REPORT

FORMATIVE STUDY

ON

COMMUNITY MOBILISATION INTERVENTION MODEL

ON

PMTCT/ART

By ISLAMIC MEDICAL ASSOCIATION OF UGANDA

In collaboration with
Centers For Disease Control (CDC Uganda)

April 2003

Report on the Formative Study

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Acronyms

AIC	AIDS Information Centre
AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti Retro Viral Drugs
ART	Anti Retro Viral Therapy
ANC	Antenatal Care
CAAP	Community Action for AIDS Prevention
CDC	Centers for Disease Control
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
IEC	Information Education Communication
IFNAU	Interfaith Network Against AIDS in Uganda
IMAU	Islamic Medical Association of Uganda
LC	Local Council
JCRC	Joint Clinical Research Centre
MTCT	Mother to Child Transmission
NACWOLA	National Community of Women Living with HIV/AIDS
PLWHA	People Living with HIV/AIDS
PMTCTP	Prevention of Mother to Child Transmission Programme
PMTCT	Prevention of mother to child transmission
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infection
TASO	The AIDS Support Organization
TBA	Traditional Birth Attendant
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counseling and Testing

Abstract

In order to avert the burden of vertical transmission of HIV, the GOU, UNICEF UNAIDS and other partners have initiated to date 28 sites countrywide in 21 districts where women and their infants have received antiretroviral drug regimen designed to reduce mother to child transmission (MTCT). However pregnant women are not fully utilizing the PMTCT services. The aim of the study was therefore to ascertain the factors that promote or hinder the use of these services. It examined specifically knowledge, attitudes, beliefs and practices (KABP) regarding HIV status; MTCT; health care seeking behavior of pregnant mothers; identified key actors and IEC messages in use, and solicited suggestions on how best PMTCTP should be implemented.

The study was conducted in Kampala district in three divisions of Kawempe, Makindye and Rubaga. A total of 12 FGDs were conducted covering 39 community leaders and 73 community members.

The perceived knowledge of HIV sero-status was found to be very low in the communities since few people have taken the endeavor to test. There was also little awareness of the importance of couple undertaking VCT or of the prevalence of discordance. Most participants thought it was impossible to have discordance within marital relationship. A number of constraints to VCT were noted such as stigma, emotional stress, lack of confidentiality at some testing centers, lack of information to the community, accessibility and related costs. Suggestions for promoting VCT were given as IEC, reducing the testing fee further and if possible making it free, increasing service access and making testing mandatory so as to involve men.

In addition, participants recommended that IMAU should educate the community on the benefits of VCT and strategies on how best to do this. Furthermore, the program should aim to integrate other HIV/AIDS interventions since most community members did not know their status or that of their partners. Such interventions can include: increasing the acceptance of condom use, the reduction in risk behavior, prevention of mother to child transmission activities and empowerment of women to negotiate with their husbands or partners for condom use, VCT and other reproductive health services.

Co-opting men into the program was indicated as very critical in increasing participation and support, since some men are non-committal to the health needs of their wives and children. The public awareness program should particularly target men and efforts should be made to encourage them to accompany their wives to the health centre. In addition, men should be sensitized on the benefits of VCT and ART services as well as the advantages of their wives seeking health services from the health facilities.

The study also identified hospitals and health centers as the main sources of health care for pregnant women. However, household poverty, poor quality services, ignorance of some mothers about the benefits of utilizing health facilities and irresponsible husbands were cited as important barriers to utilization of services in health facilities.

Generally there was very low knowledge on PMTCT and PMTCTP. Whereas a good proportion of participants seemed to have acknowledged that mother to child transmission of HIV can be possible, however, most participants were not aware that MTCT can be prevented and there was a program for prevention, which could enable a HIV positive mother to produce HIV negative

integration. The main persons recommended for IEC were community leaders (religious leaders and LCs).

Knowledge on ART was also limited. Only one third of the participants knew about ART. Participants therefore recommended sensitization on costs of ART, source, benefits, side effects, eligibility criteria, skills for demystifying counter productive myths, management of ART and dosage. In all, the PMTCT program is fundamental and highly supported by the community. Sensitization of the potential beneficiaries should be the starting point and backbone of the program.

Chapter 1. Introduction

1.1 Background

According to HIV/AIDS Surveillance Report 2002, the HIV prevalence in Uganda was estimated to be 6.5%, reflecting a significant burden on the health care and community systems. The problem is compounded further with women of reproductive age (15-49 years) forming a significant proportion of those infected with HIV, hence having serious implications on the mother to child transmission of HIV. Epidemiological study at Mulago hospital from 1991- 1995 that looked at the consequences of HIV-1 in pregnancy showed that the vertical transmission rate is about 27% without any intervention. From this rate, an estimated 30,000 of the 109,200 babies born to HIV infected mothers are infected annually (Ministry of Health, PMTCT Scale-Up Plan, 2001-2005).

Several studies showed that the administration of ARV therapy in pregnant women was associated with tremendous reduction of mother to child transmission (MTCT) of HIV by up to 50% (Ministry of Health, July 2001). In order to avert the burden of vertical transmission of HIV, the Government in collaboration with UNAIDS, UNICEF, and other partners initiated a pilot PMTCT program in 2000 as part of the fulfillment of the National Strategic Framework for HIV/AIDS Activities in Uganda 2000/1-2005/6. Following promising results, the National PMTCT program began scaling up in district –level hospitals. The national PMTCT program targets all pregnant women attending ANC at the PMTCT sites and their husbands to provide a comprehensive package of PMTCT services including: HIV prevention services; screening; treatment; care and follow-up.

To-date, 28 sites are operational countrywide where women and their infants have received anti-retroviral drug regimen designed to reduce MTCT. Within Kampala district, several sites have been set up to implement PMTCT interventions and to provide antiretroviral drugs. However, pregnant women are not fully utilizing PMTCT services. Anecdotal reports reveal serious misconceptions about the use, benefits and side effects of antiretroviral (ARV) drugs. Inadequate education and sensitization of the concerned communities on issues related to PMTCT and antiretroviral treatment are major contributing factors to this aforesaid status quo. Besides, not all pregnant women attend ANC so as to access PMTCT services. However, information about PMTCT and ARVs is evolving rapidly. There is therefore urgent need to educate communities and to keep them updated on new developments in these areas.

Given the magnitude of the problem, Uganda's Ministry of Health and other PMTCT stakeholders including UNAIDS support increased private sector participation in the campaign to reduce MTCT. They embrace the role that private sector institutions would play in ensuring the appropriate provision of VCT, inclusion of PMTCT information in ANC sessions, administration of nevirapine and provision of safe infant feeding guidance in select private sector health care facilities. It is therefore on this background that the Islamic Medical Association of Uganda (IMAU), an NGO with headquarters in Kampala would like to start community sensitization program. IMAU is a registered non-governmental organization established in 1988. The association consists of over 300 Muslim health

IMAU has experience in educating communities on issues related to HIV/AIDS. Through the project entitled **Community Action for AIDS Prevention (CAAP),** IMAU has developed a network for community mobilization in Kampala district. The approach chosen for the CAAP project was to train religious and community leaders of different faiths jointly on issues of HIV/AIDS prevention and control. The religious leaders included those from mosques, catholic churches, protestant churches and independent churches. Other community leaders included local council leaders and occupational group leaders like market vendors and *boda-boda* operators (bicycle and motorbike taxis). The trained leaders later trained their communities through group talks and home visits. Therefore IMAU plans to replicate the CAAP approach that has proven to be successful not only in mobilizing communities but also in achieving greater acceptance rates of the program by the communities.

IMAU plans to use this network in a new project focusing on PMTCT to: -

- Educate selected communities in Kampala on issues of PMTCT and antiretroviral treatment
- Work with the Interfaith Network Against AIDS in Uganda (IFNAU) to reach all the identified stakeholders
- Use mass media to reinforce the education of the communities on PMTCT and
- Anti-retroviral treatment
- Expand the PMTCT and ARVs to other communities if the program proves successful.

Before starting the PMTCT program, there was then need to conduct the formative research to provide baseline data for the project.

1.2 Objectives of the formative research

The main objective of the formative research was to establish baseline data on community knowledge and beliefs related to PMTCT and antiretroviral treatment.

Specific objectives were to:

- Identify knowledge gaps of community members and community leaders on HIV sero-status; discordant couples; ART, mother to child transmission of HIV, prevention as well as the PMTCT program.

- Explore issues pertaining to health care for pregnant women such as benefits of seeking health care from health facilities, barriers and ways of encouraging the utilization of health centres by pregnant women.

- Assess the attitudes of the community leaders and community members about the PMTCT program as well as strategies for involving men.

- Identify the key actors within the community and IEC messages for community mobilization and education.

- Solicit suggestions as to how the PMTCTP should be implemented.

Chapter2. Methodology

2.1 Introduction

The chapter provides a description of the research methodology including the settings and geographical coverage of the research, the different groups, number of participants, major themes for focus group discussion (FGD) and quality control aspects.

2.2 Study Design, Setting, Method used and Participants

The study design was cross sectional and descriptive. A qualitative research approach using focus group discussions was conducted in Kampala district in the three divisions of Kawempe, Makindye and Rubaga. A total of 12 FGDs were conducted covering 39 community leaders and 73 community members. Religious leaders and local councilors were particularly selected because of the good experience acquired from previous health education programmes held by IMAU. Through this previous programme, IMAU has already established a solid base for community mobilization since religious leaders are respected in the communities. A broad spectrum of community members were interviewed to provide comparative views and knowledge related to PMTCT with details presented in the table below.

Table: FGD participants by group category and division

Group Category	No. of Participants			Location	Division
Community Leaders	M	F	Total		
1) Christian faith leaders (Mixed sex)	4	3	7	St. Noah Church, Makerere West	Kawempe
2) Muslim faith leaders	11	NA	11	Katwe Jamia Mosque- Mengo	Rubaga
3) Christian women in positions of leadership	NA	6	6	St. Agnes Church	Makindye
4) LCs	4	6	10	Kibuye P7 – Najanankumbi	Makindye
5) Muslim women leaders	NA	5	5	Diniya Mosque, Ndeeba	Rubaga
Subtotal	19	20	39		
Community members					
6) Christian men	9	NA	9	Kagodo Church	Makindye
7) Christian women	NA	10	10	Kasubi	Kawempe
8) Muslim men	17	NA	17	Rayyat Mosque	Makindye
9) Muslim women	NA	12	12	Bwaise	Kawempe
10) HIV Positive women	NA	10	10	AIC-Kisenyi	Rubaga
11) HIV Positive men	9	NA	9	AIC- Kisenyi	Rubaga
12) Women who are ANC health care providers	NA	6	6	IMAU	Rubaga
Subtotal	**35**	**38**	**73**		
Grand Total	**54**	**58**	**112**		

NA= Not Applicable

2.3 Research process and quality control:

1) Meetings were held with community leaders from the three divisions to inform them about the activities of the project including the baseline formative research.

1) Trainers were interviewed, and 25 selected by IMAU Project Management Team. Ten of the trainers were then trained as facilitators for the formative research for 4 days. The training focused on the background to PMTCT, VCT, basic information on HIV/AIDS and the project, FGD theory, note taking and report writing skills as well as field mobilization of participants.

2) The survey instruments for the formative research (FGD guides) were designed and refined with technical assistance from CDC-Atlanta and CDC-Uganda. They were pre-tested in 2 communities of Kampala district, which were later excluded from the actual study to avoid any possible bias. Pre-testing was conducted for 2 days involving 10 interviewers and 2 supervisors from CDC. Later the three FGD guides were translated into Luganda, the main local language.

3) The community leaders were requested to identify suitable participants for Focus Group Discussions (FGDs).

4) Focus Group Discussions were conducted for all the selected groups. Data was collected on various issues related to VCT, Health care for pregnant women, ART and PMTCT (see annex for details).

6) The data collection exercise was closely monitored and supervised by a senior staff of IMAU. The supervision was to ensure that interviewers were promptly deployed, good arrangements and mobilization of study participants and that FGD's were well facilitated and discussions appropriately recorded. The FGD discussions were recorded on tape recorders to capture details to augment the short hand notes.

7) **Debriefing session**
After field work-data collection process, a one-day debriefing session was held drawing the health education consultants from Makerere University School of Education, CDC trainers, IMAU senior management as well as trainers of community educators who also doubled as interviewers. During the debriefing, interviewers shared their field experiences and provided results of their preliminary field analysis and recommendations for the IMAU community education programme.

8) **Data analysis**
After the transcription and translation of the tape-recorded data, CDC facilitators using Ethnograph did detailed data analysis. The data was entered in Microsoft word and imported into Ethnograph, formatted and coded according to themes. Frequencies for the various themes were generated and comparisons were done for different groups (e.g. Muslims, Christians, HIV positives, men and women).

Results

Chapter 3. Voluntary HIV Counseling and Testing

3.1 Introduction

The study assessed knowledge on HIV sero status and the circumstances that prompt people to go for voluntary counseling and testing (**VCT**). In addition, the enabling and constraining factors for HIV testing, advantages and disadvantages of testing, suggestions for promoting VCT services and implications for the IMAU program were assessed.

3.2 Perceived Knowledge of HIV Sero-status

Majority of the Focus Group Discussion (**FGD**) participants across the different groups noted that most community members did not know their HIV status. The most common reason given by participants was that most people had never gone for VCT services. One Local councilor said that only 10% of the people go for VCT services. In addition, a Muslim woman, a Christian male teacher, a Christian religious leader, two ANC health workers and two positive men all noted that people fear to test, they fear the outcome of a positive result which can lead to suicide/death, stigmatization and rejection from the social group. A Christian woman with secondary education noted that even if some people knew their status, very few would publicly disclose their status. A Muslim leader also noted that some members of the community would not bother to test since they felt they were in very faithful sexual relationships.

A few participants however acknowledged that some community members felt they "knew" their status even without testing especially when they had observed signs and symptoms associated with HIV/AIDS or lost a partner or child(ren).

On the other hand, a few respondents (3) noted that some community members felt that the disease was wide spread and everybody will die. They did not therefore feel obliged to test since they felt they already had the virus.

> *"We all have it.* ***'Fenna twafa dda'*** *translated as we are all dead",*
> (Muslim 33 years, O'level, FGD Muslim leaders, Mengo).

A local councilor/social worker noted that the youths were particularly more vulnerable to the afore-mentioned behavior especially those who attend disco dances and engage in risky sexual activities.

3.3 Perceived Knowledge of discordance

The study assessed community knowledge on discordance. Level of awareness on discordance was generally very low. Only one quarter of the participants had heard of discordant couples (38/112). Surprisingly, the knowledge was proportionately higher

participants thought it was impossible to have discordance and more so within marital relationship. They argued that a partner could still be in the window period and may later test positive. A female participant, Christian and teacher doubted the effectiveness of condoms incase discordance was attributed to the use of condoms, she felt that the virus could pass through even if people use condoms. Another female participant felt it was impossible for one partner to escape the infection since most times couples have unprotected sex.

On the other hand, participants who had knowledge of discordant couples argued that they had evidence of some neighbours and relatives living for long years even after the death of their partners. Two participants thought it could be because of separation or couples living far apart, one participant felt consistent use of the condom was the reason for discordance, yet two Muslim women and a positive woman thought it was because of Gods mercy. Two others attributed it to luck. Another male Muslim leader related discordance to lack of faithfulness among couples while a Christian religious leader attributed discordance to the differences in the blood cells. He said some cells are castrated 'obulaawo' while others are not.

Three participants related discordance to the manner in which sexual activity takes place. One female and two male Muslims attributed discordance to women who allow easy penetration, men who take short time to ejaculate and those who are not rough during sex. A Muslim man/driver said that women who allow easy penetration because they are *anatomically wide* could avoid bruises or sores during sex that could have otherwise provided an opportunity for the virus to penetrate. A positive man attributed discordance to lack of sores in the private parts of the sexual partners during sex that could provide an optimum environment for the HIV virus to penetrate.

> " I think it is possible. I hear that if a woman is wide (mugazi) she may survive the disease especially if she has a lot of viginal fluids. This is why the young girls get it faster",
> (Female, local council leader).

3.4 Circumstances that lead people to test for HIV

The most important circumstances identified by the participants to motivate people into having HIV test were:

- **Sickness,** which was mentioned as the commonest reason for testing for most groups of people. Participants noted that people test when they begin to fall sick frequently with signs and symptoms such as fever, STDs, herpeszoster, loss of weight, uncontrolled monthly period for women, on and off fever and other unusual signs and symptoms.

- **Marriage** was the second important reason for testing among both Muslim and Christian respondents. Religious leaders noted that it is criminal and evil before God to kill a fellow human being. A couple planning to get married is advised to

- **Risky sexual behavior** was the third reason for testing. This was particularly common among the Muslim men. Participants noted that people reflect on their past risky sexual activities such as having un-protected sex with many sexual partners and prostitutes. Some Moslem women noted lack of faithfulness among married couples especially in polygamous relationships. A Muslim leader noted that people go to test when they have gotten involved in sexual relationship with "nakyeyombekedde" –a woman who doesn't have a husband or concubine. Based on these experiences they felt obliged to confirm their sero-status:

> "We all mess at times. Whenever you are skeptical of the past behavior and the health care providers are suggesting you ascertain your sero-status, it is ok to test for HIV…",
> (Male, 32 years, A' level, married, FGD Christian leaders, Makerere).

- **Death of a partner or child/children** was mentioned by participants especially HIV positive men and women as another reason that spurred some community members to test for HIV especially if the deceased were suspected to have HIV/AIDS.

- **Pregnancy:** Six participants mentioned pregnancy as a reason for testing. One elderly Christian women leader insisted that every woman in childbearing age should go for HIV test before getting pregnant or giving birth.

> "When she is not married and gets pregnant, and probably had not tested with the man responsible for the pregnancy; testing will help to plan for the child to be born especially if the mother tests positive, then PMTCT is done" (Male, P7, Widower and Volunteer, FGD Positive men AIC).

The other reasons indicated by participants (8) included; reuniting after separation, readiness to make love or sexual encounter, accidents or blood transfusions that are suspected to be unsafe.

3.5 Enabling factors for VCT

Listed below are the factors that participants noted as providing an enabling environment for VCT.

- Information provision to the community was noted by participants to be the leading factor for enhancing VCT for most groups of respondents. Once people are informed about the benefits of testing, they are more likely to test.

- Making VCT mandatory was also noted as an important factor that could compel people to have HIV test.
- Other factors noted were free or affordable tests, confidentiality exhibited by service providers, monetary incentives, attending ANC services and the provision of cheap/free ARV drugs. A female community leader (LC) argued that people need to be given hope of getting the cheap drugs, now it is so expensive and just talking is useless. A Muslim teacher also recommended that the role of age was important in attracting potential clients i.e. if young people were tested by fellow young health workers and vice versa if old people were tested by old workers it would enhance acceptance rate among the potential clients.

3.6 Constraints to VCT

The main constraints to VCT services by importance:

Emotional stress; was noted as the most important constraint to VCT especially by Muslim women and Christian men. Participants reported that HIV positive results could lead to shock and premature death especially among the youth who were said to be more likely to commit suicide. An elderly Christian women leader decried that you can get depressed when you test positive, you know that you are going to die.

> *"Some youths say they would rather die unaware than to be tested positive when they go for VCT which can make you commit suicide",* (Male 24 years, S6, Chairperson Youth/Dramatist, FGD LCs, Najanakumbi).
>
> *"There is a lot of fear especially fear of the result from the blood sample. There is also fear of living with the virus. I have a friend whose partner died prematurely because when they tested, they were discordant. He failed to cope with the situation… and died",* (Female 50years, O' level, housewife, FGD Christian faith leaders, Makerere)

Stigma was reported as the second important constraint to VCT especially among the Christian faith leaders, ANC health care workers and Muslims. Fear of not getting high posts or promotions, discriminations in the family, work places and the community and fear of family breakdowns were noted as aspects of stigma. One participant remarked that sex was becoming commercialized and therefore sex workers would fear to go for VCT as the exposure may be stigmatizing leading to loss of their customers if they came to know about their status. Some participants commented that clients would feel ashamed or shy if they found people they knew at the testing centers as it could also lead to their being stigmatized by society.

> *"Fearing to see the result because after testing positive death is the next issue. '**Okwelalikirira nokwenyamira**' [worrying and depression]. He can even be stopped from work and also experiencing a lot of stigma'*, (Male 32 years, O/level, self employed, FGD Christian men, Kagodo).

Mutual trust tallied with stigma as the second important constraint to VCT: Seven participants also observed that some couples for instance rely on the mutual trust they have for each other and therefore did not see any reason for testing.

Lack of confidentiality: Some participants reported that potential clients fear taking tests because of lack of confidentiality by the service providers who they said would gossip publicly about them.

Lack of information: participants especially Muslims noted that information was still inadequate in the communities especially regarding the benefits of testing.

> " *There is an issue of couples forgetting that each is a potential conduct for the transmission of HIV. You see partners assume each trusts the other. However, a lot of promiscuity has penetrated the family. Yet a party in a couple would be afraid to come out and insist that they together should test for HIV. Statements like don't you trust me (tonnessiga) are common, yet many times each of them has been having extra-marital affairs-often unprotected, (Female Christian faith leader/housewife – 44 years).*
>
> *"People don't know much about those facilities so we need educational seminars for all ages",* (LC 53 years, P6, farmer, FGD LCs, Najanakumbi)
> *"Couples do not see the reason why they should test after staying together for a long time, say 18 years. Yet you do not use condoms because you want children*", (Female 40 years, S1, Business woman, FGD LCs , Najanakumbi).

Costs: Some Christian men, Muslims as well as ANC workers complained that some centers were too expensive for the ordinary people to afford. Even where VCT services were cheap, there were still additional costs incurred by the clients such as transport expenses. For instance one positive male said that if ARVs were cheap, people would test

Other constraints

The other constraints that were noted by participants are lack of access to VCT service facilities, lack of trust in the facilities, lack of a cure, threat from husbands and religious discrimination. Two participants noted that some community members view VCT facilities as possible sources of infection and therefore would be less likely to utilize such facilities. Two participants reported threat from promiscuous husbands as another behavior that prevents some women from testing. In addition, one participant noted religious discrimination as an obstacle to accessing VCT services. Catholic health centers were particularly pinpointed for discriminating against Muslim women and vice versa.

> "We are told high blood pressure can not be cured….If HIV/AIDS had some treatment or a cure people would test. But the therapies available are way above what an average citizen can dream to ever afford. So people don't see any commendable reason to know and await their death",(Pastor, Christian leaders FGD)

3.7 Decision making for VCT by pregnant mothers

The opinions of the participants were sought on how pregnant mothers would react to having an HIV test during the ANC visits. Most participants noted that women would be happy with the request if they realize that they stand chances of getting healthy babies especially if this is given to them as the reason for testing. LCs, ANC health care workers and Muslim women particularly said pregnant mothers would support the idea of having them screened. They argued that getting consent from husbands would not be important since they usually go to the hospitals without their husbands. However, a few participants argued that some pregnant mothers would be hesitant to accept the test because of the uncooperative behavior of their husbands and stigma associated with the test outcomes in case it is positive.

> "In Mulago, staff encourage pregnant women to test and many feel happy for the extra care, and of course the negative kid is a miracle (Kintu Kyamagero)", (Male 34 years, S2, Volunteer, AIC, FGD positive men, Kisenyi).

The other reasons for refusal were based on the rights of the woman to make her own choice not to have the test, the unethical behavior of some health workers/counselors who may disclose their HIV status to other people and an environment that is not conducive in the institutions providing VCT services.

" I don't think many women would want to be diverted from their purpose of visiting the hospital to issues of testing for HIV", (Male 39 years, P7, Volunteer, FGD positive men, AIC, Kisenyi).

"Let me tell you sir, at Namirembe hospital, there is a sign post reading **'Okukebera Abakyala Akawuka Kaleeta Sirimu Kwa Bwerere** (HIV testing for women is free). No one goes there because there is no privacy and any one can tell what your agenda is", (Male 38 years, S4, Social Worker, FGD HIV positive men, AIC, Kisenyi).

In cases where pregnant mothers have to consult some one about the decision to have an HIV test, a bigger proportion of respondents noted that they would consult friends and other relatives. Health workers and counselors were mentioned as the second most important persons to consult while husbands and parents tallied as the third important persons to consult.

3.8 Advantages of testing

The following were participants' responses about the advantages of HIV testing:

- The ability to plan ones future was identified as the leading advantage especially by LCs, Muslim women and Christian women leaders. Participants noted that they could plan for the future of their children if they know their sero-status. One participant, for example said a mother could breast feed her baby for long if she is negative and for a short time if she is positive. One Muslim man noted that testing would help government to plan if it knows the number of positive people.

- Change of behavior was the second advantage of testing. It was reported across the different groups of respondents with slightly more Muslim women and Christian leaders reporting it. In this context, changing behavior included avoiding risky sexual behavior with multiple sexual partners, stopping alcohol drinking and smoking, avoiding transmission and re-infection in case a person is positive and learning to live positively with HIV/AIDS if possible.

- A Muslim leader, LC/Business woman, positive woman, Christian woman and Muslim woman all confirmed that knowing your HIV sero-status increased love between partners and you become very faithful to your partner especially if both partners are negative.

- A male LC, ANC health worker and a Muslim man were also of the view that testing can help a person to access treatment much earlier if she/he is positive.

- Two participants noted that, through PMTCT, a HIV positive mother can give birth to a HIV negative baby.

3.9 Disadvantages of testing

The disadvantages of testing were listed as

- Break down of marriage, which was the most important disadvantage associated with testing cited mainly by Christian women leaders and Muslim men.

- Being stigmatized, intentional spread of HIV by unscrupulous fellows and lack of morale to work and subsequent poverty were noted as the second important disadvantage associated with testing. Muslim leaders particularly noted this.

- Eight participants also felt that testing could lead to death especially through suicide. At least one respondent in each category acknowledged this as a problem.

- Three community leaders (one female LC, 2 Muslim leaders and a Muslim woman) said some people go on rampage once they have tested and found they are positive. They would want to infect other people.

> "You sit exams you expect joy when you pass and sadness when you fail. For HIV testing the chances of being negative are often bleak, and because of this, one is afraid of the future (okweralikirila). Being HIV positive is like being handed a death sentence, you see your life come to an abrupt end…," (Male 31 years, O'level, Mason, FGD Christian faith leaders, Makerere)

3.10 Suggestions for encouraging testing (especially couple testing)

The participants listed the following suggestions to encourage people to go for testing with special emphasis to encouraging the testing of couples.

- **Health awareness and education** was suggested as the commonest way of encouraging couples and the community in general to undertake VCT. It was highly recommended by Christian women, Muslim men, Muslim women, positive women and LCs. Participants emphasized that religious and community leaders, health workers and any other identified stakeholders in the community should all participate in sensitizing the people on the advantages/disadvantages of (not) testing through their institutions and organizations.

  They recommended the use of the following strategies for education interventions: -

  1) Seminars and talk shows for the sensitization campaigns for both adults and the youth.
  2) The group of positive women recommended the sharing of live testimonies by PLWHAs

> *"I am emphasizing the need for seminars still. These could be in our various churches, mosques and at local government councils. In the past PLWHAs used to be hidden, isolated, neglected etc, but seminars changed all this. So even encouraging people to test can be successfully done through seminars* (Female 44 years, P7, Housewife, FGD Christian leaders, Makerere)

1) ANC health care providers and religious leaders recommended for home visits for sensitizations.
2) Religious leaders were particularly urged to mobilize people for testing.
3) Moslem men recommended recruitment of qualified medical staff as a strategy that would attract community members to go for VCT.

> *"Teach them to abide by the law of Allah which states that if you kill [infect] a person intentionally, you will be charged in the hands of Allah*", (Male 54 years, O'level, Teacher, FGD Muslim Faith Leaders, Mengo)

4) Community based organizations and groups were asked to participate more in the mobilization and sensitization of VCT activities.
5) Christian leaders recommended HIV/AIDS educational films to be screened to the public.

- Four Christian women and LCs recommended free testing. They argued that if any costs are involved, then the cost of VCT should be brought down to an affordable level commensurate with an average Ugandan's income. Generally the charges have been reducing and most centers charge about 5,000 shillings. However, this is still seen to be high by potential clients considering that they have to foot transport costs and other unseen costs.

- A registered midwife noted that if ART is cheaper it will encourage people to test but as of now there is no need since there is no hope for treatment.

- Service access: Some Christian women, LCs and positive men recommended that health services should be taken nearer to the people. Once services are within easy reach of people, they will utilize them.

Material support and incentives. Some participants (6), particularly religious leaders were of the view that people need to be given donations or material support in order to accept the test. Three Moslem men advised that it would be important for the Imams to do home

- visits with some material and financial aid in order to attract the followers. A Christian woman leader on her part felt that if Government promised to help the vulnerable groups like the orphans of people who test positive, people would easily respond to testing since they expect this assistance later on.

> *"Seminars could be good, but people who are positive are desperate. Without material support, I don't see much of any thing to compel them to test"* (female31 years, O'level, FGD Christian women leaders, Makerere).

- Three participants recommended for mandatory testing before marriage while three others recommended provision of good quality health services as a prerequisite for encouraging potential clients to test.

3.11 Implications for IMAU program

- Most community members do not know their sero- status because they have never been tested. The culture of medical checking has not yet penetrated the communities. Most people test only if they fall sick but also fear the psychological stress and stigma associated with a positive result. However, a general feeling of apathy was noted in the community. Many people regarded themselves as having HIV/AIDS such that they felt it was useless to test since every body was at the verge of death.

- Many people may be at the risk of HIV transmission. There was little awareness of the importance of couple testing or of the high prevalence of discordance. Most participants thought it was impossible to have discordance within marital relationship. Even among the few participants who had heard about discordance, there were no clear explanations as to the cause of the scenario. There were also diverging views regarding the explanation for discordance including myths. Rigorous efforts are therefore needed for IMAU to educate the community on the benefits of VCT and strategies on how best to do this. In addition, the program should aim to integrate other HIV/AIDS interventions since most community members did not know their status or that of their partners. Such interventions can include: increasing the acceptance of condom use, the reduction in risk behavior, prevention of mother to child transmission activities and empowerment of women to negotiate with their husbands or partners for condom use, VCT and other reproductive health services.

- Awareness of the existence of preventive therapies such as INH (isoniazid) for TB or septrin for other opportunistic infections is very low. If people realized that

- Clients also need assurance that test results will be kept highly confidential. If health workers and counselors do not observe confidentiality, then potential clients may lose trust and interest in pursuing VCT services. The IMAU program should endeavor to liaise with Ministry of Health and relevant authorities to address this.

- Although group counseling may be more cost effective to the testing agents in terms of man-power and time, however, a few participants challenged the authenticity of group counseling since it removed the element of confidentiality. Therefore IMAU must assess the use of group counseling (as is done at some testing centers in Kampala) in light of the opinions voiced for the need for confidentiality.

- There was a feeling by some participants that even if rigorous sensitization is provided to the community, nothing much may change. Participants voiced this feeling in light of the fact that most VCT services are currently concentrated in and a round Kampala and therefore are not easily accessible to the people in the rural areas outside Kampala. The implication is that the PMTCTP educational program's objectives can only be fully achieved once testing centers are easily accessible to the people. Extra effort has to be made to roll these services from the National and District level all the way to the Sub-county and village levels outside Kampala considering the constant migration of people from rural to urban areas and vice-versa. Their contention was that if more centers were not opened in the rural areas outside Kampala district, then the educational impact for promoting VCT within Kampala would bear little fruit.

Chapter 4. Health Care for Pregnant Women

4.1 Introduction

The section presents the sources of health care for pregnant women, benefits and barriers of utilizing health facilities. In addition, it presents strategies for encouraging pregnant women to utilize the services offered at the health facilities and the subsequent implications for IMAU program.

4.2 Sources of health care

According to most participants of different groups, most pregnant women seek health care services from hospitals and health centers around Kampala. Only 11 participants noted pregnant women seeking the services of traditional healers and traditional birth attendants.

4.3 Benefits of utilizing health facilities by pregnant women

The main benefits of receiving health care from health facilities were given as: -

- **Acquisition of quality services,** which in their context included:
    1) Good ANC services including being informed about the position of the foetus and the progress of the pregnancy

1) Immunization and delivering healthy babies who are HIV free especially if the mother is HIV positive.
2) Proper management of complications arising from caesarean section, deliveries such as sepsis and complications from spontaneous viginal delivery like post partum hemorrhage.
3) Quality laboratory services for detection of STDs, HIV, malaria and other infections. HIV testing was mentioned as part of the routine ANC services.
4) Getting good drugs and proper instructions on the dosages
5) Relatively free services.

- **Access to good health information**: besides sharing experiences with fellow women, five participants noted that mothers are given reliable health education during ANC visits. The mothers also feel psychologically satisfied that their problems will be handled by competent health workers.

4.4 Barriers to women seeking care at health facilities

In addition to listing the benefits of utilizing the health services, the participants identified barriers that would hinder women achieving the above-mentioned benefits.

- **Poverty** was identified as the most prevalent barrier to service utilization by participants of different categories. They argued that health facility costs were unaffordable to most mothers, of whom; the majority was from low-income households. They further lamented that even where Government health facilities are supposed to be free, in reality, they are not since one often has to buy the drug or pay for unforeseen expenses. In cases where mothers cannot afford charges in government facilities, some tend to go to private clinics which are reportedly cheaper and where the terms of payment can be individually negotiated.

" Health facility costs are high and even in Mulago hospital, there is nothing free ***'tekyali kya bwerere'*** *and yet in this small clinic you can negotiate",* (Female 47years, S4, Businesswoman, Makindye).

Poor quality of services at the health facilities was another barrier that prevented women from utilizing services from the health facilities. Participants cited evidences of poor quality services as unnecessary delays and fatigue got from long waiting time at the health facilities as women go through the long queue. Negative attitudes of some medical workers who abuse mothers who are shabby also tended to discourage such mothers. Nurses were particularly reported to be harsh to pregnant women. In addition, some mothers who have had many births (multigravidas) as well as teenage mothers fear the un-conducive social interaction exhibited by some health workers who condemn them. Such mothers would then prefer to keep off and avoid being stigmatized.

" *Health workers always ask the mothers if they have no knowledge of family planning 'Nti gwe family planning togimanyi' so they fear to go to hospitals",* (Female, FGD Muslim women leaders, Ndeeba)

" Some health workers are rude 'balekerawo okuvuma abakyala –olinze kuzala Museveni'. They should stop scolding the mothers like 'are you aiming at delivering Museveni", (Female, FGD Muslim women leaders, Ndeeba).

- A few participants (3) perceived **ignorance** as a common barrier to seeking health services among some pregnant women. Specifically, the benefits of receiving health care from the health facilities are not known or properly comprehended by some pregnant mothers. Participants further noted that most pregnant women start ANC visits during the third trimester and therefore have increased risk of complications, yet some fear to be operated. Under normal circumstances, some few women admitted that they would not go for healthcare unless there is a complication.

- **Irresponsible husbands.** A few participants (3) also noted that many husbands are irresponsible. They do not provide money and assistance to their wives when they are pregnant. Poverty, lack of cooperation and negligence were pointed out as reasons for husband's irresponsible behavior.

"*We men are a problem as we don't provide money for women to go to hospitals,*" (Male 54 years, Teacher, FGD Muslim leaders at Mengo).

- **Alternative services from traditional healers and TBAs.** A few participants (4) noted that some mothers prefer to receive health services from traditional healers and TBAs. They generally felt comfortable with services from these sources. However, some participants viewed the services from traditional healers and TBAs negatively as they prevented mothers from utilizing proper modern health services from health facilities.

4.5 Recommended support for pregnant mothers

1) Mobilization of male support

Generally study respondents (30) across the different groups advised that mobilization is very critical in enhancing the utilization of VCT/PMTCT services by pregnant women. Men should be especially targeted as they were viewed to be less supportive regarding VCT.

"It is very hard for men. When I was pregnant, I went to the hospital with my husband. They told us to be tested together but my husband refused" (Female 23 years, P7, Housewife, FGD Moslem women, Bwaise).

" The only way to make men test for HIV is to force them to donate blood when their wives are pregnant and afterwards have this blood tested for HIV"(Male. LC, Najanakumbi).

"*Our men are big headed, it is very difficult to make them accept the test,"* (Female, S4, Teacher/housewife, FGD Christian women; and Female, 32 years, House wife, P6, Christian women, Kasubi)

Therefore the study participants recommended persuasive methods like sensitization and counseling.

" Men are difficult to change. While promoting 'clear 7' [a socially marketed STD treatment package], women would take brochures back home and place them in strategic places for men to read. These brochures advocated for joint couple treatment, and the response was positive. We could do the same here", (Male, 32years, S3, Volunteer, FGD positive men, AIC, Kisenyi).

"*We need group training for men. We need seminars on responsible parenthood with focus on relevant fields. Incentives like snacks are not so attractive, but appreciation of the time spent is vital and probably money could do best. Akantu koteka Munsawo" (*Male 32 years, A' level, Assistant Pastor, Christian leaders, Makerere)

Two participants also felt that where persuasive approaches fail, stricter legal measures should be instituted in order to make the participation of men mandatory. IMAU was urged to liaise with the Government to pursue this strategy. Seven community leaders (LCs) including some women participants suggested that force should be used to make their husbands go for VCT where necessary. However, the male participants claimed that they did not actually refuse to go for the service, instead they were the breadwinners and therefore time was their major constraint.

"Men have busy schedules through the week. Their free day- Sunday is a day off for most health care providers. So for men to be asked to escort women for ANC would need some very serious structural adjustment on this issue", (Male 27 years, S6, Volunteer/Artist, FGD Positive men, AIC, Kisenyi).

"As for us Moslem women, I don't think our husbands can take all of us for screening as we are many wives", (Female, Moslem women leader, Diniya, Ndeeba).

One female participant also suggested that pregnant mothers who defy the VCT/PMTCT service should be tested by force. Four LCs officials felt that an important, moreover, free service (PMTCT) should be utilized by all the mothers without any negotiation since it was for the good of their own health and that of their babies. They therefore noted that all women who go to attend ANC services in various health facilities should be tested.

2) Community education/sensitization: Community education/sensitization was recommended by all categories of study participants as the second most important way of encouraging pregnant women to go for HIV testing and utilization of health services from

- Sensitization through workshops, home visits seminars and counseling sessions for pregnant women.

- Religious leaders recommended that they would use places of worship to sensitize people on PMTCT program and health issues in general. There was concern however that sensitization had never been an important component of their programs. In addition, 4 church leaders acknowledged finding difficulties counseling clients or PLWHAs who are already stigmatized after the death of their loved ones. They feared that since they had not been trained as HIV counselors, they were likely to find difficulties in presenting HIV/AIDS messages to the members of the congregation.

- Four participants suggested that religious leaders like Imams should take HIV test so as to act as role models for their followers to emulate.

> " *If we can make arrangements for the Imams to be encouraged by their Sheikhs or Muftis to go for HIV tests with their spouses, their followers can emulate their example to have it also* (Male, 41years, O level, Muslim leader/Teacher, Mengo)

- Participants felt that health education was important for pregnant women to know the advantages of testing and dangers of being pregnant when HIV positive if one does not receive PMTCT treatment.

- Participants recommended that the sensitization should incorporate men and community leaders so that everybody in the community is informed of the importance of this initiative.

- Men who accompany their wives for ANC services should be encouraged to join health education talks and support their wives (recommended one midwife).

- Participants recommended encouraging men whose wives were pregnant to test for HIV. In cases where this failed, 4 participants agitated for mandatory tests for men.

3) Accessibility and affordability of quality services: A good proportion of community leaders (15) recommended that:

- Quality service delivery should be ensured and made accessible.
- Modalities to enhance the motivation of health workers should be worked out by government.
- Education of more females in the medical profession especially doctors should be encouraged, as mothers would feel freer with their female counterparts.
- Mobilize male support and funds for providing health services.

4) **Confidentiality:** Some participants (11) recommended that medical personnel should observe confidentiality in order not to scare away people who would like to take HIV test. Some participants were of the view that testing should be done privately in homes to further enhance privacy and confidentiality.

5) **Incentives**: Providing incentives to women was the fifth most important recommendation by participants (7) as a way of attracting them to utilize the services. The incentives suggested ranged from provision of transport refund, food, free testing and safety of testing facilities to provision of quality care to the women. This was envisaged to attract mothers especially those who are already weak and financially incapacitated. They cited an example of TASO that provides some sugar and tea as a form of incentive.

"*To truly and deeply influence our people, concerned groups need to offer some help. Ambassadors of Hope for instance offer aid in form of school fees to orphans. Whenever they wish to have anything done by the community it is very easy to mobilize the people through the children. People have trust in them and would not like to lose their support" (*Female, 50 years, O level, Housewife, Christian leaders, Makerere).

"*If some women are tested HIV positive something could be given to them to encourage others to come e.g. transport refund"*(Senior Enrolled Midwife, 45 years, Mulago).

If there were incentives given, for instance TASO gives people some sugar, women would be pulled if they expect some things …", (Female 36 years, Diploma, self-employed, FGD Christian leaders, Makerere).

4.6 Implications for IMAU program

- IMAU should recognize the importance of awareness creation among all the identified stakeholders on the benefits of pregnant women utilizing health services as a way of enhancing participation in VCT.

- Co-opting men into the program is very critical in increasing participation and support, since some men are non-committal to the health needs of their wives and children. The public awareness program should particularly target men and efforts should be made to encourage them to accompany their wives to the health centre. IMAU should develop diverse and more flexible strategies such as prayer times, use of the print media, television and radio broadcasts. Men should be sensitized on the benefits of the VCT and ART services as well as the advantages of their wives seeking health services from the health facilities.

Government and other service providers need to improve the quality of services in the health centers as poor service in some health centres was reported as one of the main factors hindering utilization of health facilities. Clients usually prefer to get services from facilities where they can get drugs, good laboratory examinations, short waiting time, friendly health workers, affordable services and where health workers maintain

- build the capacity of the health facilities together with the service providers in order to motivate them to improve the quality of services delivered.

- Female medical personnel were said to be more empathic with the patients than their male counterparts. The implication is to train/retrain more females for delivery of services for the pregnant women.

- Religious leaders have been recommended as key actors in the community education program and therefore are expected to be role models in their communities. Participants felt that religious leaders should be exemplary by going for VCT, which would then motivate the followers to emulate. If they act contrary to what they preach, then followers will not trust them. IMAU therefore should co-opt as many religious leaders as possible into the design and implementation of the PMTCTP.

- Integrating HIV/AIDS related service deliveries. In the bid to enhance the utilization of health services by pregnant women, there is need to integrate services like VCT, STI management, care and support of orphans and vulnerable children, condom use and family planning as part of the health care package.

- IMAU will have to facilitate the process of empowering women with skills of negotiating with their husbands or spouses on their reproductive rights. Such negotiations would dispel off the cultural monopoly of decision making by men.

- The culture of donations or dependence is still strong in these communities. Participants felt that provision of incentives like transport refund, nutritional support and other forms of assistance to the family would motivate potential clients to test. The request for the humanitarian support arises from the support TASO and other organizations have been providing to the affected and infected people, majority of who are poor. However, this support is not sustainable as evidenced by the reduction in handouts by NGOs previously involved in such activities. IMAU should therefore sensitize the community on self-sustaining coping mechanisms. Promoting the culture of incentives sets a bad precedence and implies that interventions in which such incentives are not provided, no tangible results would be achieved.

5. Prevention of mother to child transmission

5.1 Introduction

The section presents findings on community knowledge about Mother to child transmission (**MTCT**), Prevention of mother to child transmission (**PMTCT**) and Prevention of mother to child transmission program (**PMTCTP**). The section also presents issues and concerns participants expressed on the PMTCTP as well as the IMAU program implementation and participation.

5.2 Knowledge issues

Most of the respondents knew that an HIV positive pregnant woman could pass HIV on to her unborn baby across the different groups of respondents. However, only a small proportion (a third) of the respondents knew that HIV transmission from the mother to the unborn baby can be prevented and a third had heard about the program for preventing the transmission. ANC health care workers, HIV^{+} men and women, and Christian women were relatively more knowledgeable on PMTCT compared to Muslim women, Christian men and LCs. Among the Muslims it was mainly the Muslim men who knew or had heard about the prevention of mother to child transmission. The pattern was similar for knowledge on the existence of PMTCT program. The source of information on PMTCTP was mainly from health workers and the media (especially the radio).

5.3 Attitudes towards the PMTCT Program

The participants had different opinions towards the intended PMTCTP. These can be divided into the following distinctive categories: -

- **Benefits to the Mothers**: Most study participants supported the PMTCT program saying that it will be beneficial to the mothers, the general community and the nation at large. They felt that it was a good program and that HIV positive mothers will be particularly happy if they deliver HIV negative babies as remarked below.

"Some people living with HIV/AIDS who haven't had children were desperate saying 'wakiri nandizaddeko omwana; nebwabaffa wakiri' (meaning at least if I bore a child of my own and it died of AIDS, it would be fine). Now they may aspire to bear children who will be negative. Its very dear 'kintu kya mewendo nnyo okuzaalayo omwaana' to have your own child", (Male 27years, S6, volunteer/artist, AIC, Kisenyi).

"HIV positive couples will have hope of leaving behind a child of their own who can run the family after they have died", (Female 61years, P4, Business woman, FGD LCs, Najanankumbi).

- **Limited Coverage**: However, 6 respondents were concerned about the limited time span as well as the limited geographical coverage of the program. They recommended that it should not only be concentrated within the city but should be spread to cover the different areas in the country.

"My worry is about the duration of time Mulago will assist mothers on the PMTCT program. The duration of support with powdered milk is very brief. If it were longer, say 2 years, it would be better. You know PLWHAs are already vulnerable to opportunistic infections, are not optimally productive at their work places and are not taken care of, which makes the whole program leave a lot of issues un-resolved", (Male 34 years, S2, Volunteer, FGD Positive men, AIC, Kisenyi*).*

- **Ethical Issues**: Four participants noted the ethical problem of saving only the life of the children who will be orphans since their mothers will eventually die.

" It would be a good program but it does not take the mother into account. It is absurd that these kids MUST stay orphans", (Male 39years, P7, Volunteer AIC, Kisenyi*).*

5.4 Activities for Integrating IEC services

In order to make the IEC practical the study respondents identified four main activities through which IEC services should be integrated if they are to reach their main targeted recipients.

- **Public meetings/seminars:** The main activity identified is community or public meetings or seminars by most groups of respondents, which are organized by local councilors, health workers and other government officials. This is evidenced by the following comment:
  It is important to note however that the following concerns were voiced.

*" In my area, LCs tend to be money minded. We had a program that stalled because I could not satisfactorily answer their questions. ' **Naye murimu sente**?' Meaning shall we benefit cash wise?"(Male 27, S6, Volunteer, AIC Kisenyi).*

" I have a problem with LCs. Remember the sugar we used to receive through LCs (1986). The LCs took it all. We depend on concerned NGOs. We may use religious leaders of the different faiths". (Male 27, S6, Volunteer, AIC Kisenyi).

"Politics has spoilt us. Today people want incentives, without these, it becomes hard for the LCs to do this kind of work", (Male, LC FGD, Najanankumbi).

- **Prayers**: The second important activity for community education is prayer times in the mosques, churches and other places of worship. It was felt that it is easier to meet community members during Juma prayers on Fridays for Moslems, Saturdays for Seventh Day Adventists and Sundays for other Christians. Other religious functions like Ramadan seminars; Mauledi (religious ceremonies) and Buluda for Moslems were also recommended. Special prayer programs like funeral services were recommended to be important for community education

"Some people are ardent church goers-they would hear from the pulpit leaders like reverends, pastors and fathers" (Male, 30 years, Mason, FGD Christian leaders, Makerere).

- Ten participants recommended occasions or festivals like birthday parties, wedding ceremonies, Christmas and Easter periods as important days for community education.

- Recreational activities like drama, football, video shows, drinking joints/bars and market days were envisaged to be important for community education.

- Existing television and radio programs were recommended as activities for IEC integration.

- Other activities identified were home visits and street broadcasts.

5.5 Preferred Sources of Information

The main preferred sources of information on PMTCT and ARV's are:

- Religious leaders and local counselors were recommended as the most important sources of information particularly by Muslim leaders, Christian women, Muslim women and positive men.

"*They believe in talks and prayers from church leaders that it can heal, they tell them to say in the name of Jesus you are healed" (Female 47, years S.4, Business Woman, FGD Christian Women Leaders, Makindye)*

"LCs are concerned people. They are generally respected and would do the work easily". Male, 36 years, S2, Volunteer, AIC, Kisenyi)

The other sources are:

- Media (radio broadcasts, television, newspapers, posters and brochures), NGOs, peer educators, health workers, teachers and students could pass over information to their parents and HIV positive people.

"The villagers may not listen to them (religious leaders). But if health workers with new faces come with the program in the village, people can listen" (Male 33 years, O level, builder, Muslim leader, Mengo)

"I see my neighbors there called NACWOLA, they use drama and songs to spread the news" (Female 35 years, P7, Business Woman, FGD Christian Leaders).

5.6 Most likely questions to be asked by women in PMTCT seminars (Topics needing clarification)

- Whether the treatment will be free. (Women need to be told that treatment for PMTCT is free)
- Whether there will be any material benefits and health related benefits

Other likely questions to be asked;

- What the side effects of the drugs are
- Whether there is treatment in case found HIV positive
- What they will do regarding sex if found positive and yet their husbands are against condom use
- What to do if husbands want more frequent sex yet they are positive
- Some women make a livelihood from prostitution, how do they come to terms with sustaining the trade and having less sexual encounters?

5.7 Anticipated Barriers to Community Education

- A major barrier cited was lack of appropriate skills to transfer knowledge by the community educators. For example, use of unfamiliar language and terminologies may make it hard for the community education sessions to be appreciated by the minorities who are not fluent in Luganda. Furthermore, some community educators may not prepare adequately for their sessions thus making the sessions uninteresting to the recipients.

- Poor facilitation was mentioned as another set back to the success of the community education. Poor facilitation meant lack of transport, financial rewards, materials/teaching aid and refreshments.

> *" The rewards for engaging in such community education may not be monetized, yet we depend on money. Remember time is money…. Unless there is a monetary reward, it is a hard task",* (Female 50 years, housewife, FGD Christian leaders, Makerere).

Other barriers

- Negative attitudes by some community members

- Time constraint was also noted as another potential barrier for the community education program. Some community leaders noted that life in urban areas was largely dependant on money. People have to spend time to look for money to fend for their families. They therefore felt that the health education program may interfere with their scheduled activities.

- Non-involvement of the Men in the program. The involvement of men is central in the success of the PMTCT program. However, it is a big task to get the men fully mobilized to participate in the program. Men claim they are the breadwinners and will less likely accompany their wives for VCT and PMTCT services.

5.8 Implications for IMAU program

- **Building the capacity** of the organizations as well as the individuals that do community education. This can by done through the following methods:-

- be to equip them with adult education skills that would help them design and deliver health education sessions that are appropriate and interesting for the adult.

- **Motivating the community educators**: Although voluntarism is often envisaged to be an excellent approach for program sustainability, it is not itself sustainable. The volunteers will not stay long on the project especially if they realize that the program is a burden to them and they do not see any compensation for their time. It is therefore important that some incentives recommended by the study participants such as transport refund for the community educators should be taken into consideration.

- **Limiting the time for each session** without compromising the quality of training given. To avert the problems of unrealistic monetary expectations, education sessions should be very brief (10-30minutes). Where long sessions are planned, there will be need to consider providing refreshments especially for the educators. Preferably worship days and other community meetings would be more cost effective moments for community education

· **Involvement of men into the program**. More persuasive approaches like sensitizing men on the benefits of the services as well as giving case examples would greatly motivate men towards the program. Arrangements to sensitize men at their duty places could also be explored. It would be of benefit to include more male trainers into the community education program who would act as peer trainers for their male counterparts.

· **Facilitating the process of the community shifting their paradigm on short-term material benefits**. The culture of dependence is endemic in the local communities. Introducing new programs with long-term benefits to the community are often not appreciated. Community expectations are tilted towards donations and free drugs, and it is these donations that are valued as the real benefits of the program. This is likely to be a challenge for the program. Therefore it is important that IMAU at every stage of the program cycle concisely and precisely defines the objectives and benefits to all stakeholders particularly, the would be beneficiaries. Community members need to be told that benefits of the program can be both short term and long term. In the long term, the society will be AIDS free and therefore benefits do not only have to be measured in monetary terms.

· Pregnant mothers and their husbands also need to be sensitized on the importance of reducing other risk factors like injuries on pregnant mothers inflicted during physical assaults, infection from STDs and other diseases.

· Shifting the thinking of HIV positive mothers from breastfeeding to other breast milk substitutes will require intensive sensitization. Most mothers are poverty-

- Counseling of discordant couples.

- The community's positive attitude about PMTCT program as a means for HIV positive women to have children needs to be balanced by family planning information. IMAU will need to ensure thorough discussions at the community level about the benefits and consequences of child bearing for HIV positive women.

Antiretroviral Therapy for Treatment of HIV

6.1 Introduction

This section presents the findings on knowledge about (**Antiretroviral Therapy**) ART, persons likely to benefit from ART and type of information required. The section also presents suggestions for enhancing the utilization of ART services and implications for IMAU program.

6.2 Knowledge of ART

Study participants had limited knowledge about ART. Only a third of the participants admitted having heard about ART. The source of the knowledge was the radio and health workers from health facilities around the city such as Mulago, Mengo, JCRC, Nsambya, Rubaga, House of Health and Mildmay. These facilities were also recommended as potential centers for ART. A bigger proportion of the participants had heard about the herbal medicine popularly known in Luganda as '*Kadomola'* which is believed to work well and the '*Mariandina'* of Dr. Ssali, which was popular some few years ago.

Participants generally knew that ART was not a cure for AIDS but rather a pain reliever ***'Bukakanya obulwadde'*** that reduced the viral load in the blood thereby prolonging life ***'Linafuya sirimu'***. Only a few participants were aware that people have to take the drug for life. Below are remarks by study participants on ART.

> *"I attended a seminar on ARVs, and I was told these are normally a combination of 3 drugs, which when used, attack and destroy HIV from the body except the brain and spinal cord. We were told one type encircles the HIV in the white blood cells and deters the HIV from reproducing. The other type of the drug kills the HIV, so indeed HIV is destroyed apart from those in the brain cells and spinal cord"*, (Male 36 years, S2, Volunteer, FGD HIV Positive men, AIC, Kisenyi).
>
> *"I have heard about it, but there are some people who pretend to be specialists and yet they end up giving clients poor combination*", (Male, LCs FGD, Najanankumbi).

Only a small proportion of the respondents knew the precise costs of ART. Others did know that the cost depended on the type and source of the drug. For instance prices in NGOs like JCRC and Mildmay were thought to be low because of government and donor subsidy. However, private pharmacies were reported to sell ART at high prices. The average cost per month was about Shs.100,000 and annual cost of about 1.8 million shillings were mentioned.

6.3 The Main Beneficiaries from the Knowledge of ART

The main beneficiaries of the knowledge of ART were: -

- **Clients:** Whereas respondents felt clients would be the main beneficiaries of the ART knowledge/service, they lamented that ART drugs are too expensive for the poor and therefore it will mainly be the rich to benefit as remarked by one participant.

- **Drug sellers** or **scientists** who manufacture the drugs
- **Family members** of the clients
- **Community** at large.
- **The Government** would benefit in the following ways: -
  1) By increasing the productive years of the workforce (for instance doctors, ministers, specialists) the government would reduce on the attrition rate for her human resources.
  2) By increasing the period one works, government will increase the years that person would be able to continue paying taxes that would help in the development process.

> *"Healthy people are productive, less costly to the nation in terms of health care costs"* (Male, 27 years, Volunteer, AIC, Kisenyi).

6.4 Type of Information Required for Community Education

The critical areas for community education identified by the respondents included:

- Costs of the ART and what the government is planning or doing to make the drug accessible and affordable to the poor.

> *"Knowing the cost per-se is not helping, people would want to know what the government is trying to do to enhance availability of the drug at costs that people at the grass roots can ably afford" (Female, 36 years, diploma, Business Woman, Christian Leaders, Makerere).*

- Sources of ART

- Reasons and benefits for the use of ART

> *"Does ART weaken the virus or kill it?" (Female, 61, P4, Business Woman, Najanankumbi)*
>
> *"People should be taught on how ARVs are administered. People simply use these drugs for only a few months and cannot afford it any more and stop. This is dangerous as ARVs must be used for life once started on"(Male, 36 years, S2, Volunteer, AIC, Kisenyi)*

- Side effects

> *"It is good if it has no side effects on the health of the person. I have heard that the drug has a virus in it (akawuka) which can cause more harm",* (Male 40 years, S6, Muslim leaders FGD, Mengo).

- Eligibility /criteria used to make ART accessible to those who need it.

"People need information on the actual purpose of ART, where ARVs could be got and at what cost. Hospitals offering this therapy should categorize which patients or at what point in the progression of HIV one would need to receive the therapy" (Male, 30 years, S6, Volunteer, AIC Kisenyi).

6.5 Implications for IMAU program

- Potential beneficiaries will most likely want to know when they should start ART. IMAU should make this very clear during the sensitization campaigns. In case children have to be given ART, what should be the dosage, what eligibility criterion should be used? In particular, people need to know that only people with CD4 counts less than 250 are likely to benefit from ART. They may also need to know what risks children are likely to face, the different drugs or drug combinations to be taken. Clear and satisfactory information receives a warm response from the beneficiaries.

- Management of ART in totality i.e. the lab testing, side effects etc. People need to be informed about the side effects of ARV and how these side effects can be managed. They also need to understand whether the benefits of ARV outweigh the associated side effects. If such services were centrally done, then clients would respond positively.

- Myths about ART can make potential beneficiaries develop negative attitudes towards ART. For instance, some members in the community think that ARV is not safe, that is, it does more harm. IMAU may need to explore more on these myths and integrate them in the sensitization campaigns. Myths can be detrimental to the success of an intervention of this nature.

- Issues related to the cost of ARV need to be explained very clearly to the community. For instance, the community did not include the costs of laboratory monitoring in their cost estimates for ARV, yet the laboratory costs may actually double the overall cost of ART. Due to the high costs, some participants already complained that ARV is not beneficial to the common man, which is a challenge to IMAU if they encourage people to get ARV yet they cannot afford.

- The benefits of ARVs, should be explained to the community. People want to know the out come after taking the drug whether it is a cure, for prophylactic or just a pain reliever. They also want to know examples of people who have benefited from the ARVs before they can take decisions to accept the drugs. It is also important to inform people of the various sources where they can get the treatment. IMAU might need to liaise with AIC, TASO, Mildmay center, and other organizations to identify some PLWHAs to go for live testimonies during community education programs in order to enhance the acceptance rate.

Chapter 7. Conclusion

- **VCT:** The perceived knowledge of HIV sero-status as well as discordance was found to be very low in the communities since few people have taken the endeavor to test. The main circumstances for testing were given as sickness, marriage, previous risky sexual behavior, death of a partner or child and planning to get pregnant or having had pregnancy from untrustworthy relationship.

- **Constraints to VCT** were noted as; stigma, emotional stress, lack of confidentiality at some testing centers, lack of information to the community, accessibility and related costs. Suggestions for promoting VCT were given as IEC, reducing the testing fee further and if possible making it free, increasing service access and making testing mandatory so as to involve men.

- **Health care for pregnant women:** There was an overwhelming recognition of health centers as the main sources of health care to pregnant mothers. However, increased use of the health centers would largely depend on improvements in the household income, improvements in the quality of services, IEC, increased male support. In addition, community leaders recommended for health worker motivation, training of more females in the medical profession and confidentiality in the health facilities.

- **PMTCT:** Generally there was very low knowledge on PMTCT and PMTCTP. Whereas a good proportion of participants seemed to have acknowledged that mother to child transmission of HIV can be possible, however, most participants were not aware that MTCT can be prevented and there was a program for prevention, which could enable a HIV positive mother to produce HIV negative baby. Muslim women, Christian men and LCs were particularly less knowledgeable. The low knowledge provides a desperate need for sensitization on PMTCT evidenced by the overwhelming support for the program. Public meetings, seminars and prayer sessions were recommended as the most suitable activities for IEC integration. The recommended persons for IEC are community leaders (religious leaders and LCs), media, peer educators and health workers/counselors.

- **ART:** Knowledge on ART was also limited. Only one third of the participants knew about ART. Participants therefore recommended sensitization on the following areas: costs of ART, source, benefits, side effects, eligibility criteria, skills for demystifying counter productive myths, management of ART and dosage.
- Overall, PMTCT and ART interventions program is timely and highly supported by the community. Evidence of lack of knowledge is clearly manifested in the discussions above. Once this intervention is pilot tested, IMAU should discuss with Government of Uganda the possibilities of expansion to the wider community.