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# **Acceptance and Access: Home-based HIV Counselling and Testing and Barriers to Care in Rural Western Kenya**

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# TABLE OF CONTENTS

<b>Table of Contents</b> .....	<b>1</b>
<b>Declaration</b> .....	<b>4</b>
<b>Acknowledgements</b> .....	<b>5</b>
<b>Funding</b> .....	<b>6</b>
<b>Abstract</b> .....	<b>7</b>
<b>List of Figures</b> .....	<b>8</b>
<b>List of Tables</b> .....	<b>9</b>
<b>Abbreviations</b> .....	<b>10</b>
<b>CHAPTER 1: Introduction</b> .....	<b>11</b>
1.1 Problem Statement .....	11
1.2 Justification, Aims and Objectives.....	11
1.3 Project Overview.....	14
1.4 Mini-dissertation Overview.....	14
<b>CHAPTER 2: Background</b> .....	<b>16</b>
2.1 The Global Burden of HIV.....	16
2.1.1 HIV in Kenya .....	17
2.2 Voluntary Counselling and Testing (VCT).....	19
2.2.1.Efficacy of Voluntary Counselling and Testing (VCT) .....	20
2.2.2 Acceptance of VCT and Reasons for Non-participation.....	21
2.2.3 Voluntary Counselling and Testing (VCT) in Kenya .....	24
2.3 Home-based HIV Counselling and Testing (HBCT).....	25
2.3.1 Home-based HIV Counselling and Testing (HBCT) in Kenya.....	28
2.4 Access to HIV Care and Treatment.....	29
2.4.1 Access to HIV Care and Treatment in Kenya .....	30
<b>CHAPTER 3: Background on the Parent Programs</b> .....	<b>31</b>
3.1 Introduction .....	31
3.2 Centers for Disease Control and Prevention (CDC) and CDC Kenya.....	31
3.3 The Health and Demographic Surveillance System (HDSS, or DSS).....	32
3.4 The International Emerging Infections Program (IEIP) Morbidity Study .....	32
3.5 The Home-based Counselling and Testing (HBCT) Study.....	33
<b>CHAPTER 4: Project Design and Methods</b> .....	<b>34</b>
4.1 Overview .....	34
4.2 Clarification of the Mini-dissertation Project.....	34
4.3 Study Design, Study Population, and Setting .....	35
4.4 Sampling and Representativeness of the IEIP Population .....	38

4.5 Pilot Study, Instrument/Variables, and Data Recording .....	39
4.6 Hiring and Training of Counsellors .....	40
4.7 Community Outreach and Engagement .....	41
4.8 Study Implementation .....	43
4.8.1 Flow Chart Summary .....	43
4.8.2 Procedures for Home-based Counselling and Testing (HBCT) .....	44
4.8.3 Referral to Patient Support Centres (PSCs) for HIV Care .....	45
4.8.4 Data Cleaning and Security .....	46
4.8.5 Statistical Analysis .....	46
4.9 Ethical Considerations.....	47
4.9.1 Autonomy .....	47
4.9.1a Informed Consent/Voluntary Participation .....	47
4.9.1b Confidentiality.....	47
4.9.2 Beneficence .....	48
4.9.2a Risks .....	48
4.9.2b Benefits.....	49
4.9.3 Justice: Respect for Participants/Social Value .....	49
4.9.4 Conflict of Interest.....	49
4.9.5 Additional Ethical Issues: Consideration of Minors .....	49
<b>CHAPTER 5: Results .....</b>	<b>51</b>
5.1 Population Characteristics.....	51
5.2 Acceptance of Home-based Counselling and Testing.....	56
5.2.1 Overall Acceptance of HBCT .....	56
5.2.2 Acceptance of HBCT by Village, Sex, Age, and Marital Status.....	56
5.2.2a Acceptance of HBCT by Village and Sex .....	56
5.2.2b Acceptance of HBCT by Age.....	59
5.2.2c Marital Status of Those Accepting HBCT .....	60
5.2.2d Acceptance of HBCT by Village, Sex, and Age .....	61
5.3 Reasons for Non-participation in Home-based Counselling and Testing.....	62
5.4 HIV Prevalence .....	66
5.5 Prevalence of Prior HIV Testing.....	70
5.6 Follow-up Visit for Individuals Testing HIV Positive during HBCT.....	70
5.7 HIV Positive Individuals Seeking Care at a Patient Support Centre .....	71
5.8 Reasons for Not Presenting to a Patient Support Centre, among HIV Positive Individuals.....	73
<b>CHAPTER 6: Discussion.....</b>	<b>75</b>
6.1 Potential Explanations of Key Findings.....	75
6.1.1 Acceptance of Home-based Counselling and Testing.....	75
6.1.2 Reasons for Non-participation in Home-based Counselling and Testing .....	76
6.1.3 HIV Prevalence .....	77
6.1.4 Prevalence of Prior HIV Testing .....	78
6.1.5 Follow-up Visit for Individuals Testing HIV Positive during HBCT.....	78
6.1.6 HIV Positive Individuals Seeking Care at a Patient Support Centre .....	78

6.2 Limitations .....	79
6.3 Implications of the Findings and Next Steps .....	80
6.4 Conclusion.....	82
<b>Bibliography .....</b>	<b>83</b>
<b>Appendices.....</b>	<b>95</b>
Appendix A: HBCT Survey Tool.....	95
Appendix B: Follow-up Visit Survey Tool.....	100
Appendix C: Consent and Assent Forms .....	102

## **DECLARATION**

**I, Jolene H. Nakao, hereby declare that the work on which this mini-dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.**

**I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.**

**Signature:**

**Date: February 15, 2009**

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## ABSTRACT

The HIV prevalence rate in Kenya is 7.4% among adults age 15-64, one of the highest national prevalence rates in the world. Although centres for HIV Voluntary Counselling and Testing (VCT) have been made numerous throughout Kenya and care/treatment for people HIV positive has been made available to patients free of charge, the proportion of the population who has been tested for HIV and who knows his/her HIV serostatus is surprisingly low, at 36% of adults ages 15-64. Furthermore, the proportion of HIV positive people in need of treatment who are actually receiving treatment is also surprisingly low, at 35%. Home-based HIV counselling and testing (HBCT) is a way to provide confidential HIV testing in a person's home. As home-based testing has not yet been evaluated on a wide scale in Kenya among adult individuals, this project is designed to assess in rural Kenya 1) overall acceptance rates and variables that predict differential acceptance rates of home-based HIV testing, 2) reasons for refusal of home-based testing, and 3) barriers to seeking treatment for people who are HIV positive. A one-time door-to-door individual survey was performed among 4675 adults and minors over age 15 in the rural community of Asembo in western Kenya from January through August 2008; a follow-up survey was offered to those who tested positive. Trained HBCT counsellors visited households in 14 villages to offer home-based HIV testing, counselling, survey participation, and a referral for free care as needed. Overall, the HBCT acceptance rate was 76.9%, and HIV prevalence was 13.8% among those testing during HBCT. Participants did not directly report stigma to be the main reason for refusal of HBCT or the main barrier to seeking treatment for those testing HIV positive. These study results may be used to alter current HIV prevention/care/treatment efforts to appropriately serve the demand/need.

## **LIST OF FIGURES**

**Figure 2.1:** HIV Prevalence in Kenya by Province

**Figure 4.1:** The Study Population—Asembo, Bondo District, Nyanza Province, western Kenya

**Figure 4.2:** The Study Population—Delineation of the 33 villages in the IEIP in Asembo, Bondo District, Nyanza Province, western Kenya

**Figure 5.1:** Number of individuals visited to offer HBCT, by sex and age

**Figure 5.2:** Proportion of individuals at home who chose to receive HBCT, by age

**Figure 5.3:** HIV test results for individuals who accepted HBCT and received an HIV test, by age

## LIST OF TABLES

**Table 5.1:** Number of individuals visited to offer HBCT, by village

**Table 5.2:** Proportion of individuals visited who were at home during the visit and offered HBCT, by sex

**Table 5.3:** Proportion of individuals visited who were at home and offered HBCT, by age

**Table 5.4:** Proportion of individuals at home who chose to receive HBCT, by village

**Table 5.5:** Proportion of individuals at home who chose to receive HBCT, by sex and village

**Table 5.6:** Marital status of those who chose to receive HBCT

**Table 5.7:** Multivariate analysis of HBCT acceptance by village group, sex, and age

**Table 5.8:** Reasons why individuals did not accept HBCT

**Table 5.9:** Reasons why individuals did not accept HBCT, by sex

**Table 5.10:** HIV serostatus for individuals who accepted HBCT, by past testing experience

**Table 5.11:** HIV test results for individuals who accepted HBCT and received an HIV test, by sex

**Table 5.12:** HIV serostatus for individuals who accepted HBCT, by HBCT or past testing experience

**Table 5.13:** Proportion of HIV positive individuals who report presenting to a Patient Support Centre after HBCT, by sex

**Table 5.14:** Proportion of HIV positive individuals who report presenting to a Patient Support Centre after HBCT, by age

**Table 5.15:** Reasons why individuals did not present to a Patient Support Centre

**Table 5.16:** Reasons why individuals did not present to a Patient Support Centre, by sex

## ABBREVIATIONS

CDC	Centers for Disease Control and Prevention
IEIP	International Emerging Infections Program
GAP	Global AIDS Program
HBCT	Home-based HIV Counselling and Testing
VCT	Voluntary Counselling and Testing
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
PSC	Patient Support Centre
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV and AIDS
WHO	World Health Organization

**Of note:** The South African English spellings for the words ‘centre’ and ‘programme’ have been used, with the exception of proper titles. The official spellings (in American English) for the ‘Centers for Disease Control and Prevention,’ ‘International Emerging Infections Program,’ and ‘Global AIDS Program’ have been used.

# CHAPTER 1: INTRODUCTION

## 1.1 Problem Statement

Although centres for HIV Voluntary Counselling and Testing (VCT) have been made numerous throughout Kenya and care/treatment for people HIV positive has been made available to patients free of charge throughout the country, the proportion of the population who has been tested for HIV and who knows his/her HIV serostatus is surprisingly low. The most recent data from the National AIDS and STD Control Programme (NAS COP), Ministry of Health (MoH), Government of Kenya (2008) reveal that only 36% of Kenyan adults ages 15-64 have been tested at least once for HIV and received results. Although VCT centres are arguably effective in preventing HIV transmission and unequivocally essential in linking HIV positive people with resources for care, the impact of this intervention is negligible if the community of HIV positive people and others at risk for HIV do not visit them.

## 1.2 Justification, Specific Aims and Objectives

Home-based HIV counselling and testing (HBCT) is a model by which to provide confidential HIV testing in a person's home, eliminating the need to travel to a likely conspicuous VCT centre. Two studies in Uganda (Were et al. 2003, Wolff et al. 2005) suggest widespread acceptance of home-based HIV testing among rural communities. Two pilot tests in Kenya in 2006 show similarly promising results, but home-based testing has not yet been evaluated on a wide scale in **Kenya. Therefore, the first aim of this project is to assess the acceptance among 4675 adults and minors ages 15 and over of home-based HIV counselling and testing in the rural community of Asembo, Bondo District, Nyanza Province, western Kenya.** The specific objectives related to this aim are to estimate overall acceptance and to identify variables—including sex and age—that predict a differential response rate regarding acceptance/refusal of the service. Recent data from Kenya suggest HIV testing rates are

higher among women compared to men, and younger individuals compared to older individuals (NASCOPI 2008).

Based on this objective, the following is hypothesized:

***Hypothesis 1:*** *The rate of accepting home-based HIV counselling and testing will be significantly greater in women than men and younger than older people.*

***Null Hypothesis 1:*** *There will be no significant difference between the rates of accepting home-based HIV counselling and testing between sexes and age groups.*

The two pilot tests conducted on home-based HIV counselling and testing in Kenya in 2006 suggest that among those people who chose not to participate in the service, confidentiality—simply, the fear of someone else finding out about their serostatus—was often a concern (Feikin, unpublished data). Investigating why some people may refuse home-based counselling and testing will further help evaluate the acceptance of HBCT. Hence, this project also aims **to determine why people among 4675 adults and minors ages 15 and over in the rural community of Asembo, Bondo District, Nyanza Province, western Kenya refuse home-based HIV counselling and testing.** Our specific objective is to estimate and compare the frequencies of different reasons given for refusal.

Based on this objective, the following is hypothesized:

***Hypothesis 2:*** *The most common reason for people to report refusing home-based HIV counselling and testing is that they fear others finding out their status.*

***Null Hypothesis 2:*** *Out of the reported reasons for refusal of home-based HIV counselling and testing, the fear of others finding out one's status will occur no more often than any other reason.*

With the consideration of accessing testing comes the parallel consideration of accessing treatment. Although 390,000 people in Kenya are in need of antiretroviral therapy, only 35% of them were receiving ART in 2007 (NASCOOP 2008). The great stigma that still exists around carrying an HIV diagnosis has been hypothesized to explain such a low proportion. Hence, the final aim of this project is **to determine why the people among 4675 adults and minors ages 15 and over in the rural community of Asembo, Bondo District, Nyanza Province, western Kenya who know they are HIV positive may not seek out available treatment.** Our specific objective is to estimate and compare the frequencies of reasons given for not seeking treatment.

Based on this objective, the following is hypothesized:

***Hypothesis 3:** The most common reason for people who are HIV positive to report not seeking treatment is that they fear others finding out their status.*

***Null Hypothesis 3:** Out of the reasons HIV positive people report not seeking treatment, the fear of others finding out one's status will occur no more often than any other reason.*

Investigating acceptance of home-based counselling and testing, reasons why some people may refuse home-based testing, and reasons why people who are HIV positive may not present to a Patient Support Centre for treatment and care will inform future programmatic choices, in Kenya and throughout the world, regarding how to best identify individuals who are HIV positive and enable them to access needed treatment and care.

### **1.3 Project Overview**

In order to accomplish these aims, a one-time survey is being performed among adults and minors ages 15 and over in the rural community of Asembo, Bondo District, Nyanza Province, western Kenya. Four thousand six hundred seventy-five (4675) people have been offered the survey over a period of 8 months, and a follow-up survey is being offered to those who test positive. The survey is being given as part of an addendum to a larger five-year study on emerging infections being conducted in Asembo by the Centers for Disease Control and Prevention (CDC)—Kenya. Trained Voluntary Counselling and Testing counsellors are visiting nearly all households in 33 villages to offer pre-test counselling, home-based HIV testing, post-test counselling, and referral to a local Patient Support Centre (PSC) at Lwak Mission Hospital to receive free treatment and care as needed; the results from the first 14 villages will be analysed in this mini-dissertation project. Survey participants will be limited to adults and minors ages 15 and over in this analysis. The data was gathered and analysed in STATA, the results of which follow in this mini-dissertation.

The government of Kenya and other health care providers and aid organizations may use the information found by this project to alter the nature of existing Voluntary Counselling and Testing programs to more appropriately serve the demand/need, target outreach regarding HIV testing to particular segments of the population, and consider the development of new projects to increase not only the rate of people who seek HIV testing but also the rate of HIV positive individuals that seek treatment and care.

### **1.4 Mini-dissertation Overview**

This mini-dissertation is organized into five chapters. ‘Chapter 2: Background’ presents a review of the literature on the epidemic of HIV throughout the world and in Kenya in particular; an introduction to Voluntary Counselling and Testing (VCT), its efficacy and acceptance; an introduction to the intervention of interest in this mini-dissertation, Home-based Counselling and Testing (HBCT); and a review of access to

HIV care and treatment. 'Chapter 3: Background on the Parent Programs' explains the position of this mini-dissertation project within its larger parent projects, namely the Home-based Counselling and Testing (HBCT) Study of the International Emerging Infections Program (IEIP) Morbidity Study of the Centers for Disease Control and Prevention (CDC) in Kisumu, Kenya. 'Chapter 4: Project Design and Methods' outlines the details of this mini-dissertation project, including population, setting, pilot studies, investigative instrument, study implementation, and ethical considerations. 'Chapter 5: Results' presents an analysis of the data as it relates to the three hypotheses of interest, namely acceptance of HBCT, reasons for non-participation in HBCT, and reasons for not presenting for care among those testing HIV positive. Finally, 'Chapter 6: Discussion' concludes with an interpretation of key findings, study limitations, and potential next steps as a result of this research.

## CHAPTER 2: BACKGROUND

### 2.1 The Global Burden of HIV

AIDS is the fourth leading cause of mortality around the world, with an estimated 33 million people infected with the HIV virus in 2007 (UNAIDS 2008b). Most of these cases exist in the developing world, with 67% of those living with HIV residing in sub-Saharan Africa and 75% of AIDS deaths occurring there (UNAIDS 2008b). In particular, the southern-most area of Africa bears a disproportionate share of the global HIV burden, with some country prevalence rates as high as the 20<sup>th</sup> and 30<sup>th</sup> percentiles, accounting for 35% of the world's HIV infections and 38% of global AIDS deaths in 2007 (UNAIDS 2008b). A concerted effort of by the United Nations member states began seven years ago at the first Special Session on HIV/AIDS of the United Nations General Assembly (UNGASS) to move towards universal access to HIV prevention, treatment, care, and support (UNAIDS 2008b) for all citizens of the world.

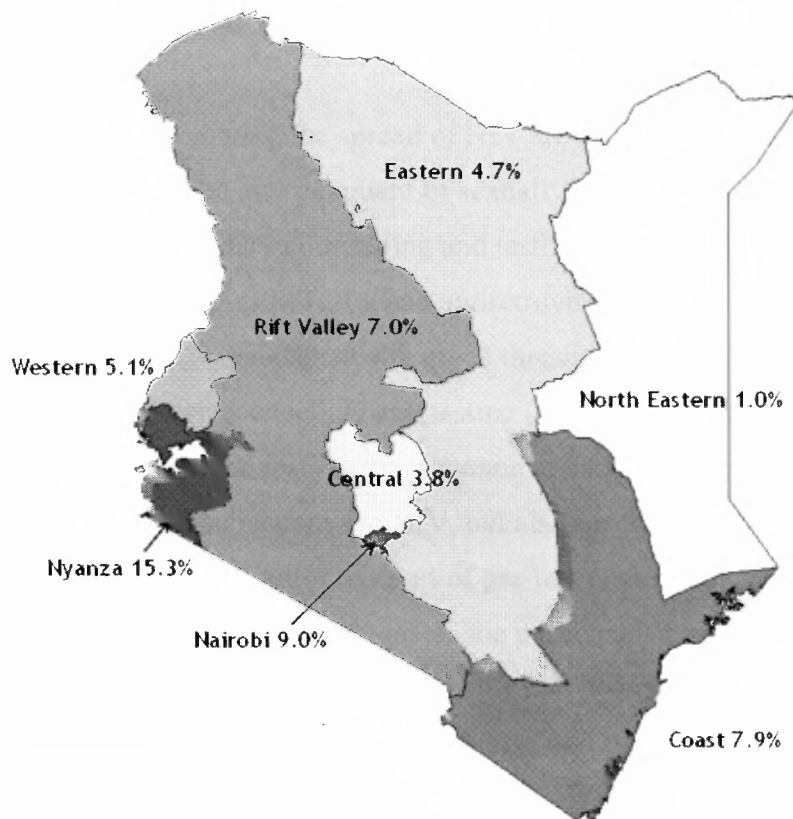
Prevention and treatment go hand in hand as key pillars in the global response to HIV and AIDS. The development of Highly Active Antiretroviral Therapy (HAART) has revolutionized the treatment and care of patients infected with HIV, particularly in resource-rich countries such as the United States. HAART has turned HIV in the U.S. into more of a chronic disease rather than an acute killer. Numerous multilateral, governmental, and non-governmental organizations throughout the world have stepped up and are funding HIV and AIDS care and treatment, including the supply of antiretroviral drugs (ARVs), to some of the hardest hit countries in sub-Saharan Africa and throughout the world. Campaigns to increase knowledge about HIV and advocate for changes in behaviours that put one at high risk of acquiring the HIV infection are concurrently conducted worldwide.

### ***2.1.1 HIV in Kenya***

In Kenya, more than 1.4 million people are currently living with HIV (NAS COP 2008). Compared to the approximate 0.5% HIV prevalence rate globally, the HIV prevalence rate in Kenya is 7.4% among adults age 15-64 (NAS COP 2008, UNAIDS 2008c), one of the highest national prevalence rates in the world. The burden of infection is borne heavily by women in Kenya, where 5 out of 8 HIV-positive Kenyans are female; this reflects an 8.7% HIV prevalence among women age 15-64 compared to a 5.6% prevalence among men of the same age group (NAS COP 2008). People living in rural areas and particular provinces are also disproportionately represented in these statistics. Seven out of 10 HIV-positive Kenyans live in rural locations, and half of all HIV-positive Kenyans live in the Rift Valley or Nyanza Provinces (NAS COP 2008). Nyanza Province specifically, bordering Lake Victoria in the southwest of the country, has an HIV prevalence rate of 15.3%, over twice the national average (NAS COP 2008; see Figure 2.1 below). In Kenya, as on much of the African continent, HIV's main mode of transmission is through heterosexual contact (Kenya National Proposal to the Global Fund 2002).

**Figure 2.1: HIV Prevalence in Kenya by Province**

*Citation: NASCOP 2008, p. 14.*



Recognizing the need for clear policies and effective structures to address the issue of HIV, the Government of Kenya approved a national HIV and AIDS policy in 1997 that supported ‘programmes to control the spread of [HIV], to protect the human rights of those with HIV and AIDS, and to provide care for those infected and affected by HIV/AIDS,’ (MoH Kenya 2008). Further, in 1999, Kenya’s government declared the HIV epidemic a ‘national disaster,’ establishing the National AIDS Control Council (NACC) to coordinate a multisectoral response to HIV/AIDS (NASCOP 2008) and developing the Kenya National HIV/AIDS Strategic Plan 2000–2005 to provide guidelines to implement HIV prevention and control interventions (Taegtmeier et al. 2005). The response to HIV in Kenya currently includes numerous initiatives and programs providing prevention education/methods, treatment, and care to HIV-positive individuals by governmental facilities and collaborations, non-governmental

organizations (NGOs), universities and research groups, and community-based and international organizations alike.

## **2.2 Voluntary Counselling and Testing (VCT)**

Interventions for preventing the spread of HIV are numerous and include mass media campaigns, education on and treatment of sexually transmitted infections (STIs), condom use/distribution, voluntary counselling and testing (VCT) for HIV, prevention of mother-to-child transmission (PMTCT), and antiretroviral therapy (ART) for HIV-positive individuals with CD4 counts below a given threshold (Creese et al. 2002, Hogan et al. 2005). Voluntary counselling and testing (VCT), one of these interventions, involves not only a test for the presence of antigens or antibodies produced by a person's body in response to HIV, but also confidential pre-test and post-test counselling by a trained counsellor. As part of pre-test counselling, the counsellor and participant discuss the testing process, assess the participant's risk of acquiring or transmitting HIV, discuss the pros and cons of testing and potential implications, discuss coping strategies related to possible test results, and reaffirm the decision to test (Denison et al. 2008, Hogan and Salomon 2005, Family Health International 2008). In post-test counselling, the participant receives the test results, the counsellor and participant discuss risk reduction strategies and disclosure of the test results, and the counsellor provides support and referral to services (Denison et al. 2008, Hogan and Salomon 2005, Family Health International 2008). Through education and the promotion of risk reduction through behaviour change, VCT's potential in HIV transmission prevention has been recognized (Taegtmeyer et al. 2005).

In addition to serving as an HIV prevention intervention, VCT has also been seen as an entry point to care for people who are HIV positive (Taegtmeyer et al. 2005). VCT is the first step in identifying and referring HIV-positive people to life-prolonging antiretroviral therapy, HIV-specific care, and additional support services (Liechty 2004, WHO 2008). Individuals must first know of their positive HIV serostatus before they know to seek out available HIV treatment and other services that would be of benefit to

them. Further, earlier knowledge of one's HIV serostatus allows an individual the opportunity to access care earlier, and, as Summers and colleagues reflect (2000), early access to HIV therapy increases therapy's effectiveness; conversely, individuals who are diagnosed late in the course of infection are known to respond less well to antiretroviral therapy and are at increased risk of illness and death (Girardi et al. 2007, as cited in UNAIDS 2008b). VCT's additional benefits include: assisting participants in making decisions about HIV tests (Allen et al. 1992); enhancing acceptance and the ability to cope with an HIV diagnosis (Taso Uganda 1995) and plan for the future (Liechty 2005); improving family and community acceptance (Taso Uganda 1995); and reducing the prevalence of gonorrhoea in HIV-positive people (Allen et al. 1992; UNAIDS 1997 as cited in Coovadia 2000).

### ***2.2.1 Efficacy of Voluntary Counselling and Testing (VCT)***

Several studies and reviews on the effectiveness of voluntary counselling and testing as a preventive measure to reduce HIV risk behaviors have found favorable results. The most recent meta-analysis conducted by Denison and colleagues (2008) examined VCT's role in reducing HIV risk behaviours in developing countries. The authors found that recipients of VCT were significantly less likely to have unprotected sex as compared to before receiving VCT or as compared to participants who had not received VCT [odds ratio 1.69; 95% confidence interval 1.25-2.31]. The largest beneficial effects were seen among HIV positive individuals and discordant couples (Denison et al. 2008), supporting results found in prior studies both in Africa (Allen, Serufilira, et al. 1992, Allen, Tice, et al. 1992, Kamenga et al. 1991, Lutalo et al. 2000, van der Straten et al. 1995, VCT Efficacy Study Group 2000 as cited in Glick 2005; Merson et al. 2000) and in reviews including studies in both developing and developed countries (Weinhardt et al. 1999, Wólitski et al. 1997). Included in the meta-analysis by Denison and colleagues is the oft-cited Voluntary HIV-1 Counseling and Testing Efficacy Study, a multi-site randomized trial on the efficacy of VCT versus basic health information in reducing unprotected sex. The study found the proportion of individuals reporting unprotected intercourse with non-primary partners declined significantly for

those who received VCT compared to those who received health information only (men: 35% reduction with VCT vs. 13% reduction with health information; women: 39% reduction with VCT vs. 17% reduction with health information; VCT Efficacy Study Group 2000).

Several earlier studies, nonetheless, have suggested less promising results regarding the efficacy of VCT as an HIV transmission prevention measure regarding those participants who are neither HIV positive nor in discordant relationships. In their 1999 review, Weinhardt and colleagues found VCT not to be an effective primary prevention strategy for HIV-negative participants. The results of the review by Wolitski and colleagues (1997) were generally mixed and hence largely inconclusive, though many included studies provided 'at least some evidence' supporting the efficacy of VCT in reducing risk behaviours (Wolitski et al. 1997). More recently, a prospective cohort study by Sherr and colleagues (2007) found no association between VCT uptake and risky sexual behaviour.

Regardless, though, of the confirmation of the efficacy of VCT as a primary prevention measure, the literature suggests its positive effect on the behaviour of HIV-positive individuals and discordant couples. Further, VCT's role in facilitating access to treatment and care for HIV-positive individuals is unequivocally essential; no matter how many drugs and treatment resources are available, without the knowledge of one's HIV positivity, a person will have no impetus to seek treatment or care.

### ***2.2.2 Acceptance of VCT and Reasons for Non-participation***

Despite the large role of voluntary counselling and testing in the global response to HIV and AIDS, more than 80% of people living with HIV in low and middle-income countries worldwide do not know that they are infected (WHO 2008). Further, Matovu and colleagues (2007) comment that in many parts of sub-Saharan Africa, the number of people who do not know their HIV status could be even greater.

A number of reasons are likely to contribute to these high proportions. First, lack of access to testing services has been cited as an obvious barrier to people knowing their HIV status, (Bwambale et al. 2008, Morin et al. 2006, Nuwaha et al. 2002, UNAIDS 2008a). Most people in developing countries (Global HIV Prevention Working Group 2007 as cited in Bateganya et al. 2008) and on the African continent in particular (Glick 2005) do not have access to HIV counseling and testing. According to UNAIDS (2008b), citing UNGASS Country Progress Reports (2008), nongovernmental sources report that HIV counselling and testing services are not widely available in 70% of countries. Even for countries making concerted efforts to scale-up VCT and roll out counseling and testing sites, full, efficacious program implementation may be hindered by lack of resources (Sweat et al. 1998) including personnel and skill shortages, unavailable medical services, and lack of support (Coorvadia 2000, van Dyk & van Dyk 2003).

Another reason for the low access to VCT services is the fear of knowing one's status and being diagnosed with HIV (Ginwalla et al. 2002, MacPhail et al. 2008, Matovu & Makumbi 2007, Morin et al. 2006, UNAIDS 2008a). Not only do individuals fear incurable disease (Iliyasu et al. 2006) and death (Day et al. 2003), but they also fear other potential consequences of testing positive, including stigmatization, discrimination, and rejection that often surround the diagnosis of HIV (Day et al. 2003, De Wit & Adam 2007).

In fact, the fear of stigma and discrimination appears to be a frequent reason why people choose not to be tested for HIV (Baiden et al. 2007, Bwambale et al. 2008, Day et al. 2003, Genberg et al. 2008, Hutchinson & Mahlalela 2006, Iliyasu et al. 2006, Kalichman & Simbayi 2003, Laver 2001, MacPhail et al. 2008, Matovu & Makumbi 2007, Reilley et al. 2004, UNAIDS 2008a, van Dyk & van Dyk 2003, Wolff et al. 2005). Because of the stigma surrounding HIV, people fear being seen by acquaintances at VCT centres (Morin et al. 2006), with women found to be more fearful than men (Hutchinson & Mahlalela 2006, Laver 2001). Not only do individuals fear discrimination themselves; it was reported by Kalichman and Simbayi (2003) that

individuals who chose not to be tested for HIV harbored stronger stigma against others regarding HIV and AIDS, 'ascribing greater shame, guilt, and social disapproval to people living with HIV' (Kalichman & Simbayi 2003).

Stemming from stigma is another issue of concern: confidentiality. Because of the potential stigmatization associated with an HIV diagnosis, people prefer to keep their act of testing and the subsequent test result confidential. Concerns over lack of confidentiality have made some people weary of seeking out VCT services (Matovu & Makumbi 2007), and lack of privacy has kept people from being tested (van Dyk & van Dyk 2003).

A further reason people choose not to be tested is that they do not believe they are at risk of contracting HIV (Killewo et al. 1998, Wringe et al. 2008). The opposite also holds: people are generally more likely to test for HIV when they perceive they have been at risk (De Wit & Adam 2007). Both higher education (Hutchinson & Mahlalela 2006, Iliyasu et al. 2006) and knowledge of HIV and VCT (Iliyasu et al. 2006, Wringe et al. 2008) have also been found to be positively associated with increased uptake of VCT services.

Logistical problems further hinder VCT uptake. This may be exemplified in the finding that people living in rural areas tend to have lower rates of testing (Wringe et al. 2008)—though, as a side note, education level may also be playing a role in lower uptake in rural areas. Distance from and time needed to travel to VCT sites, as well as convenience of location and open hours, have been found to be factors (Matovu & Makumbi 2007, Morin et al. 2006, Nuwaha et al. 2002, Yoder et al. 2006), with higher uptake found amongst people living closer to VCT sites (Hutchinson & Mahlalela 2006). Associated costs of transport have also played a role for some people (Morin et al. 2006, Nuwaha et al. 2002). Having to wait in long clinic lines has further been found to be prohibitive (van Dyk & van Dyk 2003), along with a general negative perception of testing services (Matovu & Makumbi 2007).

Lack of access to treatment for HIV (Nuwaha 2002, UNAIDS 2008a), including cost of treatment (Iliyasu et al. 2006), has also been suggested as a reason why people may refuse testing; people may figure knowing their status makes no difference if they are not able to do anything to address the result of the test.

Regarding sex as a predictive factor for VCT uptake, discrepant results have been found. One study in Nigeria found female sex to be predictive of a positive attitude towards VCT (Iliyasu et al. 2006), whereas Wringe and colleagues (2008) found lower uptake among women, and married women in particular. Factors involved in this discrepancy may include influences or pressures on women from a sex partner or spouse (Nuwaha et al. 2002), including fear of a partner's reaction and partner's attitudes towards testing (Maman et al. 2001).

Finally, both older age and higher socioeconomic status have been positively associated with increased uptake of VCT (Hutchinson & Mahlalela 2006).

### ***2.2.3 Voluntary Counselling and Testing (VCT) in Kenya***

The Government of Kenya's committed response to HIV over the past decade has included a VCT scale-up between 2000 and 2005 'unprecedented in sub-Saharan Africa,' establishing 250 VCT centres between 2000 and 2003 alone (Taegtmeyer et al. 2005), reaching 680 VCT sites by the end of 2005 (NASCOP 2005). National guidelines were drawn up to regulate voluntary counselling and testing, delineating that VCT services should be accessible, affordable, private, confidential, and convenient (NASCOP 2001), and that services must meet a number of managerial and ethical standards (Marum et al. 2006). Despite this VCT scale-up, the feasibility and apparent acceptability of VCT in Kenya (Arthur et al. 2005, Forsythe et al. 2002), and its effectiveness in reducing risk behaviours and enabling HIV-positive people to know their HIV status and access care, a surprisingly low proportion of Kenyans have ever been tested for HIV. Knowledge of HIV status was rarely mentioned in previous HIV prevention campaigns (MoH Kenya 2001). Perhaps reflecting this, a 1998 household

survey (National Council for Population and Development et al. 1999) found only 14% of women and 17% of men reported ever having been tested for HIV. Despite the subsequent VCT roll-out, the statistics are still surprising: a study in 2006 in western Kenya suggested fewer than 30% of women knew their HIV status (Breiman et al. 2007). The most recent data from NASCOP (2008) reveal that only 36% of Kenyan adults ages 15-64 have been tested at least once for HIV and received results—43% of women and 25% of men. Among older Kenyans age 50-64, testing is especially low—only 17.5% of this cohort have ever been tested for HIV (NASCOP 2008). Further, rates of testing differ substantially between urban and rural Kenya: 50% of urban residents have been tested for HIV as compared to 30% of Kenyans living in rural areas (NASCOP 2008), reflecting a trend echoed in other areas, including Tanzania (Wringe et al. 2008). Of people testing HIV positive ages 15-64, 57% reported that they had never before been tested for HIV (NASCOP 2008); had they not been tested, they would not have known they'd benefit from HIV treatment and care.

NASCOP (2008) summarizes reasons stated by Kenyans for never having been tested for HIV, which include: low perception of risk, fear of knowing the test results, fear others would know the test results, not knowing there was a test for HIV or how to access the testing, and distance to the nearest known testing site. Rarely were the cost of testing or the lack of availability of treatment cited as reasons for not testing (NASCOP 2008).

### **2.3 Home-based HIV Counselling and Testing (HBCT)**

Because of the low VCT uptake rates despite availability, alternative methods are needed in order for people to be able to learn their HIV status and seek treatment and care as necessary. Home-based HIV Counselling and Testing (HBCT) is an alternative, providing HIV counselling and testing services conveniently in a person's home and relieving the individual of the potential burden of travel cost and time. An HBCT program allows all people to access counselling and testing services, including those people who otherwise may not travel to a VCT centre. Consequently, more people

receive education on HIV prevention, and more HIV positive people are referred to Patient Support Centres (PSCs) for care and treatment services. An HBCT program may also be seen as offering a greater degree of privacy and confidentiality than visiting a VCT centre (Breiman et al. 2007, Yoder et al. 2006). Although a relatively visible intervention, the offering of HBCT to every household in a particular area may normalize the idea of testing; individuals are not offered testing based on risk profiles. Further, people tested are counselled and are provided HIV results in real time. (The exception to getting immediate results is among children less than 12 months of age, who need PCR confirmation of status.) Finally, home-based counselling and testing encourages marital partners and families to test together. Bateganya and colleagues (2008) propose that discussion about prevention and behaviour change may be more effective among family in the home, and Wolff and colleagues (2005) suggest that uptake of HIV testing may increase in a more emotionally-supportive environment. Disclosure of one's status may be made easier, important particularly in the face of the high HIV discordance rates between partners as well as the challenge for an individual of disclosing his/her HIV status to those who don't already know, especially his/her partner(s) (Bateganya et al. 2008, Breiman et al. 2007). A national Kenyan survey conducted in 2003 found 50% of married and cohabitating HIV-positive Kenyans had an HIV-negative partner (Central Bureau of Statistics [Kenya] et al. 2004 as cited in Breiman et al. 2007). HBCT may also strengthen family adherence support and risk reduction methods within HIV-discordant partners (Bateganya et al. 2008).

Despite the many potential benefits of HBCT as an intervention, it also has its limitations. Door-to-door counselling and testing services can be expensive, resource-intensive, time-consuming, and may be cost-prohibitive (Bateganya et al. 2008). Extra effort may be needed to ensure appropriate follow-up and quality of these non-centralized services. Further, disclosure of one's status before one is ready, or disclosure of a status unacceptable to family members, may lead to adverse consequences. Finally, to ensure maximum uptake of services, community involvement and engagement through mobilization is essential (Bateganya et al. 2008) and may require additional resources, time, and expenditure.

Regardless of its challenges, home-based HIV counselling and testing appears to be generally well-accepted by participants. Both studies—Fylkesnes & Siziya 2004 and Wolff et al. 2005—included in the 2008 Cochrane Review entitled ‘Home-based HIV Voluntary Counselling and Testing in Developing Countries’ by Bateganya and colleagues found high acceptance of home-based HIV testing and receiving results at home as compared to a health facility. In the cluster-randomized trial (Fylkesnes & Siziya 2004), uptake of pre-test counselling and HIV testing was 4.6 times as likely (RR 4.6 [95% CI 3.5-5.9]) among the group allocated to an optional location, mostly at home, as compared to the local clinic. Similarly, uptake of post-test counselling and receipt of results was 4.7 times as likely (RR 4.7 [95% CI 3.6-6.2]) among the group allocated to an optional location, mostly at home, as compared to the local clinic. Further, Wolff and colleagues (2005) found in their pre/post-intervention (cohort) study that offering HIV test results at home rather than at a health facility significantly increased uptake of receiving the test results from 10 to 37% for all adults aged 15 and older ( $p=0.001$ ).

As Bateganya and colleagues (2008) point out, however, these two studies do have limitations. The cluster-randomized trial (Fylkesnes & Siziya 2004) suffered from substantial loss-to-follow-up—over 50% of those randomized refused participation after randomization, introducing a possible selection bias and limiting the benefit of the randomization process. Further, the effect of clustering was not taken into effect in their analysis. Finally, this trial was conducted in an urban Zambian setting, and the cohort study (Wolff et al. 2005) was conducted in a rural Ugandan setting. These unique settings must be taken into account when assessing the generalizability of the findings. Nevertheless, the apparent acceptance of home-based counselling and testing programs that these studies suggest is strongly evident.

Home-based testing has been employed successfully in Uganda in several entire districts (Were et al. 2003, Wolff et al. 2005). In addition, two randomized trials ongoing at the time of this writing, also being conducted in Uganda, are scheduled to be

completed in the next few years (Chalebois 2007, Jaffar 2005; as cited in Bateganya et al. 2008). Increasing emphasis is being placed on home-based HIV counselling and testing in the scale-up efforts in Lesotho, Swaziland (WHO 2005 as cited in Bateganya et al. 2008), and Botswana (Botswana 2003, MASA 2004; as cited in Bateganya et al. 2008).

### ***2.3.1 Home-based HIV Counselling and Testing (HBCT) in Kenya***

In Kenya, home-based counselling and testing is not widely available, though it is currently being expanded in both research settings and as a general service (Breiman et al. 2007). The International Medical Corps (IMC), with support from the President's Emergency Plan for AIDS Relief (PEPFAR), is implementing HBCT door-to-door throughout Suba District, the district of Kenya with the highest HIV prevalence (Breiman et al. 2007). As of April 2007, over 8,000 Suba District residents had been offered HBCT, and acceptance rates have been over 90% (Breiman et al. 2007).

In 2006, two pilot studies of HBCT were conducted in the area of western Kenya where the Home-based HIV Counselling and Testing Study is now taking place (Breiman et al. 2007; Odongo, unpublished data; Orimba, unpublished data). In one of the pilots, 1,627 mothers of young children were offered counselling and testing in their homes as part of a study on risk factors for child mortality. The overall acceptance rate of HBCT among these mothers was 84%. In the other pilot, HBCT was offered to families of 687 households, and the acceptance rate among individuals was 76%. As Breiman and colleagues comment (2007), these results were encouraging that HBCT could be a well-accepted and desired service in Kenya.

The two pilot tests conducted on home-based HIV testing in Kenya in 2006 suggest that among those people who chose not to participate in the testing, confidentiality—simply, the fear of someone else finding out about their serostatus—was often a concern. Investigating why some people may refuse home-based testing will not only help evaluate the acceptance of home-based HIV testing but also inform

future programmatic choices regarding how to best identify those who are HIV positive and in need of care.

## **2.4 Access to HIV Care and Treatment**

With the consideration of accessing testing comes the parallel consideration of accessing treatment. At the end of 2007, nearly 3 million people in low- and middle-income countries were receiving antiretroviral therapy (ART), reflecting a 10-fold increase in coverage in only six years (UNAIDS 2008b). Nonetheless, this number represents only 31% of the total people who are in need of treatment (UNAIDS 2008b). This, of course, is due in great part to the variation in speed of rolling out treatment and care programs in various countries; programs of this scale take time, and many countries still have a long way to go. Whereas in Namibia, treatment coverage expanded from covering less than 1% of the population in need of antiretroviral drugs in 2003 to covering 88% of individuals in need in 2007, countries such as the Central African Republic, Mozambique, and Angola have only been able to extend treatment coverage to just above 20% of those in need (UNAIDS 2008b). Weak health care systems and infrastructure, as well as health care worker shortages, hinder the scale-up of HIV treatment programs (UNAIDS 2008b).

Further barriers to treatment access include cost. Although many countries have policies providing for free antiretroviral drugs to those who need them (UNAIDS 2008b), patients may be required to pay co-payments, user fees, or other cost for adjuvant items such as diagnostic tests and treatment of opportunistic infections (International Treatment Preparedness Coalition 2007 as cited in UNAIDS 2008b).

Finally, many barriers to VCT uptake may also apply to treatment uptake, including fear of stigmatization and logistical constraints, such as distance from health care facilities and the time and cost it may take to get there regularly. This may be particularly pertinent for residents of rural areas, for people living rurally with HIV may

need to travel hours to obtain a CD4 count or viral load test (International Treatment Preparedness Coalition 2007 as cited in UNAIDS 2008b).

#### ***2.4.1 Access to HIV Care and Treatment in Kenya***

In Kenya, antiretroviral therapy (ART) is provided for free by the Ministry of Health of the Government of Kenya, although access to it is limited. Despite the fact that 390,000 people in Kenya are eligible for and in need of antiretroviral therapy, only 35% of them were receiving ART in 2007 (NASCOOP 2008). The World Health Organization had identified Kenya to be among the 20 countries having the highest unmet need for ART (Kaiser Family Foundation 2005). According to findings presented by NASCOOP (2008), the majority of the unmet need for ART could be attributed to not knowing one's HIV status. In fact, of those eligible and not taking ART, 97% of the people reported that they had never tested for HIV (NASCOOP 2008). Among HIV-positive adults who did know their status, ART services appeared to be equitably reaching those in need (NASCOOP 2008). Outcomes research assessing HIV testing in an Emergency Department in western Kenya suggests an increase in accessing care as a result of HIV testing. A high percentage of patients newly diagnosed as HIV positive were found to present for follow-up care: within a sample group, 82% attended their initial HIV clinic visit and 65% attended their 1-month follow-up visit (Waxman et al. 2007).

For those who are knowingly HIV-positive and not accessing care (2% of Kenyans in need of ART [NASCOOP 2008]), there remains the question of why. With availability and the monetary cost of treatment out of the equation in Kenya, this leaves non-monetary costs like stigma and logistical challenges as possible barriers for these individuals.

# **CHAPTER 3: BACKGROUND ON THE PARENT PROGRAMS**

## **3.1 Introduction**

This mini-dissertation project is a sub-project of the Home-Based HIV Counselling and Testing (HBCT) Study, which is an amendment/addition to the International Emerging Infections Program (IEIP) Morbidity Study of CDC Kenya, as delineated below. The population of interest in this project and the Home-Based HIV Counselling and Testing Study are additionally a part of the Health and Demographic Surveillance System (DSS), also described below.

## **3.2 Centers for Disease Control and Prevention (CDC) and CDC Kenya**

The Centers for Disease Control and Prevention (CDC), a part of the U.S. Department of Health and Human Services, is the main United States federal agency for conducting and supporting public health activities (CDC 2008). The CDC includes the Office of the Director, the National Institute for Occupational Safety and Health, and six Coordinating Centres and Offices, including environmental health and injury prevention, health information services, health promotion, infectious diseases, global health and terrorism preparedness and emergency response, with staff based in 40 countries around the world (CDC 2008).

The Centers for Disease Control and Prevention (CDC) Research Station in Kisumu, Kenya was established in 1979, working in collaboration with the Kenya Medical Research Institute (KEMRI). KEMRI, an organization of the Kenyan Ministry of Health, is responsible for conducting research into the major public health problems of the country. Over the past 27 years, CDC/KEMRI have partnered on numerous studies on malaria, HIV and AIDS, and most recently emerging infections. The staff of the field station has grown to over 600 Kenya staff, including scientists, clinicians,

laboratory technicians, and field workers, 20 permanent non-Kenya staff, and numerous non-Kenyan temporary staff. CDC has been welcomed by and working in collaboration with the Nyanza Province communities of Asembo since 1979 and Gem since the late 1990s.

### **3.3 The Health and Demographic Surveillance System (HDSS, or DSS)**

Begun in September 2001 by CDC Kenya and KEMRI, the Health and Demographic Surveillance System is a longitudinal, population-based health and vital event registration system to measure the burden of infectious disease and evaluate public health interventions (Adazu et al. 2005). Baseline socioeconomic, educational, and demographic data have been collected on households in two rural study sites near Lake Victoria in Nyanza Province of western Kenya. Over 90% (Feikin, personal communication) of the communities of Asembo (Bondo District) and Gem (Siaya District) are covered by the DSS, totalling a population of approximately 130,000 people living in approximately in 220 villages. Households are visited every 4 months by trained Kenyan field staff, employees of CDC/KEMRI, as part of an ongoing census that includes documentation of births, deaths, pregnancies, and migrations.

### **3.4 The International Emerging Infections Program (IEIP) Morbidity Study**

In December 2005, CDC Kenya and KEMRI established an active, population-based study in the community of Asembo to determine more accurate incidence rates of infectious disease syndromes than are available through passive surveillance systems or sentinel hospital studies. A subset population—approximately 90% (Aura, personal communication)—of the DSS makes up the population of this IEIP project; this totals approximately 25,000 individuals living in 33 villages. The Home-based HIV Counselling and Testing Study is an amendment to the larger IEIP Study. This current mini-dissertation project is a sub-project of the Home-Based HIV Counselling and Testing Study.

### **3.5 The Home-based HIV Counselling and Testing (HBCT) Study**

The Home-based HIV Counselling and Testing Study has been approved by both CDC and KEMRI ethical review committees as an amendment/addition to the International Emerging Infections Program (IEIP) Morbidity Study. Because the rates of most common infectious disease syndromes (febrile illnesses, diarrheal illnesses, respiratory illnesses) addressed in the IEIP study are higher in HIV-positive people, the Home-based HIV Counselling and Testing Study seeks to determine the burden of these infectious disease syndromes in HIV positive people as compared to HIV negative people, and document the impact of treatment on the rate of these infectious disease syndromes among HIV-positive people. Once the Home-based HIV Counselling and Testing Study, as an amendment/addition to the IEIP Study, is completed, CDC plans to roll out this Home-based Counselling and Testing (HBCT) program under CDC's Global AIDS Program (GAP) into other districts of Nyanza Province as a community-based intervention in and of itself.

# CHAPTER 4: PROJECT DESIGN AND METHODS

## 4.1 Overview

**This is project a cross-sectional study designed to assess in rural Kenya 1) overall acceptance rates and variables that predict differential acceptance rates of home-based HIV counselling and testing, 2) reasons for refusal of home-based HIV counselling and testing, and 3) reasons of people who are HIV positive for not seeking treatment.** In order to accomplish these objectives, data was analysed from a one-time survey being offered as part of the Home-based HIV Counselling and Testing Study to nearly all households in 33 villages in the rural community of Asembo, Bondo District, Nyanza Province, western Kenya over a period of 18 months (January 2008-June 2009). In that study, counsellors trained in both Voluntary Counselling and Testing (VCT) and Home-based HIV Counselling and Testing (HBCT) are visiting these households to offer pre-test counselling, home-based HIV testing, post-test counselling, and referral to a local Patient Support Centre (PSC) at Lwak Mission Hospital to receive free care as needed. The analysis presented in this mini-dissertation is for the initial 14 of these villages, the HBCT of which was offered between January 2008 and August 2008, as a preliminary analysis. For those persons who test HIV positive, a home follow-up visit is made approximately 1 month after the test by the same counsellor who tested the person, based on the person's giving consent to this second visit. This visit includes the administration of a second brief questionnaire about whether the person accessed the Patient Support Centre (PSC) and if not, why not.

## 4.2 Clarification of the Mini-dissertation Project

To be clear, this mini-dissertation project involves primarily the analysis of data obtained as part of the Home-based HIV Counselling and Testing Study amendment to the International Emerging Infections Program (IEIP) Morbidity Study of CDC. It does not include an analysis of the data to address the primary goal of the Home-Based HIV

Testing Study, which is to define the true burden of emerging infectious disease syndromes among HIV-positive persons in the study population and compare them to HIV-negative persons. Rather, in complement to this, I have used the same data collected on the questionnaires of the HBCT Study to perform a secondary analysis answering the research questions as stated above. Hence, this project is a primarily analytical project that is a direct subset of the Home-based HIV Counselling and Testing Study of CDC Kenya. Below are Project Design and Methods for the Home-based HIV Counselling and Testing Study to further introduce the context into which this mini-dissertation project fits. The data presented in this mini-dissertation are from the first 14 villages out of the total 33 Asembo villages being offered HBCT as part of the Home-based HIV Counselling and Testing (HBCT) Study. The HBCT Study is currently still underway.

In addition to conducting the analysis for this mini-dissertation, I, as the author of this mini-dissertation, was integral in the start-up of the Home-based HIV Counselling and Testing Study of IEIP. My roles from September through December of 2007 in Kisumu, Kenya included outlining and adapting protocols; editing, adapting, and finalizing the questionnaires; formalizing the consent/assent forms; and compiling training manuals/materials; and planning and coordinating counsellor and staff trainings.

#### **4.3 Study Design, Study Population, and Setting**

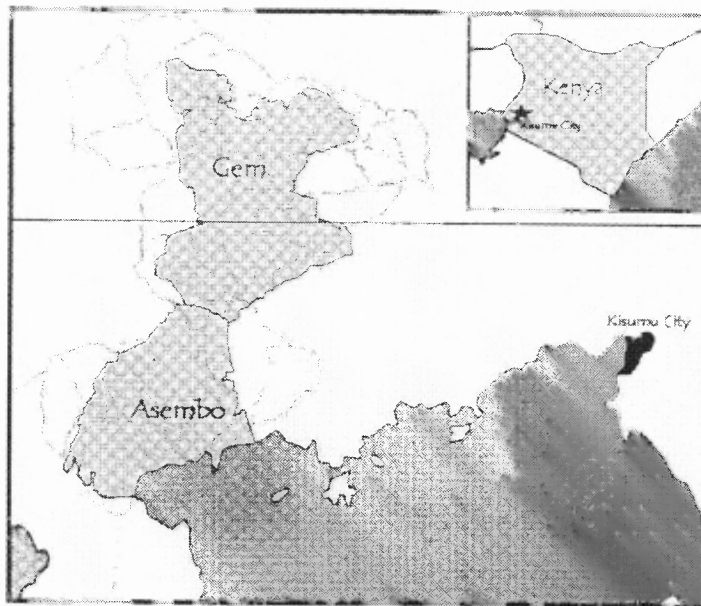
The Home-based HIV Counselling and Testing (HBCT) Study is study of 12,000 adults and minors over 13 years of age living in the 33 villages of the community of Asembo, Bondo District, Nyanza Province, western Kenya, included in the International Emerging Infections Program (IEIP) of the Centers for Disease Control and Prevention (CDC). The subset of the HBCT Study population who are of focus in this cross-sectional mini-dissertation analysis are the 4675 adults and minors 15 years of age and older living in the first 14 villages in which the HBCT Study is being conducted. Although the study design for this analysis was dictated by the structure of

the parent HBCT Study, a cross-sectional study design was nevertheless suited to the inquiries of interest. Our interests were prevalence—prevalence of HBCT acceptance—and answers to questions of ‘why’ (reasons for refusal, reasons for not presenting for care) at one ‘snapshot’ point in time. The answers to our research questions are more descriptive rather than suggestive of associations or causal relationships between an intervention/exposure and an outcome; in other words, temporality was not of primary concern. Further, the variables hypothesized to predict differential acceptance rates of HBCT—sex, age, and village group—are immutable and not subject to variations based on time. The 15-and-above age focus was chosen over the 13-and-above age focus in line with the recent publication of the National AIDS and STI Control Programme (NAS COP) of the Ministry of Health (MoH) of Kenya (2008) entitled the *Kenya AIDS Indicator Survey (KAIS) 2007*. *KAIS 2007* focuses its analyses on Kenyan adults/minors ages 15-64.

Asembo is a rural community near Lake Victoria with an area of 200 square kilometres (see Figures 4.1 and 4.2). The population of Asembo is culturally homogeneous with 95% of people of the Luo tribe, and subsistence farming comprises the principal economy (Adazu et al. 2005). Houses are made of mud, cement, or brick with roofs of thatch or iron sheets (Adazu et al. 2005). The area is one of the poorest in Kenya, with more than 70% of people living below the poverty line in Bondo District (Kenyan Central Bureau of Statistics 1997 as cited in Breiman et al. 2007). The area also has a high rate of HIV infection: greater than 10% of men and greater than 20% of women aged 13-34 years (Amornkul et al., unpublished data as cited in Adazu et al. 2005).

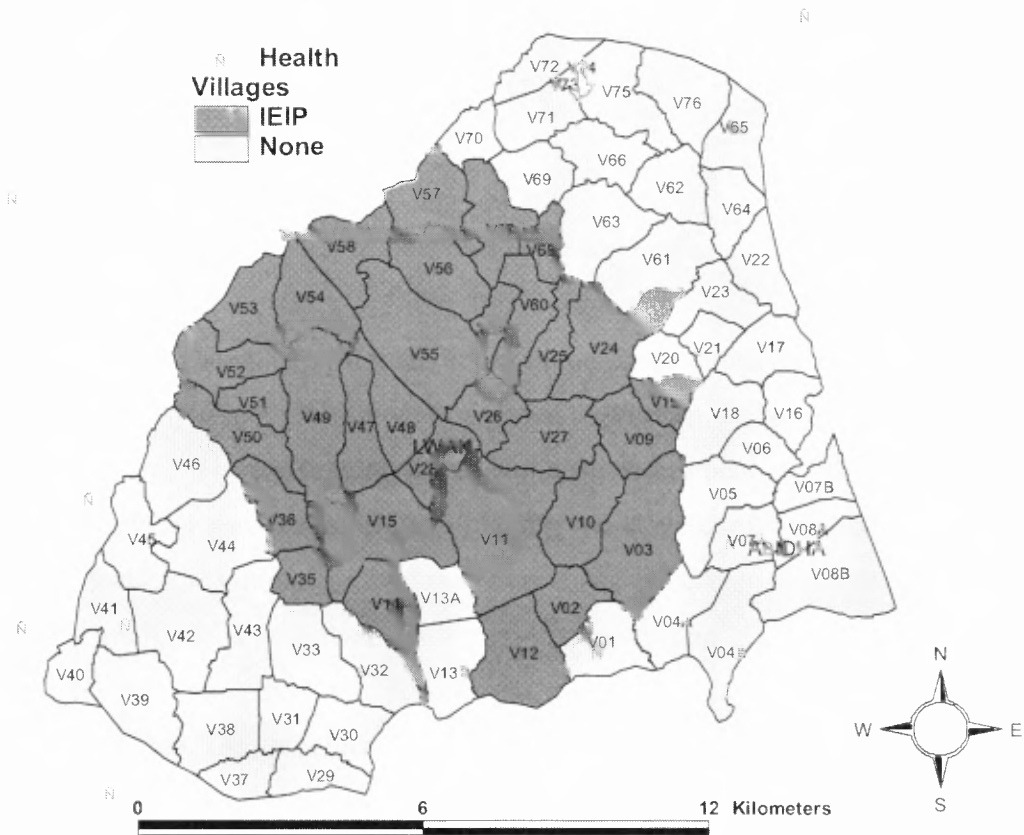
**Figure 4.1: The Study Population—Asembo, Bondo District, Nyanza Province, western Kenya**

*Citation: Adazu et al. 2005, p. 1152.*



**Figure 4.2: The Study Population—Delineation of the 33 villages in the IEIP in Asembo, Bondo District, Nyanza Province, western Kenya**

*Citation: Centers for Disease Control and Prevention—Kenya, unpublished data.*



#### 4.4 Sampling and Representativeness of the IEIP Population

No sampling was done, as home-based HIV counselling and testing (HBCT) is being offered to all individuals ages 15 and above who are participants in the International Emerging Infections Program (IEIP) in the 14 Asembo villages.

The Health and Demographic Surveillance System (DSS) includes over 90% of all individuals living in designated Asembo villages (Feikin, personal communication). In turn, the IEIP includes 90% of all individuals in the DSS living in designated villages. Hence, HBCT is being offered to approximately 81% of all individuals ages 13

and above (ages 15 and above in the case of this mini-dissertation analysis) in the Asembo villages covered by the IEIP.

Five thousand six hundred thirty-seven (5637) individuals were visited throughout the 14 villages; 4675 or 82.9% of individuals visited were at home and were hence offered home-based counselling and testing. Individuals were visited three times before being considered 'not at home.'

#### **4.5 Pilot Testing, Instrument/Variables, and Data Recording**

As mentioned above, two pilot studies of home-based counselling and testing were undertaken in 2006 by CDC Kenya in the area of western Kenya where this project is taking place. The instrument, a survey questionnaire being used in the Home-based HIV Counselling and Testing (HBCT) Study, was developed based both on participant feedback and counsellor feedback from those pilots (see Appendix A). A subset of those questions is pertinent to this mini-dissertation analysis. After the details of the HBCT project—including purpose, content, risks, and benefits—are explained, an individual is asked: “Do you consent/assent to participate?” A yes or no response is recorded. If a person chooses not to participate in HBCT, the survey question “What are your reasons for not participating?” is asked orally by the counsellor and the response corresponding to the participant’s answer is checked on the survey. The options listed as potential answers to this question are categories representing over 90% of the responses received during the pilots, including: “afraid to know results,” “afraid others will find out his/her HIV results,” “against religious beliefs,” and “spouse does not want him/her to be tested.” If the response is not listed, the counsellor fills in the “Other” blank with the patient’s response. After recording the individual’s response, the counsellor asks, “Anything else?” If the participant gives a second answer, that answer is also recorded. Counsellors continue to ask, “Anything else?” until each participant no longer gives an answer. The conscious decision was made to have counsellors read the questions orally to standardize the survey with concern for varying degrees of literacy among participants. Further, the choice was made to leave the question open-ended rather than

giving the participants a list from which to choose based on the local knowledge in this community that the power of suggestion will risk biasing results. The questionnaires were translated and are conducted entirely in the local language of the participants.

Participants who test positive during HBCT are offered a follow-up visit. During the follow-up visit, the participant is asked whether he/she has gone to a Patient Support Centre since HBCT (see Appendix B). If the participant answers “no,” the survey question: “What are the reasons you haven’t visited a Patient Support Centre (PSC) since learning of your HIV status?” is asked orally. Similar to the answer options for the afore-mentioned question on refusal, the options listed as potential answers include: “Fear/stigma of being seen at a Patient Support Centre,” “Spouse does not want him/her to go,” “Too far to travel,” “Too costly,” “Against religious beliefs,” and “Other,” with a blank beside “Other” for the patient’s answer.

Questionnaires were made as scannable forms using a commercial software package (TELEforms Enterprise, Verity). The questionnaires are attached in Appendices A and B.

#### **4.6 Hiring and Training of Counsellors**

Voluntary Counselling and Testing (VCT) centres are numerous throughout the city of Kisumu, Kenya. Twenty VCT counsellors were hired by CDC/KEMRI to work full-time on the Home-based HIV Counselling and Testing Study. Hired counsellors have all undergone the Kenyan Ministry of Health’s training program for voluntary counselling and testing, have all been certified, and all have had prior experience as VCT counsellors. In addition, all counsellors are culturally and linguistically fluent in Luo/dho-Luo and linguistically fluent in English. Counsellors were further trained over a ten-day period in particular issues unique to home-based counselling and testing (HBCT), including partner and family testing, discordant couples counselling, adolescent counselling and testing, and finger-stick HIV tests. Included in this ten-day training were two days dedicated to the proper and consistent administration of the

survey questionnaire for this analysis. Pre-test counselling, testing, and post-test counselling in the study are conducted following Kenyan Ministry of Health guidelines and recommendations.

#### **4.7 Community Outreach and Engagement**

A community advisory board (CAB) to the CDC already long-established in Asembo was consulted several times over the year-long development phase of the HBCT Study regarding the conduct of this research in their community. The CAB includes village elders, political electees and appointees, school teachers, and local health care workers. Research staff attended meetings called “barazas” held by local village chiefs and other community meetings and gatherings to inquire whether the community was receptive to HBCT dual service-research project and to provide information about the program.

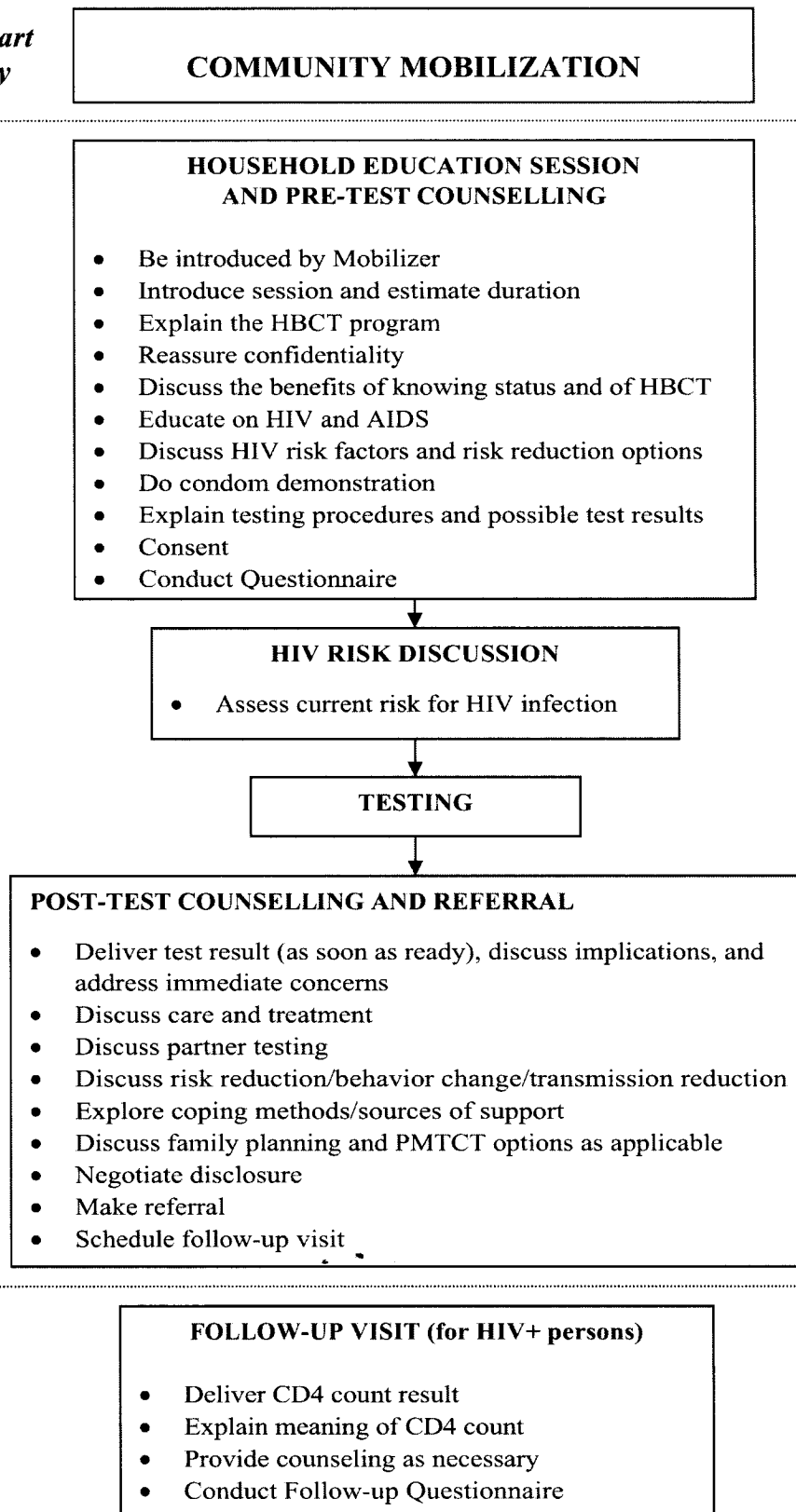
Two individuals were selected from each village to serve as “Community Mobilizers” for the project. These individuals were identified by local village members as being involved in village activities and respected in the village community. The mobilizers visit all households approximately one week prior to the visit of the HBCT counsellors. They inform individuals of the upcoming HBCT counsellor visit, inform individuals of the entirely voluntary nature of the program, and provide introductory information about HBCT.

At the initiation of the HBCT Study, pre-identified individuals who has worked before with CDC as DSS village reporters to assist in recording birth and death data were chosen to serve as Community Mobilizers for the HBCT Study. These mobilizers were coincidentally all women. After a preliminary analysis of acceptance data among the first four villages, a statistically significant difference between men and women was noted regarding acceptance of HBCT.

At this time, the sex of the mobilizers—being all female—was hypothesized based on community consultations during village Chief “barazas” and other community meetings as being a potential factor in this difference. Hence, male mobilizers were hired and trained. Before proceeding to offer HBCT to the next ten villages, general community mobilization efforts were also intensified. Speeches were given to the community by members of local Parliament, radio announcements were made, talks were given at schools, additional outreach was conducted at village Chief “baraza” meetings, flyers were posted throughout the community, and artistic performances and a community bicycle race were conducted to spread the word about the program and what participation entails. Each of the next ten villages was attended by two mobilizers, one man and one woman. This issue will be addressed in the Results section below.

## 4.8 Study Implementation

### 4.8.1 Flow Chart Summary



#### ***4.8.2 Procedures for Home-based Counselling and Testing (HBCT)***

HBCT is being offered to all the following types of persons within the International Emerging Infections Program (IEIP) Asembo surveillance site: 1) adults ages 18 years and older, 2) minors ages 13-17 years, and 3) children younger than 13 years of age who have an HIV positive or deceased mother or signs and symptoms suggestive of an HIV-related illness. This mini-dissertation project only considers individuals ages 15 and older. Each person received three visits by HBCT counsellors before being deemed 'not at home' for analysis purposes.

After an explanation of the reason for the HIV testing as part of this study, the participant is requested to sign an informed consent/assent form to give permission to perform HIV testing (Appendix C). Participants who agree to participate and sign informed consent are asked if they have ever been HIV-tested before. If a person tested negative over 6 months ago, does not have documentation of a negative test within the last 6 months, or has never had an HIV test done, he/she is offered home-based counselling and testing. Known HIV-positive persons are not retested, unless they desire to be tested again. Pre-test counselling, testing, and post-test counselling are conducted following Kenyan Ministry of Health (MOH) guidelines and recommendations, and are provided by a trained counsellor who has undergone both a Ministry of Health-approved training program for Voluntary Counselling and Testing (VCT) as well as additional training for Home-based Counselling and Testing as mentioned above.

The procedure for doing rapid HIV testing is as follows: First, 0.5 ml of blood is drawn by finger stick for rapid HIV antibody testing. Next, rapid testing is performed by a counsellor with training in HIV counselling and testing. Two test kits, Determine™ (Abbott Laboratories, USA) and Bioline™ (Standard Diagnostics, South Korea), the test kits approved by the Kenyan Ministry of Health, are used for each specimen. Finally, if either rapid test is positive, a third rapid test, Uni-gold™ (Trinity Biotech PLC, Ireland) is performed to determine the final result. The

participant is given the result of the HIV testing immediately in the home. The results of the test are entered into a scannable form that does not record the person's name or age, only a study code (see Appendix A).

Dried blood samples are taken on filter paper from 5% of the participants for quality control regarding HIV positivity. These samples are tested for HIV using ELISA.

All HIV positive persons are offered a second finger prick blood draw for CD4 count testing. CD4 count testing is done within the following week at the CDC/KEMRI laboratory. The results of the CD4 count are given to the designated Patient Support Centre (PSC) at Lwak Mission Hospital and Clinic in Asembo and are made available to the clinical officer at the Patient Support Centre at the participant's first visit. The CD4 count and clinical status help guide treatment, particularly access to antiretroviral drugs, which according to Kenya Ministry of Health guidelines are to be started at CD4 counts below 350 in WHO stage II disease (Ministry of Health, Kenya 2006). All HIV-positive persons are given cotrimoxazole prophylaxis unless contraindicated. Normally, a CD4 count is drawn at an HIV-positive individual's first visit to a Patient Support Centre and the patient must return another day for determination of his/her eligibility for antiretroviral therapy. Having the CD4 count available on the first visit to the Patient Support Centre is a potential benefit to participants in this study.

#### ***4.8.3 Referral to Patient Support Centres (PSCs) for HIV Care***

All HIV-positive persons not already accessing a Patient Support Centre (PSC) are referred to Lwak Mission Hospital and Clinic. Appointments are made 1-2 weeks from the date of the home visit by the counsellor who did the test. Care provided to HIV-positive persons at Lwak is given according to Kenyan Ministry of Health guidelines (Ministry of Health, Kenya 2006). Cotrimoxazole prophylaxis and antiretroviral drugs are available at both sites. Lwak has a functional PSC that sees almost 150 patients as of March 2006. A clinical officer is available for HIV care. In

addition, there are two clinical officers who see ill patients as part of this project who have been trained in care to HIV-positive persons and are available 6 days per week to see patients. For those persons who test HIV positive, a home follow-up visit is made by the same counsellor who tested the person approximately 1 month after the test, based on the person's giving consent to this visit. This follow-up visit is done to deliver the CD4 count result and discuss the person's eligibility for antiretroviral therapy. The counsellor also answers other questions or concerns the participant may have that came up after the positive test. The counsellor encourages the person to go to the Patient Support Centre if he/she has not already done so and explains the importance of follow-up care. The counsellor then administers the brief follow-up questionnaire about whether the person accessed the Patient Support Centre and if not, why not. Generally, individuals who are first offered HBCT in each village are first offered follow-up visits if they test positive, with logistics influencing order as well.

#### ***4.8.4 Data Cleaning and Security***

Questionnaires are scanned and initially cleaned according to standard protocol for scannable data forms. In addition, cleaning programs are run to check for logical inconsistencies in the data. Forms with errors that can be clarified in the field are returned to the field team for correction. The data is inputted into and stored in a secure Microsoft Access database with access only by staff assigned to the project/analysis.

#### ***4.8.5 Statistical Analysis***

Data analysis has been done using STATA (StataCorp LP, College Station, TX). Categorical variables (i.e. sex, age in categories, villages grouped into two groups) were compared as proportions with the indicated outcome (i.e. acceptance of HBCT) using the chi-square test of association. The variables of sex, age (as a continuous variable), and village were used to fit, through forward selection, a logistic regression model with acceptance of HBCT as the dependent variable. 95% confidence intervals were calculated around odds ratios.

Regarding reasons for refusal of HBCT and reasons for not presenting to a Patient Support Centre (PSC) for those who test positive during HBCT, respondents were allowed to provide multiple answers. These data are described and proportions are compared.

## **4.9 Ethical Considerations**

### ***4.9.1 Autonomy***

#### **4.9.1a Informed Consent/Voluntary Participation**

Participation is entirely voluntary and any participant can opt out of the project at any time if they so choose. The voluntary nature of this study is emphasized and participants are told that they can refuse at any time. Informed consent forms were translated into the vernacular language of the area, dho-Luo, and to include participants of all literacy levels the consent is read as well as given to the participants. The counsellor is a Kenyan fluent culturally and linguistically in Luo/dho-Luo; foreign staff are not present during the entire HBCT session.

#### **4.9.1b Confidentiality**

Each individual participant is offered HBCT in private in their own home and only in the company of other family/household members at the participant's discretion/choice. If the counsellor happens to know the potential participant, the offer is aborted if the participant chooses and a new counsellor assigned; this is to maintain the highest degree of confidentiality. The surveys include no identifying information and are kept track of by number. The data is inputted into a secure database with access only by staff assigned to the project/analysis.

## ***4.9.2 Beneficence***

Benefits and risks of participation in this study are clearly explained to potential participants. Benefits have been deemed to outweigh the risks for both individual participants and the society at large, as described below.

### **4.9.2a Risks**

Participants will incur no additional risk of illness or disease from participating in the study. Minimal risks are involved with the finger stick used to draw blood for 2-3 rapid HIV tests and for CD4 count if HIV positive (a finger stick draw will be used for CD4 count assessment as well). Depending on the success of the CD4 finger stick draws, there is the possibility of replacing this method with a regular venipuncture blood draw. Minimal risks are involved with either and are comparable to what may happen if a person presented to a clinic for a routine check or for illness. The participant may feel a slight sting (like a pin prick) when blood is taken from the finger or arm. It will hurt for a moment, and a participant may have a small amount of bleeding from the finger or arm. The needles used are sterile one-use disposables. The participant may have a small amount of bleeding from the finger or arm after the draw is finished.

The choice to take an HIV test may have psychological/social repercussions. The person may be scared or sad to receive positive results. Hence, counsellors trained according to guidelines delineated by the Ministry of Health of Kenya are administering the test, in addition to pre-test counselling to inform the patient what to expect in taking the test, as well as post-test counselling to help the patient interpret results and begin to deal with them. A person who tests HIV positive is also referred to the Patient Support Centre and Lwak Mission Hospital which offers care, support, and treatment to anyone seeking it free of charge as sponsored by the government of Kenya and the Centers for Disease Control and Prevention (CDC) research project of which this mini-dissertation analysis is a piece.

#### 4.9.2b Benefits

All participants have the option of knowing their HIV status free of charge. If a participant tests positive, he/she is referred to the Patient Support Centre at Lwak Mission Hospital and Clinic, and the CD4 count test results are provided to the clinical officer at the Patient Support Centre so that the test need not be repeated and to facilitate timely care. PSC care and treatment is offered free of charge; patients are offered antiretroviral therapy as needed as well as cotrimoxazole prophylaxis. These drugs are currently offered by the Kenya Ministry of Health free of charge.

#### ***4.9.3 Justice: Respect for Participants/Social Value***

To ensure that the time given by participants is not wasted, and to maximize the potential impact of the research, a number of steps will be taken to ensure dissemination of findings after the full HBCT Study is completed. An overview of the study results will be presented to study participants and the local community and government with the aim of encouraging as much as possible that the findings are taken into account to inform programme improvements leading to better services.

#### ***4.9.4 Conflict of Interest***

This project involves no conflicts of interest.

#### ***4.9.5 Additional Ethical Issues: Consideration of Minors***

Adolescents ages 13 and above are included in the greater HBCT Study, and adolescents ages 15 and above have been included in this mini-dissertation analysis. Minors (adolescents ages 13-17) who are emancipated give consent for themselves; a parent/guardian is asked for consent for a non-emancipated minor to participate. The study is explained in full to the adolescent and their parent(s)/guardian(s), and enrolment only proceeds if the adolescent assents and the parent/guardian consents.

Individuals less than age 15 have not been included in this particular mini-dissertation project.

# CHAPTER 5: RESULTS

## 5.1 Population Characteristics

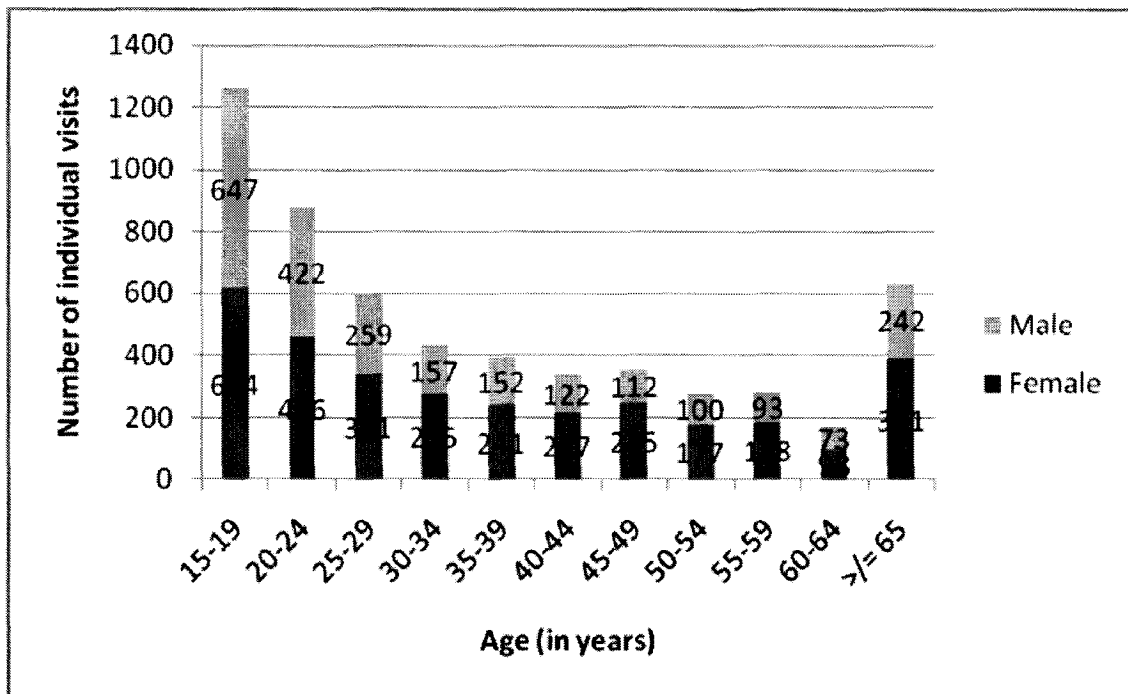
At the time of this analysis, all eligible individuals in the first four villages—Abuyu, Lusi, Ujwanga Asembo, and Majango—had been visited by women mobilizers and men or women HBCT counsellors. Nearly all individuals in the latter ten villages—Ombulu Masanga, Saradidi Miyare, Got Bondo, Sangla, Mahaya, Okenye Okiro, Rambira, Kametho, Atemo Okenye, and Siger—had been visited by either men or women mobilizers and men or women HBCT counsellors, with the exception of a fraction of minors ages 15-17 and some adults.

Five thousand six hundred thirty-seven (5637) individuals had been visited throughout the 14 villages (see Table 5.1 and Figure 5.1).

**Table 5.1: Number of individuals visited to offer HBCT, by village**

<b>Village number (in order of project roll-out)</b>	<b>Village DSS number</b>	<b>Village name</b>	<b>Number of individuals approached</b>
1	60	Abuyu	336
2	47	Lusi	273
3	48	Ujwanga Asembo	462
4	25	Majango	365
5	59	Ombulu Masanga	190
6	24	Saradidi Miyare	617
7	68	Got Bondo	271
8	49	Sangla	623
9	15	Mahaya	800
10	27	Okenye Okiro	307
11	56	Rambira	308
12	54	Kametho	257
13	26	Atemo Okenye	358
14	55	Siger	470
<b>Total</b>			<b>5,637</b>

**Figure 5.1: Number of individuals visited to offer HBCT, by sex and age**



Out of the 5637 visits made, 4675 or 82.9% of individuals visited were at home and were hence offered home-based counselling and testing. The proportion of men at home was not statistically different from the proportion of women at home (P-value = 0.139; see Table 5.2).

**Table 5.2: Proportion of individuals visited who were at home during the visit and offered HBCT, by sex**

	<b>Numbers of individuals at home - n (%)</b>	<b>Total number of individuals n</b>
<b>SEX</b>		
Female	2716 (83.6%)	3250
Male	1959 (82.1%)	2387
<b>Total</b>	<b>4675 (82.9%)</b>	<b>5637</b>

P-value = 0.139 (chi-square test of association)

Pearson's chi-square test statistic = 2.187

Regarding age, older people were generally more likely to be at home and hence offered HBCT than younger people. The mean age of people at home was 38.4 years (standard deviation = 19.5), while the mean age of people not at home was 26.2 years (standard deviation = 12.3; P-value < 0.001, two sample t-test with equal variances). The proportion of individuals who were at home and were offered HBCT is illustrated in Table 5.3, with age divided into three categories.

**Table 5.3: Proportion of individuals visited who were at home and offered HBCT, by age**

	<b>Numbers of individuals at home - n (%)</b>	<b>Total number of individuals - n</b>
<b>AGE (IN YEARS)</b>		
15-34	2372 (74.8%)	3171
35-54	1251 (91.6%)	1366
>/=55	1052 (95.6%)	1100
<b>Total</b>	<b>4675 (82.9%)</b>	<b>5637</b>

## **5.2 Acceptance of Home-based Counselling and Testing**

### ***5.2.1 Overall Acceptance of HBCT***

Overall, 76.9%, or 3,596, of the 4,675 individuals who were offered HBCT chose to participate in the program.

### ***5.2.2 Acceptance of HBCT by Village, Sex, Age, and Marital Status***

#### **5.2.2a Acceptance of HBCT by Village and Sex**

As mentioned above, an interim analysis of data for the first four villages offered HBCT revealed a statistically significant higher proportion of women (66.0%) choosing to receive HBCT as compared to men (59.7%; P-value = 0.023, chi-square test of association). Before the latter ten villages were offered HBCT, male mobilizers were hired and trained and community outreach was intensified.

Comparing HBCT acceptance rates between the latter ten villages and the first four villages among both sexes, there was a significantly greater acceptance rate of 81.6% among the latter ten villages as compared to 63.3% acceptance in the first four villages (see Table 5.4).

**Table 5.4: Proportion of individuals at home who chose to receive HBCT, by village**

	<b>Accepted HBCT - n (%)</b>	<b>Total number of individuals - n</b>
<b>First 4 villages</b>	762 (63.3%)	1,203
<b>Latter 10 villages</b>	2834 (81.6%)	3,472
<b>All villages</b>	3596 (76.9%)	4,675

P-value < 0.001 (chi-square test of association)

Pearson's chi-square test statistic = 168.217

Across all 14 villages, HBCT acceptance rates were higher among women (78.5% or 2,132) than men (74.7% or 1,464; P-value = 0.003, chi-square test of association, Pearson's chi-square test statistic = 9.091).

During the conduct of this project, it was hypothesized that a possible reason for this was the sex of the mobilizer. Hence, a comparison was made between villages had only female mobilizers (the first four villages) and villages that had both a male and female mobilize (the latter ten villages). In the table below, the data are stratified by mobilizer sex. With the effect of the sex of the mobilizer eliminated, the difference between acceptance rates among women and men still exists. In other words, there appears to be a higher HBCT acceptance rate among women than men even when controlling for village/timing (first four villages vs. latter ten villages; see Table 5.5).

**Table 5.5: Proportion of individuals at home who chose to receive HBCT, by sex and village**

	FIRST 4 VILLAGES		LATTER 10 VILLAGES	
	Accepted HBCT - n (%)	Total - n	Accepted HBCT - n (%)	Total - n
<b>Female</b>	459 (66.0%)	695	1673 (82.8%)	2,021
<b>Male</b>	303 (59.7%)	508	1161 (80.0%)	1,451
<b>Total</b>	762 (63.3%)	1,203	2834 (81.6%)	3,472

P-value = 0.023 (chi-sq. test of asso.)

P-value = 0.038 (chi-sq. test of asso.)

Pearson's chi-sq. statistic = 5.173

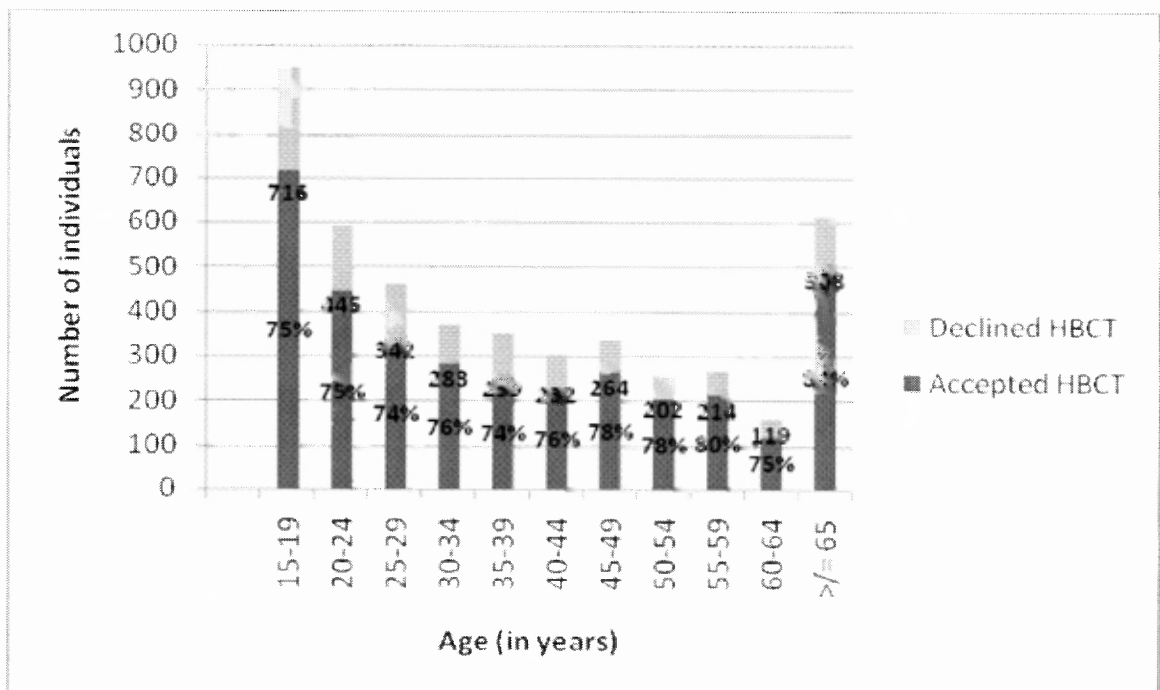
Pearson's chi-sq. statistic = 4.311

Mantel-Haenszel adjusted P-value = 0.0025

### 5.2.2b Acceptance of HBCT by Age

Those individuals who accepted HBCT tended on average to be older than those refusing HBCT. The mean age of people accepting HBCT was 39.0 years (standard deviation = 19.8), while the mean age of people refusing HBCT was 36.5 years (standard deviation = 18.6; P-value < 0.001, two sample t-test with equal variances). Acceptance numbers and rates by 5-year age groups are presented in Figure 5.2 below.

**Figure 5.2: Proportion of individuals at home who chose to receive HBCT, by age**



5.2.2c Marital Status of Those Accepting HBCT

Marital status data was collected for individuals consenting to participate in HBCT. The designations are presented in Table 5.6 below.

**Table 5.6: Marital status of those who chose to receive HBCT**

	<b>Number (n) of individuals accepting HBCT</b>	<b>Percent (%) of total individuals accepting HBCT</b>
<b>MARITAL STATUS</b>		
<b>Single</b>	1,043	29.2%
<b>Married, monogamous</b>	1,326	37.1%
<b>Married, polygamous</b>	399	11.2%
<b>Widowed and not remarried</b>	525	14.7%
<b>Widowed and remarried, or inherited monogamous</b>	108	3.0%
<b>Widowed and remarried, or inherited polygamous</b>	50	1.4%
<b>Separated/Divorced</b>	42	1.2%
<b>Other</b>	78	2.2%
<b>Total</b>	<b>3,571*</b>	<b>100.0%</b>

\* Marital status data missing for 25 individuals who accepted HBCT.

### 5.2.2d Acceptance of HBCT by Village, Sex, and Age

As suggested by the bivariate analyses above, village group (first four villages vs. latter ten villages) and sex do appear to be independently associated with acceptance of HBCT, when analyzed using a multivariate model. HBCT acceptance was 2.5 fold greater in the latter ten villages as compared to the first four villages, and men have an 18% lower likelihood of accepting HBCT than women. As for age, it was found that for each additional year older a person is, he/she has a statistically significant (P-value = 0.007) but minimal (OR = 1.01) increased likelihood of accepting HBCT. These results are illustrated in Table 5.7.

**Table 5.7: Multivariate analysis of HBCT acceptance by village group, sex, and age**

CHARACTERISTIC	ODDS RATIO (95% CI)	P- value	Beta- coefficient	Standard Error
<b>VILLAGE GROUP</b>				
Latter 10 villages vs. first 4 villages	2.56 (2.21-2.96)	0.000	0.939	0.074
<b>SEX</b>				
Male vs. female	0.82 (0.72-0.95)	0.003	0.006	0.002
<b>AGE</b>				
For every additional year of age	1.01 (1.00-1.01)	0.007	-0.193	0.072
<b>Constant</b>	---	0.000	0.421	0.099

Degrees of freedom = 4

AIC = 4874.79

### **5.3 Reasons for Non-participation in Home-based Counselling and Testing**

As mentioned above, individuals who declined HBCT were able to give multiple reasons why. The reasons most often given for declining HBCT were ‘wanting to test later’ and ‘afraid to know results:’ overall, 21.7% reported they wanted to test later and 20.9% reported they were afraid to know results. 11.3% of individuals did not participate because their parent(s)/guardian(s) did not consent to their participation—meaning they were unemancipated minors aged 15-17. 10.9% of individuals thought they did not have HIV or were not at risk for getting HIV.

A substantial 18.9% gave reasons other than the options listed on the survey. Reasons included: 27 individuals who were mentally disabled and could not consent (2.5% of 1064), 24 individuals who did not want to participate in research (2.3% of 1064), and 18 individuals whose compound (household/familial grouping) head did not approve of his/her participation (1.7% of 1064; see Table 5.8 below).

**Table 5.8: Reasons why individuals did not accept HBCT**  
*Of the 1079 individuals not accepting HBCT*

<b>REASON</b>	<b>Number (n) of individuals who reported reason</b>	<b>Percent (%) of 1064 total respondents</b>
<b>Wants to test later</b>	231	21.7%
<b>Afraid to know results</b>	222	20.9%
<b>(Other reason)</b>	198	18.6%
<b>Parent did not consent</b>	120	11.3%
<b>Does not think he/she has HIV or is at risk of getting HIV</b>	116	10.9%
<b>Already knows status</b>	90	8.4%
<b>Prefer to test away from home</b>	82	7.7%
<b>Too busy</b>	72	6.8%
<b>Against religious beliefs</b>	70	6.6%
<b>Spouse does not want him/her to be tested</b>	59	5.5%
<b>Fear of testing procedures: finger prick, rapid test</b>	35	3.3%
<b>Afraid others will find out his/her HIV results</b>	31	2.9%
<b>Too old to get HIV</b>	19	1.8%
<b>Wants spouse/partner for test</b>	18	1.7%
<b>Doesn't want spouse/partner to know results</b>	12	1.1%
<b>Prefer to test without partner present in home</b>	11	1.0%
<b>Fear of counselling procedures</b>	11	1.0%
<b>Thinks test result may be incorrect (does not trust test kits)</b>	8	0.8%

\* Reason data not given by participant or missing for 15 individuals who did not accept HBCT.

\*\*Numbers will exceed 100% when totalled as respondents may have reported multiple reasons.

When disaggregating by sex the reasons for HBCT refusal (see Table 5.9), it appears that women are more afraid than men that others will find out her HIV status: 3.8% of women reported this as a reason, while 1.8% of men reported this as a reason. Also, women appear to be more apt than men to report that her spouse does not want her to be tested: 8.7% of women report this, while 1.8% of men report that his spouse does not want him to be tested. Further, a higher proportion of men report they do not think they have HIV or are at risk of getting HIV as compared to women: 12.7% of men report this as a reason for refusal, while 9.4% of women report this as a reason.

Nonetheless, although intriguing, the number of individuals in the comparisons are too small to be powered to show statistical significance at the  $\alpha=0.05$  level of significance for these differences using the two-sided test of proportions.

**Table 5.9: Reasons why individuals did not accept HBCT, by sex**

<b>REASON</b>	<b>Number (n) of MEN who reported reason</b>	<b>Percent (%) of 490 total MEN</b>	<b>Number (n) of WOMEN who reported reason</b>	<b>Percent (%) of 574 total WOMEN</b>
<b>Wants to test later</b>	109	22.2%	122	21.3%
<b>Afraid to know results</b>	101	20.6%	121	21.1%
<b>(Other reason)</b>	105	21.4%	93	16.2%
<b>Parent did not consent</b>	55	11.2%	65	11.3%
<b>Does not think he/she has HIV or is at risk of getting HIV</b>	62	12.7%	54	9.4%
<b>Already knows status</b>	44	9.0%	46	8.0%
<b>Prefer to test away from home</b>	41	8.4%	41	7.1%
<b>Too busy</b>	34	6.9%	38	6.6%
<b>Against religious beliefs</b>	30	6.1%	40	7.0%
<b>Spouse does not want him/her to be tested</b>	9	1.8%	50	8.7%
<b>Fear of testing procedures: finger prick, rapid test</b>	11	2.2%	24	4.2%
<b>Afraid others will find out his/her HIV results</b>	9	1.8%	22	3.8%
<b>Too old to get HIV</b>	7	1.4%	12	2.1%
<b>Wants spouse/partner for test</b>	5	1.0%	13	2.3%
<b>Doesn't want spouse/partner to know results</b>	7	1.4%	5	0.9%
<b>Prefer to test without partner present in home</b>	6	1.2%	5	0.9%
<b>Fear of counselling procedures</b>	6	1.2%	5	0.9%
<b>Thinks test result may be incorrect (does not trust test kits)</b>	5	1.0%	3	0.5%

\*\*Numbers will exceed 100% when totalled as respondents may have reported multiple reasons.

## 5.4 HIV Prevalence

Three thousand five hundred ninety-six (3596) individuals agreed to participate in HBCT. Of these, 3,441 HIV test results were recorded while results were not recorded for 150 individuals (see table below). Of these 150, 139 individuals answered the question about whether he/she has taken an HIV test before, and 138 of these 139 respondents had tested in the past. Of these 138, 114 (82.6%) had tested HIV positive.

13.8% (475) of individuals accepting HBCT and receiving an HIV test (n = 3,441) tested HIV positive. Including individuals who tested HIV positive on an occasion prior to HBCT in the total number of participants who were known to be HIV positive after HBCT, that proportion rises to 16.5% (589 of n = 3,579, with data on prior testing missing for 12 individuals).

Among individuals who accepted HBCT who were taking an HIV test for the first time, 14.1% tested positive. Predictably, those who reported having had a positive HIV test previously also tested positive at HBCT. 8.4% of those previously testing negative for HIV tested positive during HBCT (see Table 5.10).

**Table 5.10: HIV serostatus for individuals who accepted HBCT, by past testing experience**

	<b>HIV Positive - n (%)</b>	<b>Total - n</b>
<b>First time testers</b>	334 (14.1%)	2,372*
<b>Tested HIV positive in the past</b>	57 (100.0%)	57**
<b>Tested HIV negative in the past</b>	84 (8.4%)	1,002**
<b>Total</b>	475	3,431

\* Data on prior testing missing for 1 individual.

\*\* Data on prior test result missing for 9 individuals.

Of individuals accepting HBCT and receiving an HIV test, more women (15.9%) tested HIV positive than men (10.9%; see Table 5.11).

**Table 5.11: HIV test results for individuals who accepted HBCT and received an HIV test, by sex**

	<b>HIV Positive - n (%)</b>	<b>Total - n</b>
<b>SEX</b>		
<b>Female</b>	321 (15.9%)	2,024
<b>Male</b>	154 (10.9%)	1,417
<b>Total</b>	475 (13.8%)	3,441

P-value < 0.001 (chi-square test of association)

Pearson's chi-square test statistic = 17.454

Again, when including individuals who tested HIV positive on an occasion prior to HBCT in the total number of participants who were known to be HIV positive after HBCT, those proportions increase, with 19.1% of tested women and 12.6% of tested men being HIV positive (see Table 5.12).

**Table 5.12: HIV serostatus for individuals who accepted HBCT, by HBCT or past testing experience**

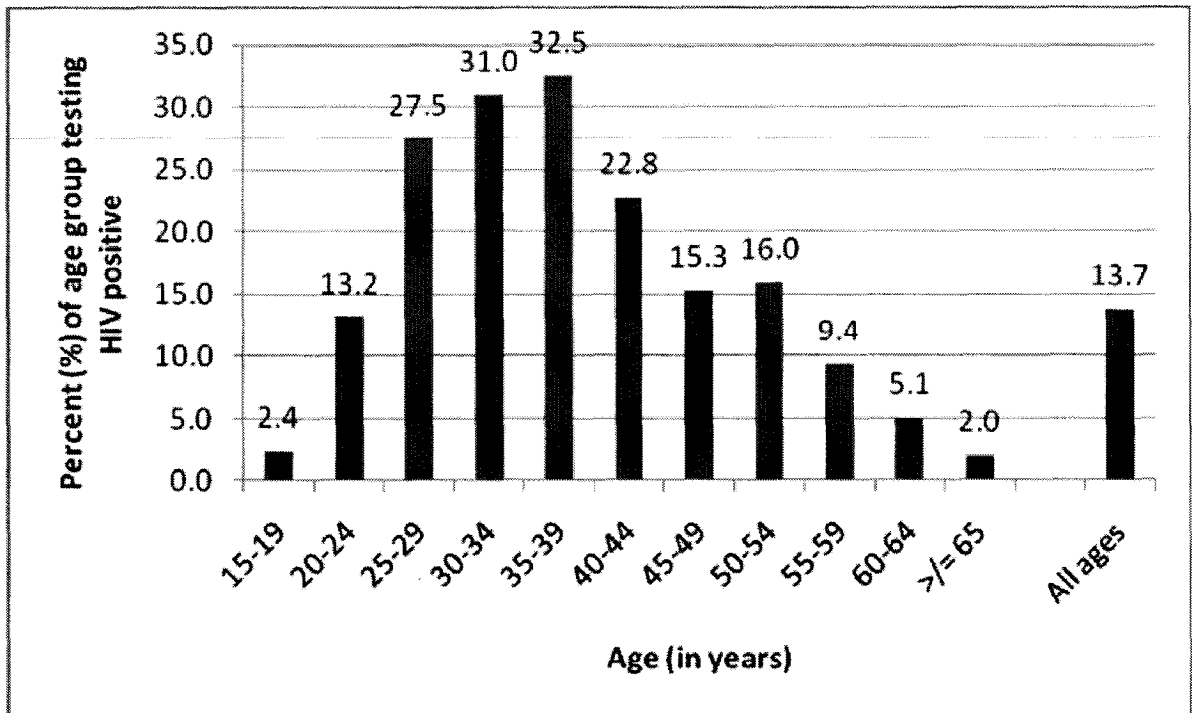
	<b>Negative</b>	<b>HIV Positive - n (%)</b>	<b>Total - n</b>
<b>SEX</b>			
<b>Female</b>	1716 (80.9%)	406 (19.1%)	2,122
<b>Male</b>	1274 (87.4%)	183 (12.6%)	1,457
<b>Total</b>	2990 (83.5%)	589 (16.5%)	3,579

P-value < 0.001 (chi-square test of association)

Pearson's chi-square test statistic = 27.145

When looking at the proportion of individuals testing HIV positive by age, a strikingly high proportion of individuals ages 25-39 tested positive: 27.5% of 25-29 year olds, 31.0% of 30-34 year olds, and 32.5% of 35-39 year olds (see Figure 5.3).

**Figure 5.3: HIV test results for individuals who accepted HBCT and received an HIV test, by age**



\*Overall proportion of those testing HIV positive appears in this figure to be 13.7% due to missing age data for 12 individuals.

## **5.5 Prevalence of Prior HIV Testing**

Delving deeper into the prevalence of prior HIV testing, 33.7% (1,206) of people who accepted HBCT and who responded to the question on prior testing (N = 3,579) report having had at least one HIV test prior to being offered HBCT. History of prior testing was not associated with HIV serostatus at HBCT (P-value = 0.489, chi-square test of association).

## **5.6 Follow-up Visit for Individuals Testing HIV Positive during HBCT**

During the time of this analysis, follow-up visits for people who tested HIV positive during HBCT had not yet been offered to all participants testing positive. The proportion of those individuals who tested HIV positive during HBCT (N = 475) who received a follow-up visit by the time of this analysis was 43.2% (205). The following analyses are based on these preliminary data. Generally, individuals who were first offered HBCT in each village were first offered follow-up visits if they tested positive, with logistics influencing order as well.

## 5.7 HIV Positive Individuals Seeking Care at a Patient Support Centre

46.8% (96) of those who tested HIV positive during HBCT who had received a follow-up visit presented to a Patient Support Centre between the time of HBCT and the follow-up visit. The proportion of men presenting to a PSC after a positive HIV test does not differ from the proportion of women presenting (see Table 5.13).

**Table 5.13: Proportion of HIV positive individuals who report presenting to a Patient Support Centre after HBCT, by sex**

	<b>Presented to Patient Support Centre (PSC) - n (%)</b>	<b>Total - n</b>
<b>Male</b>	28 (47.5%)	59
<b>Female</b>	68 (46.6%)	146
<b>Total</b>	96 (46.8%)	205

P-value = 0.909 (chi-square test of association)

Pearson's chi-square test statistic = 0.013

The data suggest older people were more likely to present to a PSC after a positive HIV test than younger people. When conducting a two-sample t-test with equal variances to compare mean age for those who presented to a PSC (38.2 years, standard deviation = 12.37) compared to those who did not present to a PSC (35.0 years, standard deviation 10.53), those who presented seemed older than those who did not (P-value = 0.049). The proportion of individuals who presented to a PSC after testing HIV positive during HBCT is illustrated in Table 5.14, with age divided into three categories.

**Table 5.14: Proportion of HIV positive individuals who report presenting to a Patient Support Centre after HBCT, by age**

	<b>Presented to a Patient Support Centre (PSC) following an HIV positive test during HBCT - n (%)</b>	<b>Total - n</b>
<b>AGE (IN YEARS)</b>		
<b>15-34</b>	41 (41.0%)	100
<b>35-54</b>	46 (51.7%)	89
<b>&gt;/=55</b>	9 (56.2%)	16
<b>Total</b>	<b>96 (46.8%)</b>	<b>205</b>

## 5. 8 Reasons for Not Presenting to a Patient Support Centre, among HIV Positive Individuals

Reasons were recorded for 89.0% (97) of HIV positive individuals who did not present to a Patient Support Centre after HBCT (see Table 5.15). An overwhelming 57.7% of individuals report they had not yet presented to a Patient Support Centre but were “planning to go later.” A substantial 32.0% reported being “too busy” to go, and 22.7% of individuals report “waiting for [the counsellor] to come back.”

**Table 5.15: Reasons why individuals did not present to a Patient Support Centre**

<b>REASON</b>	<b>Number (n) of individuals who reported reason</b>	<b>Percent (%) of 97 total respondents</b>
Plans to go later	56	57.7%
Too busy	31	32.0%
Was waiting for you to come back	22	22.7%
Not ready to seek care/treatment	9	9.3%
(Other reason)	9	9.3%
Fear/stigma of being seen at a Patient Support Centre	5	5.2%
Don't see a reason to go to a Patient Support Centre	5	5.2%
Don't believe results	5	5.2%
Nobody to accompany me	4	4.1%
Don't want to take medicines everyday	3	3.1%
Against religious beliefs	3	3.1%
Spouse does not want him/her to go	1	1.0%
Too far to travel	0	0.0%
Too costly	0	0.0%

Again, our observations are too few to comment on statistically significant differences in reporting between men and women. Nonetheless, an inspection of the crude numbers suggests that more women (61.1%) than men (48.0%) report not having presented to a Patient Support Centre yet but were planning to go later (see Table 5.16).

**Table 5.16: Reasons why individuals did not present to a Patient Support Centre, by sex**

<b>REASON</b>	<b>Number (n) of MEN who reported reason</b>	<b>Percent (%) of 25 total MEN</b>	<b>Number (n) of WOMEN who reported reason</b>	<b>Percent (%) of 72 total WOMEN</b>
Plans to go later	12	48.0%	44	61.1%
Too busy	7	28.0%	24	33.3%
Was waiting for you to come back	6	24.0%	16	22.2%
Not ready to seek care/treatment	3	12.0%	6	8.3%
(Other reason)	2	8.0%	7	9.7%
Fear/stigma of being seen at a Patient Support Centre	2	8.0%	3	4.2%
Don't see a reason to go to a Patient Support Centre	2	8.0%	3	4.2%
Don't believe results	1	4.0%	4	5.6%
Nobody to accompany me	1	4.0%	3	4.2%
Don't want to take medicines everyday	0	0.0%	3	4.2%
Against religious beliefs	1	4.0%	2	2.8%
Spouse does not want him/her to go	0	0.0%	1	1.4%
Too far to travel	0	0.0%	0	0.0%
Too costly	0	0.0%	0	0.0%

# CHAPTER 6: DISCUSSION

## 6.1 Potential Explanations of Key Findings

### *6.1.1 Acceptance of Home-based Counselling and Testing*

Overall, 76.9% of the individuals who were offered HBCT chose to participate in the program. This high HBCT acceptance rate is substantially greater than the 36% of Kenyans overall who have had an HIV test in the past (NASCO 2008). This rate supports the widespread acceptance of a home-based counselling and testing program as suggested by the pilot studies of HBCT done in 2006 done prior to this study in the same area of rural Kenya and the HBCT programming being done by International Medical Corps in a neighbouring district (acceptance rates 76%, 84%, and over 90% respectively; Breiman et al. 2007; Odongo, unpublished data; Orimba, unpublished data). It may be inferred from this high participation rate that Kenyans are not getting tested for HIV due to challenges accessing VCT services. As suggested in the Background section above, the burden of travel cost and time, the perceived cost or availability of treatment, and the concern over privacy and stigmatization may be hindering people from getting tested.

The differential acceptance rates between the latter ten villages and the first four villages may have resulted from a multitude of factors. As hypothesized by the team, the sex of the mobilizers may have played a role—perhaps Luo men are more comfortable talking with other men about HIV risk and sexual behaviour. Further, the increased efforts in mobilization—education and publicity—may have helped to increase acceptance. Alternatively, counsellors may have become better at their jobs over time, explaining the higher acceptance rates in later villages. Yet another possible factor is the post-election violence that plagued Kenya beginning in December of 2007 and coinciding with the beginning of the HBCT roll-out may have minimized acceptance among the first villages. Finally, some members of the community may have

been disgruntled as a result of certain individuals being selected as mobilizers and counsellors while others were not, and refusing to participate in protest. Again, this potential factor speaks to the importance of community entry and relations during the planning and conduct of any research or program.

Interestingly, this study found women were more likely to accept HBCT than men. Though the general literature provides discrepant results regarding sex as a predictor of VCT uptake, recent data from Kenya does suggest greater acceptance of VCT among women than men (43% vs. 25%; NASCOP 2008). One hypothesis is that this may result from real or perceived influences of or pressures from a partner or spouse.

### ***6.1.2 Reasons for Non-participation in Home-based Counselling and Testing***

The most common reason given for non-participation, ‘wanting to test later,’ does not reveal the question of true interest: why does one want to test later? This reason could alternatively mean the person really does not want to.

The second more common answer given for non-participation was that the individual was ‘afraid to know results.’ This answer speaks to possible fear of stigmatization but could also suggest fear of death or chronic illness; fear of clinics, providers, or medicines; and fear of financial consequences of being HIV positive.

Importantly, 10.9% of individuals did not think they were at risk of contracting HIV. This reason for refusal of testing has been found by other studies in the literature as well (Killewo et al. 1998, Wringe et al. 2008). Further, men seem to report this reason for refusal more often than women. Nevertheless, this perception of low risk does not necessarily correlate with a truly lower risk. For example, the Human Sciences Research Council (HSRC) of South Africa found 12.8% of females and 7.5% of males who perceived themselves to be at low risk of contracting HIV to actually be HIV

positive (Shisana et al. 2005). This observation is concerning, revealing a potential gap in HIV education efforts.

Overall, reasons for refusal did not differ greatly by sex. Of note, though, women were more likely than men to report HBCT refusal because of fear that others would find out her test results. This may be due to perceptions of infidelity for those HIV positive, while, in fact, many individuals are likely already HIV positive at the time of marriage. Women were also more likely than men to report HBCT refusal because her spouse did not want her to be tested. Again, this speaks to real or perceived pressures from a spouse.

### ***6.1.3 HIV Prevalence***

A high HIV prevalence of 13.8% was found among individuals accepting HBCT and testing for HIV serostatus. Including the individuals reporting HIV positive tests in the past (and not testing for HIV during HBCT), this rate increases to 16.5%. These data are consistent with the overall prevalence of HIV in this province of Nyanza, which is 15.3%, the highest provincially in Kenya and twice the national average (NASCOPI 2008). There is greater prevalence among women than men, a difference also consistent with current Kenyan data (NASCOPI 2008). These consistencies argue in favour of the accuracy of these data in representing true HIV prevalence in these areas.

When breaking down age into 5-year incremental categories, the greatest prevalence was among 35-39 year olds (32.5%), followed by 30-34 year olds (31.0%) and 25-29 year olds (27.5%). This is roughly consistent with current Kenya data (NASCOPI 2008), though peak prevalence was found to be among 30-34 year olds, followed by 35-39 year olds, then 25-29 year olds. The peak in our data is shifted to a slightly older age group; this may be due in part to the availability of highly-active antiretroviral therapy, prolonging life in HIV positive individuals.

#### ***6.1.4 Prevalence of Prior HIV Testing***

We found the prevalence of prior HIV testing to be 33.7%, consistent with NASCOP data (2008) finding 36% prevalence of prior testing among all Kenyans. This figure is surprisingly low for a country and area of Kenya with such high HIV prevalence some 15 years into the HIV epidemic. Nonetheless, most individuals accepted home-based counselling and testing.

#### ***6.1.5 Follow-up Visit for Individuals Testing HIV Positive during HBCT***

The follow-up visit offered after testing positive during HBCT is a unique feature of this program. The follow-up visit may influence patient presentation at a Patient Support Centre following testing. An additional unique aspect is the provision of the individual's CD4 count at the follow-up visit—this may also influence a person's likelihood of seeking treatment and care.

#### ***6.1.6 HIV Positive Individuals Seeking Care at a Patient Support Centre***

The PSC presentation rate for those testing positive was 46.8%, with no differences based on sex. This rate is lower than the 82% follow-up after a provider-initiated opt-out HIV testing study in an Emergency Department conducted in Eldoret, Kenya (Waxman et al. 2007), though notably these are two different models of HIV testing and may not be comparable. Older individuals were more likely to present than younger individuals. This finding may be influenced by available time and greater education/awareness of HIV.

The majority (57.7%) of respondents who had not presented to a PSC within one-month after testing positive during HBCT reported they 'plan to present later.' This response is difficult to interpret—it may simply be an excuse for not going to the clinic, and an alternate reason may be true. Interestingly, our data suggest that women give this reason more often than men. The second most frequently reported reason for not

presenting to a PSC is that the person was 'too busy' to do so. This response is also difficult to interpret and may also be an excuse, with the 'true' reason for one not presenting having not been expressed. The third most common response was 'I was waiting for you to come back.' With only 5.2% of respondents answering that the stigma of being seen at a PSC was keeping them from presenting, the question still remains as to exactly why more HIV positive people do not present for treatment and care. With a substantial number of participants reporting they were waiting for the HBCT counsellor to return, people may have misunderstood the services available to them and their role in accessing them.

## **6.2 Limitations**

First and foremost, the questions regarding reasons for refusal of HBCT and reasons for not presenting to a PSC as recommended within one-month of testing could arguably have been more thoroughly answered through qualitative research. As this mini-dissertation analysis was conducted on a subset of data collected as part of the parent HBCT Study that involved a large number of individual HBCT offers made, this was not logistically feasible given time constraints and scope of work. Nonetheless, this preliminary analysis provides the opportunity to inform the implementation of the parent HBCT Study, still currently underway at the time of this writing, and opens up the chance to follow-up on some responses with a qualitative mini-project.

Arguably, an 82.9% rate of people being 'at home' to be offered HBCT is high. Nonetheless, older people did tend to be at home more, and those at home may have differed from those not at home by factors not measured as part of this study. Those differences may interject bias into our results. Though the IEIP includes over 80% of the people in its catchment area, this proportion may not be representative of the area, nor Nyanza Province, and likely not Kenya as a whole. In particular, the area of Asembo may not be representative of other areas in that three decades of public health research have been conducted by the CDC in Asembo. Hence, the generalizability of the conclusions may be limited. Reasons for making choices have much to do with

perceptions and beliefs, and these differ substantially from community to community, from cultural group to cultural group.

Further, these data are preliminary data. Though HBCT offers have been made to nearly all individuals in the latter ten villages, offers were still to be done at the time of this analysis. In particular, follow-up visits throughout the 14 villages had only been conducted for somewhat less than half (43.2%) of those who tested positive. Furthermore, crude numbers of those testing positive for HIV are relatively few from the standpoint of statistics, and real differences may hence be difficult to detect statistically.

Several drawbacks are inherent to an assessment of acceptance of HBCT. Many different factors make up the home-based counselling and testing intervention, including intense counselling and education in addition to the testing itself. It is a challenge to decipher which of these factors may have an influence on the choice to test for HIV. Further, as the data regarding why a patient might refuse a home-based HIV test and why a patient might not have sought treatment for HIV disease will be based on self-reporting, there is room for error, assuming there is one 'correct' reason to explain these questions for each participant. In addition, there is the possibility that a person may have a difficult time refusing participation if a counsellor is standing in front of his house asking for permission. Finally, the fact that the counsellor who offers and administers HBCT to the individual is the same person who administers the questionnaire evaluating HBCT may interject further bias as an individual may be less likely to divulge his/her 'true' answer to the questions posed.

### **6.3 Implications of the Findings and Next Steps**

The high acceptance of home-based HIV counselling and testing suggests HBCT as an acceptable alternative to voluntary HIV counselling and testing that would likely increase rates of testing. The next step would be to consider the feasibility of implementing HBCT, initially in high-risk communities, weighing its benefits against

its resource and monetary cost. Further investigation should be pursued into the particular parts of the HBCT program that influence acceptance, and how the unique features of this particular HBCT Study, including the follow-up visit, affect rates of follow-up for HIV treatment and care.

Conversely to the purpose of this analysis, an equally interesting question is why people choose to *accept* HBCT. Identifying particular sub-populations who are relatively more receptive to HBCT may suggest along which lines to allocate scarce resources for testing through HBCT.

This work strongly suggests the importance of community involvement, consultation, and program acceptance whenever conducting community-based research or offering public health intervention. Community mobilization efforts can make or break any intervention or program. These issues should be considered in depth before embarking on any community-based project.

Finally, this analysis brought up many important questions that could be investigated through qualitative research either immediately, as part of the HBCT Study still ongoing at the time of this writing, or through future studies. Further investigation into the differences between sexes of HBCT acceptance and reasons for refusal—namely the fear others will find out one's test results and preference of spouse/partner—would suggest populations that may be more receptive to testing through HBCT. An interesting follow-up question would be to investigate how the acceptance rates differ by sex for people of different marital statuses. To test the hypothesis that the latter villages had higher rates of acceptance than the former villages because counsellors were becoming for proficient and effective in their roles could be tested by examining acceptance rates by counsellor over time. Follow-up questions of 'why?' to the most frequently given reasons for not participating in HBCT—wanting to test later and being afraid to know the test result—could provide a more detailed understanding of HBCT refusal and hence inform future programming. Regarding the 10.9% of respondents who do not feel they are at risk of contracting HIV, an interesting investigation would be an

analysis to see whether the individuals reporting this reason truly are at less risk of contracting HIV based on known HIV risk factors, such as multiple sexual partners and sex without a condom. This analysis will be possible based on data from the parent HBCT Study. If the fear of others finding out one's HIV status is based in the association of positive status with infidelity, this perception could be addressed through HIV education programs stressing that many people are HIV positive already at the time of marriage. A further interesting study would be to explore why those individuals who had never been tested before for HIV chose to receive HBCT. Finally, a follow-up question of 'why?' asked following the most common reasons given by HIV positive people for not presenting to a PSC—planning to test later, being too busy, and waiting for the counsellor to return—would help immensely in elucidating the true reasons for not seeking treatment and care. Do individuals wait because they feel healthy? A further analysis examining this issue would be to investigate an association between frequency of the response 'planning to go to a PSC later' and CD4 count.

The results of these analyses have uncovered many new questions that may be explored in a more in-depth manner, the answers of which may inform the conduct of the rest of the Home-based HIV Counselling and Testing Study to improve acceptance of HBCT and follow-up for treatment and care among those testing HIV positive, as well as future efforts to increase HIV counselling and testing and access to HIV treatment and care for those individuals most in need.

## **6.4 Conclusion**

In conclusion, this work found home-based HIV counselling and testing to be a highly acceptable option for HIV counselling and testing among the community of Asembo in Nyanza Province of rural Kenya. Contrary to hypotheses, individuals who refused HBCT and those testing HIV positive but not presenting for treatment and care do not cite stigma most commonly as their reason for refusal/non-presentation, but the true reasons for refusal/non-presentation are yet unclear.

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**APPENDIX A:**  
**HBCT SURVEY TOOL ENTITLED**  
**“IEIP HOME VISIT FORM”**

Questions applicable to this project: 1, 11

## IEIP HOME VISIT FORM

Date of survey	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <small style="display: block; text-align: center;">dd mm yyyy</small>	Key	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Starting time of survey	<input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/> <small style="display: block; text-align: center;">hour min</small>	Counselor code	<input type="text"/> <input type="text"/> <input type="text"/>

1. Was the person at home/contacted?  Yes  No "if 'No', SKIP to question 3"

2. a) Does the person consent/assent to participate?  Yes  No

b) If participant says NO, ask the following.

What are your reasons for not participating? *Gin ango ma omiyo ok ichiuwri?*

(*shade all that apply*)

- |  |  |
|--|--|
| <input type="checkbox"/> Already know status                             | <input type="checkbox"/> Prefer to test without partner present in home                |
| <input type="checkbox"/> Wants to test later                             | <input type="checkbox"/> Prefer to test away from home                                 |
| <input type="checkbox"/> Afraid to know results                          | <input type="checkbox"/> Think test result may be incorrect (does not trust test kits) |
| <input type="checkbox"/> Afraid others will find out his/her HIV results | <input type="checkbox"/> Does not think she/he has HIV or is at risk of getting HIV    |
| <input type="checkbox"/> Spouse does not want him/her to be tested       | <input type="checkbox"/> Fear of testing procedures: finger prick, rapid test          |
| <input type="checkbox"/> Dont want spouse/partner to know results        | <input type="checkbox"/> Fear of counseling procedures                                 |
| <input type="checkbox"/> Too busy  | <input type="checkbox"/> Against religious beliefs                                     |
| <input type="checkbox"/> Wants spouse/partner for test                   | <input type="checkbox"/> Too old to get HIV  |
| <input type="checkbox"/> Parent did not consent                          |  |

Other (specify)

3. Sex  Male  Female

4. Age   years   months (*if less than 2 years old*)

**If person did not consent to participate/was not at home, STOP HERE**

5. If age 13-17: Emancipated Minor  Yes  No

*"A minor is emancipated if 1) she/he is living together with a consensual sexual partner or spouse(s), or 2) if she (in the case of a female adolescent) is pregnant or a mother."*

6. a) Marital status (*Shade one*)

- Single
- Married monogamous
- Married polygamous
- Widowed/and not remarried
- Widowed and remarried/inherited monogamous
- Widowed and remarried/inherited polygamous
- Separated/Divorced

Other (specify)

b) Spouse key

Spouse 1

Spouse 2

Spouse 3

Spouse 4

*"Put spouse key for both couples and individual counseling"*

File number:

## 7. Type of counseling

- Individual  
 Couple  
 Polygamous group  
 Other group/family/guardian and child (ren)

8. a) Have you ever had sexual intercourse?  Yes  No "If 'No', SKIP to question 10"  
*Bende ise riwori/terori? Ee Ooyo*

b) If Yes, what was your age at first sexual intercourse?    Don't know/No reply  
*Ne in ja higni adi e terruok ni mokuongo? Akia/Onge duoko*

c) Did you have sex in the last 3 months?  Yes  No  Don't know/No reply  
*Bende iseterori e dweche 3 mokalo? Ee Ooyo Akia/Onge duoko*

d) If Yes, with how many partners in the last 3 months?    
*Isebedo gi joterruok adi e dweche 3 mokalo?*

Spouses  Other regular (excluding spouses)   Casual    Don't know/No reply  
*Jaot Ja terruok mapile Ja terruok ma kadichiel Akia/Onge duoko*

Jaot  
Ja terruok mapile

Ja terruok ma kadichiel

9. If more than 4 partners, ask about most recent 4 partners.

Information on partners in past 3 months (Partner 1,2,3,4) <i>Weche ewi jo terruok e dweche adek mokalo</i>	1	2	3	4
Type (1-Spouse, 2-Regular, 3-Casual, 9-D/K, N/R) <i>Jaot Ja terruok mapile Ja terruok ma kadichiel Akia/Onge duoko</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is this partners New? (in last 3 months)? (1-Yes, 2-No, 9-D/K,N/R) <i>Ja terruok manyien e dweche 3 mokalo? Ee Ooyo Akia/Onge duoko</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Condom use with partner in last 3 months(1-Always, 2-Most Times, 3-Occasionally, 4-Never, 9-D/K,N/R) <i>Tiyo gi mpira e dewche 3 Seche Thothne Kadichiel Podi Akia/Onge duoko</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Condom use during last sexual intercourse? (1-Yes, 2-No, 9-D/K, N/R) <i>Tiyo gi mpira terruok mogik? Ee Ooyo Akia/Onge duoko</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Partner HIV status (1-HIV+, 2-HIV-, 9-Unknown) <i>Chal ja terruok korka kute mag Ayaki? OK ongere</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family Planning methods (0-None, 1-Condom, 2-Pill, 3-Injection, 4-Norplant, 5-IUD, 6- Traditional, last sexual intercourse <i>mpira Amuonya Sindan 7-Other, 9-D/K Nyaluo</i> <i>Yore mag komo nyuol Moro Akia</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. a) For MALE. Are you circumcised?  Yes  No  Don't know/No reply  
*Ne CHUO Bende oteri nyange? Ee Ooyo Akia/Onge duoko*

b) For FEMALE Is your main sex partner (in the last 3 months) circumcised?  
*Ne MINE Bende ngama iterorigo mang'eny oter nyange?*

Yes  No  Don't know/No reply  N/A

11. a) Have you ever had an HIV test done?  Yes  No  
*Bende osega pimi ne kute mag Ayaki? Ee Ooyo*

If No: ask to test her/him and skip to question 13

If Yes: Ka Ee:

b) Where was the last HIV test done?  
*Ne opimi kanye?*

- Lwak Mission Hospital  
 Ongielo Health Centre  
 Abidha Health Centre  
 Bondo District Hospital  
 Nyanza Provincial General Hospital

Other (specify)

c) When did you have the test?   -     "put '9s' where unknown"  
month Year  
dwe Higa

d) What was the result of your HIV test:  Positive  Negative  Don't know/Didn't receive results  
*Duoko mar pim ne en ango?* *Duoko ni gi kute* *Duoko onge gi kute* *Akia*

e) Do you have written documentation of the result?  Yes  No  
*Bende nitie kama ondik ni e duoko?* *Ee* *Ooyo*

f). Did you disclose your most recent result to your current or most recent spouse or partner(s)?  
*Bende ne inyiso jaodi kata ngama ija terorigo duoko mar pim:*

Yes to all  Yes to some  No  No reply  
*Ee ne duto* *Ee ne moko* *Ooyo* *Onge duoko*

**If positive in the past:**

*Ka in gi kute mag Ayaki kuom ngalo mokalo:*

12. a) Have you been to a Patient Support Center for HIV care?  Yes  No  
*Bende isedhi e kar thieth mar joma ni gi kute mag Ayaki?* *Ee* *Ooyo*

b). If Yes, which Patient Support Center?  
*Ka isedhi to kar rit mane?*

Lwak Mission Hospital

Ongielo Health Centre

Abidha Health Centre

Bondo District Hospital

Nyanza Provincial General Hospital

Other (specify)

**If participant did not follow-up in a Patient Support Center, ask the following:**

*Ka jachiwruok neok odhi e kar rit, penj penjoni:*

c). What are the reasons for not visiting a Patient Support Center since learning of your HIV status?  
*Gin ango ma omiyo pok idhi kar thieth mar joma ni gi kute mag Ayaki? (shade all that apply)*

Error box 2

- Plans to go later  Don't want to take medicines everyday  
 Spouse/guardian/parent does not want him/her to go  Don't believe results  
 Not ready to seek care/treatment  Against religious beliefs  
 Nobody to accompany me  Too busy  
 Fear/stigma of being seen at patient support center  
 Too far to travel  
 Too costly  
 Don't see a reason to go to patient support center  
 Was waiting for you to come back  
 Other (specify)

d). Are you currently taking cotrimoxazole (septrin) prophylaxis?  Yes  No  Defaulted  
*Bende sani imuonyo septrin?* *Ee* *Ooyo*

e). Are you currently taking antiretroviral drugs  Yes  No  Defaulted  
*Bende sani imuonyo yedhe mag kute mag Ayaki* *Ee* *Ooyo*

f). For FEMALE *Ne MINE:*

i) Is the client pregnant?  Yes  No  Don't Know/No reply  
*Bende ipek?* *Ee* *Ooyo* *Akia*

ii) Were you HIV positive during your last pregnancy?  Yes  No  Don't know/No reply  
*Bende ne in gi kute mag Ayaki endalo mane ipek mogik?* *Ee* *Ooyo* *Akia*

iii) If Yes, did you take ARVs, including nevirapine, at the time of delivery of the child?  Yes  No  
*Ka Ee bende ne imuonyo yedhe mag kute mag Ayaki koriwo nevirapine ,sama ne inyuol?* *Ee* *Ooyo*

File number:



**APPENDIX B:**  
**FOLLOW-UP VISIT SURVEY TOOL ENTITLED**  
**“COUNSELLORS’ FOLLOW-UP FORM”**

Follow-up visit form for those individuals testing HIV positive

Questions applicable to this project: 1, 4



# APPENDIX C: CONSENT AND ASSENT FORMS

## CONSENT FORM FOR THE HOME-BASED HIV TESTING OF ADULTS AND EMANCIPATED MINORS (13-17 YEARS OLD)

### *Reason for doing HIV test/Gima omiyo itimo pim mar kute mag Ayaki*

You are part of the IEIP study. We are offering HIV tests to everyone in the IEIP study. We can do the HIV test in your home. This saves you time and money and is more private. We use the same tests the Ministry of Health advises. You learn your HIV result within a few minutes. We will offer you the chance to be tested with your partner. You have a right to decline the test.

In achiel e nonro mar IEIP. Wachiwo pim ne ji duto manie nonro mar IEIP. Wanyalo timo pim mar kute mag Ayaki e dalani. Ma konyo e thuolo mari to gi pesa, kendo en siri molooyo. Watiyo gi pim machal gi ma migao mar thieth ngade rieko ni otigo. Ingeyo duoko mari mar pim mar kute mag Ayaki kuom dakika manok. In gi ratiro mar tamori pim.

We will ask all persons a few questions, similar to those asked at the VCT center. These questions are about your age, some of your behaviors, previous HIV testing, and certain illnesses. These questions don't take long and help us counseling you.

Wabiro penjo ji duto penjo machal gi ma ipenjo e kuonde mar pim gi hocho. Penjo gi gin ewi hiki, timbegi moko, pim mari mar kute mag Ayaki mokalo, togi touché moko. Penjogi ok kaw thuolo mangeny to bende biro konyowa hoyi.

We ask to combine the HIV test result with the other data from the IEIP study and the DSS project. The IEIP field workers and the DSS field workers who visit your house will not find out these results.

Wakwayo riwo pim mar kute mag Ayaki togi weche moko maowuok e nonro mar IEIP (to gi nonro mar DSS- ma Asembo kende). Jotij nonro mag IEIP mane pap (togi jotij DSS mae pap) malimo odi, ok bingeyo duoko gi.

*How test is done and what it means/Kaka itimo pim togi tiende:* We will take a few drops of blood through a prick on the finger, like a malaria test. It will be less than a spoonful. It will be tested right away. A few drops will be kept for later testing on a piece of special paper. If you are HIV positive, we will offer to take a few drops of blood from your finger, less than a teaspoon. With this blood we can do a test at our lab called CD4 cell count. This test shows if you need treatment now or later.

The counseling and the test today will take about 30 minutes. If you are a woman who tests positive and you have children less than 13 years of age, we will offer HIV testing to test your children, since HIV can pass from a mother to her child.

Wabiro kawo odonge remo matin kuom chuoyo lith Seyi, kaka pim mar Malaria. Obiro bedo matin ne kijiko achiel. Ibiro pime seche go. Ton remo matin ibiro kan ne pim mabange e otas moro. Ka in gi kute mag Ayaki, wabiro kawo remo matin e badi, madirom kijiko ariyo. Gi remoni, wanyalo timo pim ma iluongo ni kwan mar CD4 e del. Pim ni nyiso ka idwaro thieth sani kata bange.

Hocho gi pim kawuono biro kawo madirom dakika 30. Ka in ngama miyo ma oyud gi kute mag Ayaki to in gi nyithuindo mane bwo higni 13, wabiro chiwo pim mar kute mag Ayaki ne nyithindi nikech kute mag Ayaki nyalo wuok kuom miyo kadhi ne nyathine.

*Risks of testing/Hinyruok manyalo wuok e pim:* You may feel a slight sting (like a pin prick) when we take blood. The stick we use is clean, and the small amount of blood we take will not harm you. You may have a small amount of bleeding from the stick site briefly. Also, the results of your HIV test may make you upset or sad.

Inyalo winjo rem matin (kaka chwop kipino) ka wakawo remo. Kedi mawatiyogo ler kendo remo matin mawakawo ok bi hinyi. Remo nyalo chwer matin kama wachwoyo. Bende duoko mari mar pim samoro nyalo chwanyi kata ketho chunyi.

*Benefits/Ber:* If you test positive, you can get health care for HIV at a nearby clinic. You will be referred to the Patient Support Center at Lwak. The results of your CD4 count test will be available to the clinical officer at the Patient Support Center so that you will not have to have that test done again. We will also tell you about other Patient Support Centers that are open to you in your area. At the Patient Support Center, you will be offered drugs used in HIV. This study will not pay for these drugs, but they are offered by the Kenya Ministry of Health in these sites free of charge.

If you test positive, I will ask you to visit your home again in about 1 month to discuss the results of the CD4 test and your treatment choices. On that visit, I would also ask you a few more questions. I will only do a repeat visit to your home if you allow me.

Ka duoko oyudo ni in gi kute mag Ayaki, inyalo rit korka thieth ne kute mag Ayaki e klinik man machiegni. Ibiro ori kar thieth mar joma ni gi kute mag Ayaki ma lwak e klinik machiwo rit ne jogo manigi kute mag Ayaki. Duoko mar kwan CD4 man e dendi, ibiro mi jathieth mane kar rito jotuo mondo mi kik inuo pimni kendo. Bende wabiro nyisi kuom kuonde rit jotuo ma oyawni e gwengu. E kar thieth mar joma ni gi kute mag Ayaki, ibiro miyi yedhe maitiyogo kuom kute mag Ayaki. Nonroni ok bi chulo kuom yedhegi, to ichiwogi nono kuondegi gi migao mar thieth

Ka duoko oyudo ni in gi kute mag Ayaki, abiro kwayi mondo alimi e dala kendo bang dwe achiel mondo mi wawuo ewi kwan mar CD4 e dendi to gi kit thieth ma diher. Chieng limbeni, abiro penji penjo moko be. Abiro mana duogo limi ka imiya thuolo.

*Confidentiality/Rito siri:* What we talk about and your test results will be kept as private as possible, even among your family members. We will keep the records using

numbers, not names. We will keep the records in secure files at KEMRI/CDC. However, you may decide to share the results and records with other people, like the doctors who may give medical care to you. Your name or other things that may identify you will not appear when we discuss this project.

Gima wawacho to gi duoko mari mar pim, ibiro kan mopondo kaka nyalore, kata mana kuom joodi. Wabiro kano wehegi e yor nembni, maok nying. Wabiro kano wehegi e fainde ma olor maber e ofis mar KEMRI/CDC. Katakamano, inyalo dwaro nyiso jomoko wehegi gi duoko, kaka laktar machiwoni kony mar thieth. Nyingi kata gimoro manyalo mi ongeyi, ok bi wuok ka wawuoyo ewi nonroni.

Cost/Nengo: The HIV test is free of charge to you. Visiting the Lwak Patient Support Center is also free of charge to you, except for the cost of your transportation to get there.

Pim mar kute mag Ayaki ni nono kuomi. Limo kar thieth mar joma ni gi kute mag Ayaki bende ni nono mak mana pesa wuoth makeli kanyo.

Alternatives to being HIV tested today/Yore moko mag pim kute mag Ayaki kawuono: You may choose to be tested for HIV, or you may refuse at this time. It is your choice. You will still be part of the IEIP study and the DSS. If you prefer to have your HIV testing done in the clinic, we will give you a referral note to use in the clinic for free testing. If you already know you are HIV positive, you do not need to be retested, but we would still like to ask you some questions.

Inyalo yiero pim kute mag Ayaki kawuono, kata inyalo tamori e sehegi. En yiero mari. Pod ibiro bedo achiel e nonro mar IEIP (togi DSS). Ka iyiero ni pim mari otim e klinik, wabiro miyi barua mondo mi opimi nono e klinik. Ka isengeyo ai in kod kute mag Ayaki, ok dawaher pimi, to wabiro penji penjo moko.

Persons to contact/Joma inyalo tudori go: If you have more questions or if you want to quit the study, please contact the IEIP study chief, Mr. Godfrey Bigogo at Kisian (2022983). If you have any questions about HIV testing or being HIV positive, contact Mr. Ochieng, the clinical officer at Lwak. If you have a question about your rights being in this study, please call the secretary of the KEMRI National Ethical Review Committee. Dr. Monique Wasunna, in Nairobi at 020-2722541.

Ka in gi penjo moko kata ka idwaro weyo nonro, yie itudri gi jatend nonro mar IEIP, Migosi Godfrey Bigogo e ofis ma Kisian (2022983). (kata Beatrice Olack in Nairobi at XXXX). Ka in gi penjo moko ewi pim mar kute mag Ayaki kata bedo gi kute mag Ayaki, tudri gi Migosi Ochieng, jathieth maduong man lwak. (kata Laktar Sally e Tabitha.) Ka in gi penjo kuom ratiro mari bedo e nonro, yie igo sime ne karan mar KEMRI National Ethical Review Committee. Laktar Monique Wasunna, Nairobi e namba mar sime 020-2722541.

**Consent for home-based HIV testing**

The HIV test has been explained to me. I have had a chance to ask questions and I feel that all my questions have been answered. I know that this HIV test is my choice. I have received a copy of this consent form. I agree to allow myself to be tested for HIV or give results of a HIV test done previously.

Pim mar kute mag Ayaki oselerna. Asebedo gi thuolo mar penjo kendo aneno ni penjo ga duto oseduoki. Angeyo ni pim mar kute mag Ayakini en yiero mara. Aseyudo achiel kuom otas mar yie. Ayie mondo opima kata chiwo duoko mar pimna mar kute mag Ayaki mane osetim chon.

Person	Name/Nying: .....	Signature/Seyi: .....	Date/Tarik.....
<p><i>(For those who are unable to sign their name, put an "X" on the signature line. A witness must verify and sign below./Kuom jogo maok nyal ndiko nyingegi, ket alama mar "X". Janeno nyaka ngi ma ket seyi e bwoye.)</i></p> <p>I have read and explained the consent form to the person named above and watched them make their mark./<u>Asesomo kendo lero otas yie ne jachiwre manyinge nimalo kendo ngiyo kaka giketo seyi.</u></p> <p>Signature of Interpreter/witness/Seyi mar janeno: _____</p> <p>Date/Tarik: _____</p>			

If my test result is positive today, I agree to have an HIV counselor come to my home in one month to give me my CD4 test results and to advise me on my treatment choices.

Ka duoko mara mar pim ogolo ni an gi kute mag Ayaki kawuono, ayie ni mondo jahochu mar kute mag Ayaki obi e dalana bang dwe achiel mondo omiya duoko kwan mara mar CD4 e del kendo ongadna rieko e yore mahero mag thieth.

Person	Name Nying: .....	Signature/Seyi: .....	Date/Tarik .....
<p><i>(For those who are unable to sign their name, put an "X" on the signature line. A witness must verify and sign below. /Kuom jogo maok nyal ndiko nyingegi, ket alama mar "X". Janeno nyaka ngi ma ket seyi e bwoye.)</i></p> <p>I have read and explained the consent form to the person named above and watched them make their mark./<u>Asesomo kendo lero otas yie ne jachiwre manyinge nimalo kendo ngiyo kaka giketo seyi.</u></p> <p>Signature of Interpreter/witness/Seyi mar janeno: _____</p> <p>Date/Tarik: _____</p>			

**Permission to store blood for future tests/Thuolo mar kano remo ne pim ma bange**

We would also like to ask if we could store the blood samples to do more tests at a later time. These may be tests that we do not have the ability to do at this time. Your specimen will be stored at KEMRI/CDC laboratories at Kisumu or Nairobi. Your name will not be on the specimen. Any information obtained from future tests that will be important for your health will be given to you.

Dwahir kwayo mondo wakan remo mondo otingo pim moko bange. Magi nyalo bedo pim ma ok wan gi nyalo mar timo sani. Rembi ibiro kan e ute pim mag KEMRI/CDC man Nairobi kata Kisumu. Nyingi ok bi bedo e remoni. Wach moro amora ma ibiro gol e pim mabange mabiro bedo maduong e ngimani, ibiro miyi.

If you do not want to have your specimen stored, it will be discarded. If you agree to this, but then have questions or later decide you don't want your specimen stored anymore, you can contact the people listed above.

Ka ok idwar ni rembi okan, ibiro wite. Ka iyie gi ma, to in gi penjo kata iloko pachi bange ni ok idwar ni okan rembi, inyalo tudori gi joma ondik nyingegi malogo.

The consent form has been explained to me and I agree for my specimen to be stored. I understand that I am free to change my mind at any time and that saying "NO" will have no effect on my family or me.

Otas mar yie oselerna kendo ayie mondo okan remba. Awinjo ni an thuolo mar loko pacha saa asaya kendo wacho ni "Ooyo" ok bi kelo chandruok ne jooda kata an.

Person	Name/Nying:.....	Signature/Seyi:.....	Date/Tarik
<i>(For those who are unable to sign their name, put an "X" on the signature line. A witness must verify and sign below. /Kuum jogo maok nyal ndiko nyingegi, ket alama mar "X". Janeno nyaka ngi ma ket sey e bwoye.)</i>			
I have read and explained the consent form to the person named above and watched them make their mark./Asesomo kendo lero otas yie ne jachiwre manyinge nimalo kendo ngiyo kaka giketo sey.			
Signature of Interpreter/witness/Seyi mar janeno: _____			
Date/Tarik: _____			

## **ASSENT FORM FOR THE HOME-BASED HIV TESTING NON-EMANCIPATED MINORS (13-17 YEARS OLD)**

*Mother (or guardian) should have already filled out a consent form for the child./Miyo (kata jarit) onego bed ni osendiko otas vie ne nyathi.*

### **Reason for doing HIV test/Gima omiyo itimo pim mar kute mag Ayaki.**

You are in the IEIP study. You are part of the IEIP study. We are offering HIV tests to everyone in the IEIP study. We can do the HIV test in your home today. We have talked to your parents and they said it was ok to ask you if you wanted to do this.

We will ask you a few questions. These questions are about your age, some of your behaviors, previous HIV testing, and certain illnesses. These questions don't take long and help us counseling you.

We ask to combine the HIV test result with the other data from the IEIP study and the DSS project. The IEIP field workers and the DSS field workers who visit your house will not find out these results.

In e nonro mar IEIP. In achiel e nonro mar IEIP. Wachiwo pim ne ji duto manie nonro mar IEIP. Wanyalo timo pim mar kute mag Ayaki e dalani kawuono. Wasewuoyo gi jonyuolni to giwacho ni en kare penji ka idwaro timo ma.

Wabiro penji penjo matin. Penjo gi ni ewi hiki, timbegi moko, pim mari mar kute mag Ayaki ma osekalo, togi touché moko. Penjo gi ok kaw thuolo kendo biro konyowa e miyi hocho.

Wakwayo riwo pim mar kute mag Ayaki togi weche moko maowuok e nonro mar IEIP (to gi nonro mar DSS- ma Asembo kende). Jotij nonro mag IEIP mane pap (togi jotij DSS mae pap) malimo odi, ok bingeyo duoko gi.

*How test is done and what it means/Kaka itimo pim togi tiende:* We will take a few drops of blood through a prick on the finger, like a malaria test. It will be less than a spoonful. It will be tested right away. A few drops will be kept for later testing on a piece of special paper. If you are HIV positive, we will offer to take a few drops of blood from your finger, less than a teaspoon. With this blood we can do a test at our lab that shows if you need treatment now or later.

The testing today will take about 30 minutes.

Wabiro kawo ondong' remo matin kuom chuoyo lith lweti, kaka pim mar Malaria. Obiro bedo matin ne kijiko achiel mar chai. Ibiro pime seche go. Ton remo matin ibiro kan ne pim mabange e otas moro. Ka in gi kute mag Ayaki, wabiro kawo remo matin e lith lweti, madirom kijiko matin. Gi remoni, wanyalo timo pim ma iluongo ni kwan mar CD4 e del. Pim ni nyiso ka idwaro thieth sani kata bange. Pim makawuono biro kawo dakika 30.

Risks of testing/Hinyruok manyalo wuok e pim: You may feel a slight sting (like a pin prick) when we take blood. The stick we use is clean, and the small amount of blood we take will not harm you. You may have a small amount of bleeding from the stick site briefly. Also, the results of your HIV test may make you upset or sad.

Inyalo winjo rem matin (kaka chwop kipino) ka wakawo remo. Kedi mawatiyogo ler kendo remo matin mawakawo ok bi hinyi. Remo nyalo chwer matin kama wachwoyo. Bende duoko mari mar pim samoro nyalo chwanyi kata ketho chunyi.

Benefits/Ber: If you test positive, you can get health care for HIV at a nearby clinic. I will tell your parents which clinic you can go to. If you test positive, I will ask you to visit your home again in about 1 month to discuss the results of your tests and your treatment choices. On that visit, I would also ask you a few more questions. I will only do a repeat visit to your home if you allow me.

Ka duoko oyudo ni in gi kute mag Ayaki, inyalo yudo rit korka thieth ne kute mag Ayaki e klinik man machiegni. Abiro nyiso jonyuolni klinik ma inyalo dhiye. Ka duoko oyudo ni in gi kute mag Ayaki, abiro kwayi mondo alimi e dala kendo bang dwe achiel mondo mi wawuo ewi duoko mar pimni to gi kit thieth ma diher. Chieng limbeni, abiro penji penjo moko be. Abiro mana duogo limi ka imiya thuolo.

Confidentiality/Rito siri: What we talk about and your test results will be kept as private as possible, even among your family members. However, you may decide to share the results and records with other people, like the doctors who may give medical care to you.

Gima wawacho to gi duoko mari mar pim, ibiro kan mopondo kaka nyalore, kata mana kuom joodu. Katakamano, inyalo dware nyiso jomoko wechegi gi duoko, kaka laktar machiwoni kony mar thieth.

Cost/Nengo: The HIV test is free of charge to you. Pim mar kute mag Ayaki ni nono kuomi.

Alternatives to being HIV tested today/Yore moko mag pim kute mag Ayaki kawuono: You may choose to be tested for HIV, or you may refuse at this time. It is your choice. You will still be part of the IEIP study and the DSS. If you prefer to have your HIV testing done in the clinic, we will give you a referral note to use in the clinic for free testing. If you already know you are HIV positive, you do not need to be retested, but we would still like to ask you some questions.

Inyalo yiero pim kute mag Ayaki kawuono, kata inyalo tamori e sechegi. En yiero mari. Pod ibiro bedo achiel e nonro mar IEIP (togi DSS). Ka iyiero ni pim mari otim e klinik, wabiro miyi barua mondo mi opimi nono e klinik. Ka isengeyo ai in kod kute mag Ayaki, ok dawaher pimi, to wabiro penji penjo moko.

Persons to contact/Joma inyalo tudori go

We gave your parents phone numbers of people to contact if you have questions. I can answer any questions you might have right now

Ne wamiyo jonyuolni nembni simu mag joma inyalo tudorigo ka in gi penjo. Anyalo duoko penjo moro amora ma inyalo bedogo sani.

**Assent for home-based HIV testing**

Do you want to have an HIV test done today in your home/  
Bende idwaro pim mar kute mag Ayaki e dalani kawuono?  
Yes/Ee No/Ooyo Don't know/Akia

Person	Name/Nying: .....	Signature/Seyi: .....	Date/Tarik.....
<i>(For those who are unable to sign their name, put an "X" on the signature line. A witness must verify and sign below. /Kuum jogo maok nyal ndiko nyingegi, ket alama mar "X". Janeno nyaka ngi ma ket seyi e bwoye)</i>			
I have read and explained the consent form to the person named above and watched them make their mark./Asesomo kendo lero otas yie ne jachiwre manyinge nimalo kendo ngiyo kaka giketo seyi.			
Signature of Interpreter/witness/Seyi mar Janeno: _____			
Date/Tarik: _____			

If my test result is positive today, I agree to have an HIV counselor come to my home in one month to give me my CD4 test results and to advise me on my treatment choices.

Ka duoko mara mar pim ogolo ni an gi kute mag Ayaki kawuono, ayie ni mondo jahochu mar kute mag Ayaki obi e dalana bang dwe achiel mondo omiya duoko kwan mara mar CD4 e del kendo ongadna rieko e yore mahero mag thieth.

Person	Name/Nying: .....	Signature/Seyi: .....	Date/Tarik.....
<i>(For those who are unable to sign their name, put an "X" on the signature line. A witness must verify and sign below. /Kuum jogo maok nyal ndiko nyingegi, ket alama mar "X". Janeno nyaka ngi ma ket seyi e bwoye)</i>			
I have read and explained the consent form to the person named above and watched them make their mark./Asesomo kendo lero otas yie ne jachiwre manyinge nimalo kendo ngiyo kaka giketo seyi.			
Signature of Interpreter/witness/Seyi mar janeno: _____			
Date/Tarik: _____			

**Permission to store blood for future tests/Thuolo mar kano remo ne pim mabange.**

We would also like to ask if we could store the blood samples to do more tests at a later time. These may be tests that we do not have the ability to do at this time. Your child's specimen will be stored at KEMRI/CDC laboratories at Kisumu or Nairobi. Your child's name will not be on the specimen. Any information obtained from future tests that will be important for your child's health will be given to you.

Dwaher kwayo mondo wakan remo mondo otingo pim moko bange. Magi nyalo bedo pim ma ok wan gi nyalo mar timo sani. Remb nyathini ibiro kan e ute pim mag KEMRI/CDC man Kisumu kata Nairobi. Nying nyathini ok bi bedo e remoni. Wach moro amora ma ibiro gol e pim mabange mabiro bedo maduong e ngiman nyathini, ibiro miyi.

If you do not want to have your child's specimen stored, it will be discarded. If you agree to this, but then have questions or later decide you don't want your child's specimen stored anymore, you can contact the people listed above.

Ka ok idwar ni remb nyathini okan, ibiro wite. Ka iyie gi ma, to in gi penjo kata iloko pachi bange ni ok idwar ni okan remb nyathini, inyalo tudori gi joma ondik nyingegi malogo.

The consent form has been explained to me and I agree for my child's specimen to be stored. I understand that I am free to change my mind at any time and that saying "NO" will have no effect on my family or me.

Otas mar yie oselerna kendo ayie mondo okan remb nyathina. Awinjo ni an thuolo mar loko pacha saa asaya kendo wacho ni "Ooyo" ok bi kelo chandruok ne jooda kata an.

Person	Name/Nying: .....	Signature/Seyi: .....	Date/Tarik.....
<i>(For those who are unable to sign their name, put an "X" on the signature line. A witness must verify and sign below/Kuom jogo maok nyal ndiko nyingegi, ket alama mar "X". Janeno nyaka ngi ma ket seyi e bwoye..)</i>			
I have read and explained the consent form to the person named above and watched them make their mark./ <u>Asesomo kendo lero otas yie ne jachiwre manyinge nimalo kendo ngiyo kaka giketo seyi.</u>			
Signature of Interpreter/witness/Seyi mar janeno: _____			
Date/Tarik: _____			

## CONSENT FORM FOR THE HOME-BASED HIV TESTING OF NON-EMANCIPATED MINORS (13-17 YEARS OLD)

*Read to the mothers or guardians of non-emancipated minors ages 13-17 years old.*  
Somme mine kata jorit nyithindo man ekind higni 13-17m man thuolo.

### ***Reason for doing HIV test/Gima omiyo itimo pim mar kute mag Ayaki.***

Your child is part of the IEIP study. We are offering HIV tests to everyone in the IEIP study. We can do the HIV test in your home. This saves you time and money and is more private. We use the same tests the Ministry of Health advises. You have a right to decline the test.

We will ask all persons a few questions, similar to those asked at the VCT center. These questions are about your child's age, some of your child's behaviors, previous HIV testing, and certain illnesses.

We ask to combine the HIV test result with the other data from the IEIP study and the DSS project. The IEIP field workers and the DSS field workers who visit your house will not find out these results.

Nyathini en achiel e nonro mar IEIP. Wachiwo pim ne ji duto manie nonro mar IEIP. Wanyalo timo pim mar kute mag Ayaki e dalani. Ma konyo e thuolo mari to gi pesa, kendo en siri moloyo. Watiyo gi pim machal gi ma migao mar thieth ngade rieko ni otigo. In gi ratiro mar tamori pim.

Wabiro penjo ji duto penjo machal gi ma ipenjo e kuonde mar pim gi hocho. Penjo gi gin ewi hik nyathini, timbene moko, pim mare mar kute mag Ayaki mokalo, togi touché moko.

Wakwayo riwo pim mar kute mag Ayaki togi weche moko maowuok e nonro mar IEIP (to gi nonro mar DSS- ma Asembo kende). Jotij nonro mag IEIP mane pap (togi jotij DSS mae pap) malimo odi, ok bingeyo duoko gi.

*How test is done and what it means/Kaka itimo pim togi tiende :* We will take a few drops of blood through a prick on the finger, like a malaria test. It will be less than a spoonful. It will be tested right away. A few drops will be kept for later testing on a piece of special paper. If your child is HIV positive, we will offer to take a few drops of blood from his/her finger, less than a teaspoon. With this blood we can do a test at our lab that shows if he/she needs treatment now or later.

A negative test means your child does not have HIV. A positive result means s/he has HIV. If your child is HIV positive, we will offer to take blood from your child's arm, about two teaspoons. With this blood we can do a test at our lab called CD4 cell count. This test shows if your child needs treatment now or later.

The counseling and the test today will take about 30 minutes.

Wabiro kawo odonge remo matin kuom chuoyo lith seyi, kaka pim mar Malaria. Obiro bedo matin ne kijiko achiel. Ibiro pime seche go. Ton remo matin ibiro kan ne pim mabange e otas moro.

Duoko ma negative nyiso ni nyathini onge gi kute mag Ayaki. Duoko ma positive nyiso ni nyathini nigi kute mag Ayaki. Ka nyathini nigi kute mag Ayaki, wabiro kawo remo matin e bade, madirom kijiko ariyo. Gi remoni, wanyalo timo pim ma iluongo ni kwan mar CD4 e del. Pim ni nyiso ka nyathini dware thieth sani kata bange.

Hocho gi pim kawuono biro kawo madirom dakika 30.

*Risks of testing/Hinyruok manyalo wuok e pim:* Your child may feel a slight sting (like a pin prick) when we take blood. The stick we use is clean, and the small amount of blood we take will not harm him/her. Your child may have a small amount of bleeding from the stick site briefly. Also, the results of your child's HIV test may make you and/or him/her upset or sad.

Nyathini nyalo winjo rem matin (kaka chwopo mar kipino) ka wakawo remo. Kedi mawatiyogo ler kendo remo matin mawakawo ok bi hinye. Nyathini nyalo bedo gi chwer remo matin kama wachwoyo. Bende duoko nyathini mar pim samoro nyalo chwanyou kata ketho chunyu.

*Benefits/Ber:* If your child tests positive, he/she can get health care for HIV at a nearby clinic. He/she will be referred to the Patient Support Center at Lwak. The results of your child's CD4 count test will be available to the clinical officer at the Patient Support Center so that he/she will not have to have that test done again. We will also tell you about other Patient Support Centers that are open to you in your area. At the Patient Support Center, you will be offered drugs used in HIV for your child. This study will not pay for these drugs, but they are offered by the Kenya Ministry of Health in these sites free of charge.

If your child tests positive, I will ask you to visit your home again in about 1 month to discuss the results of the CD4 test and your child's treatment choices. On that visit, I would also ask you and your child a few more questions. I will only do a repeat visit to your home if you allow me.

Ka duoko oyudo ni nyathini nigi kute mag Ayaki, onyalo yudo rit korka thieth ne kute mag Ayaki e klinik man machiegni. Ibiro ore kar thieth mar joma ni gi kute mag Ayaki ma Lwak e klinik machiwo rit ne jogo manigi kute mag Ayaki. Duoko mar kwan CD4 man e del, ibiro mi jathieth mane kar rito jotuo mondo mi kik onuo pimni kendo. Bende wabiro nyisi kuom kuonde rit jotuo ma oyawne e gwengu. E kar thieth mar joma ni gi kute mag Ayaki, ibiro miyi yedhe maitiyogo kuom kute mag Ayaki ne nyathini. Nonroni ok bi chulo kuom yedhegi, to ichiwogi nono kuondegi gi migao mar thieth

Ka duoko oyudo ni nyathini nigi kute mag Ayaki, abiro kwavi mondo alimi e dala kendo bang dwe achiel mondo mi wawuo ewi kwan mar CD4 e del to gi kit thieth ma

diher ne nyathini. Chieng limbeni, abiro penji togi nyathini penjo moko be. Abiro mana duogo limi ka imiya thuolo.

Confidentiality/Rito siri: What we talk about and your child's test results will be kept as private as possible, even among your family members. We will keep the records using numbers, not names. We will keep the records in secure files at KEMRI/CDC. However, you may decide to share the results and records with other people, like the doctors who may give medical care to your child. Your child's name or other things that may identify him/her will not appear when we discuss this project.

*Rito siri*

Gima wawacho to gi duoko nyathini mar pim, ibiro kan mopondo kaka nyalore, kata mana kuom joodi. Wabiro kano wehegi e yor nembni, maok nying. Wabiro kano wehegi e fainde ma olor maber e ofis mar KEMRI/CDC. Katakamano, inyalo dwaro nyiso jomoko wehegi gi duoko, kaka laktar machiwoni kony mar thieth. Nying nyathini kata gimoro manyalo mi ongeye, ok bi wuok ka wawuoyo ewi nonroni.

Cost/Nengo: The HIV test is free of charge to you. Visiting the Lwak Patient Support Center is also free of charge to you, except for the cost of your transportation to get there.

Pim mar kute mag Ayaki ni nono kuomi. Limo kar thieth mar joma ni gi kute mag Ayaki bende ni nono mak mana pesa wuoth makeli kanyo.

Alternatives to being HIV tested today/Yore moko mag pim kute mag Ayaki kawuono: You may choose for your child to be tested for HIV, or you may refuse at this time. It is your choice. You and your child will still be part of the IEIP study and the DSS. If you prefer to have your child's HIV test done in the clinic, we will give you a referral note to use in the clinic for free testing. If you already know your child is HIV positive, he/she does not need to be retested, but we would still like to ask him/her some questions.

Inyalo yiero ne nyathini pim kute mag Ayaki kawuono, kata inyalo tamori e sehegi. En yiero mari. In kata nyathini pod biro bedo achiel e nonro mar IEIP (togi DSS). Ka iyiero ni pim nyathini otim e klinik, wabiro miyi barua mondo mi opime nono e klinik. Ka isengeyo ai in kod kute mag Ayaki, ok dawaher pimi, to wabiro penji penjo moko.

Persons to contact Joma inyalo tudori go: If you have more questions or if you want your or your child to quit the study, please contact the IEIP study chief, Mr. Godfrey Bigogo at Kisian (2022983). If you have any questions about HIV testing or being HIV positive, contact Mr. Ochieng, the clinical officer at Lwak. If you have a question about your rights being in this study, please call the secretary of the KEMRI National Ethical Review Committee. Dr. Monique Wasunna, in Nairobi at 020-2722541.

Ka in gi penjo moko kata ka in gi nyathini dwaro weyo nonro, yie itudri gi jatend nonro mar IEIP, Migosi Godfrey Bigogo e ofis ma Kisian (2022983). (kata Beatrice Olack in Nairobi at XXXX). Ka in gi penjo moko ewi pim mar kute mag Ayaki kata bedo gi kute mag Ayaki, tudri gi Migosi Ochieng, jathieth maduong man lwak. (kata Laktar Sally e Tabitha.) Ka in gi penjo kuom ratiro mari bedo e nonro, yie igo sime ne karan mar KEMRI National Ethical Review Committee. Laktar Monique Wasunna, Nairobi e namba mar sime 020-2722541.

## Consent for home-based HIV testing

The HIV test has been explained to me. I have had a chance to ask questions and I feel that all my questions have been answered. I know that this HIV test is my choice. I have received a copy of this consent form. I agree to allow my child to be tested for HIV or give results of a HIV test done previously.

Pim mar kute mag Ayaki oselerna . Asebedo gi thuolo mar penjo kendo aneno ni penjo ga duto oseduoki. Angeyo ni pim mar kute mag Ayakini en yiero mara. Aseyudo achiel kuom otas mar yie. Ayie mondo nyathina opim kata chiwo duoko mar pimne mar kute mag Ayaki mane osetim chon.

Person	Name/Nying: .....	Signature/Seyi: .....	Date/Tarik.....
<p><i>(For those who are unable to sign their name, put an "X" on the signature line. A witness must verify and sign below. /Kuom jogo maak nyal ndiko nyingegi, ket alama mar "X". Janeno nyaka ngi ma ket seyi e bwoye)</i></p> <p>I have read and explained the consent form to the person named above and watched them make their mark. <u>Asesomo kendo lero otas yie ne jachiwre manyinge nimalo kendo ngiyo kaka giketo seyi.</u></p> <p>Signature of Interpreter/witness/Seyi mar janeno: _____</p> <p>Date/Tarik: _____</p>			

If my child's test result is positive today, I agree to have an HIV counselor come to my home in one month to give me my child's CD4 test results and to advise us on his/her treatment choices.

Ka duoko nyathina mar pim ogolo ni en gi kute mag Ayaki kawuono, ayie ni mondo jahocho mar kute mag Ayaki obi e dalana bang dwe achiel mondo omiya duoko kwan nyathina mar CD4 e del kendo ongadna rieko e yore mahero ne nyathina mag thieth.

Person	Name/Nying: .....	Signature/Seyi: .....	Date/Tarik.....
<p><i>(For those who are unable to sign their name, put an "X" on the signature line. A witness must verify and sign below. /Kuom jogo maak nyal ndiko nyingegi, ket alama mar "X". Janeno nyaka ngi ma ket seyi e bwoye)</i></p> <p>I have read and explained the consent form to the person named above and watched them make their mark. <u>Asesomo kendo lero otas yie ne jachiwre manyinge nimalo kendo ngiyo kaka giketo seyi.</u></p> <p>Signature of Interpreter/witness/Seyi mar janeno: _____</p> <p>Date/Tarik: _____</p>			

**Permission to store blood for future tests/Thuolo mar kano remo ne pim mabange.**

We would also like to ask if we could store the blood samples to do more tests at a later time. These may be tests that we do not have the ability to do at this time. Your child's specimen will be stored at KEMRI/CDC laboratories at Kisumu or Nairobi. Your child's name will not be on the specimen. Any information obtained from future tests that will be important for your child's health will be given to you.

If you do not want to have your child's specimen stored, it will be discarded. If you agree to this, but then have questions or later decide you don't want your child's specimen stored anymore, you can contact the people listed above.

Dwaher kwayo mondo wakan remo mondo otingo pim moko bange. Magi nyalo bedo pim ma ok wan gi nyalo mar timo sani. Remb nyathini ibiro kan e ute pim mag KEMRI/CDC man Kisumu kata Nairobi. Nying nyathini ok bi bedo e remoni. Wach moro amora ma ibiro gol e pim mabange mabiro bedo maduong e ngiman nyathini, ibiro miyi.

The consent form has been explained to me and I agree for my child's specimen to be stored. I understand that I am free to change my mind at any time and that saying "NO" will have no effect on my family or me.

Otas mar yie oselerna kendo ayie mondo okan remb nyathina. Awinjo ni an thuolo mar loko pacha saa asaya kendo wacho ni "Ooyo" ok bi kelo chandruok ne jooda kata an.

<b>Person</b>	<b>Name/Nying:</b> .....	<b>Signature/Seyi:</b> .....	<b>Date/Tarik</b> .....
<p><i>(For those who are unable to sign their name, put an "X" on the signature line. A witness must verify and sign below. /Kuom jogo maok nyal ndiko nyingegi, ket alama mar "X". Janeno nyaka ngi ma ket seyi e bwoye.)</i></p> <p>I have read and explained the consent form to the person named above and watched them make their mark. Asesomo kendo lero otas yie ne jachiwre manyinge nimalo kendo ngiyo kaka giketo seyi.</p> <p>Signature of Interpreter/witness/Seyi mar janeno: _____</p> <p>Date/Tarik: _____</p>			