the pre-test counselling. I personally, together with one interviewer, observed the pre-test counselling sessions during six days, two in each facility and was done during the same days as the interviews were performed.

#### *Focus group discussions and in-depth interviews (II)*

In Study II, the study participants were men from both rural and semi-urban locations, who had had a child in the past year. Data were collected at two time points: four focus group discussions

(FGDs) [31, 117] were conducted in April 2008, and five FGDs and 13 in-depth interviews were held in April 2009. This iterative process made it possible to review and carry out preliminary analysis from the first phase, before the second phase data collection, and enabled us to then explore emerging themes and issues more in detail. FGDs are group discussions that aim to explore specific issues, and the participants should discuss and interact with each other, not simply answering one by one to questions posed by the moderator. FGDs usually capture the norms and behaviours in a certain setting [118]. There were about 10 participants in each FGD, and the discussions were homogenous with respect to place of living (rural and semi-urban), age and number of children (or length of marriage in 2009). Data were collected until saturation was achieved, meaning that in relation to the research questions issues and themes were repeated. In 2008 and 2009, all FGDs included both men who had, and who had not been HIV tested. FGDs were held at times and venues that were considered convenient by the participants, usually under a big tree in the middle of the village.

Study participants were recruited by a Ugandan research assistant together with a local political leader (local council chairperson), who went around in the community to find eligible men, for example at people's homes and at places where people normally gather. Recruitment took place at different times of the day to get both those who worked outside the home and farmers working at home. The study specifics were explained to eligible men and they were invited to participate.

The in-depth interviews were conducted after the FGDs in order to explore personal experiences around HIV and HIV testing, and to follow up on issues that had been identified during the FGDs. Eligible men were those who had had a child within the past year, and men were selected from both rural and semi-urban settings, as well as men with different experiences of HIV testing: HIV tested during ANC, HIV tested but not during ANC, and never HIV tested. The interviewer, together with persons well known in the communities, recruited eligible men from their homes, or work places. The interviews were held at times and places that ensured privacy and that were convenient for the respondents, typically at their home or work place.

During both the semi-structured and in-depth- interviews as well as during the FGDs, I was part of the recruitment process, and present in the field to support and supervise the interviewers and field assistants.

The data collection tools used in interviews and discussions were topic guides modified according to each data collection method, as well as to the type of respondents in the interviews (Appendix 4). The topic guides comprised key areas such as views and experiences of couple HIV testing during ANC and HIV testing in general, experiences and perceptions of ANC attendance, and factors hindering or facilitating couple testing and ANC attendance. One male and one female sociologist collected data in the local language, Lusoga. FGDs and interviews were audio-recorded, and thereafter translated and transcribed in English. A note-taker participated in the FGDs to capture the group dynamics, gestures, and emotions of participants.

## Quantitative (Study III and IV)

### *Population-based survey, and record review at health facilities (III and IV)*

Study III and IV are based on data from a population-based cohort of pregnant women recruited within the HDSS, and record reviews at health facilities, and determined the population dropout from the PMTCT programme (III, IV). In addition, by using the population data combined with data from the districts the estimated number of HIV infected children with base-case PMTCT coverage was estimated. Further the number of HIV infected children was estimated for scenarios that assumed an increase in coverage of individual PMTCT components. (IV).

As part of the regular HDSS data collection, all households were screened for pregnant women in May-July 2008, and a list of all (n=881) pregnant women was compiled. The data collection tool, a questionnaire [119], was translated into the local language Lusoga, and piloted on eight women. Thereafter minor changes were made to clarify some of the questions. Four female field-assistants were specifically trained on how to ask questions about pregnancy and HIV, and how to use the tool (Appendix 5).

Within 2-6 weeks after the initial HDSS screening, the field assistants followed up all pregnant women in their homes. The study particulars were explained to the women, they were asked to participate in the study, and all of them agreed to do so. The questions asked included personal characteristics, ANC attendance, health facility where ANC was sought, transportation to health facility, and care received during ANC.

After the HDSS data collection, the health facilities where the women had reported to seek ANC were visited for record review, and data were collected on ANC received, including HIV testing. The data were collected by myself and two trained field assistants with experience from the ANC records, the women were identified in the records by using HDSS information such as names, age, expected time of delivery, home village and name of spouse. The data collected in the HDSS and at health facilities were then linked to core HDSS demographic data for each respondent.

### *Semi-structured interviews with HIV-infected women (IV)*

In addition to the HDSS and health facility data, for Study IV home-based, semi-structured interviews were conducted with HIV-infected women identified at the health facilities. Interviews were carried out 12-20 months after giving birth, using both closed- and open-ended questions to explore the dropout and reasons for dropout from the PMTCT programme. A Ugandan midwife with long experience from PMTCT carried out the interviews.

### *Secondary data (IV)*

To estimate the number of HIV infected children, the most recent data on MTCT rates from the UNAIDS were used [48].

## **DATA ANALYSIS**

### Qualitative content analysis (I and II)

The data used in Studies I and II, were analysed using latent content analysis as described by Graneheim and Lundman [120]. Content analysis could be of two different kinds, manifest or

latent, where the visible and obvious content is referred to manifest content, and what the text talks about, or the underlying meaning of the text is named latent content. I used the latter, and interpreted the data on a deeper and higher analytical level than the manifest analysis would do [120]. This method was employed to understand women's different experiences and perception on provider initiated, opt-out HIV testing during ANC (Study I), and men's views on couple HIV testing during ANC (Study II).

The analysis procedure was the following: it started already in the field when the research team discussed each interview/FGD, later all transcripts were first read several times, thereafter so-called meaning units were identified and labelled with codes [120, 121]. The codes were compared for similarities and differences, and grouped into categories on a descriptive level. The categories were subsequently interpreted for the latent meaning and organized into themes. This type of content analysis also share similarities with what is described by Hsieh as "Conventional Content Analysis" [121], since the research was inductive rather than deductive, and started with a research question.

During the data collection, discussions about the content were held and helped to establish when saturation had been reached.

Initial coding was done manually on paper copies of transcripts, and thereafter in Study II, handled and organized using Nvivo software 8.0.

### Statistical analysis (III)

The data were double entered in SPSS software [122], merged using STATA software [123], and linked to demographic data from the HDSS database using the women's HDSS identity numbers. For data analysis STATA software was used [123].

#### *Main outcome: Not tested for HIV during current pregnancy*

Based on existing literature, various potential risk factors for not being tested for HIV were identified. For the data analysis, the risk factors were preliminarily divided into the groups described below, and the variables presented for each of them, and individually examined for their relation the outcome.

#### *Risk factors examined:*

- *Age* was grouped into <21, 21-34, and >34 years, since young and mature-age women would have different childbirth experiences.
- *Occupation* was categorized into 'farmers versus other'.
- *Number of living children* was grouped into 0-4 children versus >4, and based on a median number of 4 children.
- *Spousal support*, women's self-report, the variable was dichotomized into yes or no according to whether their partner attended ANC.
- *Socioeconomic status (SES)* data derived from the HDSS that maintains asset-based SES data on each household as wealth quartiles generated from principal components analysis [124-126]. The two lowest quartiles were then grouped into "poorest women", and the highest two into "least poor women", due to similar associations with the main outcome for these categories.

- *Person advising woman to seek ANC*; women were asked if anyone advised them to seek ANC. This variable was categorised into: own initiative; husband; mother/ mother-in-law; other.
- *Adherence to national guidelines for ANC*: the number of ANC visits was used as a proxy for this and grouped into 1, 2 or 3 and more times.
- *Seeking ANC late* was defined as the dichotomous variable attending ANC for the first time after the sixth gestational month.
- *Type of facility where women sought ANC*: this was examined through two variables, (i) level of care, and (ii) the dichotomous variable “whether the facility had onsite HIV testing services”, yes/no.
- *Distance to the facility where woman sought ANC*, this distance variable was categorized into three equally large groups; 0-1; 2-3, and >3 kilometres.
- *Distance to nearest facility with onsite HIV testing*, initial categories 0-1 kilometres and 2-3 kilometres were merged due to their similar associations with the main outcome, and the analysis included the dichotomous variable 0-3 km and >3 km.

The distance from home to the nearest ANC health facility and to the nearest facility with onsite HIV testing, was estimated using GPS coordinates of households and health facilities to calculate the shortest distance [127].

During an initial descriptive analysis, chi-square statistics were used to compare the distribution of the independent variables for not being tested for HIV. Though we grouped the factors as described above, their association with the outcome was independently assessed.

The association between the outcome and independent variables was first assessed by calculating bivariate relative risk estimates. Independent variables with a p-value <0.25 in bivariate analysis were tested in the multivariable model, using a backward selection procedure.

The multivariable analysis indicated interaction between SES and number of living children on the outcome “Not being tested for HIV”. Hence, the subsequent analysis was stratified by SES. In the final multivariable models variables were considered statistically significant if the adjusted p-value was <0.05.

#### Decision tree analysis (IV)

Decision tree analysis was carried out to estimate the number of children infected with HIV at birth and at six months post-partum in the Iganga and Mayuge districts in 2008. In order to estimate these numbers, population-based data derived from the women in the HDSS cohort were analysed using frequency tables for the proportion of women covered by each stage of the PMTCT programme (Table 5).

The HIV prevalence used was 3.5%, based on the HIV prevalence found in the HDSS cohort.

These data were combined with the most recent UNAIDS estimates of MTCT for different ARV prophylactic regimens, as well as different feeding practices, and subsequently entered as probabilities in a decision tree analysis created in Microsoft Excel (Table 5) [48].

**Table 5. Decision tree analysis input**

<b>Data from the HDSS-cohort (base-case) on probability of coverage for individual PMTCT programme components</b>	
<b>Components</b>	<b>Probabilities</b>
ANC attendance	0.96
Attending ANC at a facility with HIV testing services	0.78
HIV tested (attending ANC at facility with HIV testing services)	0.85
HIV tested (attending ANC at facility without HIV testing services)	0.06
HIV prevalence	0.035
HIV-infected women/baby pair receiving any ARV prophylaxis	0.83
Mother ARV prophylaxis -sd-NVP	0.33
Mother ARV prophylaxis -dual prophylaxis AZT and 3TC	0.57
Mother ARV prophylaxis -ART (for her own health)	0.10
Women practicing safe infant feeding	0
<b>HIV mother-to-child transmission rates<sup>a</sup></b>	
<b>Peripartum transmission rates for different ARV regimens</b>	
No ARV prophylaxis	0.22
sd-NVP	0.12
Dual prophylaxis of AZT and 3TC	0.04
ART for her own health	0.02
<b>Postpartum transmission rates per month of any breastfeeding<sup>a</sup> (mixed or exclusive)</b>	
Mother's CD4 cell count $\leq 350/\text{mm}^3$	0.0157
Mother's CD4 cell count $> 350/\text{mm}^3$	0.0051
If mother receive ART for her own health	0.002

<sup>a</sup>UNAIDS Reference Group on Estimates Modelling and Projections, Working Paper on MTCT transmission rates for use in Spectrum, 2011, UNAIDS: Geneva.

The MTCT rates for the different ARV prophylaxis regimens are based on the WHO 2006 guidelines. The MTCT rate for women receiving ART reflect a situation where the woman started ART during pregnancy and would continue ART during the breastfeeding period.

The total population in Iganga and Mayuge districts in 2008 was 1 140 000 individuals [99]. Among them an expected 51 300 women were pregnant and 1796 women were HIV-infected based on the Ugandan crude birth rate of 45/1000 and the HIV prevalence 3.5% found in the HDSS cohort [103].

The estimated number of HIV-infected children at birth and at six months MTCT rates were calculated for the base-case, i.e. the number of children estimated to be infected when using the uptake of PMTCT services found in the HDSS cohort, presented in Table 5.

*Scenarios assuming an increased coverage of PMTCT components*

Different scenarios where the uptake of individual or combined PMTCT programme components were assumed to be increased as compared to the base-case situation, were analysed in a decision tree analysis.

For each scenario the number of HIV-infected children as well as the MTCT rates at birth and at six months were estimated. Further, the effect of each scenario was illustrated by comparing it to the base-case, and the relative effect on the number of HIV-infected children was estimated.

In addition, the number of HIV infected children for a scenario assuming that no one would receive any PMTCT service at all was estimated. This scenario was used to calculate the reduced MTCT with the base-case PMTCT coverage.

The effectiveness was estimated for the following scenarios, assuming the base-case PMTCT coverage but additionally with:

- an ANC attendance of 100%
- an uptake of HIV testing of 100%
- provision of ART throughout pregnancy and the breastfeeding period to the HIV-infected women receiving ARV prophylaxis (83%)
- an Optimal scenario, combining all the above
- an OptimalPlus scenario where uptake of ART was increased from 83% to 100%

In the above presented scenarios, the coverage of all other PMTCT components were kept at the base-case coverage level that was presented in Table 5 previously.

## **FIELD WORK**

The studies in this thesis were part of the ARVMAC project described previously. Being part of the larger consortium during my doctoral education was an advantage and offered collaborative work with experienced researchers from various institutions and coordination of research activities in the field. A possible disadvantage was that data collection was delayed at one point due to coordination with other activities within the project. Nevertheless, I have for the most part been able to carry out my studies as planned.

During the course of this PhD work, I have had the opportunity to spend approximately one year in Uganda, something that gave me a deeper understanding about the community and context where the studies were conducted. It also gave me an opportunity to spend time at the School of Public Health at Makerere University and exchange idea and experiences with my co-supervisor, other researchers and PhD student colleges, as well as participate in local research related activities such as conferences.

For all four studies I was responsible for the planning, development of the tools, and implementation and I applied for and obtained the ethical clearance.

Study II was initiated by me, and came about as a result of the findings from Study I. For Study I and II, I together with Ugandan research assistants conducted the training of interviewers and moderators. Data collection was thereafter conducted in the local language. During the data collection period I was present in the field and participated in some of the FGDs, but was not part of the interviews. However, I led the meeting that followed up on all

interviews/discussions, where the data collection was discussed with the research assistants as part of the analysis and involvement of the studies.

For Study III and IV, I led the development of tools, supervised the training and carried out the data collection together with the HDSS staff. I together with research assistants visited all health facilities and many drug-shops, traditional births attendants and private clinics in Iganga and Mayuge districts in order to conduct the record reviews and learn where pregnant women sought ANC.

In addition to the planning and data collection I was also responsible for data analysis, and manuscript writing.

### **ETHICAL CONSIDERATIONS**

The National Council of Science and Technology, Kampala, Uganda approved all studies in 2008, reference number for the approval is IRB 00011353, protocol 052.

All participants included in the studies were first informed about the studies and after that gave their written or verbal consent to participate in the studies.

In addition to asking for consent to interview the women in the HDSS, the interviewer also asked for consent to retrieve additional information from the HDSS database and from the health facilities where the women had sought ANC.

The women identified as infected with HIV were home-visited by a specifically trained midwife and asked questions about their experiences and views on the PMTCT programme, and if they had dropped out from any of the steps within the programme.

The home visits were carefully planned together with experienced staff at the health facilities. The midwife who conducted the home visits also visited neighbouring households and informed them about child health in general in order not to draw attention to households where the HIV-infected women lived. This was done to avoid stigma, since visiting only households where the HIV-infected women lived might have caused suspicion among the neighbours. All HIV infected women who were home visited were encouraged to go to the nearest health facility to receive appropriate care.

During the FGDs and semi-structured- and in-depth interviews, questions about HIV and HIV testing came up, and the moderator or interviewer answered all questions after the group discussion or interview.



## RESULTS

This section presents the crosscutting results on access to PMTCT services combining results from all studies (I, II, III, IV), as well as unpublished data.

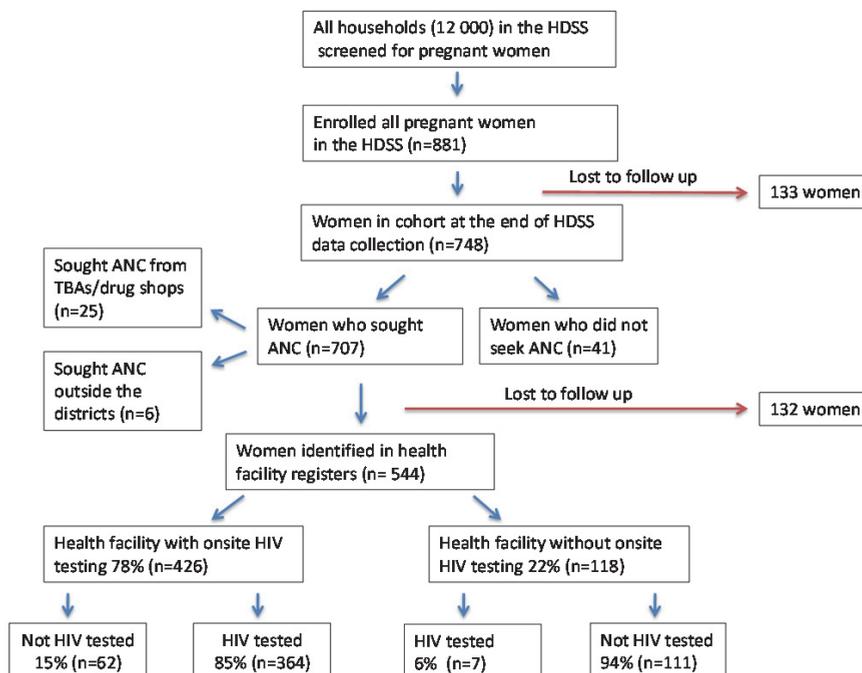
### COVERAGE OF HIV TESTING FOR PREGNANT WOMEN (III)

The coverage of HIV testing during the current pregnancy in the HDSS cohort was 64%. Figure 6 below illustrates how women in the cohort dropped-out from ANC- and PMTCT services.

Almost all women in the cohort, 96%, sought ANC at least once, and the majority (78%) of the women identified in the health facility registers (n=544) had attended a facility with onsite HIV testing services.

For the women who attended a facility with HIV testing services, uptake of HIV testing was 85%. By contrast, only 6% of the women who sought ANC from a health facility without onsite testing had followed through on a referral and been tested elsewhere.

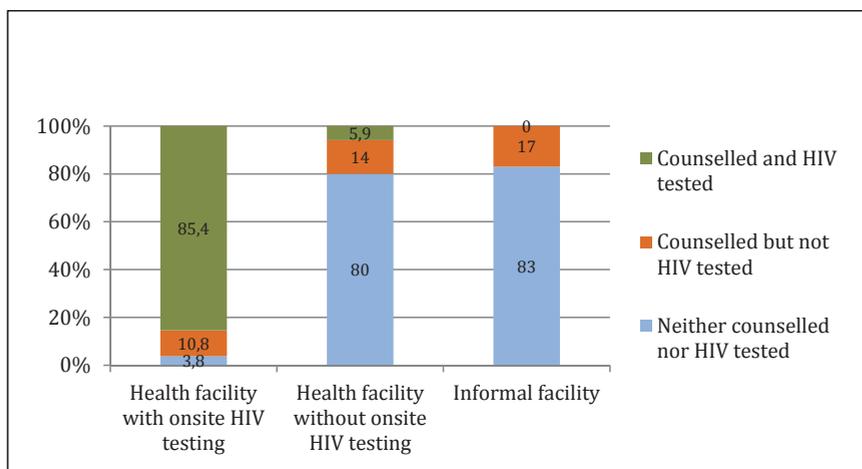
Figure 6. Study participants in Study III and IV



### Coverage of HIV counselling

Among the women who received ANC from a health facility without testing services, only 20% had been counselled about HIV, or counselled and tested, as compared to 96% among women attending a facility with testing services (Figure 7).

Figure 7. Percentages of pregnant women being counselled and tested for HIV by type of health facility where women sought ANC



\* Informal facility: Traditional birth attendant or drug shop reported as facility where women sought ANC

## CHALLENGES TO HIV TESTING DURING PREGNANCY (I, III)

### Distance, poverty and pregnancy experience (III)

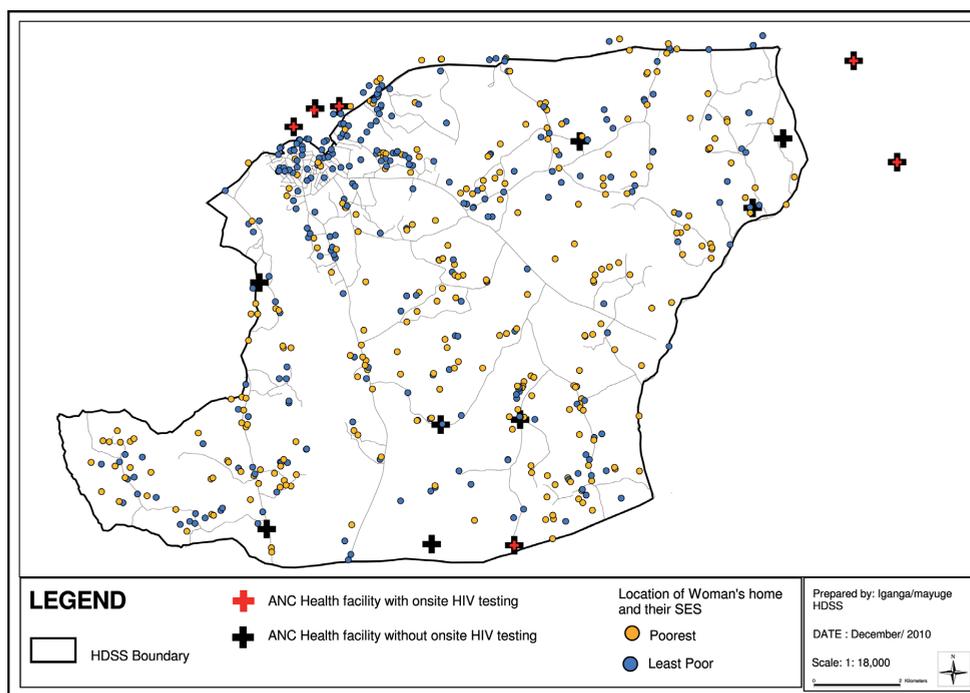
Risk factors for not being tested for HIV during pregnancy were assessed among the women in the HDSS cohort (III). The bivariate analysis found that the risk factors for not being tested for HIV were: being a farmer, being poor, having more than four living children, seeking ANC late (first visit later than gestational month six), living more than 3 kilometres from a facility with onsite HIV testing (all,  $p < 0.25$ ).

When applied in a multivariable model using a backwards selection procedure, the final multivariable model included, age, socio-economic status (SES), number of children and distance to a health facility with HIV testing services. However, since a statistically significant interaction (effect modification) between the variable “number of children” and SES was observed, the analysis were stratified by SES.

The only significantly associated variable for the poorest women was living more than three kilometres from a health facility with testing services (aRR 1.44, 95% CI 1.02-2.04). For the least poor, the variables significantly associated with the outcome were: having more than four children (aRR 1.77, 95% CI 1.00-3.16) and living more than three kilometres from a health facility with testing services (aRR 1.72, 95% CI 1.12-2.63)

Those women who had not been HIV tested had an average distance of 3.5 kilometres to the nearest testing facility, compared to 2.8 kilometres among women who had been tested (t-test,  $p < 0.01$ ). Moreover, the poorest women had 3.5 kilometres to a health facility with testing services as compared to 2.7 km among the least poor (t-test,  $p < 0.01$ ). This is illustrated in Map 2 where the women in the HDSS cohort and the health facilities in the HDSS area are plotted using GPS-coordinates.

*Map 2. The geographical distribution of all pregnant women in the HDSS cohort divided by socio-economic status, and health facilities divided into with and without HIV testing services onsite*



### Inadequate counselling and lack of referral (I)

Inadequate counselling about HIV testing refers to information given both at the health facilities with and without onsite HIV testing services.

Women seeking ANC from health facilities that did not have HIV testing services onsite were neither informed about, nor referred for HIV testing. This was observed both during the semi-structured interviews and during the sit-in observations. On the other hand, few of the women who received ANC from facilities that provided HIV testing onsite had fully understood the reasons for testing and the majority had little knowledge about PMTCT.

Another example of inadequate counselling was the fact that women who sought ANC from

facilities that provided HIV testing perceived HIV testing as mandatory and generally thought that they could not receive any other ANC services unless they accepted to be tested for HIV.

*I am told that when you come for ANC, they have to take your blood sample for testing: if you refuse they will not give you any treatment . . . No one (health worker) will care about you when you're pregnant if you don't accept to be tested for HIV (HIV status unknown, multi-gravida, health facility III).*

In addition, the women interviewed described how they would not question the recommendations from the health workers or ask questions for clarification since they felt inferior in relation to the health workers.

*What the health worker would decide upon is what I would go with, because me I am just a patient/.../ (HIV positive, multi-gravida, health facility III).*

### **COVERAGE OF COUPLE HIV TESTING (III)**

Although couple HIV testing is part of the PMTCT policy guidelines, male partner involvement during ANC was shown to be uncommon in this setting (III). Self-reports from women in the HDSS-cohort, revealed that 13% had been accompanied to the ANC by their spouse. The record reviews at health facilities showed that the uptake of couple HIV testing was even lower, only 4% of the women tested had been counselled and tested with their male spouse.

### **CHALLENGES TO COUPLE HIV TESTING (I, II)**

#### **Gender dynamics influencing uptake of couple testing HIV (I, II)**

The pregnant women were requested by the health workers to recruit their spouses for HIV testing, a request that was confirmed by the sit-in observations. Women felt obliged to accept the request to try to persuade their partners to come for HIV testing. However, the majority described it as a complicated task and a major dilemma to try to recruit their spouses while having very limited power to influence their partner's actions.

*You can tell him but he will refuse to come. He will just tell you that he is not coming. He does not give any reason why he won't come (HIV status unknown, multi-gravida, health facility II).*

The men's freedom of choice, having the possibility to decline an HIV test, was often mentioned among the women interviewed. It was seen as unfair that men, as opposed to women, could choose to opt-out of testing during ANC. The men confirmed this since they portrayed a marriage power structure where men are decision-makers and have the power over their wives' actions. Men resisted women's efforts to influence them, including when it came to HIV testing:

*We men have a mean heart; a woman will tell you to go to the health centre with her, but when you get up in the morning you tell her not to disturb you claiming that you are going to look for money. In that way you avoid her (FGD, men).*

The men had a generally negative view of couple HIV testing and the “promise” of couple HIV testing at ANC health facilities actually discouraged men from accompanying their wives on antenatal visits.

*You know in most cases, we men don't like to accompany our wives because we know about this programme whereby once you go with your wife, then you must be tested for HIV. So we are very worried about escorting our wives (IDI man).*

Both women and men feared that couple HIV testing would reveal that one in the couple had had extra-marital affairs, something that they feared could lead to relationship problems and separation.

*It is because we don't tell our wives the truth; you lie to her that she is the only one yet her friends see you with other women. So if we go for testing and find out that we are infected she will immediately start quarrelling (FGD men).*

When discussing male involvement during ANC with men, they described how they were excluded from the ANC sessions where their wives were examined, and how they had to wait outside without any information about what was happening to their pregnant spouse. Men therefore questioned the rationale for their presence during ANC.

*Now the problem with the medical staff is, you as a man, they cannot tell you what exactly they are doing inside there, instead I can sit on the veranda and they get on with whatever check-ups and you only take your spouse back home (IDI man).*

### Men reluctant to HIV testing in general (II)

The men on the other hand discussed their lack of convincing arguments for why they should go ahead and get tested for HIV. When speaking in the abstract about HIV testing, the men recognized its importance. However, despite the ability to recite the HIV testing messages broadcasted in their communities, they did not see any reason to get tested themselves.

The media, especially the radio, which was the men's main source of information about HIV, had conveyed the message that one should get tested, but the campaigns had apparently failed to motivate the men to do so. The men suggested that men who had already tested could serve as role models and talk about their experiences. Furthermore, live information campaigns at the community level instead of frequent media messages were mentioned as a more effective

strategy for getting men to test, in part because it would enable them to ask questions.

*These programmes are mostly on radio, but it would be better if you organized meetings on the LC level (i.e. in the community), rather than putting programmes on the radio/.../then I would come there and I will understand everything better (IDI man).*

General low confidence in the care provided at health facilities further eroded men's feeling that it was worth their time to go there. In addition, waiting time and distance made it inconvenient to actually get the care one needed according to the men. The health facilities with HIV testing services were often far away from where the men lived, and going there was not only costly, but took time away from work and other activities. Men reported having been forced to wait an entire day for ANC, a heavy sacrifice for someone who needs to work to support his family:

*Even the long line at the hospital (chorus answer yes....) women can be there from 08.00 a.m. in the morning up to evening, and waste all the time you would have spent looking for posho [food] (FGD men).*

The men discussed the rude treatment from health workers, experienced both by themselves and by their pregnant spouses. Some men had experienced nurses at ANC speaking disrespectfully also to them directly:

*/.../ So we sometimes feel like not going there because the nurse will be rude to us yet it is not we men who are pregnant. They use harsh language, the same kind they use with women in labour, so sometimes they want to use that same harsh language with us. Yet we men are easily provoked and could even become harsher than the nurses, so you rather stay away (many participants laugh and give signals of approval) (FGD men).*

Another barrier for HIV testing described by the men was the lack of integration between HIV care and other health services. By singling out and exposing patients seeking HIV care through special clinics or opening hours, men were further discouraged from getting tested.

*People start noticing your (HIV) status, because of the specific days you go for check up (FGD men).*

## **COVERAGE AND ESTIMATED EFFECTIVENESS OF PMTCT SERVICES (IV)**

### **Coverage of PMTCT services for HIV-infected women**

The HIV prevalence among the women in the HDSS cohort was found to be 3.5%. The coverage of PMTCT services for HIV-infected women in the HDSS cohort was assessed through record reviews and semi-structured interviews after childbirth. In Table 6 the coverage of PMTCT services is presented. The majority of the women received the dual-ARV

prophylactic regimen recommended to them by the time of the study, and all women practised breastfeeding.

**Table 6. Coverage of PMTCT programme components among pregnant HIV-infected women in the HDSS cohort**

Component	(%)
HIV-infected women/baby pair receiving any ARV prophylaxis	83
Mother ARV prophylaxis -sd-NVP	33
Mother ARV prophylaxis -dual prophylaxis AZT and 3TC	57
Mother ARV prophylaxis –ART	10
Women practicing safe infant feeding	0

#### Estimated effectiveness with base-case coverage of PMTCT services

To estimate the effectiveness of PMTCT services in 2008, the expected number of HIV-infected pregnant women in the two districts was estimated by combining the HIV prevalence of 3.5% and the Ugandan crude birth rate (45/1000 population). This calculation gave an expected number of 1796 HIV-infected pregnant women (15-49 years old) in Iganga and Mayuge districts in 2008.

The uptake of PMTCT service in the HDSS cohort, i.e. the base-case PMTCT coverage and the MTCT rates from the UNAIDS, were then combined in a decision tree analysis. The analysis showed that the base-case PMTCT coverage gave an estimated MTCT rate of 13% at birth and 16% at six months, or 240 children HIV-infected at birth and 284 children infected at six months.

In a situation without access to any PMTCT services 395 children would have been HIV-infected at birth, meaning that the base-case PMTCT coverage prevented an estimated 155, or 39%, HIV infections in children.

#### Estimated effectiveness assuming increased coverage of PMTCT services

To understand how an increased coverage of one or several PMTCT components would influence the effectiveness of PMTCT services, different scenarios were modelled in a decision tree analysis. An assumed increase in one or several PMTCT programme components were analysed to identify which intervention/s would influence the effectiveness of PMTCT services the most. The scenarios are presented in Table 7 and for each scenario; the number of children infected and the MTCT rate at birth and at six months of age are presented.

**Table 7. Scenarios with different coverage of PMTCT components, number of children infected with HIV and MTCT rates**

Base-case PMTCT coverage	At birth		At six months	
	Number of HIV-infected children	MTCT rate (%)	Number of HIV-infected children	MTCT rate (%)
Estimated effectiveness with base-case coverage of PMTCT services	240	13	284	16
Scenarios	At birth		At six months	
Scenarios assuming different uptake of PMTCT services	Number of HIV-infected children	MTCT rate (%)	Number of HIV-infected children	MTCT rate (%)
<b>100% ANC</b> Base-case coverage with 100% ANC attendance	234	13	278	16
<b>100% HIV testing</b> Base-case coverage with 100% HIV testing	172	10	217	12
<b>100% ART</b> Base-case coverage with ART provided to 100% of women receiving ARV prophylaxis	197	11	227	13
<b>Optimal scenario<sup>a</sup></b> A combination of Scenario 2, 3 and 4, 83% uptake	97	5	121	7
<b>OptimalPlus scenario<sup>b</sup></b> A combination of Scenario 2, 3 and 4, 100% uptake	36	2	56	3
<b>No PMTCT</b> No ARV prophylaxis given to HIV-infected women/babies	395	22	436	24

<sup>a</sup> Uptake of ARV prophylaxis of 83% the base-case scenario <sup>b</sup> Assumed uptake of ARV prophylaxis 100%

An assumed increase in HIV testing to 100%, keeping all other components at base-case level, would give an MTCT rate of 10% at birth. Only a combination intervention, with ARV prophylaxis uptake levels of over 83% are needed to reach the UNAIDS target of MTCT rates below 5%, i.e. the OptimalPlus scenario. The relative effect of each of the scenarios has been compared to the base-case PMTCT coverage and is illustrated in Figures 8.

HIV testing was identified as the major obstacle to PMTCT in Iganga and Mayuge districts, and the single most effective intervention would be to increase HIV testing to 100%. This would reduce the estimated number of HIV infections among children by 28% at birth and by 24% at six months as compared to the base-case PMTCT scenario (Figure 8). Obviously, the smallest increase in PMTCT effectiveness was shown for the scenario assuming an increase in ANC attendance to 100% since ANC attendance was already high at 96%.

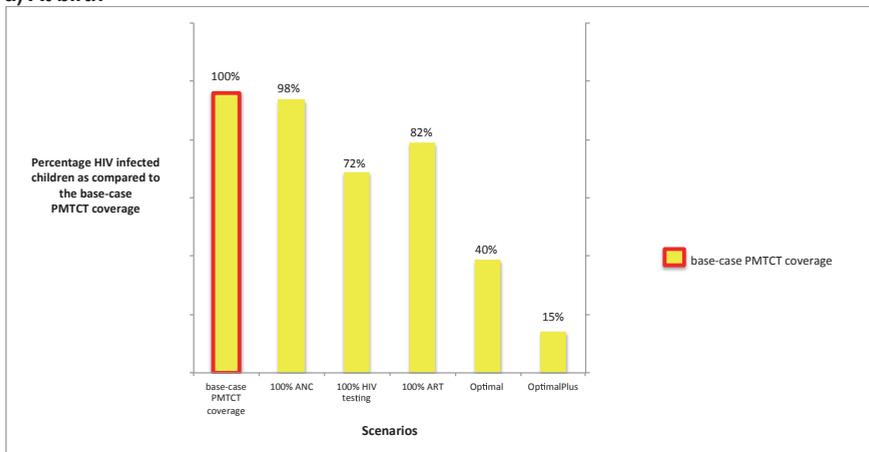
The Optimal scenario including 100% uptake of all PMTCT programme components with an uptake level of ARV prophylaxis of 83%, would give a 60% decrease of infections at birth and a 57% decrease at six months, as compared to the base-case coverage.

The OptimalPlus scenario, with 100% ANC attendance, 100% HIV testing, and providing ART to all HIV-infected women (uptake level of 100%) naturally gives the best results and would translate into an estimated reduction of 85% at birth and 80% at six months.

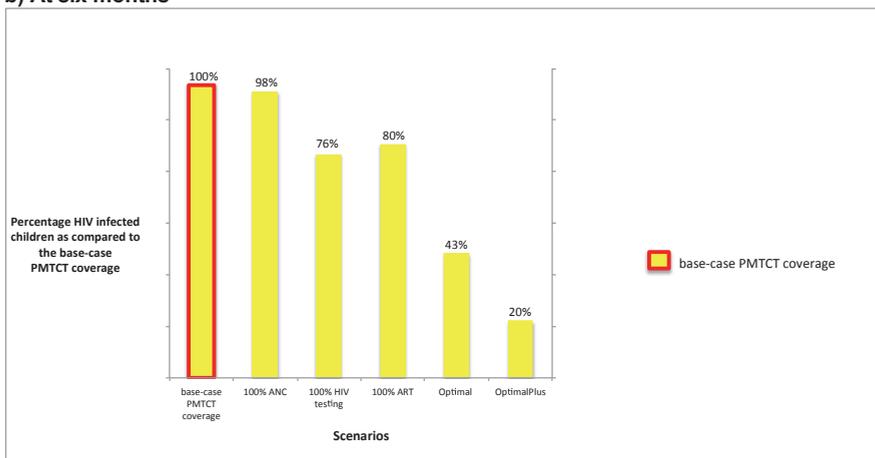
Thus, it is obvious that increasing coverage of one single PMTCT component would have relatively little effect on the MTCT rates and on the number of HIV-infected children.

Figure 8. Estimated relative effects of an increase in coverage of PMTCT components as compared to the base-case PMTCT coverage. Assuming 100% adherence

**a) At birth**



**b) At six months**



### The impact of adherence on effectiveness of PMTCT services

Adherence to PMTCT services was studied in the seven semi-structured interviews with HIV-infected women. Those interviews revealed that even though most of the women lived within walking distance of Iganga Hospital, none of them adhered to all the components in the PMTCT programme. Most of the women had missed out on more than one of the programme components.

The majority of the women who received dual ARV regimen did not complete the regimen either because they did not return on time, or at all, for refill of ARVs.

*I fear taking tablets. I was given a tin of tablets to take, but I only took them for three weeks and then stopped.*

Adherence to breastfeeding recommendations was poor and six out of the seven women reported mixed feeding. Women were generally aware of the recommendations to practice exclusive breastfeeding but unable to follow these recommendations.

*I used to give him cow's milk from 2.5 months. They (the midwives) told me about exclusive breastfeeding, and I know everything... But the baby refused to breastfeed, that's when I introduced other feeds (cows milk), but I still gave him the breast sometimes.*

None of the women who received ARV-prophylaxis had been linked to an ART clinic to monitor their HIV infection. Most of the women seemed unaware of the importance of HIV monitoring and either planned to delay care seeking until the disease had progressed, attend traditional healers or just ignored any AIDS-symptoms.

*I have never received any HIV care, I am waiting for the disease to progress, then I would go to the hospital for treatment.*

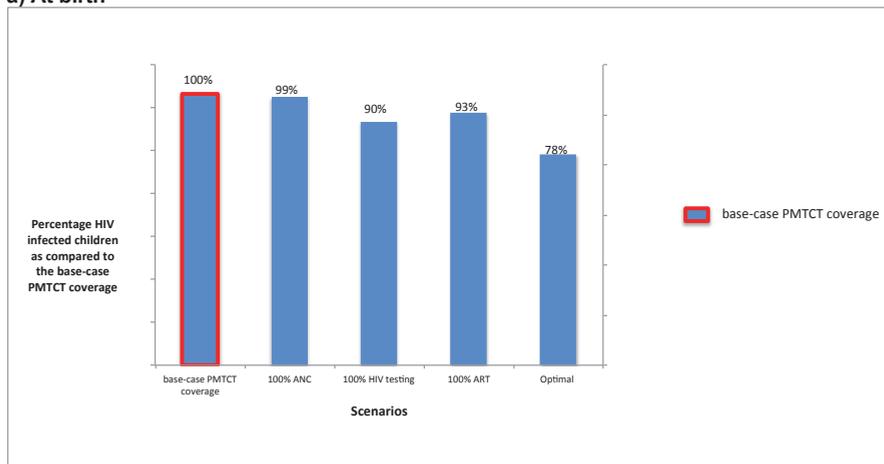
Similar to the above, interviews with HIV-infected women revealed that all but one woman failed to adhere to infant PCR-HIV testing. Most women were unaware about the importance of bringing their children for testing.

*I did not take him for PCR-testing because they (the midwives) never told me that the baby had to be tested. If they had told me, I would have done so.*

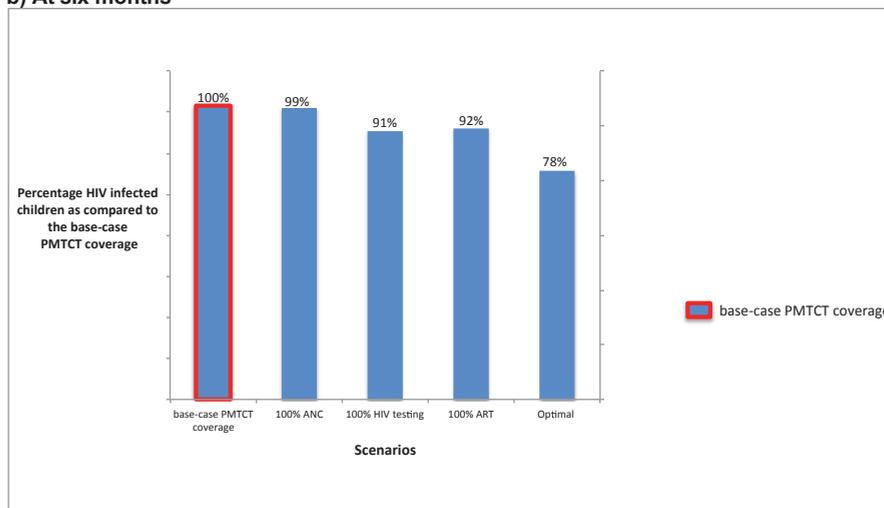
To illustrate how adherence to PMTCT services would influence the effectiveness of the PMTCT services, the same scenarios as described in Table 7 (except for the OptimalPlus scenario) were analysed for a situation where the uptake of ARV prophylaxis was set to 41.5% (i.e. 50% of the uptake for the base-case PMTCT coverage of 83%). These scenarios were also compared to the base-case PMTCT coverage and are presented in Figure 9.

Figure 9. Estimated relative effects of an increase in coverage of PMTCT components as compared to the base-case PMTCT coverage. Assuming 50% adherence

a) At birth



b) At six months



From these graphs it is obvious that to reduce MTCT rates an increased coverage of PMTCT services has to be accompanied with ensured adherence to the PMTCT services. For example the scenario assuming an increase in HIV testing to 100% would only give a 10% MTCT rate reduction at birth with an uptake level of 41.5%, as compared to 28% with an ARV-uptake level of 83%.



## DISCUSSION

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The results from this thesis show that less than two-thirds of women were HIV tested during pregnancy. Moreover, only four percent had been tested together with their spouse.

This is a missed opportunity: this low uptake of HIV testing occurs in a setting with a heavy burden of HIV, with nearly universal ANC attendance among pregnant women and with opt-out HIV testing as well as couple HIV testing policies in place. This research shows that the policies have not achieved their intended outcomes, possibly due to low community acceptance of the manner in which the policies have been implemented.

The estimated single most effective intervention to optimize PMCTC would be to increase HIV testing coverage to 100% for pregnant women. The main barriers to achieve this are health systems related: lack of HIV testing and referral, poor counselling, and gender-related power dynamics both at the household level and at the point of health service delivery.

### HIV TESTING

In a setting with almost universal ANC attendance (96%), an opt-out HIV policy and where the majority of the people lived only a short distance from a health facility with testing services, only 64% of the women had been HIV tested during pregnancy (III). Making HIV testing services accessible to pregnant women is the key to improving access to other PMTCT services. Furthermore, increasing the uptake of HIV testing to 100% was estimated to be the single most effective intervention to reduce MTCT (IV). In health facilities with HIV testing services onsite, testing coverage was high at 85% (III). One can conclude that in this type of facilities, with respect to uptake of HIV testing, the health system had succeeded fairly well with the opt-out testing strategy by making service delivery and equipment available. Similarly, high uptake levels of HIV testing during ANC have been found in other settings after implementation of opt-out HIV testing [128-131].

Consequently, the most important determinant for not being HIV tested during pregnancy was seeking ANC from a facility where HIV testing services were not available (III). Only 6% of the pregnant women who sought ANC from this type of facility had carried out referral and tested elsewhere, despite the fact that the opt-out policy clearly expresses testing referral (III). Correspondingly, a Kenyan study has illustrated the important role the health system has when it comes to the uptake of HIV testing. It also showed that significant person-level risk factors for not being HIV tested disappeared when adjusting for site, thus demonstrating how health system factors override personal level factors [132]. Hence, to increase access to HIV testing and other PMTCT services, availability of testing services for pregnant women needs to be improved.

The pregnant women in the HDSS cohort generally sought ANC from the health facility closest to their homes (III), indicating that they did not actively seek ANC where they could access HIV testing, but rather accessed testing as an extra service when the ANC facility happened to have testing services. In the McIntyre access framework described in the background section, it

is pointed out that the availability of a health service is not only about making the service *physically* available, but also about acknowledging the perceived need for the services in the community. Hence availability of a service is the fit between the health system making services available and the community's desire for the service. It is interesting to consider the issue of HIV testing availability in this setting since, even though the health facility closest to the woman's home did not have HIV testing services, the average distance to a nearby facility with HIV testing was relatively short both for women who were tested (2.8 km) and those who were not tested (3.5 km) (III). One could therefore argue that HIV testing services are available to all women in this setting. Thus, since almost all women attended ANC facilities at least once and since most of them were not tested due to lack of referral: making sure that women carry out HIV testing referral to a nearby health facility might be an easy way of increasing access to PMTCT and reducing MTCT of HIV.

One very likely explanation for the low uptake of HIV testing among women who sought ANC from facilities without onsite testing is a lack of referral and lack of counselling about HIV. Only 20% of the women who sought ANC from this type of facility had received any counselling about HIV (III), confirmed by the qualitative interviews and the observations in Study I which showed that women were not referred for HIV testing. However, there was no clear structure in place for how referral for testing should be organized. Health workers might not have received instructions from the management to prioritize referral or tools for how to handle referrals. In the light of the tough working conditions for many health workers, another possible explanation could be that the health workers consciously omitted HIV counselling to prioritize other ANC services. Especially since the attitude in general among the health workers was that there was no use of counselling the women about testing referral since they would not take action anyway. This is a missed opportunity and to increase access to HIV testing, the health system should establish a structure and organisation for testing referrals. In addition should the health workers make sure that the messages about HIV testing and the importance and benefits of testing is conveyed to all pregnant women.

In relation to the above discussion, the poorest women had worse access to PMTCT services, as compared to the least poor. This is due to the fact that the majority of the poorest women live in rural areas where the nearest health facility usually is a HCII without HIV testing services (III). Hence, when the health system fail to deliver PMTCT services to the rural areas it affects the poorest women the most. Poverty has previously been reported as an important barrier to PMTCT services in Uganda [133]. Inequity in access to health care was first reported in the 1970s, and, even though the situation has greatly improved over the years, it still exists in low-income settings where the poorest people usually have worse health-care access than the least poor [56, 134].

Other possible interventions to increase access to HIV testing could include providing transportation to a facility with HIV testing services, or carrying out outreach HIV testing to facilities without testing services. These interventions might be more relevant than expanding HIV testing services to the lower level of HC IIs, since poor-quality counselling has been reported when expanding PMTCT services to lower levels of care due to insufficient counselling or inadequately trained staff [135].

## COUNSELLING

Most of the women who were HIV tested during ANC showed little understanding of why HIV testing was being carried out, despite the fact that they had just been tested (I). This is a health system failure in the opt-out testing policy implementation since women who just have been tested have not received enough counselling to be aware of why testing was done. The pregnant women who sought ANC at facilities with HIV testing services further perceived testing as compulsory (I), confirming findings from other studies in East-Africa and Vietnam, where opt-out testing is implemented [136-138]. If testing is perceived as compulsory, it also indicates a missed opportunity in providing appropriate counselling, something that might have an effect on future risk behaviour. Poor counselling has also been reported to accompany opt-out HIV testing in other settings where this testing policy has been implemented [136].

Further, women did not dare to ask questions for clarification when health workers said things that they did not understand (I). To address this, the individual examinations taking place after the group HIV counselling could be a good opportunity to open up for women's questions since the examinations ensure more privacy than the group sessions. This could be a good strategy since another study from the same setting showed that health messages brought up during the group counselling are not repeated during the individual examinations [139]. This might therefore be a relatively easy but efficient intervention to increase the women's understanding of HIV testing.

The implementation of provider initiated HIV testing has increased the testing uptake in many settings and at the same time the number of health facilities providing HIV testing services has also significantly increased in SSA [2, 22, 140].

Despite the fact that high HIV testing uptake has been indicated where opt-out testing has been introduced, testing per se is not the final goal, but the first and crucial step to accessing PMTCT services, HIV care or counselling on how to remain uninfected. Although the health system has managed to increase the number of people tested, if testing is not followed by adequate counselling, and referral to appropriate care it might do more harm than good. It is obviously also a waste of the scarce resources available in the health systems in resource-poor countries.

The main idea of opt-out HIV testing during ANC is to get more women to test for HIV, but one could question the benefits of testing if the accessing of appropriate counselling and care does not ensue as a consequence. Concerns like whether opt-out testing would promote relevant health services and not simply increase testing with no concrete benefits to the women being tested has been raised previously in relation to opt-out HIV testing [141]. Studies from the same setting as the research in this thesis have also found poor post-test counselling to be a main barrier to pre-ARV care among HIV-infected persons, only 10% of those who tested positive came back for pre-ARV care [142, 143]. However, many health workers in SSA experience a heavy workload and would not have time for individual counselling. Hence, there might be much to win by using the health education sessions during ANC better and tailoring the messages that are already brought up during group-counselling sessions. These could be used to point out the benefits of identifying an HIV infection and in addition make sure that women's questions were followed up during the individual examinations.

## **EFFECTIVENESS AND ADHERENCE TO PMTCT SERVICES**

The PMTCT interventions implemented in this setting decreased the estimated MTCT rates at birth and at six-month post-partum by 39% as compared to a situation without any PMTCT services at all (IV). Yet, with the base-case PMTCT coverage the estimated transmission rates at population-level were still 13% at birth and 16% at six months. Low uptake of HIV testing was estimated to be the major obstacle to achieving higher PMTCT effectiveness in this setting.

Most HIV-infected women (57%) received the dual ARV regimen (IV), which was the recommended treatment by the time this research was performed. However, by providing ART (as is the recommendation today) to all women who received ARV prophylaxis, the MTCT rate could be reduced by 18% as compared to the base-case coverage.

Further, the OptimalPlus scenario with an assumed 100% uptake of ANC, HIV testing and ART together with perfect adherence gave estimated MTCT rates of 2% and 3% at birth and at six months (IV). If, for the same scenario, using the base-case ARV uptake level of 83% instead, the MTCT rates would be 5% at birth and 7% at six months. Hence, perfect adherence to and coverage of ART for all HIV-infected women would be required to achieve the UNAIDS “virtual elimination targets” of less than 5% MTCT rate. This was also illustrated in a recent modelling study that found that adherence levels of 95% to the new WHO recommendations would be required to reach a MTCT rate of below 5% [144].

However, to initiate the new PMTCT recommendations for the provision of ART, the health system not only needs to finance the more expensive regimen, but health workers also need to be trained on the new and more complex regimen to be able to deal with, for example, side-effects. Furthermore, to make the regimen available, a sustainable supply of medicines throughout a much longer period than before is needed since women would now receive ART until they stop breastfeeding. This is a big challenge and would require efforts and investments to improve the supply of medicines, especially since studies from the same setting have shown that there is an inadequate supply of ART to the patients already today enrolled on ART [90].

The semi-structured interviews with HIV-infected women revealed that completion of PMTCT programme components was not 100% for anyone, even though most of the HIV-infected women lived within walking distance from the hospital where they could access HIV care. The poor adherence to PMTCT is also in line with another study that showed an HIV testing uptake of nearly 85% but only 54% of the infected women and 4% of their infants received ARV prophylaxis [145]. One of the reasons for the poor adherence identified in this thesis was lack of continuous support to women who are identified to be HIV-infected while pregnant. To receive positive HIV test results when actually seeking ANC could obviously be tough and women might not be prepared for it or ready to at once digest all information and counselling they need to make informed decisions.

Hence, with the new and more complex ARV prophylactic regimens, a well-functioning health system is even more critical to ensure access to PMTCT, sustainable care and adherence to PMTCT throughout the breastfeeding period. By organizing continuous counselling to pregnant HIV-infected women, women might be better prepared to adhere to the PMTCT programme throughout the breastfeeding period. Peer-support groups for pregnant women, or HIV-infected

women who have been pregnant, had previously been organized in this setting and had been greatly appreciated by the participants. However, during informal conversations with the PMTCT coordinator in Iganga, I came to know that the organization of support groups had been dependent on an external donor who had financed the Ministry of Health PMTCT programme and when the donor changed, these peer-support activities were stopped. This illustrates a health system challenge in delivering sustainable care when activities like this one are donor dependant and that circumstances might change from one year to another. Furthermore, it shows some of the challenges faced by the local health officials when implementing the PMTCT programme.

The estimations of the effectiveness of PMTCT services clearly illustrate how PMTCT programmes are not a single intervention, but sequential interventions that need to be delivered to meet the goal of a reduced MTCT (IV). In order to successfully implement large-scale interventions like the PMTCT programme, a well-functioning health system is crucial, as also stressed in the Millennium Development Goal Countdown discussion [56]. In addition to strengthening the health system to deliver the services, integrating PMTCT and ART services might further improve adherence and continuity of HIV care for women identified to be HIV-infected during pregnancy. This is supported by studies that have found an increase in enrolment from PMTCT to ART care, and from HIV testing clinics to family planning clinics after integrating the services [146-148].

### **COUPLE HIV TESTING**

Only 4% of the pregnant women had carried out couple HIV testing together with their spouse (III). The rationale for couple testing stems from SSA studies that have shown an association between male partner involvement in their wives' ANC, couple HIV testing and pregnant women's likelihood of accessing and completing PMTCT services [34-37]. Couple testing might be desirable from a public health perspective, since the couple would then in theory receive the test results and counselling together and thereafter make informed decisions. This might be particularly relevant in Uganda where a large share of new HIV infections occur in stable, heterosexual relationships [101]. However, it seems more likely that pre-existing male partner involvement is what leads some men to accompany their wives to ANC and to support them during PMTCT. One could therefore question whether the few men who accompany their wives to ANC are representative of the majority. Other aspects that should be considered in relation to couple HIV testing is the fact that far from all pregnant women live with a partner, and further that polygamous marriages are widely accepted in Uganda, making the recommendation of couple testing more complex.

Another barrier to the acceptance of couple HIV testing articulated by the men was their commonly occurring extramarital affairs (II), also confirmed by ethnographic studies from Iganga [149]. Hence, the relationships, or lack of relationships, need to be acknowledged when implementing couple HIV testing during ANC and health workers therefore need to listen to the individual's wishes and need for couple testing. Perhaps a more reasonable approach would be to offer couple HIV testing in the most acceptable way and as much as possible facilitate couple HIV testing in cases where the persons could benefit from it. There are evidently advantages of identifying sero-discordant couples, something that couple testing ultimately could help to do.

Couple testing is also relevant in the light of the discussion of “test-and treat” since a multicountry study recently found that initiation of ART at the time of diagnosis significantly reduced transmission to spouse [150].

A health system barrier to couple HIV testing was that men did not feel welcome at the ANC facilities and they considered ANC to be a female domain (II). However, making couple testing services available does not only have to do with services being physically available. Though the services were available, the aspect of men's acceptance of the testing services was not taken into consideration. The norm that men should not show weakness, for example by seeking health care, dictates against men being HIV tested, especially alongside their wives [151]. Traditional gender norms in themselves constitute significant barriers to health care seeking among men across the world [151]. Much of the focus in HIV prevention and care has been targeted to women and men have often been neglected in HIV programmes [75].

This also seems to be the case here where the traditionally “exclusively-female” ANC setting suddenly would also like men to attend ANC (I, II). For men to attend ANC the setting needs to be adapted to make them feel welcome. The couple HIV testing policy, similar to other policies for male involvement in sexual and reproductive health, discusses male involvement to enable women to access health care services, rather than for the men's own good [74, 75, 152-154]. Men themselves should also benefit from the programmes rather than just be there to support their spouse. Interestingly, even publications regarding the integration of gender in HIV programmes only discusses men's participation in order to increase women's access to services, and say nothing about men's access for their own health [73]. Gender-sensitive messages together with health systems adaptation might help to make HIV testing more acceptable among men and to achieve equal access to HIV care, different strategies when targeting men and women may be needed [155].

The men in this setting were enrolled for couple HIV testing through their pregnant spouses, this way of recruiting was perceived as unacceptable by both the men and the women (I, II). The men are the breadwinners and the decision-makers in the families, thus making it difficult for women to influence their partner's actions [149].

Couple gender dynamics had seemingly not been acknowledged when introducing the policy for couple HIV testing in this setting, even though it is well known how crucial it is to understand how gender might influence the effectiveness of a programme [155]. In order to increase men's awareness about the importance of ANC, HIV testing and PMTCT, alternative ways are therefore needed. More successful methods to recruit men have been demonstrated, for example in a study where men received information about ANC services through an invitation letter from the health facility where women sought ANC, a simple intervention that increased the male partner ANC attendance and couple HIV testing [156].

Hence, scaling-up couple HIV testing has been a challenge in many different settings. Couple HIV testing might in some cases provide support to women to access PMTCT services and encourage HIV testing for men. However the bottom-line is seemingly that in the near future the significance of universal couple HIV testing both in PMTCT and for increasing the uptake of men's HIV testing seems to be limited.

## POLICY IMPLEMENTATION

The Ugandan PMTCT policy guidelines are in line with the provider-initiated HIV testing policy recommended by the WHO and aim to integrate HIV testing into standard medical care [31, 104]. However, the results from this thesis show that the wanted outcomes from these policies, i.e. HIV testing of all pregnant women and as well as couple testing have failed in this setting. Furthermore, the way in which the policies have been implemented have not found acceptance in the community (I, II).

Hence, for men and women to access services, the services need to be considered as acceptable. McIntyre writes, “acceptability problems arise where health care services are organized from the perspective of the system and its providers, i.e. a normative perspective under which individuals ‘should’ be expected to use services, as opposed to the perspective of individuals or patients”. Further, Walt describes policy development and implementation processes as either top-down or bottom-up [157]. The top-down approach clearly separates the policy formulation from the implementation; the implementation is viewed as a sequential transmission from formulation to implementation, whereas the bottom-up approach is a non-linear, interactive process, where the implementers are part of the policy formulation. Walt concludes that a successful policy implementation is a bottom-up product, where formulation and implementation is in a “continuous loop” [157]. When listening to the men and women in this setting (I, II) and looking at the uptake of services (III), the PMTCT policy implementation is apparently very much a top down product from the health system and not accepted by the men or women. Neither group (I, II) appreciated the way in which the couple HIV testing policy had implemented. Not acknowledging the target group’s opinions and ideas when implementing the PMTCT policy seems to be a major reason for the failure of testing referral for women and the recruitment of men for couple HIV testing (I, II). This further illustrates the challenge of implementing already known effective interventions in a real-life setting, i.e. the efficacy vs. the effectiveness of an intervention.

Another example of not listening to the community members’ needs was the ongoing information campaigns accompanying the implementation of HIV testing services that had failed to motivate the men to get tested (II). The men themselves suggested ways to improve their understanding about HIV testing such as live information at community level, where they could ask questions. This clearly illustrates how the community could contribute to policy implementation and make policies more acceptable. Community sensitization campaigns and peer-to-peer interventions might be one way forward and has also previously shown to have better effect than radio commercials or similar [158-160].

The opt-out HIV testing policy during ANC on the other hand seems to be introduced without enough counselling and in a way that do not support women to make informed decisions (I), a concern raised previously [141]. Including both the health workers as well as community members when implementing the PMTCT policies might have created better acceptance for the policy. Walt and Gilson states that when developing health policies a great deal of focus is on the content, but they argue that in order for health policy effectiveness, the actors, the context and the process also need to be considered during the policy formulation and -implementation [78]. Similarly, for incentives to work, people within the health system have to be involved in policy implementation, a factor that has been found to be crucial for successful policymaking in

Uganda [161]. Further, for a successful policy it is essential for the health system to have a broad understanding of the environment in which health services are delivered and health outcomes are produced to increase intervention coverage [80].

To summarize, this thesis found that lack of both availability and acceptability of services hampered the access to PMTCT services and contributed to the missed opportunities. Major reasons identified for the missed opportunities were due to the health system as well as gender dynamics.

## METHODOLOGICAL CONSIDERATIONS

### Qualitative studies

Qualitative research methods have become more used in medical research in recent years as a way of providing contextual and in-depth understanding of healthcare seeking and provision of care [117]. This research borrows from the tradition of social constructivism assuming that the social world and people's behaviour are constructed socially, politically and psychologically, as are also humans' understandings and explanations of the world [162]. This was applied, for example, when studying the interactions between health workers and the women and the men and women, and their different behaviours and point of views.

The design of qualitative research is often characterized by *emergent design*: an openness to adapt the inquiry during the course of the research as the understanding deepens or situations change, and was also my understanding when carrying out the studies [162]. This was an important principle in the data collection process and one example of this was that in Study II the data were collected in two phases which made it possible to explore issues from the first phase more in details in the next set of FGDs, and also during the IDIs.

One often used sampling strategy in qualitative research is purposive sampling [162]. This means that study subjects are selected because they are rich in information about the phenomena, that they have certain insights into or experience of the topic. For example only men who were fathers were included in Study II, since it was believed that they would have experience of pregnancy, and/or ANC and HIV testing.

Trustworthiness is a concept used in qualitative research and achieved through the measures of credibility (e.g. selection of participants, methods etc.), dependability (e.g. how time-dependent the data are) and transferability (e.g. how well the results could be transferred to other settings) [120].

Credibility was strived for through a careful selection of methods and participants relevant for the research questions. Several efforts were made to ensure credibility. Examples of such efforts were that participants with and without experiences of ANC and/or HIV testing were selected for the interviews (II), that rural/urban residents were represented to ensure that the results were applicable to both urban and rural areas (II), participants had various experiences of child bearing, and that the age of the participants were considered (I). Participants were also selected from different health facilities.

Triangulation was another measure used to create trustworthiness. Comparing findings from different methods such as semi-structured interviews and observations was one way of triangulation (I) [163]. Further, the combination of FDGs and in-depth interviews (II) gave a deeper understanding of the issues since the FDGs generated the general principles of couple HIV testing and the interviews gave the participants' personal views and experiences [117].

Analyst triangulation was applied during the analysis process and was achieved by co-authors reading selected transcripts, by discussing codes, categorization of codes and development of themes. This was done at several time points and until consensus was achieved [162]. Further, in the articles categories (I) and quotations (I, II) are presented to improve credibility and illustrate how the results were generated [120]. Presenting the results in a feedback workshop in Iganga Town with community members, health workers and district health officials provided feedback on the interpretation of the preliminary findings and during the workshop feedback to the participants was also provided [117, 121].

Prolonged engagement in the field, one year in total, was another essential aspect that was employed to improve the quality of the data collected. I spent much time in Iganga and Mayuge districts where the studies were conducted both in the community and at the various health facilities. Dahlgren et al write about "persistent observations", which are focused observations of the study subject during field work and this was employed by visiting almost all health facilities in the districts where the organization and quality of ANC and HIV testing was observed as well as the interactions between health workers and pregnant women [117].

The lengthy fieldwork further enabled me to interact with community members and health workers at district level and at the health facilities and have formal and informal conversations during and after working hours. This enriched and deepened my understanding for the context and facilitated the interpretation of the results.

### Quantitative studies

The quantitative analysis is based on data that were collected in an HDSS. The HDSS structure enabled the establishment of a population-based cohort with pregnant women, and to follow them up after giving birth. Further, since the HDSS keeps socio-demographic data, the variables for SES as well as for distance were readily available for the women enrolled in the cohort.

Two broad types of errors can normally be identified in epidemiological studies: systematic or random. The aim of epidemiological studies is usually to produce an estimate for an unknown population value, and the study design and analysis should be carried out to reduce such errors in the estimates and make them as small as possible [164]. In this research I wanted to estimate the prevalence of HIV testing among pregnant women and risk factors for not being tested. The risk of random errors decline with size of the sample and the study populations addressed in Studies III and IV were quite large, reducing the risk of random error. However, the number of women identified as HIV-infected at ANC was quite small and therefore conclusions about the completeness of PMTCT in Iganga/Mayuge based on these women's adherence patterns should therefore be interpreted with some caution.

Systematic errors, or bias, relate to the validity of a study. Bias could be defined as “error which applies unequally to comparison groups”, i.e. an error that affects one group more than another [165] and biases are often divided into selection bias, information bias and confounding. Validity of a study estimate may also be referred to as internal vs. external validity. External validity is how generalizable the study findings are to populations outside the study-base, while internal validity depends on existing biases and confounders. Below I will discuss possible errors, in particular systematic errors that this research might be subject to.

### *Selection bias*

Selection bias in cohort studies might occur at enrolment or be due to non-response or dropout from a study. Enrolment of women into the HDSS cohort was based on self-reports on pregnancy and this way of recruitment could be subject to selection bias. Women who did not seek ANC during pregnancy might have been more likely to not report their pregnancy due to social desirability, since the majority of the population know that pregnant women should seek ANC. Since women who do not seek ANC are not HIV tested either, this might have led to an over-estimation of the proportion of women HIV tested in the HDSS cohort. However, during the regular HDSS data collection rounds in this setting under-reporting of pregnancies always occurs. About 2000 births but only 1200 pregnancies (700 pregnancies/data collection round) are identified yearly in the Iganga/Mayuge HDSS; thus we knew already before study start that only about 60% of all pregnancies are normally captured. This research actually identified a higher number of pregnant women (n=881) than usual, about 77% of the expected pregnancies. In a study looking at the discrepancies between the reporting of pregnancies and reporting of births in the Iganga/Mayuge HDSS a risk factor for not reporting pregnancy was the pregnant woman being below 18 years of age [166]. If women below 18 years had a different ANC attendance behaviour and different HIV testing uptake than the women enrolled it would have influenced the results in this thesis. Other suggested reasons for not reporting pregnancies is random error caused by the cultural belief that it would cause bad-luck to tell someone about a pregnancy until late pregnancy as well as difficulty for women to know if they are pregnant given the very high fertility rate with frequent pregnancies and continued breastfeeding affecting menstrual periods, as well as the lack of pregnancy tests.

Due to the fact that pregnancies are generally missed during HDSS-data collection, and since this study captured more pregnancies than usual, this under-reporting is unlikely to have biased the results. Hence, the results are believed to be generalizable to the HDSS- and district's population.

Dropout occurred at several time-points in the cohort. First when women who had not gone for ANC at enrolment should have been interviewed after giving birth. This dropout was due to the fact that the women had moved, or were not at home during the several follow-up visits. Second, some women were not found in the registers, most likely due to poor-record-keeping. Neither of these two dropouts should have biased the results since the women who dropped out are unlikely to be different from the women who remained in the study with regard to ANC attendance, HIV testing and HIV infection.

The women further self-selected into the different ANC facilities, and women who chose facilities without HIV testing equipment could have chosen these facilities because of their lack

of HIV testing services, and could have had higher- or lower HIV prevalence than what was observed among the women tested. However, a Zambian study compared the HIV prevalence among people who had undergone provider-initiated HIV testing with those who had undergone non-provider HIV testing and did not observe a difference between the groups [24]. Further, a study from Kenya found lower HIV prevalence among women who refused HIV testing during ANC [132]. Hence, there are no obvious reasons to believe that women attended certain ANC facilities based on HIV testing services being available or not.

### *Information bias*

Information bias is often subdivided into recall bias and misclassification. Both exposure and outcome could be subject to misclassification. Misclassification might be of two different kinds: non-differential- (random) or differential (systematic). If misclassification has occurred, a person is classified into the wrong outcome or exposure category [165]. Non-differential misclassification means that measurement problems occur in all groups. Differential misclassification on the other hand occurs when either the exposure (e.g. socioeconomic status or distance to a health facility) is misclassified according to somebody's outcome status (here not being HIV tested), or if the classification of the outcome would be influenced by exposure status, meaning that the measurement problems occurs in one group differently causing a systematic error [164]. The data for this research were collected through questionnaire-based, face-to-face interviews, and responses could have been subject to reporting bias from the respondents. However, in order to get as valid answers as possible the interviews were conducted in private, and by well-trained and experienced female interviewers. Further, the questions were also structured to cover the most sensitive questions in the end of the interview to pose them when the interviewee had had a chance to get to know and gained some trust for the interviewer [119]. Much of the exposure data was also derived from the pre-existing HDSS database e.g. data on socioeconomic status, age, marital status etc., and therefore not subject to self-reports.

The record reviews at the health facilities were conducted by me and two experienced and trained assistants, and the HDSS information on woman's name, male partner's name, village, age and expected date of delivery were used to identify the "right" woman. If unsure about the identification, the woman was excluded. Data on the outcome "being tested for HIV" came from registers at the health facilities, and the quality of the outcome measure is dependant on whether the forms were filled in correctly. However, the research team spent much time at the various health facilities and observed the record keeping, and the quality of HIV testing registration seemed to work well, but there is a risk of a random error and non-differential misclassification of the outcome, in turn diluting the estimate towards the null hypothesis, making the estimated association weaker than the true population value [164].

### *Confounding*

Confounding occurs when the association between exposure and outcome is distorted due to the mix of the effect of the exposure with another factor associated with the outcome under study. A confounding factor is a third factor that is associated with both the exposure under study and the outcome, a factor that also is independently of the exposure associated with the outcome [165].

## *Discussion*

The distribution of a confounder needs to be uneven in the comparison groups. If data has been collected for a confounder that could be controlled for in the analysis phase with the goal to eliminate or reduce variation in the level of the confounding factor between compared groups.

In this research several potential risk factors associated with the outcome (not being HIV tested) were analysed, and the risk factors identified for not being tested were: being poor, having a distance longer than 3 km to a facility with HIV testing services and having more than four living children.

A possible non-collected risk factor that might have confounded the estimate for the association between having more than four living children and not being HIV tested is education. It is likely that a less educated woman has a higher number of children and also has less knowledge about the importance of being HIV tested.

### *Decision tree analysis (IV)*

The decision-tree analysis combined the empirical data from the HDSS cohort and assumptions on the most recent HIV transmission rates data used in the UNAIDS Spectrum modelling [48]. The transmission rates for the various ARV regimens, and the women's CD4 cell count levels during pregnancy and during breastfeeding, are based on a review of the available literature. The studies included in the review are not always easily comparable since they differ with regard to exposure, population etc. Nevertheless, it is the best data available, and has been reviewed by some of the most experienced researchers in the field.

In addition to what has been discussed above for the qualitative and quantitative research methods, the research in this thesis has also been triangulated by the use of different methods to study access to PMTCT services. The use of several research methods made the results and conclusions more reliable and trustworthy.

Further, the data from this research were also triangulated with data collected by other researchers within the ARVMAC project.

## CONCLUSIONS

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- Policy implementation of opt-out HIV testing and couple testing for HIV aiming to increase enrolment and completion of PMTCT has not been successful in this setting due both to health system weaknesses and failure to contextualize the programmes. (I, II, III, IV)
- Very few of the women who sought ANC from facilities without HIV testing services carried through the testing referral, and this is a major reason for the low population uptake of HIV testing during pregnancy. (I, III)
- The poorest women had the lowest access to HIV testing, primarily because of living further away from the health facilities with HIV testing services. (III)
- The opt-out HIV testing was not accompanied with sufficient counselling to empower women to make informed decisions. (I)
- Most of the HIV-infected women did not adhere to the PMTCT services, bring their babies for testing, practice safe feeding or were not referred to HIV care. This is a missed opportunity since diagnosing HIV is not the end-goal but the first and crucial step in PMTCT and the first step towards care and preventive measures. (I, IV)
- The PMTCT coverage in this setting translated into an estimated MTCT rate of 13% at birth and 16% at six months. Strengthening the health system to enhance adherence to the PMTCT services could reduce MTCT. (IV)
- Increasing access to HIV testing during pregnancy to 100% either through expanded onsite testing or better counselling and referral systems, was estimated to be the single most effective intervention to decrease MTCT in this rural setting. Yet, only combined PMTCT interventions together with perfect adherence to all PMTCT components would reduce MTCT rates to levels below the target of less than 5%. (IV)
- The implementation of couple testing for HIV during pregnancy has failed in this setting. Neither pregnant women nor men felt comfortable to test together with their spouse. Local gender norms and behaviours have been neglected when HIV testing programmes were implemented and alternative methods of male partner recruitment are needed. (I, II, III)



## RECOMMENDATIONS

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To improve access to PMTCT services, increased coverage of HIV testing during pregnancy is crucial. This thesis indicates that even though an opt-out HIV testing policy has been implemented, uptake of testing during pregnancy is far from universal. Based on the findings from this thesis, recommendations that could increase the access to PMTCT services are presented.

To increase access to PMTCT services, interventions both in the health system and the community are needed to make the services more available and acceptable.

By involving the community in policy implementation the acceptability of the policies might improve and increased access to PMTCT services attained.

Strengthening the referral structure for HIV testing or implementing outreach testing could help to increase the availability and acceptability of testing services.

Strengthened adherence support to HIV-infected women could decrease dropout from the PMTCT programmes, and structures should be established to link the woman and her infant from PMTCT- to ART and/or paediatric care.

Since gender dynamics was identified as a main hindering factor to men's acceptance of couple HIV testing, the recruitment for couple testing should be made more acceptable to men. Focusing the community messages to the men more explicitly, as well as introducing peer-counsellors or role models at community-level might increase male involvement in PMTCT. In addition, adapting the otherwise female domain of the ANC facilities to make men feel welcome might increase the male involvement.

Since couple HIV testing was not well-accepted by either men or women, increasing men's access to individual HIV testing by acknowledging their own recommendations for how that could be achieved, might be even more crucial.



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## APPENDICES

### Appendix 1. WHO staging

<b>Clinical stage 1</b>
Asymptomatic Persistent generalized lymphadenopathy
<b>Clinical stage 2</b>
Moderate unexplained weight loss (under 10% of presumed or measured body weight) Recurrent respiratory tract infections (sinusitis, tonsillitis, otitis media, pharyngitis) Herpes zoster Angular cheilitis Recurrent oral ulcerations Papular pruritic eruptions Seborrhoeic dermatitis Fungal nail infections
<b>Clinical stage 3</b>
Unexplained severe weight loss (over 10% of presumed or measured body weight) Unexplained chronic diarrhoea for longer than 1 month Unexplained persistent fever (intermittent or constant for longer than 1 month) Persistent oral candidiasis Oral hairy leukoplakia Pulmonary tuberculosis Severe bacterial infections (e.g. pneumonia, empyema, meningitis, pyomyositis, bone or joint infection, bacteraemia, severe pelvic inflammatory disease) Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis Unexplained anaemia (below 8 g/dl), neutropenia (below $0.5 \times 10^9/l$ ) and/or chronic thrombocytopenia (below $50 \times 10^9/l$ )
<b>Clinical stage 4</b>
HIV wasting syndrome <i>Pneumocystis jirovecii</i> pneumonia Recurrent severe bacterial pneumonia Chronic herpes simplex infection (orolabial, genital or anorectal of more than 1 month's duration or visceral at any site) Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs) Extrapulmonary tuberculosis Kaposi sarcoma Cytomegalovirus disease (retinitis or infection of other organs, excluding liver, spleen and lymph nodes) Central nervous system toxoplasmosis HIV encephalopathy Extrapulmonary cryptococcosis including meningitis Disseminated nontuberculous mycobacteria infection Progressive multifocal leukoencephalopathy Chronic cryptosporidiosis Chronic isosporiasis Disseminated mycosis (histoplasmosis, coccidiomycosis) Recurrent septicaemia (including nontyphoidal <i>Salmonella</i> ) Lymphoma (cerebral or B cell non-Hodgkin) Invasive cervical carcinoma Atypical disseminated leishmaniasis Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy

Appendix 2. Summary of ARVs

NRTIs	NNRTIs	PIs	FUSION INHIBITORS
zidovudine (ZDV, AZT)	nevirapine (NVP)	nelfinavir (NFV)	enfuvirtide (ENF)
lamivudine (3TC)	efavirenz (EFV, EFZ)	ritonavir (RTV)	
stavudine (d4T)	delavirdine (DLV)	saquinavir (SQV)	
didanosine (ddI)		indinavir (IDV)	
abacavir (ABC)		lopinavir/ritonavir (LPV/r)	
tenofovir (TDF)		atazanavir (ATV)	
emtricitabine (FTC)		amprenavir (APV)	
zalcitabine (ddC)		fos-amprenavir (fos-APV)	

Nucleoside analogues (NRTIs) Non-Nucleoside analogues (NNRTIs) Proteas Inhibitors (PIs)

### Appendix 3. Question guide for semi-structured interviews (I)

#### **HIV pre-test counseling**

1. *Mubulwalilo bye murwela eyidagala babawelewo mu engeli nningi nga okubabudabuda. Bakubudabuda mu kwekebeza akawuka kasilimu?*  
ANC clinics provide many different services, among them counseling. Were you counseled/taught about HIV testing?
2. *Okilowozaku ki otya kubyo kubudabudibya?*  
What do you think about the counseling?
3. *Nkoberaku ebyaliwo nga bamaze okukubudabuda/okukusomesa kubya akawuka kasilimu?*  
Could you please describe what happened after being counseled for HIV testing?

#### **HIV testing**

4. *Olowoza migasoki egili mukwekebeza akawuka ka silimu?*  
What do you think are the benefits of being tested for HIV?
5. *Wasalawo otya okwekebeza akawuka? Waliwo eyakuwaamagezi oba waliwo ekyabawo?*  
How did you decide to take the HIV test? Did someone recommend you to do it, was it a something that influenced your decision?
6. *Okilowozaku ki ekyo kukebera akawuka kasilimu nga eyiteka mubulwaliro obwokunwelamu eyidagala ekyokuba nti abakyala abaida okunya eyidagala balinobakebeza akawuka ka silimu?*  
What do you think about that HIV testing is done as routine during ANC?
7. *Okilowozaku ki ekyokwida wano okunwa eyidagala ate bamala bababudabuda kubyo okwekebeza akawuka kasilimu era olunaku lwene olwo babatolaku omusayi era bakuwelawo ebivilemu?*  
What do you think about that women during ANC receive information about HIV testing, are tested and receive the test results on the same day?

#### **Effects of HIV testing**

8. *Walowozaku kwebyo ebinava mukwekebeza?*  
Did you think about the outcome of HIV test results when you were to be tested for HIV?
9. *Onayegeraku kwekyo kyoli?*  
Would you disclose your HIV status to someone?

10. *Mubuwaliro bwemunwelamu eyidagala ebayo okubudabuda omwami no mukyala ekyo ekilowozaku otya?*  
At ANC, couples are encouraged to be counseled and tested together, what do you think about that?
11. *Owulira ofya kwekyo kyewasalawo okwekebeza?*  
How do you feel about being tested for HIV?

**Effects if tested HIV positive**

12. *Singa bakukebera nga olina akawuka, ekyo kikyusa kitya obulamu bwo?*  
If you were to be tested HIV positive, how would that influence your life?
13. *Oyidi engeli omukyala alina akawuka dasobola okukozesa okuziyaza omwana okufuna akawuka?*  
Do you know how a woman with HIV can protect her baby from acquiring the HIV virus?

**Male involvement**

14. *Olina omwami? Obyi wandyenze yetabe mukwida okunwa eyidagla nga olinda?*  
Do you have a partner?  
If yes, would you like your partner to be involved in ANC during pregnancy?
15. *Omwami wo yakuwaku amagezi okwekebeza akawuka oba be nga olinda?*  
Did your partner influence your decision whether to be HIV tested or not during pregnancy?
16. *Olinayo ekindi kyona kyona kiwandyenze okwongera kubigemangana no okwekebeza akawuka kasilimu, nokkusiyiza akawuka obutagema mwana nga kava ku maamwe ku bulwaliro yemunwela eyidagala obo eliyi ekindi kyonakyona kwebyo byetwoegeileku.*

Is there anything you would like to add regarding HIV testing and PMTCT at ANC, or any other issues that we have discussed?

*Webale ino okwetaba mu musomo guno, kibaile kyamugaso ino okuwayamu nife kwebyo ebikugemaku*

**Appendix 4. Topic guide (II)**

1. First, what do you think are men's roles for antenatal care during pregnancy?
2. Are you aware of any services that can help parents to prevent HIV transmission to the unborn child?
3. Would you like to receive those services?
4. How do you see the benefits from the PMTCT services at ANC?
5. Today, few men attend ANC health units, what do you think are the reasons for this?
6. Today, few men are HIV tested at ANC health units, what do you think are the reasons for this?
7. How do you think you and other men would like to be involved in the PMTCT programme?
8. What would be the consequences for you and your partner if you came to know that your pregnant wife (partner) is HIV positive?
9. What if one in a couple is tested positive and the other negative, what effect could that have for their lives?
10. If your partner was tested HIV positive, how would you act after the result was given?
11. If you were tested HIV positive, how would you act after the result was given?
12. What do you think about the different places where women deliver from?



<p><b>Visit</b></p>	<p><b>5</b>  <b>Nsonga ki eyakuleta okufuna obwidhandabi?</b> For what reason did you seek care? (whycare)  <i>(Do not read out the alternatives, tick what is mentioned, SEVERAL REASONS COULD BE MENTIONED)</i></p>	<p><b>6</b>  <b>Wabufuna gha?</b>  Where did you go? (whereancare)</p>	<p><b>7. Nsonga ki enkulu eyakuviraku okufuna obwidhandabi mukifo ekyo?</b> What was the reasons for choosing this care provider? (whycareprov)  <i>(Do not read out the alternatives, tick what is mentioned, SEVERAL REASONS COULD BE MENTIONED)</i></p>
<p><b>Visit 1</b></p>			
<p><b>Visit 2</b></p>			
<p><b>Visit 3</b></p>			
	<p><b>Alternatives</b></p>	<p><b>Alternatives</b></p>	<p><b>Alternatives</b></p>
	<p>1. Fever</p>	<p>1. Hospital</p>	<p>1. Anonymous care provided (Privacy)</p>
	<p>2. Bleeding</p>	<p>2. Health centre</p>	<p>2. Qualified provider</p>
	<p>3. Cough</p>	<p>3. Private clinic</p>	<p>3. Close to home</p>
	<p>4. Pain when passing urine</p>	<p>4. Private midwife</p>	<p>4. Cheap prices</p>
	<p>5. Stomach ache</p>	<p>5. Drug shop</p>	<p>5. High availability of drugs</p>
	<p>6. Back ache</p>	<p>6. Traditional birth attendant</p>	<p>6. Acquaintance with the provider</p>
	<p>7. Failure to gain weight</p>	<p>7. Traditional healer</p>	<p>7. Decided/suggested by others</p>
	<p>8. Worry</p>	<p>8. Other pls specify  .....</p>	<p>8. Time of onset of disease</p>
	<p>9. Violence</p>		<p>9. Severity of disease</p>
	<p>10. Other pls specify  .....</p>		<p>10. Other pls specify  .....</p>

**C. ANTENATAL CARE**

**8. Kumabundha ganho, wali ogireku mukifo ekinwerwamu obulezi?**

*During this pregnancy have you attended ANC health unit/s? (anccare)*

Yes = 1 → **question 10**

No= 2 → **question 9**

**9. Nsonga ki edhakulemessa okuja okunwa obulezi? What was the reason/s for not going for ANC? (reasonnoanccare)**

*(Do not read out the alternatives, tick what is mentioned, SEVERAL REASONS COULD BE MENTIONED)*

	Yes=1	No=2
1. Pregnancy is still young		
2. Was not feeling ill		
3. Lack of money		
4. Fear		
5. Distance to health facility		
6. Staff attitudes at health facility		
7. Weather conditions		
8. Partner did not agree on visit ANC		
9. Don't know the importance/benefits of visiting ANC		
10. Other pls specify		

After answering question 9 → **question 27 (FIRST READ THE HIV PREAMBLE)**

**10. Anhi eyakuwa amagezi okuja okunwa obulezi?**

When you sought ANC during this pregnancy, who advised you to do so? (whoadvicancecare) (do not read out, circle what is mentioned)

1. You yourself	
2. Husband	
3. Your mother	
4. Mother in law	
5. Other pls specify	

**11. Gha wotera okuja okunwa obulezi kumabudha ganho? During this pregnancy, where do you normally go for ANC? (whereanc)**

1. Hospital	
2. Health centre	
3. Private clinic	
4. Private midwife	
5. Traditional birth attendant	
6. Other, pls specify	

**12. Musawo wangeriki atera okukolaku nga ogire okunwa obulezi?**

What type of health care staff do you normally see at ANC health unit? (whoseneanc)

1. Medical doctor/Clinical officer	
2. Midwife	
3. Nurse	
4. TBA	
5. Other pls specify	

**13. Nandyenze okunkoberaku erinha eryekifo kyonweramu obulezi niwe kyaganibwa? (ancfacility)**

Please tell me the name and place of the facility?

.....

For official use only;

14. **Ntambulaki yotera okukozesa nga oja okunwa obulezi?** What type of transport do you normally use to get to the

ANC health unit? (transpnc)

I	Bus
II	By foot (walking)
III	Ambulance/facility vehicle
IV	Motorbike
V	Taxi
VI	Private Car
VII	Bicycle
VIII	Other (Specify):

15. **Kikutwalira kiseraki okuva wano okutuka wonwera obulezi?** How long does it normally take to go from your home to the ANC health unit? (do not read of the alternatives) (timetoanc) ?

1.	less than 1 hour
2.	1-2 hours
3.	3-4 hours
4.	5-12 hours
5.	13-24 hours
6.	more than 1 day
98.	Do not know

16. **a) Kumabudha ganho, mirundi emeka gyewakaja okunwa obulezi? (timesanc)** During this pregnancy, how many times have you attended ANC?

..... times

**b) Amabudha ganho gali gamyezi emeka wewatandikira okunwa obulezi era wakajayo emirundi emeka?**

At what month of pregnancy did you attend ANC health unit and number of times? (ancvisitrim)

	Number of ANC visits/trimester
1. Months 1-3	
2. Months 4-6	
3. Months 7 or more	

17a. **Wasulayo ekintu kyona kyona bwewaja yemunwela obulezi?** Did you pay anything during the ANC visits?

Yes = 1

No= 2

→ question 17b

→ question 18

17b. **Osasula otya buli murundi gwaja okunwa obulezi?** How much did you pay for ANC, including transport?

(whatpayanc)

	1. ANC visit (including official and non official payment) (USh)	2. Transport (Ush)	3. Kind (specify)
VISIT 1			
VISIT 2			
VISIT 3			
VISIT 4			
Total			

18. **Kumabudha ghanho, mwajaku nomusadha wo ewomusawo gyonwera obulezi?**

During this pregnancy, has your partner ever attended ANC with you? (partnanc)

Yes = 1 → question 20

No= 2

→ question 19

*Appendices*

**19. Lwaki omusadhawo tiyaja nhiwe gyonwera obulezi?** What was the main reason why your partner did not attend ANC with you? (whynotpartnanc)

1. He is rarely at home
2. He does not want to
3. He fears
4. I did not ask him to attend ANC
5. He does not see the benefits/ importance of attending ANC
7. Other pls specify

**D. HIV TESTING**

**Twogeireku kubigemagana n’ofuna obwidhandhabi no’kunywa obulezi nga oli mabundha. Mu madwalilo agandi basomesaku kubya kawuka kasilimu no’kwekebeza. Buti ndiija kubuzaku kubigemagana no’kwekebeza akawuka.**

**We have talked about health care during pregnancy and especially ANC. At some health facilities they carry out HIV counselling and testing at ANC, now I would like to ask you some questions about HIV testing.**

**20. Kumabundha ganho, bakusomesaku ebigemagana nokwekebeza akawuka akasilimu yonwera obulezi?**

During this pregnancy, were you counselled for HIV testing at the ANC health unit? (womcounslanc)

Yes = 1

No= 2

**21. Kumabundha ganho, bakukeberaku akawuka akaleta silimu?**

Have you been tested for HIV during this pregnancy?(testpreg)

Yes = 1 → question 23

No=2

→ question 22

Do not know = 98 →

question 22

**22. Lwaki tiwekebezangaku akawuka ka silimu kumabundha ganho?** Why have you not taken an HIV test during this pregnancy? (whynottest) (Do not read out the alternatives, tick what is mentioned, SEVERAL REASONS COULD BE MENTIONED)

	Yes=1	No=2
1. Fear/stigma		
2. Testing services were not available		
3. Transport costs		
4. Lack of transport		
5. Testing site is too far		
6. Don't know where to get HIV tested		
7. Don't need the results		
8. Need permission		
9. Weather		
10. Long waiting time		
11. Other pls specify		

After answering this question → 27

**23. Kumabundha ganho, wekebereza gha akawuka kasilimu?**

Where did you take the HIV test during this pregnancy? (whrtest)

(pls specify name and location of the health unit)

.....



*Appendices*

Yes = 1

No = 2

Do not know = 98

**31. Kumabundha ganho, omusadhawo yakeberwaku akawuka eyo gyonwera obulezi?** Has your partner been HIV tested at ANC health unit during this pregnancy? (parttestanc)

Yes = 1

No = 2

Do not know = 98

**32. Omusadhawo yakukoberaku engeri gyayemereremu kubigemegana nakawuka?** Has your partner disclosed his HIV status to you? (mandisclo)

Yes = 1

No = 2

Do not want to answer = 3

**33. Olina kakadha oba ekitabo kyonweraku obulezi?** Do you have an ANC card or ANC book? (anccard)

Yes = 1

No = 2

**If No, answer question 34 and then end the interview. If yes and an ANC card/book is available, ask to see it and fill in the answer to question 35-38 after the interview, do not ask the questions**

**34. Lwaki ozira kadha eyo oba ekitabo kyonweraku obulezi?** Why don't you have an ANC card/ book? (whynoanccard)

1. I have not gone for ANC	<input type="checkbox"/>
2. I went for ANC but did not get a card/book	
3. I went for ANC but I lost the ANC card/book	
4. Other, pls specify	

**NB. BE VERY CAREFUL ABOUT TAKING DOWN THE RIGHT ANC CARD/BOOK NUMBER AND THE NAME OF THE HEALTH UNIT**

**35. Write the ANC card/book number (crdnr)**

.....

**36. Write down the name of the facility name and location where health care was sought (village or parish) (crdfac)**

.....

**For official use only;**

**37. How many times has the mother attended the ANC health unit?** (count the number of visits, using the dates indicated in the book/card) (crdtimanc)

..... times

**38. Is the following information written on the card/book?** (crdinfo)

(NB information can be found on the first page) (circle all appropriate)

	Yes=1	No=2
<b>C</b>		
<b>T</b>		





# Opt-out HIV testing during antenatal care: experiences of pregnant women in rural Uganda

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Two years after the introduction of provider-initiated, opt-out HIV counselling and testing during antenatal care (ANC) in Uganda, HIV testing uptake is still low. This study was carried out to explore pregnant women's experiences of, and views on, the policies for opt-out, and couple HIV testing, and to understand how the policy implementation could be improved in order to increase access to prevention of mother-to-child-transmission (PMTCT) services.

The study was conducted at three ANC health facilities at different levels of care in rural eastern Uganda. Data were collected through sit-in observations during ANC and 18 semi-structured interviews with pregnant women receiving ANC, and thereafter analysed using latent content analysis.

Pregnant women who received ANC from facilities that provided HIV testing on-site perceived HIV testing as compulsory without actually fully realizing the benefits of HIV testing and PMTCT. No referral for HIV testing or information about testing was given at ANC facilities that lacked HIV testing on-site. A major challenge of couple HIV testing was that pregnant women were made responsible for recruiting their spouses for testing, a precarious dilemma for many women who tried to fulfil health workers' requests without having the power to do so.

In order to increase uptake of PMTCT services, the pre-test counselling in groups that precedes the provider-initiated HIV testing should be adjusted to inform women about the benefits of PMTCT. Further, if testing is perceived as compulsory it could potentially deter some women from seeking ANC services. In order to increase HIV testing of male partners new strategies are needed, for example peer-sensitization and male clinics. Moreover, to achieve the desired outcomes of the PMTCT programme, monitoring and evaluation should be built into the programme.

**Keywords** Provider-initiated, HIV testing, gender, antenatal care, Uganda

## KEY MESSAGES

- Counselling preceding provider-initiated HIV testing during antenatal care should be improved to inform women about the benefits of HIV testing and prevention of mother to child transmission services.
- In order to increase male partner HIV testing during antenatal care, recruitment strategies that are more gender-sensitive are needed.

## Introduction

In 2003, only 10% of Ugandan women giving birth were tested for HIV, despite the fact that 94% attend antenatal care (ANC) and that Uganda has an overall HIV prevalence of 6.4% (Karamagi *et al.* 2006). Three years later, the proportion of pregnant Ugandan women receiving pre-test counselling (40%) and HIV testing (21%) had doubled but still remained unacceptably low (Ministry of Health [Uganda] and ORC Macro, 2006).

Consequently, the goal of 80% coverage of prevention-of-mother-to-child-transmission (PMTCT) services and a reduction of new paediatric infections by 50% by 2010 as stated in the universal access declaration, does not seem to be within reach (WHO *et al.* 2008). HIV testing during ANC is the entry point to PMTCT services, and in order to increase coverage of PMTCT, the Ugandan government launched new policy guidelines in 2006, moving from voluntary counselling and testing (VCT) to a provider-initiated opt-out HIV testing model (Ministry of Health 2006). The new policy states that all pregnant women and their male partners should routinely be offered counselling and testing for HIV during ANC, and that health facilities without testing services should refer couples for testing to a nearby facility with HIV testing.

In Uganda, HIV counselling and testing is organized similarly at most government health facilities: all women who come for ANC, receive pre-test counselling combined with general health information, together in a group. Thereafter, a venous blood sample for a rapid test for HIV antibodies is taken and analysed while the pregnant woman receives a physical check-up. Test results can be received the same day during individual post-test counselling (Ministry of Health 2006).

The Ugandan policy is in line with the policy for provider-initiated HIV testing recommended by the World Health Organization (WHO) for countries with a generalized HIV epidemic, aiming to integrate HIV testing in standard medical care at all health facilities (WHO and UNAIDS 2007). The rationale is that if more people get to know their HIV status, the number of people linked to treatment and prevention interventions would increase (De Cock *et al.* 2003; De Cock *et al.* 2006). Health facility-based studies from sub-Saharan Africa, including Uganda, show that opt-out HIV testing during pregnancy may increase the testing uptake by up to 80% (Perez *et al.* 2006; Chandisarewa *et al.* 2007; Creek *et al.* 2007; Homsy *et al.* 2007; Dahl *et al.* 2008; Mugore *et al.* 2008). However, the latest UNGASS progress report from Uganda shows that despite a substantial improvement in coverage doubling the number of ANC sites offering PMTCT, only 30% of all pregnant women estimated to be HIV infected received

prophylactic antiretroviral drugs (ARVs) for PMTCT in 2007 (Ministry of Health 2008). The policy of couple HIV testing during pregnancy, i.e. offering joint HIV testing for pregnant women and their spouses, has shown to increase women's access to and completion of PMTCT services, but the uptake of couple HIV testing in Uganda and other sub-Saharan Africa countries remains low at 5–12% (Farquhar *et al.* 2004; Homsy *et al.* 2006; Elisabeth Glaser Pediatric AIDS Foundation 2008; Msuya *et al.* 2008).

Changing policies is a complex process and the effect of the opt-out HIV testing policy has mostly been evaluated quantitatively; for example, in Zimbabwe it was shown to contribute to high uptake of HIV testing (Walt 1994; Mugore *et al.* 2008). The aim of this study was to explore how the intended target group, i.e. pregnant women, experience the new HIV testing policy since, to the best of our knowledge, this has never been evaluated in-depth in sub-Saharan Africa (Gruskin *et al.* 2008; Thorsen *et al.* 2008). Further, the aim was to understand how the policy implementation could be improved in order to increase access to PMTCT services.

## Methods

### Study setting

This study was carried out in the rural districts Iganga and Mayuge, 120 km east of Uganda's capital city Kampala, between February and March 2008. In these rural districts all health facilities provide ANC, ranging from level II up to hospital level. Level II health facilities provide outpatient services; level III health facilities include a general ward, a laboratory and maternity services; and level IV health facilities also have operation theatres.

HIV testing and PMTCT services were introduced at Iganga district hospital in 2004 and soon thereafter expanded gradually to lower-level health facilities. The policy for opt-out HIV testing during ANC was introduced in the two districts in 2006, and implemented similarly regardless of level of care. Pre-test counselling is always provided in groups during the general health education sessions. The number of women per counselling session varies with the level of care, ranging from five at level II facilities to 40 at hospitals. The duration of a group counselling session is about 15 minutes regardless of facility level. Most of the health facilities in the two districts are government health facilities but a few are run by non-governmental organizations. The majority of the facilities are level II, and most of them cannot perform HIV testing. Instead, according to the guidelines, these lower level facilities should

provide HIV counselling to all pregnant women and their partners, and then refer them for testing at higher level of care.

### Study design

This study included both semi-structured interviews and sit-in observations. The interviews aimed to investigate pregnant women's experiences of provider-initiated HIV testing, and included questions about how women experienced the pre-test counselling received; what information they had received about HIV; whether they had understood the purpose of HIV testing; and their view on couple HIV testing. In order to get views from women who received ANC from different levels of care, respondents were recruited from three purposely-selected health facilities: one district hospital ( $n=10$ ), one health facility III ( $n=6$ ) and one health facility II ( $n=2$ ). The hospital and the health facility III provided HIV testing during ANC, while the health facility II was supposed to refer patients for HIV testing. All pregnant women visiting one of the three facilities were eligible to participate.

In total 18 women were interviewed. Purposive sampling was performed in order to obtain the views of both first-time pregnant women ( $n=4$ ) and women who had been pregnant before ( $n=14$ ), as well as women with unknown ( $n=10$ ) vs confirmed HIV infection ( $n=8$ ). Women were approached at registration for ANC in collaboration with a nurse working at the health facility. The aim of the study was described to eligible women, and they were invited to participate in an interview while waiting for their HIV test results or other ANC services. The interviews were conducted in a separate room at the health facilities in order to ensure confidentiality. Each interview was carried out in the local language Lusoga by one of two Ugandan female sociologists with previous experience of qualitative and HIV research, and the interviews lasted for about 40 minutes. Four women attending ANC at the hospital declined participation since they had to attend to their children. The interviews were audio-recorded, transcribed verbatim and translated into English by one person, and thereafter checked for errors by a second person.

Sit-in observations during ANC were also performed at all three health facilities. The aim of the sit-in observations was to explore the organization of PMTCT services and the content of the pre-test counselling. The interviewer together with the first author observed pre-test counselling sessions during the same 6 days as when the interviews were performed. Through interviews and sit-in observations at the level II health facility it was found that no information about HIV testing was given, nor were women referred for testing. Since the aim of this study was to explore women's experiences of routine HIV testing during ANC, no more respondents were included from that facility for this reason.

### Data analysis

We analysed the data using latent content analysis which aims to analyse the underlying meaning of the respondents' statements (Graneheim and Lundman 2004). Analysis started during data collection. Transcripts were read and discussed

within the research team after finishing an interview to identify probes or follow-up questions to be included in the next interview. These reviews also helped to decide when saturation for the main research question had been reached. After data collection, the transcripts were read several times to get a feeling for the data. Thereafter so-called meaning units were identified and labelled with codes (Graneheim and Lundman 2004). The codes were compared for similarities and differences, and grouped into categories on a manifest level. The categories were subsequently interpreted for the latent meaning and organized into themes on an abstract level. The first author initially coded the data. Analyst triangulation was applied during the process: co-authors read selected transcripts, discussed codes, categorization of codes and development of themes at several points, until consensus was achieved (Patton 2002). An additional source of triangulation regarding the content of the pre-test counselling came from comparing the findings with findings from another study in the same setting exploring the quality of ANC (Patton 1990). This is described in a forthcoming article from the same research consortium ([www.arvmac.eu](http://www.arvmac.eu)) (Conrad, undated).

### Ethics

Ethical approval was obtained from the Makerere University School of Public Health Institutional Review Board and the Uganda National Council of Science and Technology. All participants received detailed information about the study, and were informed that their participation was voluntary. It was emphasized that they could decline participation without any negative consequences for their ANC, that information obtained would be kept confidential and that data would be analysed after de-identification. All respondents gave written informed consent before participation.

### Results

Two main themes were identified during the analysis: 'To test or not is not a woman's choice' and 'Absent partners: the responsibility of women?'. Themes and categories are summarized in Table 1. The themes are described and illustrated with quotes below.

#### To test or not is not a woman's choice

Respondents from the ANC clinics that provided HIV testing generally thought that they could not receive any ANC services unless they accepted being tested for HIV.

*"I am told that when you come for ANC, they have to take your blood sample for testing: if you refuse they will not give you any treatment (ANC)... No one (health worker) will care about you when you're pregnant, if you don't accept to be tested for HIV."*  
(unknown HIV status, multi-gravida, health facility III)

On the other hand, sit-in observations and interviews in the health facility that did not provide HIV testing on-site revealed

**Table 1** Summary of themes and categories

Themes	To test or not is not a woman's choice	Absent partners: the responsibility of women?
Categories	<ul style="list-style-type: none"> <li>• HIV testing is mandatory</li> <li>• Poor knowledge of HIV</li> <li>• Health workers decide for me</li> <li>• Not possible to ask questions</li> <li>• Health workers know what is best for me</li> </ul>	<ul style="list-style-type: none"> <li>• Health workers request that we bring our partners</li> <li>• Male partners refuse to come to antenatal care clinics</li> <li>• Bringing the message causes anxiety</li> <li>• Risk of discordance—a challenge</li> <li>• Partner would not disclose</li> <li>• Health workers should teach partners</li> </ul>

that women there were neither informed about, nor referred for HIV testing as the PMTCT guidelines prescribe.

Few of the women who received ANC from clinics that provided HIV testing on-site had fully understood the reasons for testing and the majority had little knowledge about PMTCT.

*"I also do not understand why they examine us and even go ahead to take off blood..."* (unknown HIV status, primi-gravida, hospital)

Women further commented that they felt inferior in relation to the health workers and that they would never question anything a health worker said, or ask questions for clarification.

*"What the health worker would decide upon is what I would go with, because me I am just a patient..."* (HIV infected, multi-gravida, health facility III)

Another example of the power imbalance described by the pregnant women was the fact that staff often took blood samples for testing without informing the women about why they did so. The women themselves did not dare to question the rationale behind it, but suspected that health workers did it in order to test women who otherwise would not accept being tested.

*"That is why they take the blood before telling you, because if they tell you before, you can dodge and tell them that I will come back and fail to come, because not everybody is willing to test."* (unknown HIV status, multi-gravida, hospital)

The power asymmetry between the pregnant women and health workers was further made clear by the fact that some women had to pay informal payments to staff. Although women knew that they should not have to pay for ANC services, they felt unable to demand the services they were entitled to free of charge.

In contrast to the negative view of opt-out testing among most respondents, there were women who viewed the new testing policy during ANC as something positive that could benefit both them and their children.

*"...it was compulsory to test...It is good because I got to know my status, and yet before I used to produce children without knowing that I was positive. But now health workers counsel me well, they carry my baby whenever I come and they give me Seftrin."* (HIV infected, multi-gravida, hospital)

#### **Absent partners: the responsibility of women?**

The PMTCT policy in Uganda states that all pregnant women and their male partners should be offered HIV testing routinely

during ANC. However, since very few men spontaneously accompanied their wives for ANC, health workers tried to recruit men for testing through the pregnant women. This was also confirmed by the sit-in observations.

*"...health workers asked if I could convince my husband to also come for testing."* (HIV infected, multi-gravida, hospital)

Women felt obliged to accept the request to try and persuade their partners to come for HIV testing. However, the majority described it as a complicated mission and a major dilemma to try to recruit their spouses while having very limited power to influence their partner's actions.

*"You can tell him but he will refuse to come. He will just tell you that he is not coming. He does not give any reason why he won't come."* (unknown HIV status, multi-gravida, health facility II)

Since the women rarely felt they could just ask their partners directly, they talked about using alternative strategies, including lies, to get their spouses to come to the health facilities, hoping that once there, the health workers would help to convince the men to be tested.

*"Maybe we can get somebody to go and deceive him that his wife is stuck in the clinic, then I think he can come."* (unknown HIV status, primi-gravida, hospital)

Some health workers offered HIV-infected women assisted disclosure and recommended that the women should delay partner disclosure until the man had joined them at the ANC clinic.

*"She (health worker) also told me that when I go back home I shouldn't tell my husband directly. That I should tell him to come along with me to the health centre such that they can test both of us."* (HIV infected, multi-gravida, hospital)

Some women with a confirmed HIV infection revealed that they felt forced by the ANC staff to unwillingly disclose their HIV status. Their fear of abandonment made some refuse to bring their partner for testing.

*"He told me that he tested and was negative though it was some time back and he is faithful, he does not cheat on me. If we test positive it will be me who infected him. That's why I cannot come along with him to let him know that we are positive... He will chase me away..."* (HIV infected, multi-gravida, hospital)

There were a few women who felt ready for couple testing and realized that the assisted disclosure would release them from the burden of being the messenger.

*"When we come here together, it would be easy for the health worker to explain to him all the details of my sickness unlike me who would not tell him everything that I was told at the health centre."* (unknown HIV status, multi-gravida, health facility III)

In general, couple testing was not appreciated, and for the women, bringing home the message of HIV testing to the spouse was associated with great anxiety due to fear of negative reactions, and severe consequences.

*"Because there is a time I jokingly told him that if the test results show that we are infected, what do you do? And he said that he can kill himself."* (unknown HIV status, primi-gravida, hospital)

The fear of HIV sero-discordance within the couple, especially if the woman would be infected and the man not, was a common concern and a major barrier to couple testing. Many feared being accused of infecting their partners, something that could lead to relationship problems and separation.

*"When you test as a couple, you may turn out to be discordant; when one of us is positive and the other is negative this may lead to separation and misunderstanding, and the man will claim that it's the woman who brought the infection. Men will never accept their mistakes. They are normally rude."* (unknown HIV status, multi-gravida, hospital)

When the male partner was known to have concurrent sexual relationships, the value of couple testing was described as limited, and the women asked the health workers for advice on how to protect themselves against being infected during pregnancy.

*"For my husband, I don't know whether he would take my advice. So I don't know how I would protect myself, maybe I can consult a health worker. For instance if the husband has got other sexual partners, it is easy to infect me, yet I might not have the virus [now]."* (unknown HIV status, multi-gravida, health facility III)

Men's freedom of choice, having the possibility to decline an HIV test was often mentioned. It was seen as unfair that men, as opposite to women, could choose to opt-out of testing during ANC, to test alone without informing their partners, or even receive antiretroviral treatment without disclosing this to their partners.

*"...for example there was a couple that was infected but the husband used to take care of himself alone, even treatment, without taking care of the wife. The wife passed away last year..."* (unknown HIV status, multi-gravida, hospital)

## Discussion

This study found that women who received ANC from health facilities that provided HIV testing on-site generally perceived

testing as mandatory, and rarely fully understood the benefits of HIV testing or PMTCT. Women who received ANC from health facilities that lacked on-site testing were neither informed about nor referred for testing. Couple-testing was generally not appreciated and put women in a precarious dilemma where they felt forced to comply with health workers' requests to recruit their husbands for HIV testing while fearing negative consequences at home. Below, these findings are discussed in relation to how implementation of provider-initiated HIV testing during ANC in Uganda could be improved.

The fact that HIV testing was viewed as compulsory is in line with recent concerns that the global policy change from VCT to provider-initiated HIV testing could make patients feel obliged to test (Maman and King 2008). Despite the fact that we interviewed women who had just attended a group pre-test counselling session, many did not fully understand the benefits of HIV testing and PMTCT, and since they felt submissive in relation to the ANC staff, they avoided asking questions. In order to improve the outcome of counselling, it is crucial that women feel comfortable to ask questions, and that the power-imbalance between health workers and pregnant women is taken into account during ANC. Requests for informal payment during ANC were reported, and further emphasized the power hierarchy between health staff and pregnant women.

HIV testing of pregnant women is the first step in the PMTCT programme and the entry point for HIV-infected women to receive other PMTCT services. The new opt-out HIV testing policy aims to achieve higher coverage of PMTCT and to reduce HIV transmission, but since women did not fully understand why HIV testing was carried out, the current pre-test counselling seems to be insufficient for reaching these goals (WHO and UNAIDS 2007; WHO *et al.* 2008). Similarly, since existing data on provider-initiated HIV testing show that this testing model results in an increased workload and less time for counselling, new strategies for counselling need to be considered. One option is sensitization campaigns about PMTCT at the community level to raise awareness among both women and men before they come to the health facilities (Evans and Ndirangu 2009).

The reported lack of counselling and referral from health facilities without HIV testing capacity on-site has confirmed our observations from the same district, that referral systems for PMTCT need further review (Larsson *et al.* 2009). Since the majority of health facilities that provide ANC belong to this category, the failure to counsel and refer pregnant women for HIV testing means that these women miss the opportunity to receive other PMTCT services as well. One strategy to improve both quality and access to pre-test counselling would be to monitor and evaluate pre-test counselling at all health facilities, including level II, as well as monitoring the referral system on a regular basis. Further, a more robust referral system should be introduced to follow up those who have been referred for testing. For example, women who receive ANC where testing is not available could be given a referral note to present at the testing facility that should then be fed back to the first ANC facility. Another option could be to introduce HIV testing at lower level health facilities, perhaps through outreach activities from a higher level of care or by diverting more resources for

testing equipment and staff training to lower level health facilities. Independently of where pregnant women receive ANC, they should be empowered with information about the importance of HIV testing during pregnancy.

Being asked to recruit male partners for HIV testing was associated with anxiety due to perceived risk of intimate partner violence among our respondents. These findings appear to be supported by studies in similar settings in Botswana, Kenya and Tanzania (Taegtmeier *et al.* 2006; Weiser *et al.* 2006; Msuya *et al.* 2008). The Ugandan PMTCT policy is based on evidence that male partner involvement is associated with women's completion of PMTCT in sub-Saharan Africa (Farquhar *et al.* 2004; Ministry of Health 2006; Homsy *et al.* 2007; Sarker *et al.* 2007; Kasenga *et al.* 2010; Msuya *et al.* 2008). However, our findings raise the question of whether using women to recruit their unwilling male partners for HIV testing is the best way to get men involved. WHO emphasizes that gender patterns need to be considered in order to successfully implement policy, but gender aspects in terms of decision-making power and women's financial dependency on their male partners is rarely integrated in policy development and implementation, and few countries have followed the call from the United Nations to integrate gender dimensions into HIV plans (Vlassoff and Garcia Moreno 2002; WHO 2002; WHO 2003; Greig *et al.* 2008; WHO 2009). Though the Ministry of Health in Uganda has incorporated gender into the Health Sector Strategic Plan, our findings suggest that a more gender-sensitive implementation of the PMTCT policy could improve community effectiveness of couple testing during ANC (Theobald *et al.* 2005). Instead of targeting men through their pregnant wives, more men could be reached by using gender-sensitive interventions at community level, i.e. community health workers or male peers informing men about the potential benefits of HIV testing and PMTCT. Another solution might be to have male clinics in connection with ANC, where men could receive counselling and HIV testing and meet other men.

The current study focused on the pregnant women's experiences; no self-reported experiences of health workers and men are included, nor have we interviewed women visiting private ANC providers. However, our respondents were selected to represent various levels of care, different HIV statuses and different previous pregnancy experience, and we found consistency in the findings among these different groups, and concordance between interviews and sit-in observations. Since the ANC offered at different health facilities in the districts is rather similar, we believe that our findings are applicable also to other ANC facilities in Uganda. We used analyst triangulation within the research team, and in addition triangulated our findings with data from another study on the quality of ANC in the same setting. The two women interviewed at a health facility that did not provide testing were included in the analysis since quantitative studies from the same district confirm that despite PMTCT guidelines, few women are referred for, or carry through, any referral for HIV testing (Larsson *et al.* 2009; Larsson *et al.* 2010). The fact that interviews were conducted at the health facilities could have hampered some potential criticism about health workers or care received, but the interviews were always

conducted in a private space separate from the health workers. To create trustworthiness, both the first and the fourth author had prolonged engagements in the field at the health facilities.

Four women, all from the hospital, declined participation for the reason that their children needed their attention and as we observed them taking care of their children, we have no reason to doubt their reasons for declining.

In conclusion, provider-initiated HIV testing during ANC is crucial to increase the coverage of testing and PMTCT. Moreover, the preceding counselling needs to be improved so that women are properly informed about the benefits of HIV testing and PMTCT. However, this cannot be achieved unless pregnant women are empowered with information to make informed choices, and if testing is perceived as compulsory this could potentially deter some women from seeking ANC services. As health workers often are overburdened, one possible solution might be to use community health workers or peers to counsel women about HIV testing in the community before the women come for ANC. Moreover, alternative ways to recruit male partners for HIV testing during ANC are needed, for example through peer-sensitization and male-friendly clinics. Lastly, improved monitoring and evaluation should be built into the PMTCT programme to improve pre-test counselling as well as the referral system, in order to improve on the desired outcomes of the PMTCT programme.

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RESEARCH ARTICLE

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# Mistrust in marriage-Reasons why men do not accept couple HIV testing during antenatal care- a qualitative study in eastern Uganda

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## Abstract

**Background:** A policy for couple HIV counseling and testing was introduced in 2006 in Uganda, urging pregnant women and their spouses to be HIV tested together during antenatal care (ANC). The policy aims to identify HIV-infected pregnant women to prevent mother-to-child transmission of HIV through prophylactic antiretroviral treatment, to provide counseling, and to link HIV-infected persons to care. However, the uptake of couple testing remains low. This study explores men's views on, and experiences of couple HIV testing during ANC.

**Methods:** The study was conducted at two time points, in 2008 and 2009, in the rural Iganga and Mayuge districts of eastern Uganda. We carried out nine focus group discussions, about 10 participants in each, and in-depth interviews with 13 men, all of whom were fathers. Data were collected in the local language, Lusoga, audio-recorded and thereafter translated and transcribed into English and analyzed using content analysis.

**Results:** Men were fully aware of the availability of couple HIV testing, but cited several barriers to their use of these services. The men perceived their marriages as unstable and distrustful, making the idea of couple testing unappealing because of the conflicts it could give rise to. Further, they did not understand why they should be tested if they did not have symptoms. Finally, the perceived stigmatizing nature of HIV care and rude attitudes among health workers at the health facilities led them to view the health facilities providing ANC as unwelcoming. The men in our study had several suggestions for how to improve the current policy: peer sensitization of men, make health facilities less stigmatizing and more male-friendly, train health workers to meet men's needs, and hold discussions between health workers and community members.

**Conclusions:** In summary, pursuing couple HIV testing as a main avenue for making men more willing to test and support PMTCT for their wives, does not seem to work in its current form in this region. HIV services must be better adapted to local gender systems taking into account that incentives, health-seeking behavior and health system barriers differ between men and women.

## Background

In 2002 the World Health Organization (WHO) formulated recommendations advising couple HIV testing in settings with high HIV prevalence [1,2]. The policy guidelines are based on the assumption that couple testing would help increase spousal support for women to use prevention of mother to child transmission (PMTCT) services, create opportunities for secondary prevention by counseling both men and women about

HIV, and increase the uptake of testing and identification HIV infected persons [3-5].

In 2006, following the WHO policy, Uganda's Ministry of Health formulated PMTCT guidelines that promoted couple HIV testing [4,6]. Mother to child transmission (MTCT) accounted for 16% of new HIV infections in Uganda in 2008, despite a reported coverage of PMTCT services of 50% [7]. PMTCT is a short-term and relatively inexpensive intervention that can reduce MTCT rates to just over 1%, and therefore it is vital to find effective ways to increase women's access to and completion of PMTCT services [7].

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However, the uptake of couple HIV testing during ANC in SSA, including Uganda, has so far been very low, only 5-12% of pregnant women are HIV tested with their spouses [8-12]. Studies from SSA have shown an association between male partner involvement in their wives' ANC, couple HIV testing, and, pregnant women's likelihood of accessing and completing PMTCT services [9,10,13,14]. These associations led to the assumption that couple testing would be key for increasing male partners' involvement in PMTCT. Instead, it seems more likely that preexisting male partner involvement is what leads some men to accompany their wives to ANC and to support them during PMTCT, and it is possible that the few men who accompany their wives to ANC are not representative of most men.

Men's uptake of HIV testing is lower than women's in most low and middle-income countries since women are tested more often when pregnant, and as a consequence men also have less access to antiretroviral treatment [5,6,15,16]. In Uganda, virtually all adult men (99%) have heard of HIV, but only 11% have ever tested for HIV, while 57% of all pregnant women have been HIV tested [17-22]. The low testing rate among men in Uganda is disappointing since HIV was first acknowledged by the Ugandan government already in the late 1980's, and large-scale information campaigns about HIV and prevention, including HIV testing, have been carried out at all levels of society [17,23].

A recent study of pregnant women's experiences of the implementation of the couple HIV testing policy in the same population, revealed that many women felt subordinate to their partners and burdened by health workers' demand to bring their male partners in for HIV testing[24].

Couple HIV testing during ANC has obvious potential benefits. However, the poor uptake of couple testing and the difficulties of reaching men suggest that the current approach needs to be reevaluated. The present study examines men's own perspectives by exploring fathers' views on, and experiences of couple HIV testing in two rural Ugandan districts.

## Methods

### Study setting

The study was conducted in Iganga and Mayuge Districts, Busoga region, eastern Uganda. More than 80% of the population in the two districts lives in rural areas and only Iganga town is semi-urban. The majority of the population are subsistence farmers, but in Iganga town many are also involved in small businesses such as selling vegetables and fruits in the market (mostly women) or working as bicycle taxi drivers (only men). The literacy rate among men in the region is in line with Uganda's national rate of nearly 90%.

Approximately half of the population is Muslim and half is Christian. Polygamy is common irrespective of religion. In most families, men are the breadwinners and the decision-makers [25]. Although "zero-grazing" and "Western" norms of monogamy have been communicated through the media, and are seemingly becoming the norm, many men still adhere to the traditional practice of having several concurrent partners [23,25].

The total fertility rate is high at 6.7 and is similar to the Ugandan average. About 70% of the population lives within of 5 km from a health unit. The HIV prevalence in Busoga region is about 6.2% among women and 4.4% among men [17]. Free HIV testing, including couple HIV testing during ANC should be offered at hospitals and most health centers in the districts. The lowest level health facilities without onsite HIV testing are supposed to refer couples for testing [6]. A number of non-governmental organizations occasionally provide HIV testing through outreach activities in the communities. According to national guidelines, counseling that addresses people's concerns and fears should precede all HIV testing.

### Study participants and data collection

Study participants were fathers from both rural and semi-urban locations who had had a child in the past year. Data were collected through nine focus groups with about 10 participants each, four held in April 2008 and five held in April 2009, as well as through 13 in-depth interviews held in April 2009, until saturation was achieved. An iterative process was used whereby the data from 2008 were reviewed and preliminary analysis carried out before the next data collection. This preliminary analysis enabled the team to explore emerging themes and issues more in detail.

Participants in the 2008 FGDs were homogenous with regard to place of living (two in rural and two in semi-urban settings) and then sub-divided based on number of children (one child vs. two or more children) in order to capture views from men with similar potential ANC exposure. Both in 2008 and 2009, all FGDs included both men who had and who had not been HIV tested. FGDs were held at times and venues considered convenient by the participants, usually under a big tree in the middle of the village. Study participants were in each data collection location recruited by a Ugandan research assistant together with a local leader (local council chairperson). The two together found eligible men at peoples' homes and at places where people normally gather. Recruitment took place at different times of the day to get both those who worked outside the home and farmers working at home. The study specifics were explained to eligible men and they were invited to participate.

For the FGDs in 2009 we used the same recruitment procedures and similar inclusion criteria as in 2008 except for the criteria of the number of children, where we instead used years in stable relationship with partner (less than vs. more than five years). The in-depth interviews were conducted after the FGDs in order to explore personal experiences around HIV and HIV-testing and to follow up on issues identified in the FGDs. As with the recruitment of FGD participants the aim was to include both rural and semi-urban men who had had a child within the last year. We also sought men with a range of experiences of HIV-testing: HIV tested during ANC, HIV tested but not during ANC, and never HIV tested. Interviews were carried out at times and places that ensured privacy and that were convenient for the respondents, typically at their home or work place.

The data collection instruments were topic guides modified according to each data collection method, as well as to the type of respondents in the interviews. The topic guides comprised key areas such as views and experiences of couple HIV testing during ANC and HIV testing in general, experiences with and perceptions of ANC attendance, and factors hindering or facilitating couple testing and ANC attendance. One male and one female sociologist collected data in the local language, Lusoga. FGDs and interviews were audio-recorded, and thereafter translated and transcribed in English. A note-taker participated in the FGDs to capture the group dynamics, gestures, and emotions of participants.

The atmosphere during the FGDs was open and men seemed to enjoy discussing this topic. They were interested in knowing more and the research team often stayed after the discussion to answer questions about various issues related to HIV. Men commonly asked questions about how they could obtain condoms, how one use them, if they could use the same condom only once, and why they should be HIV tested before developing symptoms.

#### **Analysis**

Data were analyzed using latent content analysis as described by Graneheim and Lundman [26]. All through the data collection periods the author ECL was present in the field. For the first phase of data collection she joined the discussion before and after the formal FGDs, and during the second phase she and author XN observed all FGDs. FGDs were discussed in detail by the research team immediately after each session to guide subsequent FGDs, and to identify issues that should be followed up in the interviews. This initial discussion also helped establish when saturation had been reached. After data collection, ECL read all transcripts repeatedly, and written comments were made on the texts. All

authors then read selected transcripts. Within the texts meaning units (i.e. individual sentences related to a certain concept) were identified. Meaning units were then condensed and assigned codes. Initial coding was done manually on paper copies of transcripts, and thereafter handled and organized using Nvivo software 8.0. The codes were compared and grouped into categories with similar topics, which were in turn grouped into themes. The themes developed were developed based on the interpretation of underlying meaning on a higher analytical level as compared to the more descriptive categories. All steps of the analysis were discussed among the co-authors.

Triangulation in the analysis of the data was achieved by having researchers with many different backgrounds analyze the data separately (pharmacist, epidemiologist, M.D., anthropologist, sociologist). Another source of validation was through presenting the results on a feedback workshop to people living in the study area.

#### **Ethics**

Ethical approval was sought and obtained from Makerere University School of Public Health Institutional Review Board and the Uganda National Council of Science and Technology. Eligible men were informed that their participation was entirely voluntary and all signed an informed consent form when they agreed to participate in the study.

#### **Results**

We identified a number of reasons for the low uptake of couple HIV testing, including lack of understanding of why testing was important, the perceived stigmatizing nature of HIV care, and perceived rude attitudes among health workers. Most prominent, however, was men's descriptions of their marriages as fundamentally unstable and distrustful, making the idea of couple testing unappealing because of the conflicts it could lead to in marriages. Secondary prevention of HIV or partner support was not stated reasons to test. The men's answers did not differ by place of residence or age.

#### **Mistrust in marriages hinders men from accepting couple HIV testing**

During the discussions and interviews, the men often talked about the nature of their marriages. They rarely portrayed marriages built on love and understanding, instead they described relationships where mistrust was widespread, and extramarital affairs were common, especially among men. Extramarital affairs were in general tacitly accepted within a marriage, and rarely discussed between spouses. However, the ever-present suspicion, that one's partner would be unfaithful, created a pervasive atmosphere of mistrust between husbands and

wives. It was nevertheless evident that the men valued family harmony and were unwilling to do anything that could provoke outright family conflict.

The men had a generally negative view of couple HIV testing and the “promise” of couple HIV testing at ANC health facilities actually discouraged men from accompanying their wives on antenatal visits. In fact, the men saw the situation where one might receive HIV-test results in the presence of one’s spouse as a disadvantage rather than as an advantage:

*You know in most cases, we men don't like to accompany our wives because we know about this program whereby once you go with your wife, then you must be tested for HIV. So we are very worried about escorting our wives (for ANC).*

In-depth interview participant, henceforth “IDI”

*We are told that when you go for ANC, they screen you for HIV, syphilis and other diseases. So this makes one fear.*

Focus group discussant, henceforth “FGD”

Instead men felt that voluntary individual testing was preferable, because it would enable them to keep a positive test result from their wives, if they felt it necessary.

*We do not want to disclose our status to our partners; when you go for HIV testing you even never tell your wife that you went. So you and your wife test in different places. (FGD)*

Since trust and love were uncommon ingredients in a marriage, disclosure that one or the other spouse was HIV positive would not elicit supportiveness in the other spouse, men explained, but rather would risk creating a lot of arguing and could easily disturb a fragile family harmony.

*It is because we don't tell our wives the truth; you lie to her that she is the only one yet her friends see you with other women. So if we go for testing and find out that we are infected she will immediately start quarrelling since already there is no love that we show each other. (FGD)*

The ever-present possibility that either member of the couple was having an extramarital affair only made the “offer” of couple HIV testing and the risk of discordance more unappealing, as the following men explained:

*This issue is big, the root cause of all these problems is the issue of adultery, couples are not open to each other and therefore fear to discuss those things together.../(FGD)*

*It affects us negatively; for example if you have been together for 10 years and they tell you that she is infected and you are not, it causes misunderstanding in the home/.../.*

*It brings a lot of thoughts in a home, you really get strong thoughts...you start wondering where this person got the infection. You really live in total/.../You wonder a lot where she got this infection and you may even develop diseases like high blood pressure. (FGD)*

Since men were, by general agreement, the ones who were more likely to be having sexual relationships outside of the marriage, the risk of testing, getting a positive result, and having it made known to their spouses was perceived as especially threatening.

*It is because men have so many extramarital relationships. They lie to their wives that they are faithful, but actually they have many women, not wives but women with whom they have sexual relationships. So when they think about the women they have had intercourse with, they choose to rather stay in the dark without finding out their HIV status. (FGD)*

*The wife feels so bad because in everyday life women know that it is we men who are promiscuous, so she would straight away know that I got infected from the places I visit, and from that moment my wife never stays. She would say that I am going to infect her with HIV.*

Men’s portrayed tendency to deceive their wives was supported by the power structure of marriages in which men are decision-makers and have the power over their wives’ actions. Men resisted women’s efforts to influence them, including when it came to HIV-testing:

*We men have a despising heart; a woman will tell you to go to the health center with her, but when you get up in the morning you tell her not to disturb you claiming that you are going to look for money. In that way you avoid her. (FGD)*

As to why some men did go for couple HIV testing, the men we interviewed speculated that these were men who had a good relationship with their wives, and had marriages marked by mutual love, trust, and understanding.

*Few men go for testing, and only those who are close to one another get tested (together with their wife), because they encourage each other/.../*

*It depends on the way you believe/live in the home, a man may say that if you are willing to go, you go, but as for me I won't. But it should be that there is a good relationship between wife and husband, that's when she tells you to go and you go. (FGD)*

In other cases the men emphasized a sense of responsibility to their wives and families, along with love:

*To me what forces me is my responsibility. I fear to spoil my love, a problem to come and it is a result of my failure to escort my wife, so it gives me the responsibility to go with her when she starts to go for antenatal care, and they tell us, and I do what they have told us. And also because of the love, I have with her. (FGD)*

#### **Men can recite HIV testing messages but this does not induce them to test**

When speaking in the abstract about HIV testing, men recognized its importance. However, despite the ability to recite the HIV testing messages broadcasted in their communities, they did not see any reason to get tested themselves. Most of the men in the study had not been tested and only very few had been tested during ANC. Among the men who had never tested, some went so far as to agree that it would be good to get tested, but most reasoned firmly that they did not want to get tested at all.

How was it that they could recite the messages about HIV testing but not see any reason why they themselves should actually go for testing? A topic that came up in all FGDs and interviews was that men wanted more convincing arguments for why they should be tested. The men described again and again how they had been informed that they should be tested but not why it would be advantageous to identify a possible HIV infection before symptoms arise.

*I could say that people need to be informed thoroughly, rather than telling them, friends "come for blood testing, come for blood testing". But we have to sit down and teach people that a person should have his/her blood tested when he/she is still healthy (meaning without symptoms). (IDI)*

That men lacked the kind of information they needed to motivate HIV testing was further reinforced by the men's questions and curiosity around HIV-related issues in the discussions that immediately followed the interviews and FGDs.

The media, especially the radio, which was the men's main source of information about HIV, had conveyed the message that one should get tested, but the campaigns had apparently failed to motivate the men to do so. The men suggested that live information campaigns at the community level instead of frequent media messages would be a more effective strategy for getting them to test, in part because it would enable them to ask questions.

*These programs are mostly on radio, but it would be better if you organized meetings on the LC level (i.e. in the community), rather than putting programs on the radio/.../then I would come there and I will understand everything better. (IDI)*

Men also suggested that men who had been HIV tested should serve as role models, talking about their experience to other men. This strategy, men felt, would have a greater impact on their willingness to get tested than radio messages. Along the same lines, they also suggested they might be more motivated to test if men who where HIV positive came and talked to them about their lives.

*Like in our village, there is no person who has ever been ill to the extent of dying as a result of HIV/AIDS. So it is needful for you to get somebody who had suffered a lot from HIV/AIDS and you walk with him as a testimony for the people, to let them understand that this (HIV) cannot kill a person if he gets good medicine and care. (FGD)*

Interestingly, none of the respondents mentioned secondary prevention, neither to the wife nor to extramarital partners, as a motive for HIV testing. This is in line with their description of their marriages where concern for their wives' well being did not seem to dissuade many men from having unprotected sex outside the marriage.

The expressed need for more information and different kinds of information to motivate testing in the community was reinforced by the story one focus group participant told of finally being convinced to get tested:

*I had never been tested, but we were taught and we finally went for testing after 2 days. So the issue is having people taught first so as to be strong in heart in that they give you time with some examples given to you and after which you are tested, that even if you are found infected, you have a look at your sick colleague and get encouraged because I took some given days being taught and as a result I become strong and went for testing. (FGD)*

#### **Perceived deficiencies and problems in the health care system discouraged the men from testing**

The problems men raised with the health care facilities were many, but can be divided into four overarching categories: the distance and cost of getting there, organizational problems at the facilities, the perceived rudeness of many health care workers, and the perception that informal payment was required to obtain medicine and good care.

Health facilities were often far away from where the men lived, and going there was not only costly, but took time away from work and other activities:

*Now, this becomes a long distance.../in order for the person to go and have a blood test.../it is just a long distance. (IDI)*

Furthermore, when one finally got to the health facility, organizational problems made it cumbersome to actually get the care one needed. Men reported having been forced to wait an entire day for care, a heavy sacrifice for someone who needs to work to support his family:

*Even the long line at the hospital (chorus answer yes....) women can be there from 08.00 a.m. in the morning up to evening, and waste all the time you would have spent looking for posho [food]. (FGD)*

Another health system weakness pointed out as a barrier for HIV testing, was the lack of integration between HIV care and other health services. By singling out and exposing patients seeking HIV care through special clinics or opening hours, men were further discouraged from getting tested.

*People start noticing your (HIV) status, because of the specific days you go for check up. (FGD)*

While HIV care put patients too much in the lime-light, at the ANC the problem was the opposite. Men were excluded from the sessions where their wives were examined, and had to wait outside without any information about what was happening to their pregnant wives. A number of men therefore questioned the rationale for their presence during ANC.

*Now the problem with the medical staff is, you as a man, they cannot tell you what exactly they are doing inside there (during ANC), instead I can sit on the verandah and they get on with whatever check-ups and you only take your spouse back home. (IDI)  
We are not allowed to go in, it is only the Doctor and the woman, so we are left outside, helpless until the woman comes out.../. (FGD)*

Lack of drugs at the health facilities and general low confidence in the care provided further eroded men's feeling that it was worth their time to go there:

*.../most of the times when you go to the hospital they tell you that there are no drugs they tell you to go to such and such a clinic and buy the drugs.../. (FGD)*

The organizational issues the men cited at the health facilities were compounded by their experience that, in the end, payment was required to really get any medicine. Although most men knew that antiretroviral treatment (ART) was provided for free by several organizations, many feared not having access to care if they tested HIV positive. Even if the drugs were free, some noted, there were additional costs such as transport to treatment sites, leading them to argue that in reality, HIV treatment is only for the rich.

*When you join TASO (The AIDS Support Organization, which provides ART for free), you may even fail to get transport to go for medication. So such issues discourage people from going for HIV testing. (FGD)*

Even when men did accompany their wives to ANC or attend the health facilities, most men had experienced the demanding of informal payments from health care workers.

*The doctors normally demand money for "Sumbusa" literally meaning paying them for their services (all the men in the group laugh since they recognize the scenario). (FGD)*

Above and beyond waiting times, lack of drugs, costs, and the demanding for money, however, perhaps the most unpleasant aspect of accompanying their wives to ANC that men discussed was enduring the rude treatment their wives often received at the hands of some health care workers.

*Sometimes nurses abuse our wives in our presence saying, "whoever owns this one might be having problems." If a nurse abuses your wife in your presence, you can't go back to that place again. In fact going to the hospital for ANC is not easy but we just endure. In fact most times we are just forced to go the health units but it is not easy. (FGD)*

The health workers' mistreatment of the spouses made the men feel uncomfortable and embarrassed. The men's feeling of embarrassment actually seemed to be more important than the fact that women were abused.

*You may go with your wife but on reaching there and looking at the way they are treating your wife is unkind, it is not good for the man to be there. These nurses, there is a way these women are treated.../she is abused and embarrassed. So for us men, we just choose not to accompany our wives to avoid such things. (FGD)*

Some men had experienced nurses at ANC speaking disrespectfully also to them directly:

*./.../sometimes when you get there (to the ANC clinic) the nurse wants to talk to you in a dominating way just like she talks to the pregnant women. So we sometimes feel like not going there because the nurse will be rude to us yet it is not we men who are pregnant. They use harsh language, the same kind they use with women in labor, so sometimes they want to use that same harsh language with us. Yet we men are easily provoked and could even become harsher than the nurses, so you rather stay away (many participants laugh and give signals of approval). (FGD)*

Given all of the above, it is not surprising that seeking health care in general seemed to be rare among these men.

*./.../but they will get a few patients because there are people who have take even 40 years without going to the hospital so it's so hard because if someone buys Panadol (pain killers) and feels better... (FGD)*

Respondents' reasons for not accepting couple HIV testing, and factors that would make them accept couple testing, are summarized in Table 1.

## Discussion

According to our study, couple HIV testing during ANC is unpopular among rural Ugandan men primarily

**Table 1 The men's reasons for not accepting couple HIV testing, and suggestions for how to increase men's acceptance of couple HIV testing**

A. The men's reasons for not accepting couple HIV testing
<ul style="list-style-type: none"><li>• Worries and fear related to relationship problems</li><li>• Lack of fully understanding of why they should be tested</li><li>• Distance to health facilities and waiting time</li><li>• HIV is treated as a special disease at health facilities and this is stigmatizing</li><li>• Health facilities are not male friendly</li><li>• Health workers treat the men and their wives badly</li></ul>
B. Suggestions for how to increase men's acceptance of couple HIV testing
<ul style="list-style-type: none"><li>• Community based information campaigns</li><li>• Peer influence and role models</li><li>• Avoid treating HIV as a special disease at health facilities</li><li>• Make HIV testing easier through:<ul style="list-style-type: none"><li>a. More flexible opening hours for testing at health facilities</li><li>b. Provide testing from non-governmental organizations</li><li>c. Provision of transport to testing site</li><li>d. Provision of home-based testing</li></ul></li></ul>

because they fear relationship conflicts in case of HIV sero-discordance. The men lack incentives to be tested, partner support, or secondary prevention of HIV is not considered as important reasons for testing. Furthermore, the men feel unwelcomed and disrespected at antenatal care facilities.

Set against the background of the actual marriage relationships described by men in our study, the widely implemented policy of couple HIV-testing appears to be based on an unrealistic view of the nature of marriage in rural Uganda. The "promise" of couple HIV testing seemed to make the men less likely, not more likely, to test. The risk of one partner turning up infected and the other not, could easily create suspicion that one or the other partner had been unfaithful, and was thought to threaten marriage stability and family harmony. Previous research in Uganda has shown that marriages can also be easily destabilized by fertility issues such as lack of a male child [27].

On a theoretical level, our study supports previous research that has pointed out how traditional gender norms in themselves can constitute significant barriers to health care seeking among men across the world [28]. The norm that men should not show weakness, for example by seeking health care, dictates against men being HIV tested, especially alongside their wives [28]. Social structures, cultural norms, and implicitly gender-biased health systems stand in complex relationships to one another, and influence health outcomes for men and women differently [29]. Former research has shown that HIV-infected men find it more difficult than HIV-infected women do to disclose their infection directly to their spouse, and that men prefer to use a third party as a mediator [30]. The results from our study provide a robust example of gender as a social determinant of health since men are expected to enter the female domain of the ANC clinic to be tested and counseled alongside their wives. The couple HIV-testing policy runs up against the more common pattern in Uganda of a clear division between male and female domains [25].

Another way in which the interaction of gender and health systems plays out in our research is in the rhetoric of couple HIV testing. The ANC is perceived as largely catering to women, failing to take men's needs into account. The couple HIV testing policy mimics the discourse common when discussing male involvement in sexual and reproductive health programs in general, where men's involvement is introduced to enable women to access health care services, rather than for the men's own good [31-35].

According to men in our study, and also shown in other research, separating HIV testing, care and treatment from other kinds of health care only increases the stigma of living with HIV [36]. Integrating HIV care

into general health care would not only make testing, monitoring and ART provision more sustainable, but would also reduce the stigma that research has already related to the vertical organization of HIV care [37]. Alternative HIV testing methods such as mobile clinics, work-place testing opportunities, and door-to-door testing, suggested by our study participants, have also been shown to increase uptake of services and reduce stigma [38,39]. A further factor in men's reluctance to go for testing was the perceived rude behavior among health workers', a factor also found in studies in Tanzania [40,41]. Therefore interventions targeting health workers also seem to be crucial.

The WHO recommends that the implementation of policies encouraging male involvement during ANC should always be accompanied by awareness campaigns in the community, to help men - and women- to understand why the policies are put in place[42]. The policy for couple HIV testing might have created awareness about couple testing among these Ugandan men, but the policy did not make them act and get tested. The men pointed out, for example, that the mass media were their main source of information about HIV, but that they would prefer live sensitization programs in their communities. Several studies in Uganda, and elsewhere in SSA, have found that both sexual health awareness as well as increased testing, more use of condoms, more use of family planning, and less sexual risk-taking, all can be successfully achieved by "live" community, and peer-to-peer interventions [43-45]. One study found that exposure to radio programs about family planning in Uganda did not increase actual contraception except for individuals who also received "live" interpersonal communication[44]. Thus, one-way communication through media can create awareness, but live, personal communication may be needed to deepen men's understanding of the benefits associated with HIV testing and make them act.

The men in our study had several suggestions for how to improve the current couple HIV testing policy: peer sensitization of men, make health facilities less stigmatizing and more male-friendly, train health workers to meet men's needs, and hold discussions between health workers and community members.

A potential weakness of our study was that a female carried out the interviews and some of the FGDs. However, when comparing FGD responses, no differences attributable to the moderator's gender were found. Instead, the men talked very freely and often asked sensitive questions about safe sex, discordance and condom use. Since many answers were neither expected nor socially desirable, we believe that this study offers a fair description of actual attitudes and practices in this population.

## Conclusion

Pursuing couple HIV testing as a main avenue for getting men to be tested and supportive of PMTCT for their wives, seems not to work in its current form. In order to implement a successful, culturally adapted couple testing policy in this setting, our research suggests that gender differences in health-seeking behavior, health systems' different effects on men and women, and gender structures in society at large must be taken into account.

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## Authors' contributions

ECL coordinated the study. ECL, AT, XN and AME designed, planned the data study and developed the data collection tools. ECL, SN, and XN collected the data. All authors took part in data analysis. ECL and XN drafted the first manuscript. All authors read and approved the final manuscript.

## Competing interests

The authors declare that they have no competing interests.

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# Missed opportunities: Barriers to HIV testing during pregnancy from a population based cohort study in rural Uganda

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## Abstract

The aim of this study was to assess population-level HIV-testing uptake among pregnant Ugandan women, key for access to prevention-of mother to child transmission (PMTCT) services, and to identify risk factors for not being tested for HIV,

The study was conducted May 2008- May 2010 in the Iganga/Mayuge Health and Demographic Surveillance Site (HDSS), Eastern rural Uganda, during regular surveillance of 68,000 individuals. All pregnant women identified to be pregnant May-July 2008 (n=881) were included, interviewed about pregnancy-related issues and linked to the HDSS database for socio-demographic data. Women were followed-up via antenatal care (ANC) register reviews at the health facilities to collect data related to ANC services received, including HIV testing. Adjusted relative risk (aRR), and 95% confidence intervals (CI) for not being HIV tested were calculated using multivariable binomial regression among the 544 women who remained after follow up and record review.

Despite high ANC attendance (96%), the coverage of HIV testing was 64%. Only 6% of pregnant women who sought ANC at a facility without HIV testing services were tested for HIV and only an additional 14% received any type of counseling regarding HIV. At ANC facilities with onsite HIV testing, 85% were tested. Less than 13% of the women reported ever being accompanied by their male partners to ANC, and only 4% of the women tested had been couple tested for HIV. Living more than three kilometers away from a health facility with HIV testing services was associated with not being tested both among the poorest (aRR,CI; 1.44,1.02-2.04) and the least poor women (aRR,CI;1.72,1.12-2.63), but the poorest generally lived farther away from HIV testing services (t-test p<0.01).

In summary, the lack of onsite HIV testing services and distant ANC facilities leads to missed opportunities for PMTCT in rural Uganda, especially for the poorest women. Referral systems for HIV testing need to be improved and testing should also be expanded to include

lower level health facilities through targeted capacity strengthening. This in order to ensure that the policy of HIV testing during pregnancy is implemented more effectively and that testing is available and accessible for all.

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**Keywords:** HIV testing, prevention of mother-to-child transmission, coverage, pregnancy, Uganda, population-based, health and demographic surveillance site (HDSS)

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## Introduction

An estimated 17,000 children in Uganda were infected with HIV through mother-to-child transmission (MTCT) in 2009, despite a stable HIV prevalence of 7.5% among women of reproductive age (15-49 years) and high (94%) uptake of antenatal care (ANC)[1, 2]. HIV testing is the first and crucial step in prevention of MTCT (PMTCT); however, only 63% of pregnant Ugandan women were tested in 2010 [3]. A reduction in MTCT rate from roughly 40% to around 1% is possible through the provision of prophylactic therapy with three antiretroviral medicines (ARVs) administered to HIV infected women before, during and after delivery, cesarean section, and provision of prophylactic ARVs to newborns and replacement infant feeding[4]. In low-income countries with limited access to combination ARV regimens or the capacity to provide cesarean section and replacement feeding, the rate of MTCT can still be reduced to around 5%, provided that women are tested, enrolled in and complete the PMTCT program [5-7].

Long waiting times at health facilities and lack of comprehensive information about HIV and PMTCT, spousal disapproval and stigma, are generally suggested as barriers to the uptake and completion of PMTCT [8-11]. The World Health Organization (WHO) recommends that countries with generalized HIV epidemics implement opt-out or provider-initiated HIV testing during ANC to increase likelihood of HIV testing among pregnant women [12]. Health facility-based studies have indicated an increase in HIV testing rates during pregnancy and thus support utilization of these recommendations [13-18]. Accordingly, the Ugandan national policy guidelines for PMTCT recommends that all pregnant women are counseled and tested for HIV during ANC, provided they do not actively opt-out, or referred for testing if onsite services are not available [19]. Additionally, but so far with limited success in practice, joint couple HIV testing including the pregnant woman and her spouse has also been introduced in Uganda, hoping to expand the coverage of HIV testing and to reduce barriers to accessing PMTCT services [20-24].

Despite these efforts at the national level, evidence on the effectiveness of policy implementation at population-level is still lacking. This study examines barriers to HIV testing in the context of the national opt-out HIV testing policy and assesses population-based coverage of HIV testing during pregnancy in a prospective cohort of pregnant women identified through a health and demographic surveillance site in Uganda.

## Methods

### Study setting

This population-based cohort study was conducted between May 2008 and May 2010 at the Iganga/Mayuge Health & Demographic Surveillance Site (HDSS), a designated area across parts of the Iganga and Mayuge districts in eastern Uganda. The HDSS is predominantly rural, but also partly semi-urban (Iganga Town). The main source of income in the area is subsistence farming[25]. In 2008, the HDSS population was 68,000 individuals among 12,000 households. HDSS activities include data collection on births, deaths, pregnancies, and migration three times per year and have been described elsewhere [26]. Add-on surveys for special studies, such as part of this study, are also conducted between or during regular data collection rounds.

The estimated HIV prevalence among Busoga women aged 15-49 years is 5.6%, which, for this regionally dominant ethnic group, is lower than the Ugandan average for women of reproductive age (7.5%)[27]. Ugandan health facilities range from the lowest level II health centres (midwife available) to hospital level (level V). ANC is provided at all levels and should include a physical examination, the provision of necessary medicines, health education, and HIV counseling and testing, or HIV testing referral. The Ugandan national guidelines recommend at least four ANC visits per pregnancy[28]. In the HDSS area, 13 health facilities provided ANC, and one-third of these offered PMTCT services, a proportion corresponding to the overall accessibility to PMTCT services across the two districts. Very few other options for HIV testing existed in this area at the

time of study and to our knowledge, no home-based HIV testing or out-reach testing was carried out.

At the time of enrolment for this study, WHO recommended the use of dual ARV prophylaxis of zidovudine (AZT) and lamivudine (3TC) from pregnancy week 28[29]. The ARV regimen used at lower level health facilities in the two districts was single dose nevirapine (sd-NVP), while the hospital provided either sd-NVP or the dual ARV regimen, or triple ARVs for women eligible for that for her own health. Most of the HIV-infected women in this setting received a dual combination ARV prophylaxis.

### **Study design and data collection**

Ethical approval was obtained from Makerere University School of Public Health Institutional Review Board and the Uganda National Council for Science and Technology (Ref.nr. HDREC, 052). The HDSS setup was used to determine the population coverage of HIV testing. All women in the 12 000 households who were pregnant (n=881) at the time of study enrollment May-July 2008 were identified through self-reports as part of routine data collection on pregnancies in the HDSS. Within 2-6 weeks after this screening, field-assistants visited these women at their homes and after describing the purpose and specifics of study, invited the women to participate in an interview. All women agreed. Written informed consent was obtained from all participants at this point of enrolment, which included consent to link women's interview data to health facility and core HDSS data.

Four field-assistants (females due to the sensitive nature of some questions related to women's health and pregnancy) were trained for three days. The training focused on how to ask questions about pregnancy and HIV and how to use the questionnaire, which included questions about personal characteristics, ANC attendance and care received. The questionnaire was translated into the local language, Lusoga, piloted and adjusted to clarify some minor issues. During data collection, a field-supervisor held daily meetings with the field-assistants to deal with any problems arising.

At enrolment, 412 (47%) of the 881 women had not yet attended ANC during the current pregnancy, most of them because they were in an early gestational stage. These 412 women were therefore followed up for second interview after their expected delivery (interviewed May-August 2009) to capture any information regarding ANC attendance. The follow up interviews covered the same questions as those put to the women who had sought ANC already at enrolment in 2008. Out of these 412 women, 279 (68%) could be followed up and of these 41 women had not sought ANC at all (31 because they had had a miscarriage and 10 declined to give any reason). The 133 women that could not be followed up had either moved or were otherwise unavailable (some were not at home during any of the three study visits) and therefore excluded from the study. Hence, a total of 707 women (881-41-133) were followed up through ANC record reviews at the health facilities where they had sought ANC, to collect data on type of ANC received, including HIV testing. The first author and two trained field-assistants with ANC experience carried out the record reviews (in February- May 2010).

Identification was confirmed by the use of available HDSS information on name, age, expected time of delivery, home village and name of spouse. Interview and record data were thereafter linked to core HDSS socio-demographic data and distances to health facilities for each respondent.

### **Data**

Data were double entered in separate entry forms in SPSS software[30], merged using STATA software[31], and linked to demographic data from the HDSS database using the women's HDSS identity numbers.

The outcome under study was: "not being tested for HIV during current pregnancy" (obtained from record reviews). Based on existing literature, various potential risk factors for not being tested for HIV were then identified, and preliminarily divided: (i) socio-demographic characteristics (ii) health-seeking behavior (iii) health facility-related factors and (iv) distance to health facilities (GPS data).

Socio-demographic characteristics included age, occupation, household size, number of living children, spousal support and socioeconomic status (SES). The HDSS keeps asset-based SES data on each household as wealth quartiles generated from principal components analysis [32, 33] and asset variables identified by the Uganda Bureau of Statistics, which have been described in detail elsewhere[26]. We first examined wealth quartiles and the two lowest quartiles were then grouped into “poorest women”, and the highest two into “least poor women”, due to similar associations with the main outcome for these categories. Age was grouped into <21, 21-34, and >34 years, since young and older women would have different childbirth experiences. Occupation was categorized into ‘farmers versus other’ and number of living children into 0-4 children versus >4, based on a median number of 4 children.

Data on health-seeking behavior were defined as adherence to national guidelines for ANC, type of facility where women sought ANC, whether anyone advised the woman to seek ANC. Seeking ANC late was defined as attending ANC after the sixth gestational month.

The shortest distance from home to the nearest ANC health facility and to the nearest facility with onsite HIV testing, was estimated using GPS coordinates [34]. Distance was first categorized into three equally large groups; 0-1; 2-3, and >3 kilometers, but the first two categories were later merged when analyzing “distance to nearest facility with onsite HIV testing”, due to their similar associations with the main outcome.

During an initial descriptive analysis, chi-square statistics were used to compare the relationship between the risk factors and not being tested for HIV). Though we grouped the factors as described above, their association with the outcome was independently assessed, first by calculating bivariate relative risk estimates, using binomial regression models with link log. Independent variables with a p-value <0.25 in bivariate analysis were tested in the multivariable model. By using a backward selection procedure we came up with a final multivariable model that included SES, num-

ber of children and distance to a health facility with onsite HIV testing. In the multivariable models variables were considered statistically significant if the adjusted p-value was <0.05.

The initial analysis showed a statistically significant interaction between the variables “number of children” and SES for the main outcome. Therefore we stratified the data analysis by SES to account for effect modification. The association between the distance to a health facility with vs. without HIV testing services (t-test), for the poorest vs. the least poor, differed by SES. We therefore thought it would be interesting to show stratified analysis also for this variables even though the interaction was not as statistically significant the interaction between SES and number of children.

## Results

### Uptake of ANC and HIV testing

Figures 1 and 2 depict the flow of study participants and show the percentages of those women who sought ANC and received HIV testing. Of the 707 women who reported they sought ANC 25 (4%) attended ANC from a traditional birth attendant (TBA) or at a drug-shop, hereinafter termed “informal facility”, hence 682 women (96%) sought ANC at least once. Four hundred and twenty-six (78%) out of 682 received ANC at a health facility that offered onsite HIV testing, while 118 women (22%) attended a health facility that did not offer onsite HIV testing. The majority (n=544; 80%) of the women reporting ANC visits could also be traced back to the ANC registers. Overall, only 64% (371/579) of the women were HIV tested during the current pregnancy (the denominator of 579 includes 544 found in registers +10 who did not seek any ANC at all+25 who sought ANC at informal facilities, Fig 1).

### ANC and HIV testing by health facility

Figure 3 shows the proportion of women tested for HIV by the type of health facility. The majority of the women who attended a health facility that offered onsite HIV testing, 85%, were counseled and HIV tested. However, only 20% vs.

17% of women who attended health facilities that did not have HIV testing onsite vs. informal facilities, respectively, were counseled about or counseled and tested for HIV. Only 6% of pregnant women who initially went for ANC at a

health facility that did not have onsite HIV testing were HIV tested, either because they were not referred by the staff or because they had not followed-up on the recommendation to test elsewhere.

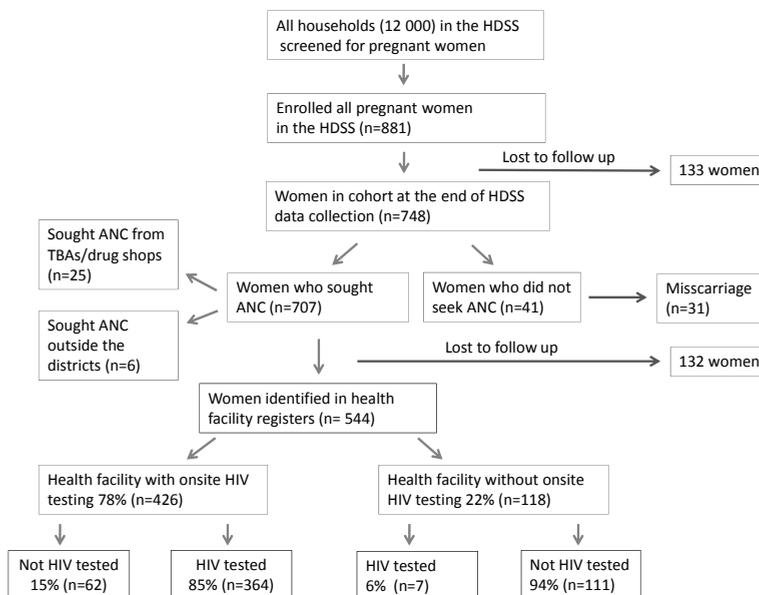


Figure 1. Flow of study participants: pregnant women enrolled, seeking ANC and being tested for HIV

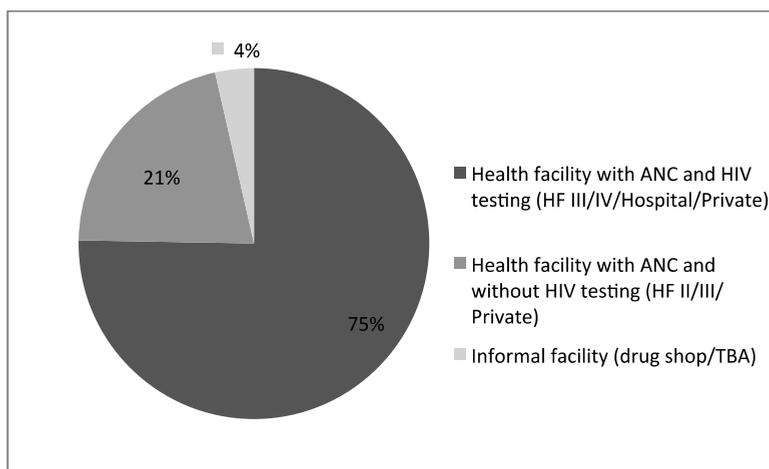


Figure 2. Type of health facility where the women sought ANC

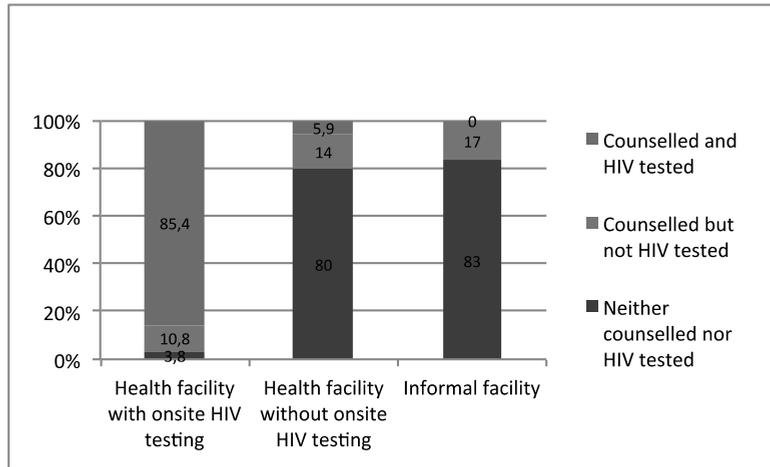


Figure 2. Type of health facility where the women sought ANC

### Sample characteristics and health-seeking behavior and distances to health facilities

Table 1 presents the sample characteristics and health-seeking behaviors among the women. About half of the women who sought ANC did so at hospital-level (50.1%). Although 96% did at least one ANC visit, only 28% fulfilled the three ANC visits. Using GPS coordinates, about one-third (30.7%) had to travel four kilometers or more to access a facility that offered onsite HIV testing. Very few male partners attended ANC with their wives (12.7%). The record reviews per-

formed at the ANC health facilities that provided HIV testing showed that the uptake of couple testing was only 4% among women who tested for HIV.

Women who had not been HIV tested had an average distance of 3.5 kilometers to the nearest testing facility, compared to 2.8 kilometers among women who had been tested (t-test,  $p < 0.01$ ).

Moreover, the poorest women had 3.5 kilometers to a health facility with testing services as compared to 2.7 km for the least poor (t-test,  $p < 0.01$ )

Table 1. Socio-demographic factors, health-seeking behavior and likelihood of not testing for HIV during pregnancy among women seeking ANC (n=707)

Characteristic	All women, n (%)	Not tested for HIV, n* (%)	Tested for HIV, n* (%)	Crude RR** (95%CI)
<b>Demographic information</b>	<b>Column %</b>	<b>Row %</b>	<b>Row %</b>	
	<b>Median: 25.5</b>	<b>Median: 25.7</b>	<b>Median: 24.7</b>	
	<b>Range: 14-50</b>			
<b>Age 14-20</b>	140 (19.2)	34 (34.7)	64 (65.3)	
<b>Age 21-34</b>	510 (70.1)	115 (31.8)	247 (68.2)	
<b>Age 35+</b>	78 (10.7)	18 (39.1)	28(60.9)	
<b>Number of people living in the household</b>				
<b>1-5</b>	199 (30.9)	69 (32.9)	141 (67.1)	
<b>6-9</b>	324 (50.2)	53 (35.0)	96 (64.4)	
<b>10+</b>	122 (18.9)	29 (35.4)	53 (64.6)	
<b>Occupation</b>				
<b>Subsistent farmer</b>	511 (73.0)	146 (37.2)	247 (62.8)	1
<b>All other</b>	189 (27.0)	27 (17.9)	124 (82.1)	2.08 (1.36-3.18)

Characteristic	All women, n (%)	Not tested for HIV, n* (%)	Tested for HIV, n* (%)	Crude RR** (95%CI)
<b>Demographic information</b>	<b>Column %</b>	<b>Row %</b>	<b>Row %</b>	
	<b>Median: 25.5 Range: 14-50</b>	<b>Median: 25.7</b>	<b>Median: 24.7</b>	
<b>Socio-economic status<sup>a</sup></b>				
Least poor	283 (49.7)	57 (29.2)	138 (70.8)	1
Poorest	287 (50.3)	81 (40.7)	118 (59.3)	1.39 (1.05-1.84)
<b>Number of living children</b>	Median 4.0 Range: 1-11			
0-4	433 (80.2)	122 (28.2)	311 (71.8)	1
5+	107 (19.8)	47 (43.9)	60 (56.1)	1.56 (1.21-2.00)
<b>Mean of transport to ANC</b>				
By foot	304 (43.0)	98 (42.1)	135 (57.9)	
Other means	403 (57.0)	75 (24.1)	236 (75.9)	
<b>Travel time from home to ANC health facility</b>				
< 1 hr	320 (45.3)	88 (34.8)	165 (65.2)	
1-2 hrs	363 (51.3)	81 (29.5)	194 (70.6)	
3-4 hrs	23 (3.3)	4 (26.7)	11 (73.3)	
5-12 hrs	1 (0.1)	0	1 (100)	
<b>Partner attended ANC during current pregnancy</b>				
Yes	90 (12.7)	15 (23.1)	50 (76.9)	1.22 (0.74-2.01)
No	617 (87.3)	158 (33.0)	321 (67.0)	1
<b>Health-seeking behavior</b>				
<b>Person advising woman to seek ANC</b>				
Nobody	587 (83.0)	139 (30.3)	320 (69.7)	1
Spouse	62 (8.8)	18 (40.9)	26 (59.1)	1.35 (0.94-1.94)
Mother/ Mother in-law	43 (6.1)	8 (26.7)	22 (73.3)	0.88 (0.47-1.66)
Other	15 (2.1)	8 (72.7)	3 (27.3)	2.40 (1.60-3.59)
<b>Number of ANC visits during current pregnancy</b>	Median: 2 Range: 1-6			
1	206 (38.1)	56 (27.2)	150 (72.8)	1
2	181 (33.4)	60 (33.1)	121 (66.9)	1.22 (0.90-1.66)
3+	154 (28.5)	54 (35.1)	100 (64.9)	1.29 (0.94-1.76)
<b>Seeking ANC the first time after month 6</b>				
Yes	219 (44.2)	67 (30.6)	152 (69.4)	1
No	276 (55.8)	67 (24.3)	209 (75.7)	1.39 (1.00-1.94)
<b>Level of care where ANC was sought</b>				
Hospital	350 (50.1)	33 (12.1)	239 (87.9)	1
Level III/ Level IV	184 (26.3)	49 (32.0)	104 (68.0)	2.64 (1.71-4.06)
Private clinic/Level II	165 (23.6)	91 (76.5)	28 (23.5)	6.30 (4.24-9.37)
<b>Seeking ANC from a health facility without onsite HIV testing services</b>				
Yes	173 (24.7)	111 (94.1)	7 (5.9)	6.46 (5.16-8.10)
No	527 (75.3)	62 (14.6)	364 (85.4)	1

Characteristic	All women, n (%)	Not tested for HIV, n* (%)	Tested for HIV, n* (%)	Crude RR** (95%CI)
	Column %	Row %	Row %	
	Median: 25.5 Range: 14-50	Median: 25.7	Median: 24.7	
<b>Amount paid for ANC (USD)</b>				
0	253 (31.2)	42 (39.2)	65 (60.8)	
0.1-1	340 (41.9)	86 (31.2)	190 (68.8)	
1-max (11.7)	219 (27.0)	45 (27.9)	116 (72.1)	
<b>Received counseling for HIV testing (self-reported)</b>				
Yes	484 (68.6)	60 (15.2)	334 (84.8)	
No	222 (31.4)	113 (75.3)	37 (24.7)	
<b>Ever HIV tested before this pregnancy (n=812)</b>				
Yes	569 (70.1)	75 (17.6)	351 (82.4)	
No	243 (29.9)	98 (83.0)	20 (17.0)	
<b>Distance</b>				
<b>Distance to health facility where woman sought ANC</b>	Range: 0-4 km			
0-1 km	216 (37.2)	60 (33.2)	121 (66.8)	1.65 (1.13-2.41)
2-3 km	171 (29.4)	27 (19.7)	110 (80.3)	0.887 (0.63-1.26)
4+ km	194 (33.4)	39 (26.9)	106 (73.1)	1
<b>Distance to nearest health facility with HIV testing</b>	Range: 0.12-6.7 km			
0-3 km	461 (69.3)	94(25.9)	269 (74.1)	1
4+ km	204 (30.7)	69 (45.4)	83 (54.6)	2.57 (1.36-4.86)

<sup>a</sup> Calculated using principle component analysis on household assets divided into two groups<sup>b</sup> Adjusting for age  
\*n=544 with information on HIV testing \*\* Crude RRs shown only for variables with p-value <0.25

### Risk factors for not being tested for HIV during pregnancy

The bivariate analysis identified several risk factors ( $p < 0.25$ ) for not being tested for HIV: being a farmer, being poor, having more than four living children, living more than 3 kilometers from a facility with onsite HIV testing, not seeking ANC at one's own initiative, seeking ANC late (first visit later than gestational month six) and, somewhat surprisingly but inversely related to seeking ANC late (Table 1). Table 1 also presents other potential risk factors that were analyzed but that was shown to be non-significant ( $p > 0.25$ ) and not analyzed in the multivariable model.

The risk factors ( $p < 0.25$ ) were then analyzed in a multivariable model using a back-

wards selection procedure. The multivariable analysis showed that when stratifying by income level, the only significant risk factor for not being tested for HIV among the poorest women was living more than three kilometers away from a health facility with testing services (aRR 1.44, 95% CI 1.02-2.04), adjusting for age. Among the least poor, having more than four children (aRR 1.77, 95% CI 1.00-3.16), and living more than three kilometers from a health facility with testing services (aRR 1.72, 95% CI 1.12-2.63), came out significant after adjusting for age.

For the women who attended ANC at a facility without HIV testing, but who reported that they had been counseled for HIV testing, 13% were HIV tested, as compared to

4% among women who said they had not been counseled.

## Discussion

This population-based study from two rural Ugandan districts found that the uptake of HIV testing among pregnant women was 64%, i.e. very similar to the WHO 2010 estimate of 63% testing coverage at national level [3]. The study also provides further insight into why less than two-thirds of pregnant women ever pass the key entry-point to access PMTCT. Apparently, non-referral for HIV testing from more distant health facilities that lack HIV testing onsite poses a major bottleneck for increased PMTCT coverage, especially for the poorest women and despite higher than national average levels of ANC attendance in this setting 96% vs. 94%[2].

The opt-out testing policy seems to work fairly well in facilities where HIV testing is available onsite since 85% of the women who attended such facilities were tested. This finding is also supported by previous research[37]. However, very few women, only 6% who attended ANC at health facilities without testing onsite, were referred or carried out referral for testing. Moreover, only 20% of the women seeking ANC at facilities without testing had been counseled about or counseled and tested for HIV; and yet, the Ugandan PMTCT guidelines state that all pregnant women should be counseled[19]. This finding is consistent with a recent qualitative study conducted from the same area which suggested inadequate HIV counseling and a lack of testing referral from this type of facility[10]. Our analysis further reports that male partner support was low, only 13% of the pregnant women reported being accompanied to the ANC facility by their spouse, and 4% of the women had had couple HIV testing.

Previous findings from the same setting suggest a combination of health system failures and traditional gender structures as im-

portant barriers to male partner involvement [11, 34]. Firstly, men are recruited for couple HIV testing through their pregnant spouse who are told by the midwife to fulfill the challenging, and often impossible task to convince the male family decision-maker to go for couple testing[34], especially for women in unstable relationships. Secondly, men are less likely in general to seek any type of health care and especially ANC, which is viewed as a female domain [11]. For more successful policy-implementation and involvement of male partners in ANC and PMTCT, knowledge about local gender structures are needed, including a direct targeting of men at their own conditions.

Poverty has also previously been reported as an important barrier to PMTCT services in Uganda [41]. Thus, although inequity in access to health care has improved dramatically since the 1970s, when it was acknowledged at global level, much remains to be done in terms of poor people's right to basic health care and before universal access could become more realistic [36, 40].

The increased risk for not being HIV tested among women with many children corresponds to a previous finding in the same setting indicating that women who are tested during a previous pregnancy feel less motivated to test again[38]. Nevertheless, failure to test for HIV during all pregnancies could have important implications for MTCT in Uganda, which has one of the highest fertility rates in the world (6.7) as well as a high prevalence of concurrent partnerships[39]. Our population-based findings differ from those from a hospital-based study, also in eastern Uganda, where having more children was associated with a positive attitude towards testing during ANC [33]. Having many children might also be confounded by educational level or staff attitudes towards the benefit of PMTCT, factors not analyzed here.

The known inverse relationship between distance to a health facility and health care

seeking played an important role also for HIV-testing in this setting where a previous study also showed that living three kilometers or more from a health facility decreased the likelihood of seeking facility care for febrile children [40]. The Ugandan National Health Policy recommends that all people should have a maximum distance of five kilometers to a health facility, and reducing that distance to three kilometers, the cutoff barrier identified in our study for seeking adequate care, appears unrealistic [41]. Thus, to improve effective PMTCT coverage in Uganda, referral systems for HIV testing must improve, in parallel with an expansion of onsite and/or out-reach HIV testing to lower level facilities as part of routine care. Scaled-up out-reach testing may be preferable due to human resource shortages in Uganda and the risk of insufficient quality of counseling as PMTCT services are expanded to lower levels of care with inadequately trained staff [42]. However, the feasibility of testing at lower-level facilities may be enhanced if accompanied by community-based peer-counseling [43].

The low coverage of HIV testing and the above discussion clearly illustrates the Millennium Development Goal Countdown discourse on the importance of well-functioning health systems to successfully implement large-scale interventions, such as PMTCT [36].

None of the eligible women declined participation, possibly due to the fact that the HDSS collect data regularly, making women used to responding to questions and possibly more keen to participate in research. The women lost to follow-up did not differ significantly from the responders in terms of socio-demographic baseline information. The loss of respondents at health facility level was due to random mistakes by the midwives and evenly distributed among the facilities, thus should not have biased the results. For the record reviews we used the HDSS information described in the method section and when uncertain about identification, the woman

was excluded. We relied on register data for some variables, and must therefore contend with the possibility that what is defined as lacking in receipt of certain care aspects, might in some cases be due to mis- or unregistered information. However, most registers appeared to be completed appropriately for the selected variables, especially for HIV testing.

### **Conclusion**

High ANC attendance, yet low HIV testing coverage, demonstrates missed opportunities to enroll women into PMTCT services. This study shows, at population-level, that lack of onsite HIV testing services, poverty, failure to adjust to existing gender norms and distance to health facilities are clear barriers to effective policy implementation and high HIV testing uptake. The health system in terms of policies, funds, and human resources, needs to be mobilized to ensure that HIV testing is available and accessible for all pregnant women during ANC. Without increasing the uptake of this first and crucial component of the PMTCT program, the UNAIDS call for “Virtual elimination of HIV infections due to MTCT” is unachievable.

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# Prevention of mother-to-child transmission of HIV in rural Uganda

## Estimated effectiveness and potential impact of scaling-up service delivery

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### Abstract:

*Objective:* To estimate the effectiveness of a prevention of mother-to-child transmission (PMTCT) programme, and to estimate the effect on child HIV infections when assuming an increase in coverage of individual PMTCT components.

*Design:* Population-based data combined with mother-to-child transmission (MTCT) rates in a decision tree analysis.

*Methods:* Coverage on individual PMTCT programme components was derived from a cohort of 881 pregnant women in the Iganga-Mayuge Health and Demographic Surveillance Site, rural Uganda. The population-based data on the proportion of women covered by each of the PMTCT programme components were combined with known MTCT rates in a decision tree analysis. The number of children infected with HIV at birth and at six months post-partum in the Iganga and Mayuge districts was estimated for the base-case PMTCT coverage, and for scenarios with an assumed increase in coverage of individual PMTCT components.

*Results:* With the base-case PMTCT coverage, the estimated transmission rates were 13 % at birth and 16% or 21% at six months, depending on the woman's immune status. Increasing HIV testing uptake to 100% was estimated to reduce MTCT rates by 28% at birth and 24% at six months, while a combination of 100% uptake of ANC, HIV testing and triple-ARVs was estimated to reduce MTCT rates by 85% at birth and 80% at six month, as compared to the base-case coverage.

*Conclusion:* By increasing HIV testing coverage to 100%, MTCT rates could be reduced with almost one third, and would be the single most effective PMTCT intervention. However, only combined PMTCT interventions together with perfect adherence would reduce MTCT rates to levels below the target of less than 5%.

### Keywords

prevention of mother-to-child transmission (PMTCT), effectiveness, Uganda, population-based, health and demographic surveillance site (HDSS), HIV testing

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## Introduction

The reported coverage of antiretroviral prophylactic therapy for prevention of mother-to-child transmission (PMTCT) services has increased in the sub-Saharan African region in recent years, but was still limited to 60% in 2010.[1] The estimated coverage of PMTCT services in many low-income countries however are subject to overestimations since they only consider enrolment into the programmes, but does not include whether the individual PMTCT components are fulfilled or not.[2] PMTCT is a complex intervention and built on sequential interventions taking place in order to reduce mother-to-child transmission (MTCT) of HIV,

starting with antenatal care (ANC), HIV testing, and ending with antiretroviral medicines (ARVs), and breast feeding advice.[3] Without any intervention, MTCT is 35-40% but may be brought down to around 1% in high-income settings with optimal resources available, and has been reported at 5% in trial settings in low- and middle-income countries.[4-6] However, health systems' shortcomings, such as poor referral systems for HIV testing, inadequate PMTCT counseling, and dropouts from the programme, hamper the effectiveness of PMTCT services and lead to HIV infections among children that could have been prevented.[7-9] Barker et al. have modelled that an 80% uptake in each of the PMTCT programme-components of: ANC access, HIV- and CD4 testing, and ARV prophylaxis, would translate into a situation where only 51% of women in need in the end would receive ARV prophylaxis.[8]

In Uganda, the estimated proportion of HIV positive pregnant women that receive any kind of ARVs for PMTCT has increased from 34% in 2007 to 53% in 2009.[2, 10] Most estimates, as well as research on coverage, and effectiveness of PMTCT programmes, like the Barker study, use national, aggregated data, or are health facility-based.[8, 11-13] Hence, the actual effectiveness of PMTCT programmes at population level has not been assessed.

This study is based on a population-based cohort of pregnant women recruited in a Health and Demographic Surveillance Site (HDSS) in rural Uganda. The aim of the study is to estimate the number of children infected with HIV at birth, and at six months post-partum in a district population, by using recent empirical cohort data on uptake of PMTCT programme components in combination with the latest data available on MTCT rates. Further, we modelled different scenarios assuming increased coverage of individual PMTCT programme components, in order to estimate the impact on HIV infections among children for each scenario.

## Methods

### Study setting and data collection

The empirical data on PMTCT programme coverage derives from a population-based cohort study carried out between 2008 and 2010 in the Iganga-Mayuge HDSS in rural Uganda. Data were collected on ANC attendance, HIV testing, ARV prophylaxis, type of ARV prophylaxis provided to the mother and mode of infant feeding, and dropout at each step was analysed.

The Iganga-Mayuge HDSS population consists of an estimated 68,000 individuals living in 12,000 households that are followed-up regularly and data on vital events such as births, deaths, and migration are collected. The HDSS area is predominantly rural (80%), apart from Iganga town which is semi-urban, and the main source of income is subsistence farming. The adult HIV prevalence in Eastern Uganda is estimated at 5%.[14] ANC is available at health facilities at all levels with an estimated ANC attendance of 96% in this setting.[15] At the time of study, about half of the health facilities also provided HIV testing services and one third accredited to have ARV prophylaxis for PMTCT. According to the national PMTCT guidelines, women visiting facilities without testing services should be referred to neighbouring health facilities for HIV testing. The ARV prophylactic regimens at the time of study were based on the WHO 2006 recommendations and were for the mother either dual ARVs with zidovudine (AZT) and lamivudine up to one week after delivery, or single dose nevirapine. Babies received AZT for one week or sd-NVP. Triple ARVs (ART) was only provided to women eligible for that for her own health.

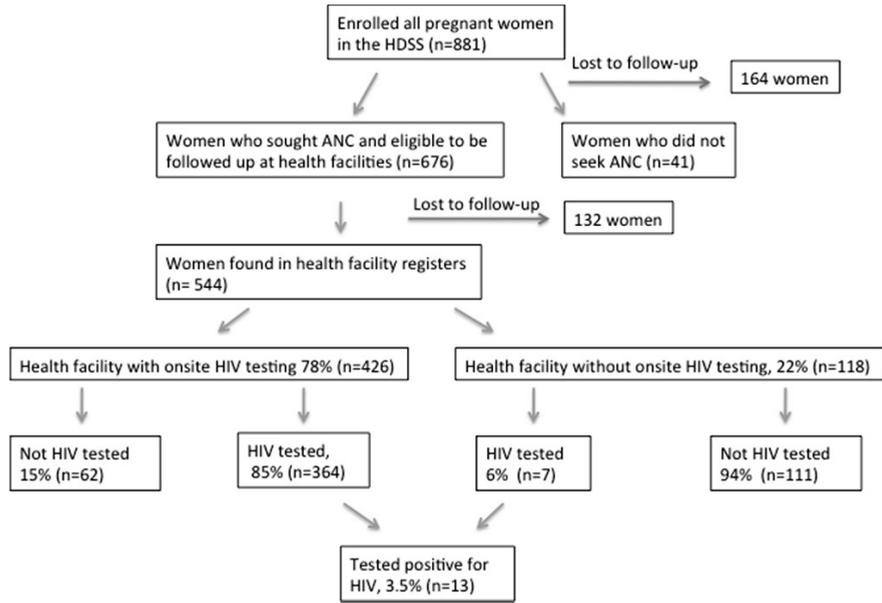
### Base-case HDSS-cohort study

During the regular HDSS data collection in May-July 2008, all households were screened for pregnant women and all of these women (n=881) were followed throughout their pregnancy (Figure 1). In addition, record reviews were performed at the health facilities where the enrolled women had sought ANC. The data collection process has been described in detail elsewhere.[15] Data on PMTCT-dropout among HIV infected women (n=13) was collected from the ANC records for everyone, and through semi-structured interviews for about half of them (n=7). Five of the HIV infected women could not be interviewed; one because she was not found, three women had moved out of the HDSS area, and two denied being HIV infected. The interviews were home-based, semi-structured using both closed, and open-ended questions and conducted 12-20 months after delivery by a Ugandan midwife with long experience of PMTCT work.

### Decision tree analysis

We performed a decision tree analysis with the main outcome being the estimated number of children infected with HIV at birth and at six months post-partum in the Iganga and Mayuge districts. In the analysis, the population-based data for the HDSS-cohort were analysed using frequency tables to define the proportion of women covered by each stage of the PMTCT

**Figure 1.** Iganga-Mayuge Health and Demographic Surveillance site- cohort of pregnant women



**Table 1.** Decision tree analysis input

**Data from the base-case (HDSS-cohort) on probability of coverage for individual PMTCT programme components**

Components	Probabilities
ANC attendance	0.96
Attending ANC at a facility with HIV testing services	0.78
HIV tested (at facility with HIV testing services)	0.85
HIV tested (at ANC without HIV testing services)	0.06
HIV prevalence	0.035
HIV infected women/baby pair receiving any ARV prophylaxis	0.83
Mother ARV prophylaxis -sd-NVP <sup>a</sup>	0.33
Mother ARV prophylaxis -dual prophylaxis AZT <sup>b</sup> and 3TC <sup>c</sup>	0.57
Mother ARV prophylaxis -ART (for her own health)	0.10
Women practicing safe feeding	0
HIV mother to child transmission rates <sup>d</sup>	
Peripartum transmission rates for different ARV regimens	
No ARV prophylaxis	0.22
sd-NVP	0.12
Dual prophylaxis of AZT and 3TC	0.04
ART for her own health	0.02
Postpartum transmission rates per month of any breastfeeding (mixed or exclusive)	
Mother's CD4 cell count $\leq 350$ mm <sup>3</sup>	0.0157
Mother's CD4 cell count $> 350$ mm <sup>3</sup>	0.0051
If mother receive ART for her own health	0.002

programme, referred to as the base-case PMTCT coverage. These data were combined with the most recent UNAIDS estimates of MTCT rates for different ARV prophylactic regimens, for different feeding practices, and for different CD4 cell count levels among the women. The combined data were subsequently entered as probabilities in a decision tree model created in Microsoft Excel and the model inputs are presented in Table 1. [16] The HIV prevalence of 3.5% used in the analysis is derived from the number of pregnant women that tested positive for HIV in the HDSS cohort. Blood samples for CD4 cell count are not routine in the two districts, therefore the number HIV infected children at six months is presented for both MTCT rates below and above 350 mm<sup>3</sup> CD4 cell counts.

<sup>a</sup> single dose nevirapine <sup>b</sup> zidovudine <sup>c</sup> lamivudine <sup>d</sup> UNAIDS Reference Group on Estimates Modelling and Projections, Working Paper on MTCT transmission rates for use in Spectrum, 2011, UNAIDS: Geneva.

Inference to Iganga and Mayuge district population

In order to estimate the number of HIV infected children in the whole of the Iganga and Mayuge districts, we inferred the base-case probabilities in Table 1 to the districts population of about 1 140 000 individuals in 2008. [17] Based on the Ugandan crude birth rate of 45/1000 and the HIV prevalence of 3.5%, there was an expected 51 300 pregnant women in the two districts in 2008 of which 1796 were estimated to be HIV infected.

Estimated effectiveness for scenarios with an assumed increased coverage of PMTCT components

Different scenarios were modelled where the base-case PMTCT coverage was used and then an increased coverage of individual PMTCT programme components was assumed. This was done to estimate how an increased coverage of individual PMTCT components would impact the number of HIV infected children at birth and at six months.

The effectiveness was estimated for the following scenarios, assuming the base-case PMTCT coverage but additionally with:

- an ANC attendance of 100%
- an uptake of HIV testing of 100%
- provision of ART throughout pregnancy and the breastfeeding period to the HIV infected women who received ARV prophylaxis

- an Optimal scenario, combining all the above
- an OptimalPlus scenario, same as Optimal scenario but where uptake of ART was increased to 100% instead of the base-case uptake of 83%

In the above presented scenarios, the coverage of all other PMTCT components were kept at the base-case coverage level presented in table 1.

To estimate the effectiveness of the base-case PMTCT coverage as compared to a situation without any PMTCT services at all, a scenario that assumed that no one would receive any PMTCT service at all was also modelled.

Further, for the scenarios presented above the number of children infected with HIV at six months was calculated for two different situations; one with the mothers CD4 cell count levels set to > 350 mm<sup>3</sup> and one with CD4 cell count levels set to ≤350 mm<sup>3</sup>.

To estimate the relative effect on the number of HIV infected children for each scenario, all scenarios were compared to the estimated number of HIV infected children with the base-case PMTCT coverage. For those comparisons, the postnatal transmission rate for CD 4 cell count of >350 mm<sup>3</sup> was used.

In the scenarios modelled, adherence to the ARV prophylaxis is assumed to be 100%, if medicines were disbursed. Since perfect adherence to ARV prophylaxis is rare, we also created alternative models for all the scenarios described above but assuming 50% adherence to ARV prophylaxis.

## Ethics

All women participating in the study gave their informed consent. The home-based interviews with HIV infected women after birth were carefully planned in order not to reveal the women's HIV status to anyone. Ethical approval for the study was obtained from Makerere University School of Public Health Institutional Review Board, and the Uganda National Council of Science, and Technology in 2008 (Ref.nr. HDREC, 052).

## Results

HIV infected children at birth and at six months with the base-case PMTCT coverage

Given an HIV prevalence in the HDSS cohort of 3.5%, 1796 HIV infected pregnant women and the base-case PMTCT coverage, an estimated 240 children would be HIV infected at birth in the

Iganga and Mayuge districts (Table 2). At six months of age, this number would have increased to 284 or 369 depending on maternal CD 4 cell count levels being  $\leq$  or  $>$  350  $\text{mm}^3$ , respectively. This corresponds to an MTCT rate of 13% at birth, and 16% or 20% at six months (Table 2). If comparing to a situation without any PMTCT programme, the base-case PMTCT coverage did prevent 155 (39%) child HIV infections at birth and 152 (35%) or 149 (29%) child HIV infections at six months of age, again depending on the mothers immune status.

83% uptake of ARV prophylaxis, empirical finding, <sup>b</sup>100% uptake of ARV prophylaxis.

### MTCT rates for the different scenarios

The MTCT rates for the different scenarios range from above 13% for the base-case PMTCT coverage to just above 2% for the OptimalPlus (Table 2). Interestingly, the Optimal scenario using the base-case ARV prophylaxis coverage of 83%, which is rather high, would give an MTCT rate of 5.4% at birth, which is still above the WHO target of MTCT rates below 5%. For the OptimalPlus scenario assuming 100% adherence both during pregnancy and during the breastfeeding period the MTCT rates are 2.0% and 3.1% at birth and six months respectively. Hence, adherence levels are crucial, especially during the breastfeeding period

**Table 2.** Scenarios with different coverage of PMTCT components, number of children infected with HIV and MTCT rates

Scenario	Description	At birth		At six months- CD 4 cell count $>$ 350 $\text{mm}^3$		At six months- CD 4 cell count $\leq$ 350 $\text{mm}^3$	
		Number of children	MTCT rate (%)	Number of children	MTCT rate (%)	Number of children	MTCT rate (%)
Base-case PMTCT coverage	Number of HIV infected children the Iganga-Mayuge district population based on the empirical HDSS cohort data	240	13.4	284	15.8	369	20.5
100% ANC	Base-case scenario but 100% ANC attendance	234	13.0	278	15.5	363	20.2
100% HIV testing	Base-case scenario but 100% HIV testing	172	9.6	217	12.1	303	16.9
100% ART	Base-case scenario but ART provided to 100% of women receiving ARV prophylaxis	197	11.0	227	12.6	265	14.8
Optimal scenario	A combination of Scenario 2, 3 and 4 (uptake 83%) <sup>a</sup>	97	5.4	121	6.7	135	7.5
OptimalPlus scenario	A combination of Scenario 2, 3 and 4 (uptake 100%) <sup>b</sup>	36	2.0	56	3.1	56	3.1
No PMTCT	No ARV prophylaxis given to HIV infected women/babies	395	13.4	436	15.8	518	28.8

Effects of base-case PMTCT coverage together with an assumed increased coverage of PMTCT components with 100% adherence to ARV prophylactic drugs

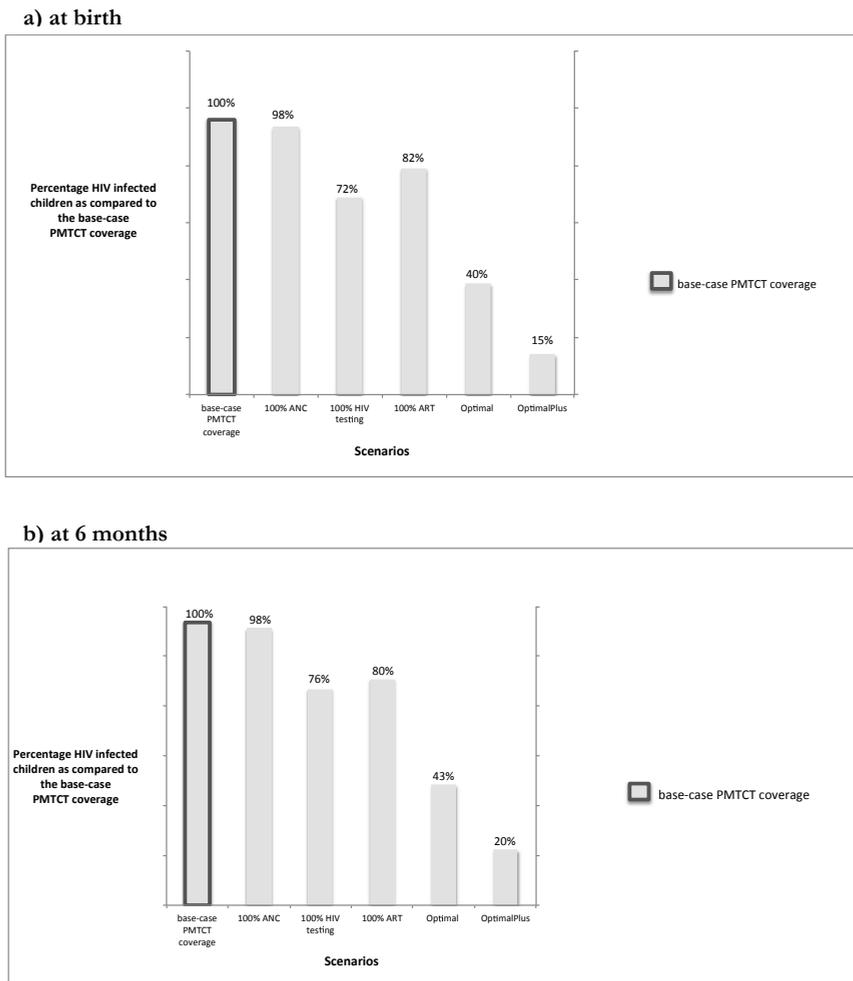
Since ANC attendance in this setting is as high as 96%, the effect on MTCT of increasing ANC attendance to 100%, is limited (Figure 2 a and b). Instead, the low coverage of HIV testing appears to be the major bottleneck for PMTCT in Iganga-Mayuge districts. An assumed increase of HIV testing coverage to 100% among pregnant women attending ANC could reduce the number of HIV

infections among children at birth by 28%, or by 24% at six months (Figure 2 a and b).

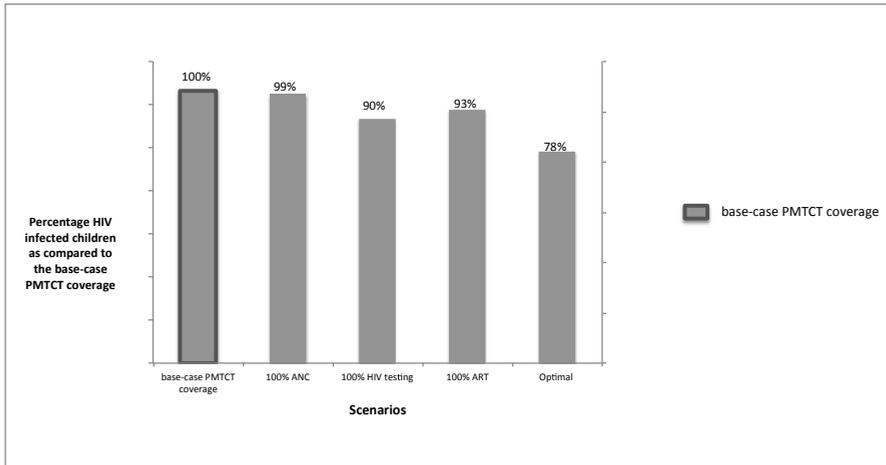
Increasing ART coverage to all women receiving ARV prophylaxis, while keeping all other components constant, would comparably only give an 18% reduction of infections at birth and 20% at six months.

The Optimal scenario with 100% ANC attendance, 100% HIV testing and ART to all women receiving ARV prophylaxis (uptake 83%), translates into a 60% decrease of infections at birth, and a 57% decrease at six months compared

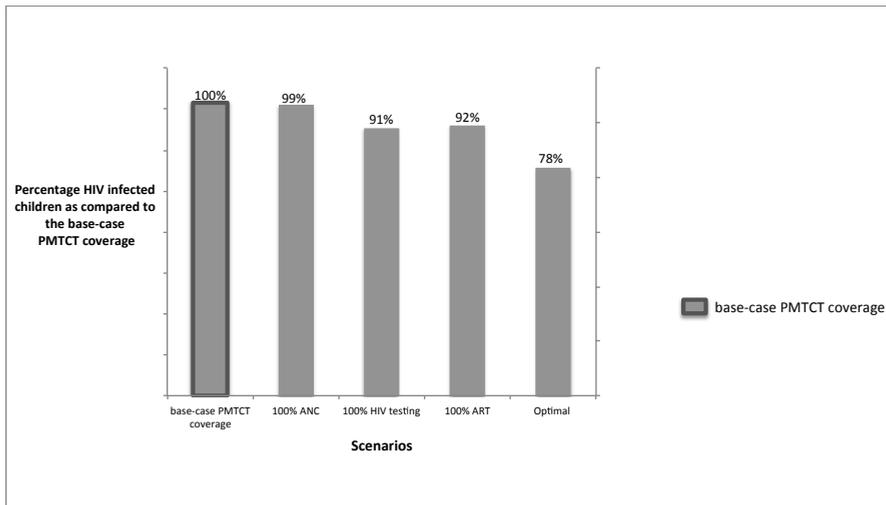
**Figure 2.** Estimated relative effects of an assumed increase in coverage of individual PMTCT programme components as compared to the base-case PMTCT coverage Assuming 100% (a,b) and 50% (c,d) adherence



c) at birth



d) at 6 months



to the number of children HIV infected with the base-case coverage (Figure 2 and b).

The OptimalPlus scenario, with 100% ANC attendance, 100% HIV testing, and providing ART to all HIV infected women (100% vs 83% in the Optimal scenario) would give the best results and translate into an estimated reduction of 85% at birth and 80% at six months.

Effects of base-case PMTCT coverage together with an assumed increased coverage of PMTCT components with 100% adherence to ARV prophylactic drugs

Assuming a lower adherence level of 50%, and assuming 100% HIV testing uptake, the number of HIV infections among children would be reduced by 10% at birth, and 9% at six months compared to the estimated MTCT rate for the base-case PMTCT coverage (Figure 2 c, d).

In this case the Optimal scenario with ANC, HIV testing, and ART set to 100%, would only provide a total reduction of 22% of infections at birth and at six months compared to number of children estimated to be HIV infected with the base-case PMTCT coverage (Figure 2 c, d).

## Discussion

To our knowledge, this is the first study to use population-based data on coverage of PMTCT components to model the effectiveness of a PMTCT programme in a Sub-Saharan African population. Our results show that in this Ugandan setting, with a poorly resourced health system, the existing PMTCT programme is estimated to have averted up to 35% of HIV infections among six-month-old children yearly depending on maternal CD 4 cell count levels, when comparing to a situation without any PMTCT programme.

The estimated MTCT rate is still considerable, 13% at birth, and 16% at six months, which is far from the MTCT elimination targets to reduce global child HIV infections by 90% by 2015.[18] In addition, 80% of HIV infected children have a high probability of dying before five years of age due to poor access to HIV treatment for children.[19, 20]

Our study highlights the fact that single, or multi-component health system interventions aimed at increasing the uptake of HIV testing, and/or increased access to ART, could significantly reduce MTCT of HIV. The possibility to reach significantly better results by increasing HIV testing is especially interesting. We found in an earlier study from the same area that the main determinant of being HIV tested among women seeking ANC, was whether the facility could offer onsite HIV testing or not since referral from rural peripheral ANC clinics for HIV testing did not work.[7] Hence, by upgrading facilities to supply rapid HIV testing, refer women for testing, or otherwise increase HIV testing uptake, keeping all other components constant, the PMTCT programme effectiveness could according to our results be significantly increased.

The challenges associated with large-scale implementation of PMTCT programmes have generally been underestimated, partly because of the assumption that it may piggyback on an already established intervention with high coverage, ANC.[21] However, our study emphasises the complexity of the PMTCT programme, and that the effectiveness of the programme is dependent on the uptake of each of the PMTCT programme components. Almost all HIV infected women (96%) have been in contact with the health care system during ANC, and should have received PMTCT programme components according to the PMTCT guidelines,[22] thus the failure to motivate women

to test for HIV, and to deliver a complete PMTCT programme reflects missed opportunities and a health system weakness. With the base-case PMTCT coverage, 13% of the HIV exposed children were estimated being infected at birth. This could be compared to Barker et al's modelling showing that 80% ANC attendance, 80% HIV testing, and 80% access to ARV prophylaxis would translate into a 16% versus 12% MTCT if women with CD4>350 received sd-NVP versus AZT/3TC.[8] Our results support, but do also complement the Barker study since we used population-based cohort data, and included all PMTCT programme components, including the crucial step of feeding practices. We reach similar conclusions on the urgent need for health system strengthening and to make already known efficient PMTCT interventions more effective in order to reduce the MTCT in sub-Saharan Africa, while we also point at striking effects of increasing e.g. HIV testing in this specific context.

Hence, a well-functioning health system is crucial to deliver the interventions that build the PMTCT programme, something that has also been described in previous studies.[7, 15, 21] A Rwandan study demonstrated that women attending ANC clinics where PMTCT, and ART had been integrated were almost twice as likely to enrol in ART care as compared to women attending stand-alone clinics for ANC.[23] The authors attribute this to comprehensive support to HIV infected pregnant women, and stress that integration of HIV care is crucial.[23] In addition to health systems interventions to increase access to the PMTCT programme components, our earlier studies highlight how HIV prevention, and care is still threatened by stigma, and lack of knowledge among the pregnant women.[7] Increased awareness at community level, and general de-stigmatising interventions will be of benefit to staff handling HIV testing, for pregnant women as well as for women in need of the full PMTCT programme.[7, 24, 25]

The "100% HIV testing" Scenario reduced HIV infections by 28% at birth and by 24% at six months, as compared to the "OptimalPlus"-scenario, that reduced the number of infections by 85%, and 80% at birth and six months of age, respectively. These results highlight the necessity of increasing capacity for HIV testing at ANC facilities but also the need to implement the newest PMTCT guidelines from the WHO, stating that HIV infected women should receive ART throughout the breastfeeding period to reduce MTCT of HIV. The interventions needed

to increase the effectiveness of PMTCT programmes differ between context, and countries. As shown previously, in a country with poor ANC attendance, increasing ANC attendance could be the best intervention to increase PMTCT effectiveness.[13]

Our results show that uptake and adherence to ART, especially throughout the breastfeeding period is crucial in order to decrease the MTCT. If keeping uptake and adherence at 100% throughout the breastfeeding period MTCT rates would be 3.1%, and for the base-case coverage of 83%, which might be more realistic in real-life, MTCT rates at the same time would be 6.7% or 7.5 depending on maternal immune status while breastfeeding. Thus, support to both midwives at ANC, and pregnant women to get a solid understanding of the importance of taking drugs as prescribed, and following feeding advice, is equally necessary.

### **Methodological considerations**

By visiting the households twice during the study we hope to have minimised the risk of missed pregnancies. If pregnant women with HIV were more likely to avoid the data collection, MTCT rates have been underestimated. Studies have shown that HIV infected women may be less likely to be HIV tested.[9]

Open-ended questions on PMTCT adherence to women enrolled in the Iganga-Mayuge PMTCT programme revealed that our assumption of 100% adherence to any ARV regimen provided was unrealistically optimistic, therefore we also modelled all scenarios assuming 50% adherence. A study from Zambia found that only 68% of women that had received the simplest ARV prophylactic regimen, NVP, had actually taken it as prescribed.[26]

### **Conclusions**

In this setting, HIV infections could be reduced by 28% by increasing HIV testing capacity at health facilities to ensure 100% testing among women seeking ANC. Importantly, more infections would be averted by increasing HIV

testing as compared to increasing the supply of the ART prophylactic drugs used in this context, however both interventions are obviously needed and highly cost-effective means of prevention. Our analyses further highlight gains in following the latest guidelines on ART prophylactic drug regimens, as well as enforcing the urgency in scaling-up delivery of HIV testing at all ANC facilities, and ensuring high adherence. Further, in order to determine the effectiveness of PMTCT programmes in different settings, it is crucial to analyse at what stages of the PMTCT programme dropouts occur and target interventions accordingly.

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### **Authors' contributions**

EL, GS, AME, and AT designed the study. EL, RB, and GP were involved in the data collection. EL and GS have conducted the analyses, supervised by AT. EL, AME and AT have drafted the manuscript, and critically revised it. GP and GT have provided comments on the manuscript. All authors have reviewed the final draft manuscript.

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### **Conflict of interest**

There is no conflict of interest to declare.

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