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# HOME-BASED HIV TESTING AND COUNSELLING IN A SURVEY CONTEXT IN UGANDA

HOME-BASED HIV TESTING AND COUNSELLING IN UGANDA



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# Home-Based HIV Testing and Counselling In a Survey Context in Uganda

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## ACRONYMS

AIC	AIDS Information Centre
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
CDC	United States Centers for Disease Control and Prevention
CHDC	Child Health and Development Centre
HIV	Human Immunodeficiency Virus
LC	Local Council
MOH	Ministry of Health
ORC	Opinion Research Corporation
TASO	The AIDS Support Organisation
UHSBS	Uganda HIV/AIDS Sero-Behavioural Survey
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing



# SUMMARY

## Objectives

This report examines the results of a study in which respondents who participated in a population-based survey were offered free HIV and syphilis testing and next-day test results if they consented to give a blood sample. The survey itself, known as the home-based voluntary counselling and testing (VCT) survey, was conducted by the Ministry of Health (MOH) of Uganda in order to test the feasibility of offering HIV test results and counselling at home within a survey, and to see what effect offering home-based VCT might have on rates of participation in the survey and in the blood draw. The survey interviewed respondents in the Central, Western, and West Nile regions of Uganda, with a questionnaire that had been used earlier in a national survey on sexual practices and HIV/AIDS.

Conducted by the Child Health and Development Centre (CHDC), this study observed the interaction between the MOH survey teams and survey respondents. This survey process included interviewing survey respondents during the initial survey and again some months later, administering the informed consent statement for drawing blood, drawing blood for testing, and delivering the test results at home. The CHDC study sought to understand how and why respondents consented to have blood drawn and agreed to a home visit by a counsellor to learn their test results. A return visit several months later examined the social consequences related to receiving HIV test results at home.

## The Home-based VCT Survey

The home-based VCT survey was conducted in 33 clusters in three regions to test the feasibility of offering HIV test results at home as part of a population-based survey. Some people expected that if respondents were offered the opportunity to get their HIV test results at home the next day, it would affect the rates of participation in the survey and in the blood draw. Similarly, it was thought that if respondents were offered a free HIV test and delivery of the results at home, a much higher proportion of respondents would learn their HIV status than if vouchers were given out for a free HIV test at a nearby health care facility.

The offer of providing free HIV test results did not change the rates of participation in the survey or the blood draw for women, but participation rates dropped slightly for men. This approach did dramatically increase the proportion of respondents who learned their HIV status, because nearly all respondents who gave blood also received their HIV test results at home. In all, 86 percent of respondents in the 33 clusters surveyed chose to receive their HIV test results (83 percent of men and 88 percent of women). Most respondents were pleased to receive their test results for syphilis and for HIV at home.

## Participation in the Blood Draw and Testing

This study was designed to understand why survey respondents in the home-based VCT survey decided to participate in the blood draw or not, to learn their HIV test results or not, and to receive their test results at home or elsewhere. In the design phase we thought of these

decisions as separate and sequential. In the field, however, these decisions relating to whether to give blood for an HIV test or not, whether to learn test results or not, and the venue in which to receive test results were largely collapsed into one main decision about whether to cooperate with the survey teams. Thus, the analysis focused less on those three decisions and more on the overall decision to participate in the blood draw and then receive HIV test results at home, and on the privacy afforded by the home visits.

The interviews with respondents showed that the issues they most often cited as relevant to their decision to participate in the survey were the following. First, this was a study being conducted by the government, because the survey team represented the MOH. Second, the research teams were accompanied by local community leaders—the Local Council (LC) Chairperson—who helped not only in identifying the selected households but also formally introduced the teams to the households and asked household members for their cooperation. Third, those conducting the study were not from the communities where the study was conducted and thus would not know the respondents. Fourth, the households included in the study were randomly selected and listed prior to the study, and people in the community were not quite sure how this was done and what criteria were followed. Each of these reasons deserves attention.

The high rates of participation can be explained in part by the fact that the survey was an official government-sponsored exercise. The survey team members were there as representatives of the MOH, and they wore the white coats of health care providers. A number of respondents mentioned that they felt obligated to participate in the survey and blood draw simply because it was a government exercise. A few even mentioned they might suffer consequences in the future if they refused.

The fact that the survey teams were accompanied by LC Chairpersons, who introduced them and asked the household members to cooperate, seemed to make a great deal of difference for many respondents. In many cases, an LC Chairman came to a household and told household members to be present the next day so they could participate in the government survey. The participation of community leaders was often cited by respondents as an explanation for their participation.

The identity of the interviewers and laboratory technicians added to the anonymity of the participation in the blood draw and the testing. Respondents took comfort in the fact that those who took the blood and conducted the tests for HIV and syphilis did not know them personally, and thus would not talk about them to their neighbours or anyone else.

The randomness of the selection of households and the fact that several households in each cluster were selected seems to have removed stigma from getting an HIV test. Many of the respondents assumed that their decision to participate or not in the blood draw had to some extent already been made for them by the pre-selection of their homes. Respondents talked about ‘our villages and our homes were selected, so we were tested’ instead of ‘I was selected and tested.’ Getting tested for HIV was something done by households more than individually.

Respondents said they would not want to be seen going for an HIV test, since others would wonder why they wanted to discover their HIV status. However, the randomness of the

selection of households in the 33 cluster survey seems to have removed that stigma by identifying households rather than individuals for getting tested. It seems important to take note of this difference, for it offers one way to get individuals tested in a context with little or no stigma attached to the action. Whether home-based VCT will be recommended to be included in a survey or not, this effect of designating a group of persons rather than an individual may offer a way for programs to encourage HIV testing.

### **Acceptance of HIV Test Results at Home**

Nearly all respondents said they preferred to receive their test results at home rather than somewhere else. This finding must be, in part, a result of the way the options were presented to respondents, since laboratory technicians sometimes just told respondents that a counsellor would come to the house the next day. However, respondents welcomed the test results at home because it was free, and no one could see what happened inside the household. In the minds of respondents, the cost in time and money to travel to a facility, and the risk of being seen by those who knew them, were the two main drawbacks to getting tested for HIV. Both of those drawbacks were removed by home counselling and testing.

Homes were perceived by almost all the respondents who participated in the blood draw as spaces where they could receive their test results in privacy and with confidentiality. Places were found within the homes where the presentation of the results and the counselling process could be done without any witnesses, and people found that satisfactory with regard to privacy and to confidentiality. The fact that the testing and counselling was being conducted by 'outsiders' further reinforced respondents' perceptions of their test results being private and confidential. The assumption was that because the teams were from outside of the community, they were unlikely to disclose people's test results to others in the community.

For married persons, this was an opportunity to test for HIV without having to give an explanation to one's spouse as to why one had decided to take an HIV test, as would be the case if one decided to seek an HIV test at a health unit or a VCT facility. A person seen visiting a health unit where HIV testing takes place would be considered as someone who was worried about being HIV positive.

The study found some difference by gender in response to getting tested at home. The interviews conducted after the blood draw revealed that couples, especially those who did not fully trust their partners, perceived the study as an opportunity to learn their individual status and in some cases that of their partner as well. The opportunity provided by the survey was new and welcome, especially for the women. Given the unequal gender and power relations that often exist within households, women often find it difficult to go on their own for an HIV test, even if they are willing.

### **Social Consequences of Home Visits**

Phase II of this study consisted of conversations with respondents who had been seen by the CHDC team in Phase I to determine if the visit of the survey team and the delivery of HIV test results had any repercussions in the households concerned. Those conversations confirmed

earlier findings that showed a general preference for receiving HIV tests at home rather than elsewhere. Also discussed was the disclosure of HIV test results. Among the 34 individuals who were married, 21 had disclosed their HIV test results to their spouse, while 13 had not done so.

After extensive discussion of their memories of the visit of the MOH survey team, and of family and other events since the team's visit, respondents did not give any examples of problems created by the delivery of test results at home. We did not find many examples of social or family disruption after someone learned their HIV status. We learned of one case of a wife who decided to leave her husband after she discovered that she was HIV positive.

However, this evidence does not allow us to say that there are few social disruptions after delivery of HIV test results at home, since we do not have either the numbers or the social contexts to show that. We would expect more of a reaction to finding someone HIV positive than negative, and the highest chance of disruption when a married woman is found HIV positive. Phase II found only nine of 61 individuals HIV positive: six men and three women. Three of the men did not disclose to anyone. While all three women told their results to others, these women were not married. In order to answer the question of the social consequences of providing HIV test results at home, we would need larger numbers of HIV-infected individuals, including HIV-infected married women.

### **Pros and Cons of Offering VCT at Home within a Survey**

Overall, this study found that survey respondents welcomed the opportunity to get tested and counselled at home within a survey organized by the government. Respondents readily accepted testing because it was an official operation of the government, it was introduced by local political officials, the process was free, and respondents were shielded from the eyes of others. The main benefit of such an operation is that most of the individuals in the sample learned their sero status.

Several drawbacks to offering VCT at home should be noted. First, the exercise is quite expensive because of the materials to be purchased, the extra time and personnel involved, and the training of counsellors and support staff. A sizable amount of extra funds is needed to supplement survey costs if VCT is included. Second, the process is cumbersome, for four counsellors and three laboratory technicians are required to accompany the four interviewers and a team leader. Moving a team of 12 people around from village to village presents a challenge. Third, it is not likely that counsellors have the time for proper counselling in the field as they would do in a health facility. And fourth, devoting so much time and resources to training for drawing blood and testing may take away time and attention from training in proper survey practices. These are all drawbacks related to the functioning of a survey team.

From the standpoint of the respondents, the main drawback is the lack of any services available for those who test positive for HIV. While learning one's HIV status may be beneficial, if there is no follow-up service available, either social or medical, the benefits of that knowledge may be wasted. It should also be noted that it would not be easy to explain to an ethics review board why, in a survey context, only some households should receive the service.

Considering all aspects of the home-based VCT survey in 33 clusters, we would not recommend that this approach be generally adopted in survey research in Uganda. The effect on the entire survey process is large, and those who learn their sero-status in this manner have nowhere to turn if they need assistance. The resources necessary for such an effort would be better spent elsewhere.

# **CHAPTER 1**

## **Introduction**

### **1.1 Purpose of the Study**

This study examined how respondents participated in a population-based survey that offered free tests and test results for syphilis and HIV in three regions of Uganda. The survey, known as the home-based voluntary counselling and testing (VCT) survey, interviewed respondents in Central, Western, and West Nile regions with a questionnaire that had been used earlier in a national survey on sexual practices and HIV/AIDS. By observing the informed consent process for drawing of blood, and then interviewing survey respondents, this study sought to understand how and why respondents accepted the blood draw and consented to a home visit by a counsellor to learn their test results.

After providing some background on VCT in Uganda and a few key results from the home-based VCT survey itself, this report focuses on the data and findings of the qualitative study that examined how and why survey respondents participated in the blood draw and accepted home visits to learn their HIV test results. The conclusion summarizes the findings and describes lessons we have learned about HIV testing in Uganda.

### **1.2 The Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS)**

In late 2004, the Ministry of Health (MOH) of Uganda, supported by the United States government, conducted a national survey with questions that addressed demographic issues, sexual practices, and HIV/AIDS. The UHSBS, directed by the MOH with technical assistance from the United States Centers for Disease Control and Prevention (CDC) and Opinion Research Corporation (ORC) Macro, interviewed more than 21,000 adults 15-59 years old in 417 clusters around the country. Respondents were asked to give venous blood so it could be tested for syphilis, HIV, herpes simplex, and hepatitis B. Respondents who tested positive for syphilis were offered free treatment the next day. All respondents who agreed to participate in the survey were given a referral voucher that could be used at a local health facility or a mobile unit to obtain a free HIV test and counselling. The MOH tracked the use of the vouchers in order to determine the proportion of survey respondents who learned their HIV status through participation in the survey.

### **1.3 The Home-based VCT Survey**

In the original planning for the UHSBS, the issue of providing HIV test results at home is raised, but was not adopted. Instead, the MOH decided to test the feasibility of offering home-based VCT as part of a survey by implementing a smaller survey, known as the home-based VCT survey, right after the main survey. The MOH wanted to determine if it was possible and if it made sense technically, socially, and economically to offer HIV test results at home as part of a general survey. Survey respondents had never been given such an option in Uganda before.

The issue of home-based VCT was not new to Uganda; several research programmes have offered VCT at home as a way to increase participation in testing and counselling

programs. For example, the CDC in Uganda has been assisting the AIDS Information Centre (AIC) in providing home visits for HIV testing and counselling in two eastern districts since 2003. Also, the Medical Research Council conducted a study of providing home-based VCT in a cohort of adults in 15 villages in southern Uganda from 2001 to 2003 (Wolff et al., 2005).

The home-based VCT survey was conducted in 2005 soon after the completion of data collection for the national UHSBS. The home-based VCT survey covered 33 clusters with a household sample drawn separately from the UHSBS sample. The main objective was to test the feasibility of offering HIV test results at home as part of a survey. The survey followed the protocol of the UHSBS in all respects except that instead of providing vouchers for a subsequent free test and counselling, respondents in this survey received their HIV test results, at home if they wished, the day after they were interviewed.

#### **1.4 Origin of the Qualitative Study**

Asking survey respondents to give blood for screening tests raises issues of informed consent and confidentiality not present in standard demographic surveys. If they are to give blood, survey respondents need to give their 'informed consent,' indicating that they understand that participation is voluntary, that they know what tests will be conducted with the blood and what will happen to the blood, and that the test results will be kept confidential. But what is meant by 'informed' and 'consent'? How do we judge whether or not participation is truly 'voluntary'? Does the responsibility of survey researchers extend to being certain that respondents have understood what they were told? Such questions must be considered in planning surveys that take blood for screening tests. While we can suppose that local understandings of concepts such as 'informed', 'consent', and 'confidential' are different from those of researchers, we cannot know what they might be without examining the process of data collection in the field.

It was anticipated that analysis of the survey data would provide some understanding of the types of persons who agreed to give blood, who agreed to learn their test results, who accepted a home visit, and who preferred a mobile unit. The survey data, however, would not contain information on how and why individuals chose one or another option, nor would it provide any information about the social context of the choices or the factors involved from the respondents' point of view. Furthermore, there was some concern about the social consequences of providing HIV testing and counselling at home. Would individuals who opted for home visits share their test results with family or friends? Would some persons be pressured by family members to reveal their test results when they would prefer not to do so? Would there be negative social repercussions for those who were found to be HIV positive?

The qualitative study was conducted to answer these questions by having fieldworkers observe what was communicated during the informed consent statement presentation, interview respondents after they were asked to give blood and again after they had received their HIV test results, and then return to households for a second visit several months after the departure of the survey team.

Very little is known about how or why individuals choose to learn their test results at all, and the advantages they would see in getting their results at a health centre, a mobile unit, or at home. There are, in fact, several distinct issues that are relevant to the focus of this qualitative study. 1) Did the knowledge that respondents had the option of getting their HIV tests results at home influence their willingness to give blood? That issue can be largely resolved through the analysis of the small survey data. 2) How and why did people decide they wanted to know their sero-status in the first place, or decide they did not want to know? Evidence about this process was obtained in the conversations held immediately after respondents gave blood. 3) For those who wanted to know their test results, what factors entered into their decision of where to learn their test results? For those who accepted a home visit, what advantages did they see in a home visit as opposed to going to a health centre? These issues were also covered in the initial conversation. 4) What was their experience of learning test results and being counselled at home? That issue was discussed in the interview that took place after the test results were given and the counselling was completed.

## **1.5 Qualitative Study Objectives**

The overall objectives of this study were to understand the choices of respondents as they decided to give blood or not and then chose to learn their test results or not, and to understand the social situation of individuals who requested a home visit and their experience in learning their test results at home. The study sought to understand the factors that individuals consider in deciding to give blood and then deciding to learn their HIV test results, as well as how and why respondents accept a home visit from a counsellor or refuse such a visit. In addition, the study looked for evidence that the delivery of HIV test results at home might have changed the social relations of family members who received their test results.

## **1.6 Study Organisation**

The study was implemented through a contract between ORC Macro and the Child Health and Development Centre (CHDC) of Makerere University in Kampala, Uganda. The CHDC participated in the training of fieldworkers and development of instruments, conducted the fieldwork and data processing, and took the lead in much of the analysis and report writing. Funding for this study was provided to ORC Macro by the Global Bureau of the United States Agency for International Development (USAID)/Washington.

Through a combination of structured observations and individual interviews with respondents who participated in the home-based VCT survey, the research team collected data on respondents' experiences with the survey team, the laboratory technicians, and the counsellors. Fieldworkers observed how laboratory technicians administered the informed consent statement to draw blood and make a home visit to provide test results. They also interviewed respondents after the blood draw and after the post-test counselling to obtain information about what respondents recalled about the informed consent process, the options they were given, and their preference for receiving HIV test results at home or elsewhere. Fieldworkers also returned to households several months after the departure of the survey team to look for indications of social tensions or other reactions to the delivery of HIV test results to households.



## **CHAPTER 2**

### **VCT in Uganda**

#### **2.1 Prevalence of HIV in Uganda**

Specialists in HIV/AIDS around the world agree on the critical importance of obtaining accurate estimates of HIV prevalence at national and sub-national levels. An assessment of HIV prevalence is needed for estimating the demand for medical services as well as anticipating changes in morbidity and mortality. Until the past few years, HIV prevalence rates in Asian and African countries have most often been based on data from sentinel surveillance sites that collect blood from women seeking antenatal care. This has been the case for Uganda until recently.

The national UHSBS provided population-based estimates of HIV prevalence in Uganda for the first time. Preliminary survey data showed an overall prevalence of HIV of 7.0 percent among adults 15-59, with differences by sex and by urban/rural residence. Prevalence was 6.0 percent among males and 7.9 percent among females. Prevalence was 6.5 and 10.7 percent among rural and urban residents, respectively. These estimates, although slightly higher, are similar to those found in sentinel surveillance sites over the past two years.

Since 2002, ORC Macro has provided technical assistance for Demographic and Health Surveys that have included HIV testing to a number of countries: Mali, Senegal, Guinea, Burkina Faso, Cameroon, the Dominican Republic, Zambia, Kenya, and Tanzania. In each of these countries where results are available, the HIV prevalence level found was less than the estimates obtained from sentinel surveillance site data. Most experts agree that population-based data—albeit with its own potential biases—provide a more accurate reading of HIV infection rates than other methods (Boerma et al., 2003; Fabiani et al., 2003). Procedures for conducting surveys that include HIV testing have now been standardized within ORC Macro.

All of the implementing agencies of surveys that offer HIV testing have offered vouchers to respondents so that those who want to know their HIV test results can obtain them free of charge and receive counselling. So far, it appears as though relatively few people in the countries surveyed have used the vouchers to obtain their test results. In fact, it has proved extremely difficult to determine the proportion of respondents who use the vouchers for a free HIV test, because the proportion cannot be determined without making visits to all the health care facilities involved in the redemption of the vouchers.

#### **2.2 Importance of Testing for HIV**

Efforts to prevent the transmission of HIV in most countries have long been hampered not only by a lack of good data about HIV prevalence, but also by poor access to HIV testing facilities, public reluctance to get tested for HIV and thus gain access to social and medical services, and the limited availability of antiretroviral (ARV) therapy for individuals infected with HIV. The government of Uganda, assisted by numerous donors, has been creating VCT centres around the country over the past 15 years, and has promoted HIV testing as a means of HIV prevention and access to care.

### **2.3 Interest in VCT**

Specialists in HIV/AIDS research recommend that VCT services be dramatically expanded so that more individuals learn their HIV status and gain access to social and medical services as needed. A number of scholars are convinced that VCT is an effective intervention for preventing HIV transmission (Coates et al., 1998; Horizons, 2001). The Voluntary HIV-1 Counseling and Testing Efficacy Study Group recently directed a study of the efficacy of VCT in reducing unprotected intercourse in Nairobi, Dar es Salaam, and urban Trinidad, with mixed results (Voluntary HIV-1 Counseling and Testing Efficacy Study Group, 2000). Data from VCT centres in the United States shows that VCT can lead to changes in behaviour. On the other hand, the extensive study in Rakai, Uganda, which followed a cohort of more than 11,000 men and women over an extensive period of time, did not find evidence that counselling led to a reduction in risk for HIV infection (Nyblade, 1998).

There is also an on-going debate among HIV/AIDS specialists about the level of demand for VCT in African countries and the type of services preferred. The evidence from sub-Saharan African on the effectiveness of VCT in reducing risky actions overall remains unclear. The Horizons project conducted research in Kenya and Uganda in facilities offering HIV tests, including the experiences of young people being tested. In both countries, they found a wide range of configurations of testing and counselling offered (Horizons, 2001). Researchers found that youth were concerned that the test results remain confidential, and that they could be tested without anyone else knowing about it.

### **2.4 Access to VCT Services**

In Uganda, the AIC has led efforts to offer VCT services since 1990. AIC established regional centres in five cities by the mid 1990s, and added three more in 2004. By 2002, AIC was operating some 70 sites, but most of them were outreach posts in 34 districts. The AIC branches and outreach posts use rapid test kits and charge a fee for their service. Nearly 75 percent of funding for AIC activities comes from USAID contributions. Counselling and testing for HIV at district hospitals is free.

In an evaluation report covering the first eight years of AIC activities, the authors mention several key lessons learned from their experience to date (Alwano-Edyegu and Marum, 1999). One lesson is that VCT should be offered as part of a comprehensive HIV prevention programme, and so in contexts where no supportive services exist, it may not be appropriate to offer VCT. A second lesson is that anonymity is very important to clients of VCT services. In this context, anonymity means not only that no name is attached to test results, but also that a person can use VCT services without her/his identity being recognized. This lesson parallels the concerns found by the Horizons Project in Kenya and Uganda.

The AIC summary report of 2004 activities (AIC, 2004) noted that a total of 219,520 clients were seen during the year: 26 percent in the eight regional offices (Kampala, Jinja, Mbarara, Mbale, Arua, Soroti, Kabale, Lira); 67 percent in district health facilities supported by AIC; and the rest (7 percent) in outreach posts and home visits. Among all these clients, 18 percent tested positive for HIV, with 21 percent of females and 14 percent of males testing

positive. The AIC clients showed a much higher sero-prevalence than the estimated national average, which indicates that AIC clients, being self-selected, have been at higher risk for HIV than the average population. By the end of 2005, AIC centres operated in at least 38 districts (out of 56) in Uganda.

The other major non-governmental organization that provides VCT is The AIDS Support Organisation (TASO). For many years, TASO provided care and support services for those who tested positive for HIV. TASO now offers VCT services in dozens of sites around the country and also provides support services. In its early years, the AIC offered mostly HIV testing with little or no social support, while TASO offered mostly social support to those infected with HIV. By 2005, both organizations offered both HIV testing and social support.

The options for getting tested are no longer dominated by the facilities of the AIC and TASO. There are now private medical facilities throughout the country that offer HIV testing, counselling, and even ARV therapy, as well as other government services that offer VCT. The MOH monitors most of these services in an effort to provide similar services related to HIV/AIDS to most of the population of Uganda.

## **CHAPTER 3**

### **Results of the Home-based VCT Survey**

#### **3.1 Rationale for the Home-based VCT Survey**

The home-based VCT survey was conducted in 33 clusters in three regions to test the feasibility of offering HIV test results at home as part of a population-based survey. The feasibility was thought of in economic, logistical, and social terms. That is, would this approach to providing test results be too expensive? Would it be cumbersome and difficult to manage? Would it be socially acceptable and not disruptive?

Conducting HIV testing in a survey context presents not only logistical and technical but also ethical challenges. Survey organizers believe they have an obligation to provide respondents with a way to learn their HIV test results if they so choose, while individuals have the right to refuse participation in testing. The obligation to provide respondents with a way to learn their sero-status if they so wish is most often satisfied through the distribution of vouchers for obtaining a free HIV test. If survey respondents are offered the chance to learn their test results at home rather than using a voucher at a health centre, the survey team needs more laboratory technicians and counsellors to conduct the rapid tests and provide counselling.

In the initial consent form for obtaining agreement to be interviewed, respondents were told that survey participation included a home visit for counselling and receiving HIV test results. Overall, it was thought that by offering individuals the option of learning the result of their HIV test at home and also of receiving counselling, the proportion of those tested who chose to learn their sero-status would dramatically increase. Although the MOH set up a system for monitoring the distribution and use of the vouchers, quite a few facilities did not report on the use of the vouchers distributed during the survey. Therefore, it is not possible to know the proportion of respondents who used a voucher to obtain an HIV test, although it has been estimated to be from 35 to 40 percent if the data from reporting facilities are accurate. In addition, this approach provided an opportunity to assess the proportion of the survey population willing to accept a home visit, and to identify the kinds of individuals most likely to accept a home visit in order to learn HIV test results.

#### **3.2 Organisation of Survey**

The MOH selected interviewers and supervisors who had conducted the national UHSBS and organized them into six teams to cover the three regions chosen. Each MOH survey team included four interviewers, three laboratory technicians, four counsellors and one team leader. Counsellors were trained to accompany the survey teams to counsel respondents who agreed to get an HIV test and who obtained their HIV test results.

By offering HIV test results at home in this small survey, several aspects of the survey process changed from the procedure of the UHSBS just completed: 1) during the social mobilisation activities, people were told that home-based testing and counselling would be part of the survey; 2) in the informed consent procedure before the blood draw, respondents were told

about the home-based VCT option; and 3) laboratory technicians performed rapid HIV tests in field laboratories.

### 3.3 Participation Rates for Survey and Blood Draw

This approach sought to test the effects of the home-based VCT option as part of a survey on participation in the survey itself and on participation in the blood draw. Many persons in the MOH thought that the inclusion of home-based VCT for HIV would affect participation in the survey itself and also in the blood draw. Participation rates in the home-based VCT survey were to be compared to those of the UHSBS.

The rates of participation in the UHSBS and in the blood draw were relatively high for both men and women. Table 3.1 shows these rates for the UHSBS survey, for the three regions of the UHSBS survey in which the home-based VCT survey was implemented (Central, Western, West Nile), and for the 33 clusters of the home-based VCT survey. The row for the UHSBS survey appears in the table as a reference to determine if the three regions in which the home-based VCT survey was conducted differed from the national figures. Participation rates for the three regions are higher than the national survey, but only slightly, most likely because the three regions include relatively few urban residents. In the home-based VCT survey, a total of 1686 respondents (902 women, 784 men) were found eligible to be interviewed.

	Participation in survey		Participation in blood draw	
	Men	Women	Men	Women
UHSBS	89.1	94.5	83.8	89.1
Three regions of UHSBS	91.9	95.1	87.3	90.8
Home-based VCT survey	87.1	94.5	84.9	90.8

Both vertical and horizontal comparisons show very little differences for men and women. A horizontal comparison between the rates of men and of women shows that participation in the blood draw is only two or three percentage points less than for participation in the survey. In other words, very few respondents who accepted participation in the survey did not have their blood drawn. Vertical comparisons between the home-based VCT survey and the national survey in the same three regions shows a small decrease in rates for men but not for women.

### 3.4 Acceptance of Testing and Counselling at Home

Just as the MOH survey teams achieved quite high participation rates for the blood draw, they were also successful in getting nearly all respondents to accept their HIV test results. Table 3.2 shows the percentage of men and women in the home-based VCT survey who accepted to learn their HIV test results, who refused their test results, and who refused the blood draw.

Table 3.2 Distribution of eligible respondents, by sex, who gave blood or not, and who accepted or refused their HIV test results				
	Accepted test results	Refused test results	Did not give blood	Total
Men	83.3	0.9	15.1	784
Women	87.8	1.4	9.2	902
All	85.8	1.2	11.9	1686

The figures in Table 3.2 reinforce the evidence from Table 3.1 that shows the small proportion of men and women who refused the blood draw and who refused to learn their HIV status. Nearly all respondents who participated in the blood draw accepted their HIV test results.

### **3.5 Implications of Home-based VCT as Part of a Survey**

The 33 cluster survey showed that individuals will agree to participate in a survey and to give blood to a team from the MOH on an official mission, and that most people are willing to learn their HIV status at home. Because so little is known about home-based VCT, we conducted a special study of the process and feasibility of offering home-based VCT as part of a population-based survey and the social consequences of receiving HIV test results at home. The rest of this report presents the results of this study, including an examination of how the survey teams obtained such high rates of participation and how and why people accepted home visits.

## **CHAPTER 4**

### **Qualitative Study Design and Research Questions**

#### **4.1 Specific Study Objectives**

The overall objectives of this qualitative study were to understand the factors involved in the respondents' decisions to give blood or not and learn their test results or not, as well as understand the social situation of individuals who accepted or refused a home visit and their experience in learning their test results at home. The study was designed for implementation in two phases.

In Phase I, the researchers sought to understand the reasoning behind the choices of respondents to participate in the survey, to participate in the blood draw, and to learn their HIV test results, as well as their preferred place for learning test results and counselling. The research strategy was closely tied to the activities of the MOH survey team as they interviewed respondents and asked for consent to draw blood. CHDC fieldworkers observed the process of administering the consent statement, interviewed respondents after they were asked to give blood, and then interviewed them again after they received their test results. Information obtained through observations and the two short conversations with respondents was used to learn how individuals made their decisions about participating in the blood draw and getting their HIV test results.

In Phase II, the CHDC interviewing teams returned to some households that had been surveyed months earlier where one or more individuals had received their HIV test results at home. This part of the study looked for events or social changes in the households and the community that had occurred since the survey visit that might be linked to the home delivery of HIV test results. In other words, the study sought to assess the social implications of learning HIV test results at home.

#### **4.2 Research Questions**

This study aimed to provide information about the social situation and the experience of individuals as they participated in counselling and testing in their homes or in another place nearby, and individual experiences in disclosing test results to others. The study explored the following issues:

- 1) The factors involved in participation in a blood draw if the home-based VCT option is explained to them;
- 2) The factors involved in deciding they want, or do not want, to learn their results;
- 3) The factors involved in choosing to get results at a mobile unit or at home;
- 4) The experience of learning the results and being counselled by a counselling specialist who visits an individual at home; and

- 5) The experience of respondents who received their test results and either chose to disclose or not to disclose their results to others, whether they learned their test results at home, at a fixed health facility, or from a mobile VCT team.

Among the specific research questions that guided this study were the following:

- What factors are involved in a person stating that s/he wants to learn the results of an HIV test?
- What factors are involved in the choice of venue for learning one's HIV test results?
- How do the family situations differ for those individuals who accept a home visit compared to those who say they prefer going to a health facility?
- What are the desires of individuals regarding privacy, confidentiality, and anonymity in the process of getting tested and learning one's results?
- How will a counsellor assure the privacy and confidentiality of test results during a home visit?
- How and with whom did respondents share their HIV test results?
- How did family members react after a home visit for VCT for one of them?

These questions were used to orient the questioning guides developed during training, in the analysis of the interviews, and in the writing of the final report.

### **4.3 Assumptions**

The study proposal made several assumptions about the survey and about respondents' reactions to the presence of the survey team that guided this study design. Among those assumptions were the following:

- Most individuals are somewhat afraid of learning their HIV test results.
- Individuals who take an HIV test prefer to get tested in a place where no one knows them.
- Survey respondents would much rather get their HIV test results from a mobile unit than from a static health facility.
- Most individuals will not share their HIV test results with family members or with friends.

The research questions and the assumptions were discussed extensively during the training for fieldwork so that all participants could present their own knowledge of such matters and state their expectations for the study. The group also referred to the research questions during the development of the conversation guides in order to better focus on essential matters.



## **CHAPTER 5**

### **Methodology and Fieldwork**

#### **5.1 Preparation for Data Collection and Data Processing**

The preparation for data collection consisted of training fieldworkers in principles of qualitative research, on the objectives and procedures of the study, and on techniques of interviewing. The first two days of training were devoted to discussions of the principles of qualitative research, to the HIV/AIDS situation in Uganda, and to an examination of the study proposal in order to give everyone attending the same understanding of the objectives, the use of forms and questioning guides, and the operating methods for the research. The rest of the training period was devoted to principles of interviewing, the development of instruments and informed consent statements, translations from Luganda and Runyoro/Rutooro into English and back again, and role plays. The questioning guides were substantially modified during the role plays of the interviewing process, since oral language differs so much from written text.

#### **5.2 Development of Instruments**

The study directors, along with the training participants, developed three separate instruments—an observation form and two questioning guides—to structure the data collection during fieldwork for Phase I.

The first instrument was an informed consent observation form (Appendix A) adapted from an earlier study that monitored the administration of a consent form for taking blood in Mali. The form allowed the observer to note which issues were mentioned by the person administering the consent, how the presentation was made, the attention paid by the respondent, and several answers provided by respondents. Written comments were required at several points in the process.

Two short questioning guides (Appendix B) were also developed. The first questioning guide asked respondents about the informed consent procedure, about how and why they decided to participate in the blood draw, and about their decisions regarding their HIV test results. This interview provided information about their decisions related to the blood draw and HIV and syphilis testing. The second questioning guide focused on their experience in being counselled after they had learned their test results. Fieldworkers asked about the questions respondents may have asked during the counselling session, the advice given, and their overall impression of the experience. Working from the research questions found in the proposal, the group in training formulated a short series of questions in Luganda and Runyoro/Rutooro to guide the conversations with respondents.

A questioning guide for Phase II (Appendix C), which involved return visits to households that had been part of the Phase I interviews, was also developed during the training period.

### **5.3 Sampling**

The sampling of households for the MOH survey teams in the home-based VCT survey was determined by the MOH in conjunction with the Uganda Bureau of Statistics using the 2002 Housing and Population Census records as the sampling frame. The survey teams had a list of 25 households to visit in each cluster; the number of households actually located and respondents interviewed was usually 21-23 per cluster.

Each of the two CHDC teams had a target of interviewing adults in 18-20 households per cluster, or nearly everyone interviewed by the MOH survey teams. The group of respondents who were invited to participate in the blood draw by the laboratory technicians comprised the denominator from which the sample for the qualitative study was drawn. The CHDC team sought to interview all eligible respondents (household members 15-59 years old) in the first 18-20 households visited. With an average of two eligible respondents per household, the study expected to visit 150-160 households and observe about 300 respondents in the informed consent procedure.

For both logistical and linguistic reasons, the CHDC team chose to exclude the West Nile region because of its location so far from Kampala. The team worked in the Central and Western regions only, because they were more accessible from the capital, and it was assumed that nearly everyone could speak either Luganda (Central) or Runyoro/Rutooro (Western). Each district in these two regions contained two or three survey clusters identified through the sampling process.

The CHDC trained two four-person teams to conduct fieldwork along with the MOH teams; one team worked in Luganda, and one worked in Runyoro/Rutooro. In the end, the two teams worked in 10 clusters, rather than eight, in seven districts, because two clusters in districts designated for pre-testing were actually included in the study analysis. The CHDC teams followed the movements of the MOH survey teams as they chose clusters where respondents spoke one of the two languages of the study (Luganda and Runyoro/Rutooro). In the Central region, the survey was conducted in the districts of Mubende, Rakai, and Sembabule, while in the Western region, the districts covered were Hoima, Kabarole, Masindi, and Kyenjojo.

### **5.4 Fieldwork Procedure**

The six MOH teams that collected data in the 33 cluster survey were composed of 12 members: four interviewers, three laboratory technicians, four counsellors, and a team leader. During fieldwork, two sub-teams were formed to ease the data collection process and to avoid having a crowd visit a household. Each sub-team had one laboratory technician in their group; the third laboratory technician remained at one station that served as the laboratory.

The MOH teams followed the protocol process of obtaining a letter of introduction from district officials to the local leadership before beginning their work. The Local Council (LC) officials then designated a local leader to introduce the teams to the selected households. Having a local leader as a guide to the team was helpful in creating trust and allaying suspicion among respondents of many households. MOH plans also called for social mobilisation among local officials and the general population before the arrival of MOH teams in the area. Mobilisers were

supposed to inform the community about the objectives of the survey and that home-based HIV counselling and testing would be part of the survey. However, most of the respondents learned about the survey at that time when the team visited their homes, and some respondents were perplexed when they saw the team arrive in their homes.

One interviewer described the reaction of the respondents in one of the homes as follows:

*What I noticed about them was that they were all scared about seeing vehicles outside and they looked at the team suspiciously.*

One respondent observed:

*I did not know anything. I got to know just now when you came. The chairman (of the LC) told me that 'you have visitors' and that I should answer all questions they ask.*

However, some respondents had received prior information about the survey, some receiving it from public places such as churches. One respondent noted that:

*I heard in church that people are coming to look for those with AIDS and to test those who wanted. I did not put much thought to it, but I am surprised to see you.*

From the interviewers' observations, those who acknowledged having prior knowledge about the survey team seemed to be more cooperative and willing to participate in the study and accept the blood draw. One of the fieldworkers commented:

*This family expected us and had been informed about the ongoing survey. We were received (in the home) by one of the eligible household members. The people were aware of our coming here and willing to participate in the exercise.*

On reaching the household and after the introduction of the team by an accompanying local person, each eligible respondent was interviewed on average for about 45 minutes. The individual interviews by the MOH team were comparable in their subject matter to risk assessment sessions conducted at an AIC or MOH VCT centre. In some cases, the interviewers used these interviews to predict if the respondent would accept or decline to have their blood drawn, and to subtly communicate to the laboratory technicians how the respondent was expected to react to the blood draw.

After each individual interview was completed, the laboratory technicians were called over to administer the informed consent statement for the blood draw. Respondents were told about receiving HIV test results in their homes or other options, such as from a mobile VCT clinic team or in a static health facility, and were told about the other possible tests that could be done and the availability of syphilis treatment if necessary. The process of requesting permission for the blood draw was observed by the CDHC team members. For those respondents who

accepted to learn their HIV test results, counsellors provided them with pre-test counselling, and also returned the following day to provide post-test counselling and to deliver the results of the syphilis and HIV tests.

## **5.5 Collaboration with Survey Team**

The qualitative study combined both observation and short interview methods for data collection. Observations involved monitoring the process of administering the consent form for the blood draw by the laboratory technicians. The CHDC team observed a total of 328 cases of presenting the informed consent statement to respondents. After the blood draw and administration of the consent form, plus a short pre-test counselling session, respondents were contacted by the CHDC interviewers for a short interview. The CHDC interviewers also accompanied the counsellors the following day to the homes of those respondents who accepted to receive their HIV test results, so that they could interview respondents a second time just after they had received their HIV and syphilis test results.

Most respondents in the 33 cluster survey accepted the blood draw (only 12 percent of survey respondents refused to participate). Similarly, nearly all respondents observed by the CHDC teams accepted the blood draw. In fact, fewer than 10 respondents among the 328 respondents observed refused to have their blood drawn. Those individuals who refused were interviewed only once following their rejection of the blood draw. Furthermore, only a few of those who had their blood drawn chose not to receive their HIV test results.

The CHDC strategy of working in only two languages in two regions made it possible to find a common language with respondents in nearly all cases. However, in a few cases in the Western region, the interviewers were not able to use Runyoro/Rutooro as anticipated; two of the interviews were conducted in Swahili and seven were conducted in Rukiga. The rest of the interviews (n = 174) were conducted in Runyoro/Rutooro. The teams also found three cases where respondents were deaf and mute, and the conversations were held with the aid of a family member who knew the local sign language.

The CHDC teams held meetings every evening to discuss the day's work and plan for the following day. The meetings provided an opportunity to reflect on fieldwork and discuss interesting issues and challenges as they arose, as well as noting successes. In some instances, there were meetings with the main survey team to plan for the following day and decide on how to handle frequent problem situations, such as absent or unwilling respondents.

## **5.6 Approaching Respondents**

The social environment in the field was influential in determining the process and level of interaction of the CHDC study teams with respondents. According to the study protocol, the place of interaction was meant to be the home. However, sometimes the visit took occurred at the respondent's place of work, especially in the urban settings. The local field guides provided by the LC to assist survey teams in locating households knew the respondents' places of work (for example, those operating shops) and would take the team members there when respondents were

not found at home. Other respondents were found in their gardens and would be called by the guides to return home.

The home environment differed from one home to another, and from one community to another. Some homes, particularly those in rural communities, appeared to have more places with privacy than those in the urban areas. Some homes were inhabited by very large families, while others were made up of married couples only, or unmarried couples, widows, etc. Thus, the possibilities of finding private spaces for interviewing varied greatly with household composition and spatial configurations. The descriptions by CHDC interviewers show the range of the home environments:

*Quite a big house; about four rooms made of mud and iron sheets, and the compound is clean. It is isolated from other houses and is surrounded by gardens.*

*It is within the town of Kassanda, adjacent to a maize/coffee store, with a pit latrine directly opposite the rooms. It is one-roomed and she is a tenant. She occupies the side room as you enter the place and there are six other rooms occupied by other tenants.*

*It is a big house and another one in one compound. I think it is the biggest house in this village. It is newly built with blocks (bricks) and iron sheets and well ventilated. It is around 2 km from the trading centre, and there are many fruit trees around with a banana plantation behind.*

*It is a small house in a miserable state, partly roofed with grass and partly with iron sheets and bound by a log of wood on top.*

The study protocol required that the process of interviewing, administering the consent form, and counselling all had to be in a private place. In some cases, the protocol was difficult to observe because of the home environment, whether for lack of space or for too many persons present. The CHDC teams faced the same challenges in finding private spaces for interviewing, as did the MOH teams for conducting their interviews and blood draws. Other members of the family sometimes kept peeking in, wanting to see what was going on. Sometimes, when neighbours saw vehicles at someone's home, they also came to see the visitors. One of the fieldworkers wrote this comment on their visit to a household:

*A neighbour come to see what was happening when she saw our cars stopping at her neighbour's home. As interviews began, the neighbour, who also was carrying a baby on her back, helped her friend (the respondent) with one of the twins as the respondent continued the interview.*

These conditions made privacy difficult to achieve, even during the blood draw, as one interviewer observed:

*There was a lot of conversation going on around; thus, the respondent was distracted. The family members hung around and there was no privacy during the blood draw.*

Interviewers further observed that some business owners had to be interviewed while they attended to their customers, in the case of shop keepers, or those with eating places. It was difficult to convince these individuals to temporarily close their businesses and take time off for an interview or even to receive HIV test results. There was also an incident where HIV test results were given at the place of work in an open space.

The current practice in Uganda of the government providing social and medical services for the public may well have influenced respondents to regard the research team as a provider of another service. The service in this case was confirmation of the presence or absence of syphilis, and information about individual HIV sero-status. After learning his test results, one respondent said:

*Now, musawo (health worker), what should I do?*

Some respondents also expected material assistance from the team, and they focused their attention on that rather than on the study process. One of the CHDC team members commented:

*The interaction with the old lady was good, although the lady was more concerned about the assistance we could provide to the children.*

Another woman in a polygamous marriage asked the team to help with her marital problems. She offered to give her blood even before the individual interview began, perhaps expecting that this would encourage the team to help her with her problems.

Although some respondents were amazed to receive a visit by a team from the MOH and others seemed frightened by the sheer number of people who showed up, there were those who were happy to be visited and regarded the exercise as an opportunity because the MOH had offered to bring a health service to their home.

## **CHAPTER 6**

### **Obtaining Informed Consent for a Blood Draw**

This first phase of the study explored, through observation and in-depth interviews, the factors that individuals considered in deciding whether to give blood for an HIV test or not, whether to learn their test results or not, and the venue in which to receive their test results. The interaction that determines participation in the blood draw is the presentation of the informed consent statement by the laboratory technicians of the survey team. A structured checklist (Appendix A) was used by the researchers to observe the administration of the informed consent statement and respondents' reactions to the process.

#### **6.1 Presentation of the Informed Consent Statement**

The laboratory technicians had a written informed consent statement in English or in a local language to administer to respondents after the individual interview. However, rather than reading an extended text designed as an informed consent statement, the laboratory technicians usually gave brief explanations of the main elements of what was expected of survey respondents. In that process, the laboratory technicians would sometimes forget to mention some issues in the consent form. For example, nearly half (48 percent) of the 328 respondents were not informed explicitly about the three possible options of where they could receive their HIV test results, and 42 percent were not told directly that participation was voluntary. It is important to remember also that some respondents just wanted the laboratory technician to go ahead with her work without much explanation.

With regard to other important aspects of the consent statement, confidentiality of results was only directly explained in 55 percent of the cases observed. In 58 percent of the cases observed, the respondents were informed that their participation in the study was voluntary, and in 59 percent of the cases observed, the risk of the study to the respondents was explained. With regard to getting tested for HIV, more than half (58 percent) were explicitly told they could accept or refuse an HIV test. Although these figures are lower than expected, they are low in part because some individuals just wanted the laboratory technicians to draw their blood quickly, and they did not give the technician the opportunity to present the basic elements of the consent statement.

It is possible that the individual interview that preceded the administration of the informed consent influenced the informed consent process. As noted earlier, interviewers would gauge the person who was likely to accept the blood draw, based on her/his answers, and they would subtly communicate that to the laboratory technicians. It is likely that such communications contributed to the laboratory technicians omitting some issues in the consent form.

The fact that the survey teams were identified as being officials from the MOH in Kampala, and that they were accompanied by local leaders, is likely to have encouraged participation in the survey and the blood draw. Respondents were willing to set aside time,

however busy they were, to respond to the questions from the laboratory technicians and the survey team. In this respect, one of the team members observed:

*They actually cooperated because the husband was in a hurry, but when the wife requested him to first attend to visitors (Abasawo), he accepted.*

The relationship between respondents and the laboratory technicians appeared asymmetrical both socially and politically, with the laboratory technician in control. In one-quarter of the cases, the laboratory technicians did not ask respondents if they had any questions to ask before consenting to a blood draw. In this respect, the CHDC interviewers made the following observations:

*The interaction was one-sided; the man did not want us there and didn't want to see the blood draw.*

*I observed that this respondent did not give any comments nor did he ask questions. At one point, it's like he wanted either to ask a question or to comment, but the laboratory technician did not give him the chance.*

Despite that, slightly more than half (56 percent) of respondents asked questions during the administration of the consent form, asked questions about the drawing of blood, and asked what would be done with the blood. As one interviewer remarked:

*I observed that the woman was so receptive and humble. She paid close attention to the interviewer and it was a dialogue; while the man (husband) had a lot of questions.*

The observations of the informed consent process made it clear that respondents were expected to comply and accept participation in the blood draw. When respondents attempted to refuse, the laboratory technicians would try to persuade them to accept. The CHDC fieldworkers reported that sometimes when a respondent refused a blood draw, the laboratory technician would re-explain the objectives and benefits of participation. If this failed, s/he would call on the colleague to do the explanation. Often respondents would not refuse outright, but they would use different reasons in an attempt to refuse. For example, some women said they had to wait for their husbands.

A few respondents regarded the study team as intruders and wanted them to leave their compounds as quickly as possible. This probably explains why some of the respondents would simply accept a blood draw even before the interview and administration of the consent form.

## **6.2 Common Responses of Survey Respondents**

Most respondents were very attentive as the laboratory technicians explained the consent form. The reaction of respondents to the administration of the consent form can be seen in Table 6.1, below:



Table 6.1 Relative attentiveness of respondents during presentation of consent form		
Attention	Number	Percent
Pays no attention	2	0.6
Pays a little attention	41	12.5
Pays close attention	266	81.1
Missing data	19	5.8
Total	328	100

A few respondents were nervous or distracted by events around them, such as children who needed attention during administration of the consent form or someone else who urgently needed something from a respondent. Most respondents, however, tried to pay attention to laboratory technicians as observed below:

*He was very attentive, following everything being said. He was first distracted by a crying kid who was handled by the wife and all his attention was shifted to the laboratory technician.*

The observations revealed that the majority of respondents (81 percent) paid close attention to what was being explained to them, and in nearly all cases observed (85-86 percent), an introduction to the study was made where the objectives of the survey were explained to the respondents. In 95 percent of the cases observed, respondents were informed that the blood draw was for an HIV and syphilis test, that their results for both these tests would be available the following day, and that those testing positive for syphilis could receive treatment.

In considering the presentation of the informed consent statement, it is important to remember that the interaction between the respondent and the laboratory technician did not take place in a vacuum. Rather, the interaction was conditioned by the interview that was just completed, comments that the respondent may have made, and the overall approach of each laboratory technician.

## **CHAPTER 7**

### **Participation in the Survey and the Blood Draw**

The home-based VCT survey obtained high rates of participation in the survey and in the blood draw, as shown earlier in Table 3.1. A total of 87 percent of men and 95 percent of women participated in the survey, and 85 percent of men and 91 percent of women gave blood for screening tests. This chapter discusses how the survey teams achieved such high rates, as seen through comments made by respondents after the blood draw.

#### **7.1 Options Presented to Respondents**

This qualitative study was predicated on the assumption that respondents would be offered a series of options that would involve deciding whether to participate in the survey or not, whether to give blood for an HIV test or not, whether to learn their test results or not, and the venue in which to receive their results. The study further assumed that the respondents' decisions would be made in a sequence. In most cases, however, this did not happen. Rather, the main decision to be made was: will you cooperate with the survey team who has come to your house, often with an LC member to request your cooperation? Therefore, the discussion of the reasons for participation refers to both the survey itself and the blood draw. Reasons for accepting the HIV test results, however, involve another set of issues and are thus discussed separately.

#### **7.2 Reasons for Participation**

After the laboratory technicians drew blood and a counsellor had conversed with the respondents, the CHDC interviewers conducted a brief interview to discuss participation in the survey and in the blood draw. Among the issues that respondents often cited as relevant to their decision to participate in the survey were the following. First, this study was being conducted by the government, since the survey team represented the MOH. The laboratory technicians and all other members of the survey team were called *musawo* (health care workers or doctors). Second, the research teams were accompanied by local leaders, sometimes LC Chairpersons, who helped not only in identifying the selected households but also in formally introducing the teams to the members of the households and asking for their cooperation. This gave the exercise an additional stamp of authority. Third, those conducting the study were outsiders to the communities where the study was conducted, and thus did not know the respondents. Fourth, the households included in the study were randomly selected and listed before the study, and people in the community were not quite sure how this was done nor what criteria had been used.

The local leaders who moved with the MOH survey teams legitimized the presence of the team and were significant in persuading respondents to participate in the survey. In fact, it was difficult for the respondents to refuse, considering the team was representing the government, and they were well aware that the local leaders were people who knew them. There were respondents who did not think that they had much of a choice, especially where the authority behind the exercise filtered through, as two of the respondents remarked:

*Who am I to refuse to participate in this exercise when my name is already on the list?*

*If you refuse to participate and they take note of you, you can easily end up with problems, so why should I refuse? After all, I may as well learn my status.*

*I will just help the government and participate, but I don't want my results.*

Others were satisfied with the explanations given by the LC leaders and the research teams:

*I gave blood because I was requested to test for syphilis and AIDS and you are the very people who said you were going to test for syphilis and you are the ones who said that you would come and inform me of the results.*

*The Chairman LC came to our place and told us that some people have come to our area from the Ministry of Health and that they will be coming to treat us. He said it was important that these people find us at home. He told us that they were going to draw blood to test for syphilis and mentioned that it's up to me to decide whether to participate or not. He told me that the results will be brought back and those people found with syphilis will be treated. He told me that if I want I could test for either HIV or syphilis, and even if I tested for both I could decide to receive the results for only one....*

*The chairman told us that you were coming, but I did not understand who was coming, what they are going to do and he did not give us any more information. He just told us that they are from Kampala. The lab tech told me that you are going to reduce on STDs and that the blood draw was going to help us get medicine that will treat those diseases, also cure them completely. So the message I got is that you are going to help treat and prevent these diseases.*

*On Sunday the Chairman read out the list of the homes which were going to be visited.*

Other respondents stated:

*I did not know about your coming. If I had not come back you would not have gotten me, for I was going to see my friend. I came back yesterday I didn't know... The lab tech told me that he was going to draw my blood and test to see some diseases and treat me.*

*I had not heard about you, I only heard that if you are tested and found with AIDS you get some drugs.*

Respondents took comfort in the knowledge that those conducting the study were outsiders to their communities and thus did not know them personally. This fact was important to respondents. A visit to a VCT facility can be problematic, because people who know them might see them going for an HIV test, and would begin talking. Giving blood for a syphilis test and an HIV test at home did not expose respondents to the view of anyone who knew them.

Finally, the households included in the study were randomly selected in advance before the study. For the respondents, this meant that their homes were selected without any prior knowledge of their personal backgrounds. Interestingly, while some respondents were not aware of other households that had been sampled, others in the village knew because the list of sampled households was made public in some villages. In one village, the names of the selected households were read out in church, and in another village the names were read out in a public meeting. There were cases where members of the sampled households were absent, so instructions were left behind with others in the neighbourhood informing them to expect visitors from the MOH and not to leave their homes until the team arrived. One respondent explained:

*When I went to the shop someone told me that I am on the list of the health workers. I asked them which health workers...later they came to my home.*

Another respondent said that she was confused when informed that she was on the list:

*I came from the gardens and passed by the shop, I found ladies seated on the verandah and they told me you are also on the list of the doctors. I asked them what kind of doctors, and they replied, the doctors who are here. They have gone to so-and-so's place but you are also on the list. They are around working, so I returned to my place and stayed there... now at around 2 pm I saw ladies going for a meeting. They said they thought I had visitors and one of them who is my friend said to me "I waited for you to call me so that we can meet the visitors together, but you did not send for me..." Then the LC Secretary for information came and I asked her how come I did not know about the visit. She told me that the Chairman should have informed me. So I told her that I wanted to go somewhere, and she said I should not go. I cancelled my journey and stayed around.*

Although there was no anonymity in as far as the sampled households were concerned, this was not a concern for respondents. The participation of the LC Chairpersons and other members of the LC Executive in identifying the sampled households and introducing the research teams to the members of the households was usually enough reason for the respondents to cooperate.

While some of the respondents agreed to participate without asking too many questions, the majority (56 percent) asked questions before giving blood. After the LC Chairman left, one of the household heads asked the research supervisor:

*First of all, explain to me how my household was chosen yet others were left out.*

In this particular case, the research supervisor had to explain the sampling procedure briefly to the respondent, and it was only after the explanation that the respondent agreed to collaborate with the team. Another respondent said:

*I want a clear explanation about what this study is about. (An explanation was then given by the team supervisor.) I have now understood your intentions that the government is investigating some illnesses that are disturbing us, especially syphilis. Syphilis has many types. The machine will be able to find whether I have syphilis or not. You can now go ahead with the exercise.*

*Why are many people in this area not being checked?*

Another important general factor that favoured cooperation with the MOH team was that the study offered respondents free health services at home in the form of free counselling and testing for HIV, and free testing and treatment for syphilis. This was perceived as an incentive by those who agreed to participate.

Results from the 33 cluster survey indicate that about 30 percent of those who refused the blood draw request were between the ages of 15 and 24. More males (38 percent) than females (24 percent) in this age group refused the blood draw request. Cases of refusals reported by researchers who conducted the in-depth interviews suggest that some individuals found it difficult on short notice to make up their minds as to whether they should test for HIV. There were cases where individuals approached the teams for the test the following day after thinking about it and deciding that they wanted the test after all, but it was too late. There were also cases of those who indicated that they did not want their HIV test results, but then when they saw the teams bring back other people's results, they decided to ask for theirs as well. There were still other cases where people hid from the teams or gave the excuse that they could not take the test because their spouses were absent and they needed their permission.

The interviews with respondents showed that social mobilisation, the introduction of the survey teams by local leaders, the identification of the survey teams as health care personnel from the MOH in Kampala, and the fact that HIV test results were being offered in homes all played a role in encouraging participation in the survey and the blood draw. It is difficult to conclude which one of these was most important in encouraging respondents to participate in the research. Interviews with respondents after the blood draw suggested that the introduction of the survey team by local officials, and the identification of the team as health care personnel, were likely the most important factors in assuring a high rate of participation in the blood draw.

## **CHAPTER 8**

### **Choosing to Learn HIV Test Results**

In Uganda today, anyone wanting an HIV test or a test and treatment for syphilis must usually go to a health unit or to an outreach centre with units offering such services. In most cases, individuals would have to pay for transport to and from the health unit, for the test itself, and for treatment. This suggests that, in normal circumstances, an individual would engage in a lot more reflection prior to making the decision to take an HIV test.

This survey presented a somewhat different scenario, in that not only were VCT services being offered at home, but they were being offered free of charge. In addition, there was also the option for a syphilis test and an offer of free treatment for those found to have syphilis. In a context where a fee is usually charged for such services, the offer of a free test by the survey team was perceived as a rare opportunity. However, respondents did not have much time to reflect on the decisions that they were making. In the majority of cases (79 percent), respondents were either informed the day before the team arrived or on that very day.

*Yesterday evening I was not at home; then Chairman LC 1 came and told the children that they should tell me that there were visitors coming tomorrow, and so I should not leave home. But I did not know where they were coming from and for what...*

Most respondents (83 percent) agreed to learn their HIV test results, whether or not they had been explicitly told that they had a choice to learn them or not. Of those who agreed, 96 percent wanted their syphilis test results, 92 percent wanted their HIV test results, and 93 percent wanted their test results at home. This chapter explains these high rates.

#### **8.1 Acceptance of Test Results**

The original research design had anticipated that respondents would be asked directly if they wanted to learn their HIV test results or not. The results of the observation of the administration of the consent statement suggest that many respondents were not asked explicitly if they wanted their test results or not. Rather, many of those who accepted the blood draw were simply told that they would receive their HIV test results the next day. Thus, the large majority of respondents did, in fact, receive their HIV test results.

The in-depth interviews conducted with the respondents after the blood draw suggest that for the majority of respondents, the choice to receive their results was an easy one. There were very few cases where people indicated that they were not interested in their results. One of the respondents told the research team at the time of the blood draw that they were giving their blood just to help them with their work; otherwise, they were not interested in the outcome. In some other cases, respondents hid from the team when it returned with the results, or they were absent from home.

As previously discussed, interviews with respondents revealed that wanting treatment for syphilis and wanting to know their HIV status were the major reasons that the respondents agreed to the blood draw in the first place:

*I was worried very much that I would be found to have the HIV virus, and my wife would leave me, or if she stayed, there would be no peace in the home. But now that I have found out that I do not have it, I feel something good has come out of all this, now I am going to stick to one woman.*

Some respondents wanted to know their status for purposes of planning their future actions:

*I don't move, I have taken many years like twenty without engaging with men outside of marriage...for my partner I don't know his movements but if he can come and teach both of us or give us those cards to warn us about the disease I will be very happy.*

*I want to know my health status, I may be moving around when I am sick.*

Those most concerned were parents of young children who spoke of needing to plan for their future. Results from the 33 cluster survey show that 94 percent of the currently married respondents agreed to be given test results, and they represented the lowest category of refusals (4 percent) for blood draw requests. Young couples also felt that by finding out their HIV status, they would be able to make decisions on how best to live in the future. Respondents pointed out that in case they found out that they were negative they would make joint decisions with their partners to live faithfully and to continue to protect themselves. One of the respondents explained:

*I want to know my status and be able to plan for the future and for my children. If I am sick I may get treatment and live for some time as my children grow. But even if I am in good health (HIV negative) then I will continue protecting myself and stick only to my husband.*

Another remarked that:

*I need to know my status so that I can plan and make some decisions about the future. I have children but I do not have parents. If I die now and leave my children unplanned for, they will suffer in future, so if I learn that I will die soon I may buy them land.*

Others were concerned about who would remain to care for their children if they contracted HIV and died:

*If I have AIDS then there is need to test my children also, because I would want to know who will survive, who is going with me and maybe who is to inherit me.*

*I want to know our status because it can enable us to stay in peace, have better plans and even caring for our children without any fear or worry... for example you can fail to dig when results are bad and the reverse is true.*

Those who were currently single were also keen to learn their results:

*I want to find out if I am not sick or if the illness has got me.... the lady I date is still around, she has not yet died but they say she is sick, they talk but they don't know that I went there.*

*Because I want to find out my status, the man I had an affair with ten years ago fell sick and died, but not of slim. Now this man I have married has affairs outside more than the first one...I don't know if I can survive those too. I see my condition, I get sick every now and again with fever that is why I want to test...I need to find out if I am sick I start going for treatment.*

Most respondents were willing to learn their test results for both syphilis and HIV. It was found that a slightly higher percentage of respondents were more willing to take and receive their results of a syphilis test (96 percent) than an HIV test (92 percent). This slight difference in enthusiasm may have had to do with the fact that HIV is more stigmatized than syphilis and the fact that there was an offer of treatment for syphilis but not for HIV/AIDS. It was interesting to note, for example, that unlike HIV/AIDS, several of the respondents were very open in their discussions about the possibility of having syphilis and how they saw this study as an opportunity to confirm whether they had it and to get treatment for it. One of the respondents explained:

*I decided to test for syphilis because I have had syphilis since childhood. That has always been my problem so I would like to be tested and get treatment. Now that I also have children they could also have it and I want them to be treated also.*

Another respondent explained that:

*Sometimes when I go to hospital they tell me that I have syphilis. They asked me whether I experience itching in my private parts. When I said yes, they said I had syphilis.*

Another respondent observed that:

*It is good that the government is investigating some illnesses that are disturbing us especially syphilis. Syphilis has many types.*

Syphilis was perceived to be hereditary. Some respondents believed that they were born with it. Others explained that they had it since they were young. Some of its perceived symptoms included miscarriages, skin rash, sores, fungal infections between the toes and fingers, and pain all over the body. It should be noted that the term 'syphilis' is translated into Luganda as



*kabotongo*, an illness similar to syphilis in English, but an illness that has both symptoms and causes that are unlike syphilis. Therefore, when the survey asked respondents questions about ‘syphilis,’ or the CHDC team asked respondents about ‘syphilis testing,’ respondents answered with *kabotongo* in mind, not syphilis.

One of the respondents remarked that:

*I want only to know whether I have syphilis since treatment is free because I feel general pain all over the body. I don't want any other results. I think I have syphilis.*

Another respondent remarked:

*I want to check myself because the doctors said I once had syphilis, which is one of our ancient diseases, that is what my decision was based on so that I can know what is in me. Now what if they find both AIDS and gonorrhoea in my blood?*

Another respondent explained that:

*I heard on the radio, they were saying that it is good to test for HIV and know your status...the lab technician said he was going to test me after the blood draw and tomorrow morning he will treat me if I have syphilis.*

For many, the decision to give blood was also greatly influenced by the fact that they saw this as an opportunity for them to learn their HIV status at no cost at all and possibly to get treatment. Some respondents indicated that they had wanted to establish their HIV status a long time ago, but had been unable to due to the costs involved (e.g., time away from work, transport, and fees for the actual tests).

*Why I want to be bled is because I have never been bled before and I've never tested for AIDS. So when I heard I can test for free, be given free medicine, I decided to accept to be bled. If I am found to be sick, I know that I will get a chance to be treated.*

*In the past, we were ignorant, but now I see that the blood check is a good idea. We want it, but our problem has been where to go, the town is far and transport is too much... Now we are happy to see that you have reached us. So we dedicate ourselves to see that we have been checked.*

Others indicated that although they wanted to establish their HIV status, they had feared going for the test. Bringing these services into their homes was an opportunity to find out their status, for which they were very grateful. As one of the respondents commented:

*I wanted to go for the test a long time ago but I feared. Yet when you are not checked you remain in fear.*

Another explained that:

*I think your coming to our homes is good because some people fear to go and get checked from hospital, so this has been a privilege.*

Others equated not knowing their status with living in darkness, not knowing what the future holds. Opting to test was a way out of this kind of situation:

*The reason is that we should not be in darkness without understanding. Let them take my blood and tell me the results...when you know early enough you can start taking better care of yourself.*

## **8.2 Expectations for Treatment**

Some respondents gave blood and accepted the home visit of a counsellor in order to gain access to treatment. Some perceived it as an opportunity to get advice and treatment for HIV/AIDS.

*I agreed to give blood because I want to know my status for HIV; I also want free advice from the health workers in case I do. I want to know if I have AIDS so that I do not spread it and I also need to face reality. I will have to accept that I have it and to look for ways of prolonging my life. I will also gather the courage to live positively.*

*I have slept with women in the past, but I have never had them tested for HIV, not even my wife with whom I am currently living.*

*I thought, let them check so that I know the disease in my body and they can treat me and maybe I will get cured and feel more settled.*

Of particular interest for some was the perceived possibility of accessing treatment that could prolong their lives if found to be HIV positive.

*I am happy because if I am found to have AIDS and I am given medicine, I will be okay.*

*In case you have checked and found that I am suffering from say syphilis or AIDS or any other disease, will they give us the medicine or they are leaving us like that?*

Another remarked that:

*If I test positive the health worker has said that there are some drugs for prolonging AIDS patients' lives I want to take that opportunity. If I realize that I am sick I will stop going with men in order not to spread the disease. If I test negative, I will not go with men again as they can infect me. I also need treatment for the disease that I have.*

The possibility of receiving free ARV drugs provided some hope to those who suspected that they may be HIV positive, and it gave an impetus to get tested. The fact that the MOH has announced plans to make ARV drugs available for free seems to have, in effect, resurrected the hopes of many HIV-infected people who had not obtained the drugs through private means. Respondents explained that they wanted to establish their status in order to get treatment to prolong their lives in case they were found to be HIV positive. For others this would enable them to plan for their future and for their children. In a context where the majority of the rural population is poor and where access to free health services is next to impossible, home-based VCT as provided by the VCT survey was perceived by many as a real opportunity that should not be missed:

*You have really helped us; I want my children to grow up like me their parent. If I am sick, I can plan for them, so that by the time I die they should have some starting capital. Whatever comes I will have known what to do. Yes, it is good to know, because you may think you are safe when you are affected. But now when you know it, you choose what is good and bad. You may start saving money, instead of using it carelessly and you can start getting treatment early.*

For others this was an opportunity to confirm their status:

*I felt if I am not bled and maybe I have one of those diseases I would have missed this opportunity to know whether I am still okay.*

*Both my wife and I tested before we got married. So when I heard that people from the Ministry were testing, once again I was not afraid, since I know I have been faithful to my wife and she has been faithful to me.*

Another respondent explained that:

*I had tested some years back and found that I was not sick. Now I would like to test again and see if I am still negative.*

Another respondent remarked that:

*I tested before and I was told I was positive but I did not believe that machine. Now I want to see if the machines were correct; sometimes they make mistakes.*

### 8.3 Gender Differences

The MOH survey in 33 clusters showed that while the majority of both men and women agreed to be given their test results, on average, slightly more women (90 percent) than men (86 percent) in the age group between 20 and 49 agreed to be given their test results. However, among those who never married, more men (96 percent) than women (91 percent) agreed to be given their test results. Interestingly enough, among those who were currently married, there were no differences between men and women (94 percent) who agreed to be given their test results. Among those who were formerly married, more women (94 percent) than men (85 percent) agreed to be given their test results.

The interviews conducted after the blood draw revealed that couples, especially those who did not fully trust their partners, perceived the study as an opportunity to learn their individual status and in some cases that of their partner as well. The opportunity provided by the survey was new and welcome, especially for the women. Given the unequal gender and power relations that often exist within households, women often find it difficult to go on their own for an HIV test, even if they are willing. There were cases where women refused to participate in the blood draw because their husbands were not at home and they did not have prior permission to do so. In one particular case, a man who was present in the home when the team arrived forbade his wife from participating in the blood draw and warned her that he would send her away if she did. In another case, the husband hid his wife in the house. In yet another case, the wife was defiant and she participated in the blood draw against her husband's wishes. This married woman explained that:

*I have decided to test because I want to know my status. If I know my status I may make plans instead of remaining in the dark. I do not sleep around but my husband is not faithful to me.... to know my status is something that is very important. You know after I delivered I lost a lot of weight and I was worried that I had contracted the virus. So when you came I really wanted to know my status...now that I have known my status I can now protect myself. I will tell my husband so that he can know the secret and we care for each other, maybe I will be able to convince him to test...*

Another woman remarked that:

*I just want to thank you because you have helped us to know our status and you have treated the disease you found in us (syphilis) because it would have cost us a lot of money to treat it...I really benefited, I know my status, I got treatment for syphilis and I will take care of my life.*

Another said:

*I want to know if I have HIV, syphilis or any other disease so that I can get help. We agreed with my husband that each knows the other's results, they should bring them so that each sees the others' disease.*

Another remarked that:

*I wanted to test a long time ago but because I did not have money to go for the test in a hospital, I see this as a golden chance, because they came to test us free of charge so we allowed the blood draw...I have a husband, I do not know the way he moves, so I want to know whether I am sick or not. I had another man outside this marriage; I now have only my husband.*

For married persons, both husbands and wives, this was an opportunity to test for HIV without having to give an explanation to one's spouse as to why one had decided to take an HIV test. Going to be tested at a health unit would be perceived as an indication that one has reason to suspect that they may be HIV positive, and in those circumstances, one would have to explain why they suspected that they might be HIV positive. They would also have difficulties in disclosing their test results for the same reasons.

During this study, while many husbands and wives from the same households were tested, few requested couple counselling. This might explain why, in the overall survey among the currently married, there was no difference (94 percent) between males and females who agreed to be given their HIV test results. Other men reasoned that they were negative through an elimination method, namely, that if their wives tested negative for HIV, they were most likely HIV negative as well.

One of the respondents explained this:

*I wanted to go for a blood check earlier to know whether I have the disease. But I feared what my husband will think. Checking me alone is wastage of time, so I told my husband that we should go for the test together and he refused.*

The decision to take the HIV test was in some cases not perceived necessarily as a personal decision, but as one sanctioned by higher authorities. As a result, women especially used the opportunity to test for HIV with no questions being asked as to why they were taking the test. At the same time, it gave them the opportunity to learn their own status and, in some cases, that of their husband as well.

*I know I have AIDS because my husband had an affair with a woman who has AIDS. Her husband died...so I think the results will be positive.*

A woman who had received her results had this to say:

*I feel very happy because every time I would develop a fever I would think that my husband is seeing other women. I thought he might have infected me, but I trusted God to protect me. I kept thinking if only I had money I would have gone for a test, but I don't have the money.*

In other cases, those who were faithful learned their status by default when their partners, whom they suspected to be unfaithful, were found to be negative. In one case, the husband hid his wife from the team, and took the test by himself. When he discovered that he was negative the following day, he said his wife should also be tested, but it was too late because the team was moving on.

In some cases, couples considered it an opportunity to test together:

*We once went to the hospital but the cost for the test was too much for us but now the chance has come our way. Am happy and I thank you for having drawn our blood....I want because if I check and find that the illness is there they will give me a letter/card to go to hospital.*

Some parents were keen that their adolescent children be tested:

*I want the children to be bled, especially the big one who goes to school, I wanted her tested so that I know her status, if I know her status then we can decide what to do, or we fight the disease if she doesn't have it.*

Another one remarked that:

*Please come back and test those who have gone to school, you might find that they have a problem and as a parent you don't know.*

Results from all 33 clusters, however, indicate that the younger generation, especially those aged between 15 and 19, were generally not as keen to receive their HIV test results as those in the older age brackets. This might have been because they did not perceive themselves as necessarily being at risk. Only 78 percent of this age group agreed to receive their results compared to the 88 percent of those aged between 20 and 34.

#### **8.4 Issues of Privacy, Confidentiality, and Convenience**

The original research design had anticipated that respondents would be asked directly if they wanted to learn their test results at home, or in some other place. The results of the observation of the administration of the consent statement suggest that many respondents were not asked explicitly if they wanted their test results at home or elsewhere. The majority of respondents were informed that their results would be brought to them at home. Having observed this, the research team asked the respondents during the in-depth interviews whether they would have preferred to receive their HIV test results elsewhere other than in their homes. The majority indicated that they had preferred to receive their results at home. Respondents explained in several cases that they felt their homes provided them with the confidentiality and privacy that they needed.

As previously discussed, anonymity was not much of a concern for respondents, because others in the community knew the homes that had been sampled. As one respondent pointed out:

*They did not know who was tested within the households and would not know the test results either.*

A schoolteacher in one of the clusters explained that:

*I prefer to receive my results at home, because I don't want students to know that I also went for a blood draw.*

Most respondents appreciated the opportunity to receive their test results in the privacy of their own homes. They explained that privacy and confidentiality were achieved, because in almost all the cases they were able to find a place where the counsellors could deliver their results and speak to them in private. The decision to disclose their results was then up to the respondents. While some respondents indicated that they were given the choice regarding the venue where they could receive their results, others were not given that choice, as revealed by their comments below:

*I am not the one who decided, it's the doctor who decided and he said he will be coming back to tell me. I think he saw that I could no longer walk.*

*He will bring them here...I did not know that they can find me anywhere else.*

*I was told the results would be brought to me at home tomorrow.*

*You are the ones who said that you would come and inform me. You are the people who told us the results would be brought home, we were not asked to decide. Anyway, even if I had been asked, I would have chosen here because there is no reason why I should go elsewhere for my results.*

Respondents explained that they had opted to receive their results at home for several reasons:

*I am happy to be tested at home because it does not involve movement. I want to know if we are okay and I get relieved because you can do things without worrying.*

*It is good to get them at home, because I do not want people to interpret things because my children will get worried.*

*At home because if the health worker finds me here as she found me and tells me that is my secret there is no problem. Otherwise some people may start rumor mongering and because they know we were bled they start nagging us that this one is like this and the other is like this.*

*[I prefer] at home, because it does not cost me anything.*

*Here at home, because I do not have any problem with the place. I will get them when we are two, I and the doctor, when there are no other people I mean those who will talk what they think... People don't know what is going on even when they see people going and coming.*

*I want to get my results from home. I do not know where to find you and the health worker told us she will bring them here. Home is the best because we are always at home and it is easy to get us here... If I am positive can I get treatment?*

*I chose at home because it has saved me from paying for transport.*

Some respondents were concerned that in case they agreed on a place outside of their homes, they might miss the health workers, and by so doing they would also miss the opportunity of getting their results. Others argued that since they had been found at home and the health workers now knew where to find them, it would be easier for the health workers to bring the test results back to them at home. Others felt more secure in their homes in terms of privacy. For others, it was the more convenient place because they could get on with their other household chores while they waited for the health workers to return. For those who were sick and in some cases bedridden, it was the more obvious place.

It is widely assumed that individuals prefer to learn the results of an HIV test in private, assured that no one else can learn their test results (confidentiality), and in a way that others do not learn they had taken a test (anonymity). This study indirectly took away the factor of anonymity by having a team of health workers from the MOH visit a home and by requesting all individuals in the sampled homes aged 15 years and above to participate in the blood draw. While there was almost no anonymity regarding the households where the tests were conducted, the respondents within the households did not express concern about the fact that others in the community knew that they had participated in the blood draw and that they were going to receive their test results back at home. Once they understood that their households were randomly sampled, they did not seem to mind that others in the village knew that they were participating in the study.

In this survey context, individuals found comfort in the fact that they had not been singled out as individuals for a particular reason to take the test, but rather, certain households had been selected to participate in the study. This is quite different from clients who go to a health unit for counselling and testing. These individuals usually prefer to be without a name, without identity or character (Whyte et al., 2005). This preference for not being seen is supported by literature on home-based care for HIV/AIDS patients, where those suffering from AIDS usually prefer that others in the community remain unaware that they are receiving treatment at home. Organizations are asked to park their cars some distance away from the homes where they conduct home-based care.

Almost all of the respondents who participated in the blood draw considered their homes as safe spaces where they could receive their test results in privacy and with confidentiality. Spaces were found within the homes where the presentation of the results and the counselling



process could be done in private, and people found that satisfactory. One of the respondents remarked:

*No one can tell what is happening in your home so they cannot spread unnecessary rumours, but if they see you going to a health centre they begin to suspect that you might be sick and to ask you questions.*

None of the respondents in this study expressed concern about the possible lack of privacy in their home and the need to receive their test results elsewhere. The majority of respondents felt that since their blood draw was conducted in the privacy of their homes, the same should be done with the test results. A respondent explained that:

*Home is a good place. Why I say it's a good place is because if they find anything in your body they will be able to explain it to you calmly. Even the person who would have laughed has no way of finding out. At home if your father sees you or anyone else they can't gossip about having seen you being treated. It will be your own secret and your close person.*

The randomness of the selection and the fact that it was done by people outside the community reassured respondents that their test results would be confidential. Other studies have shown that potential clients refuse to go to health units within their communities because everyone there knows them. Whyte and colleagues (2005) observe that the elaborate protection of identities and results of those who test is at odds with the public nature of the waiting area in most units where such tests are carried out. Anyone passing by can see who is sitting on the benches. The busy corridors and waiting rooms of these units are very public places. Most respondents felt that for as long as it was only them and a counsellor when their results were returned, there was sufficient privacy and confidentiality at home:

*It's a hidden place, we have been there two people and whatever we have spoken we have spoken in a low tone.*

*I am happy with the place because no one knows what we are doing.*

*At home others have no way of finding out unless you tell them.*

*We were just the two of us we talked secretly and discussed everything.*

*The home has just the two of us; we do not have any disturbance that is the truth.*

The other advantage of this procedure was that those conducting the tests and returning the results were from outside of the community, and were thus perceived as unlikely to disclose peoples' results to other community members.

The majority of respondents indicated that they would not disclose their test results to anyone, yet they were quick to disclose them to the researchers who interviewed them after their

discussions with the counsellors. This again was probably because the researchers were outsiders to the communities. Therefore, they were unlikely to spread information regarding the HIV status of anyone they tested.

Respondents thought that local health care workers would gossip about them with their friends and tell others about the HIV status of people in the neighbourhood. Then rumours would spread in the community, and others would find out. Most respondents said they would be very selective in disclosing their results to others. Many of them declared no one would find out:

*It's my secret. I will tell no one else.*

*I won't tell anyone, because that is my secret. When I am moving I don't tell anyone.*

Surprisingly, this was by far the most common response. Some of those who were married indicated that they would disclose their results to their spouses:

*I will tell my husband, because we will have to be together in case of sickness. I will tell him so that he does not look for another wife; he may keep himself safe.*

*I will not tell anyone unless it is a health worker... The other person I would have told is my husband and he already knows, so I have no one else to tell.*

*I am going to tell my husband so that he can also go and test so that we know the truth.*

*The only problem is that she did not tell me my husbands' results. I will feel sad if they happen to be different from mine... but I will tell my husband my results.*

*I will tell my husband just what the doctor told me and show him this letter.*

*I will tell my wife. I trust her. She is faithful.*

*I will first tell my wife that we are still okay so that we continue being careful. There is no other person, she is the one I will tell because it concerns me.*

Others mentioned parents and older siblings:

*I will tell my daughter, the elder one, she is my daughter. We are united and she cannot spill out my secret by telling someone else.*

*I expect to tell my mother because, my friend, these are difficult things in the village, these are not issues you just talk about, that I was tested and I don't*

*have...you may find yourself telling someone with a bad heart. It is like a will, you tell only your mother. Apart from my wife she is the only other person I can tell.*

*My mother may ask me what the results are and I will tell her...she is the one who gave birth to me. We are together just the two of us...I cannot tell those secrets to a child. I can't tell anyone else.*

*I will tell my people, my brothers and sisters, because I know they thought we were sick. Now that I have tested and found that we don't have HIV/AIDS, I am going to tell them that we are not sick.*

The majority of respondents gave reasons for choosing to disclose or not to disclose their results, and to whom. Respondents indicated that their results were their personal concern and it was up to them to decide to whom they disclosed results. In some of the villages it was explained that some people are malicious; once they learn that a person is HIV negative, they do their best to infect them. So there were cases where people felt that it was better for people to suspect that they were HIV positive than negative. In the case of younger women, they feared that once the men knew that they were negative, they could be raped. Couples, however, especially the younger ones, felt the need to disclose their results to their spouses.

## **CHAPTER 9**

### **Consequences of Delivering Test Results at Home**

Phase II of this study sought to evaluate the social consequences of the visit of the MOH survey team and their delivery of HIV test results to the homes of respondents. The concept of social consequences refers to the reactions of family members and others toward a respondent who was known to have taken an HIV test and received the results, and who may have disclosed test results to others. Possible social consequences might be thanks, arguments, threats, beatings, separation, or divorce. Fieldworkers interviewed respondents who had been interviewed in Phase I, regardless of whether they had been tested for HIV.

The interviews with respondents included questions about who lived in the same household with them, the identity of their immediate and larger family, and people in whom they confide, in order to obtain information about who might be told of a respondent's HIV test result. We wondered if individuals would find that receiving test results as part of a survey would be less stigmatizing than going for a test at a hospital or other VCT facility. If there was less stigma, would that mean that respondents would more easily share test results with people, particularly if the test result was negative? What happens in the small number of cases where the HIV test result is positive? These are the issues that were addressed in Phase II.

#### **9.1 Research Questions**

It was unclear at the outset to what extent men and women would share with family members their HIV test results received at home, or to what extent they have a choice in this matter. Respondents seen in Phase I indicated that they were satisfied with the process of testing, and that they had no problems related to privacy and confidentiality. Would that finding still hold true three months later? Family members and neighbours might know that the person received the test results but would not know those results without asking. How would receiving test results and being counselled at home be viewed in light of these considerations? How might it affect the relationship between spouses?

Those are some of the questions that underpin this second phase. We pursued a few specific questions, including the following:

- What are the desires of individuals regarding privacy, confidentiality, and anonymity in the process of getting tested and learning one's results?
- How and with whom did respondents share their HIV test results?
- How did family members react after a VCT home visit for one of them?
- Was there a relationship between the kind of social relations of respondents and the social consequences of learning their HIV test results?

## 9.2 Methods

During the first phase of this study, the study teams worked in six districts and 10 clusters in the Central and Western regions of Uganda. Because Phase II of the study involved extended conversations in which respondents discussed their thoughts in depth, a much smaller number of households were contacted. In addition, in order to conform to the resources available (time and money), the interviews were conducted in only one language rather than two in order to simplify the data collection and the analysis. Therefore, the second phase was limited to three clusters in Mubende district where interviews could be conducted in Luganda. In those three clusters, a total of 57 households had been visited by the survey team in Phase I; the target for Phase II was 40 households.

The study team (fieldworkers and supervisors) still had information about each household from Phase I and could thus identify certain households of lesser interest to the study, such as households with only one person, or those where respondents refused the blood test. In such households we would not find evidence of social consequences that stem from someone who received an HIV test result at home. Households of greatest interest to this study were the following: those with at least one person who tested positive for HIV, those with a discordant couple, those with at least one person who tested for HIV and one who did not, and households that are polygamous. Although fieldworkers never asked any questions about HIV test results, they were generally able to tell the HIV status of individuals by the way they talked about their experience in being counselled.

The CHDC study team selected 40 out of the 57 households visited in Phase I before leaving for the field. A selection of 40 households could be expected to yield between 65 and 70 interviews with persons who were interviewed by the MOH survey team and were offered HIV test results at home. The study team interviewed all of the individuals who were eligible for participation in the survey and who could be located in the return visit. In cases where no member of a household was located during the time spent in that cluster, another household was chosen to replace it.

A topic guide for these conversations was developed during the training at the CHDC by the principal researchers and three of the interviewers who had worked on Phase I. The topic guide consisted of three sections: 1) social context; 2) experience with the survey team; and 3) events that followed the survey team visit. The first section addressed the identity of the respondent, the composition of the household, her/his close relatives and friends, and the associations in which s/he participates. The second section elicited accounts of their experience with the arrival of the survey team, the process of drawing blood and receiving test results, and things that others in the neighbourhood said about the team's activities. The third section discussed social events in the household since the survey, any changes in the life of the respondent since then, and the disclosure of HIV test results to others.

Since the study sought information about the aftermath of the visit of the survey team and the delivery of HIV test results to survey respondents, a private conversation was held with respondents who had been interviewed during the first phase in selected households. Fieldworkers used a topic guide in the form of a two-page outline to guide the conversations

(Appendix C). With a few exceptions, these conversations were tape recorded for later transcription. The recorded conversations were transcribed in Luganda in a hand-written text, translated into English, and then typed in Microsoft Word. Information from the conversations was summarized in one to two pages for each respondent. Then, a one-page form was filled out for each respondent to facilitate comparison of answers to certain key questions.

Fieldwork was conducted during three weeks in July 2005 by two of the fieldworkers who participated in Phase I. A total of 61 interviews in 40 households were conducted with respondents who had been interviewed during Phase I: 27 men and 34 women. Eight of the respondents from Phase I were not interviewed in Phase II because three respondents from the selected households had left the area, three were less than 15 years old, and two refused to be interviewed.

The analysis done through the reading and rereading of the interviews involves three separate processes. One process is the examination of how respondents talk about certain events: the concepts they use, the logical connections they make, the conclusions they reach. This step is taken early on in order to understand local perspectives on issues, since a number of the concepts and connections made by respondents differ markedly from those of the researchers. For example, respondents talked mostly about ‘getting tested at home,’ a concept that includes giving blood, having the blood taken away, and having a counsellor return to the household to deliver the test results and offer advice. A second process is the recording of statements of significance to respondents that are quite different from the expectations of researchers. For example, several respondents mentioned that getting tested and receiving results at home is preferable to going to a health centre because others will see you visit a health centre and may spread rumours about you, while getting tested at home is just that: an HIV test. Finally, the third process is the checking of the proportion of people who reported a particular action such as being counselled or disclosing their test results to someone else. For example, we might want to report that only 15 of the 61 respondents stated that they did not disclose their HIV test results to anyone.

### **9.3 Talking about AIDS and Testing**

The conversations with respondents revealed a great deal about how individuals talk about HIV and AIDS, about testing, and about counselling. Respondents talked about HIV and AIDS in responding to questions about how the survey team was received and what they did in the household. Respondents talked a great deal about being bled and tested, as well as being counselled when asked about the benefits of the team’s visit. Most survey respondents were counselled two times: once just after they gave blood and agreed to get their HIV test results, and again right before and after they had received their test results.

Although a small number of respondents said they were found HIV negative or positive, it was far more common for them to say ‘I am sick’ or ‘I am not sick’ to indicate they were positive or negative. In the minds of the majority, being HIV positive means being sick and having a limited time to live. In this vein, a person who has tested positive is ‘sick’ even though no symptoms of illness have appeared. In Luganda, the term *silimu* is commonly used for the condition of having HIV and for having AIDS as well.

In speaking about testing, most people talked about testing for AIDS. That is, they would say, ‘the survey team came to see us and said they wanted to bleed us and test us for syphilis and AIDS.’ As a 49-year-old married man said:

*They took my blood and told me they wanted to test for syphilis, but they also told me that if I want, they can test me for AIDS. I told them there was no problem, they can test for whatever they want.*

A 35-year-old man who tested positive for syphilis but negative for HIV remarked:

*They take your blood and bring back the results. If they find you are sick, they come back and tell you the truth. If you are OK they still come back and tell you the truth.*

A 37-year-old married woman observed:

*They came and asked us about health topics and about who was ill. They also asked about AIDS and they drew our blood to check on AIDS and syphilis. They told me I don’t have syphilis or AIDS.*

The association of illness with being HIV positive also works in the other direction. That is, some respondents said their friends or neighbours were sceptical of the test results given, because people who were ill were not found with the virus. As someone observed, ‘How can everyone here be HIV negative when so many have been sick for so long?’ A small number (eight to nine) of respondents said that people around them did not believe the test results, because people had been sick but were not found to be sick by the survey team. Five respondents said that their own friends did not believe their results, and that they must be lying to them.

Respondents were asked what others said about the MOH survey team who came to their village and went to some households and not to others. Five respondents said that others thought the team went only to households where individuals were sick. A few more said that others told them that they would have liked to have been tested as well. More than one-third of respondents said that they did not know what others had said, because they do not talk to people about such things.

When asked about how they had benefited from the visit of the survey team, more than one-half of respondents mentioned some advice they had been given or simply said, ‘I learned how to protect myself.’ The main ways that men and women learned to protect themselves was to stay with one partner, not to sleep around, and use a condom. This message with several elements was mentioned by nearly half of respondents, so it must have been consistently delivered by the counsellors. Several individuals said that they had been given condoms and they were using them, so at least some of the survey teams had condoms to distribute.

Finally, respondents spoke of the MOH survey team as having done three things: 1) they asked so many questions about sex; 2) they bled them; and 3) they gave them their test results for syphilis and for AIDS. The survey protocol was set up so that respondents would make several

decisions when the team visited a household: to give blood or not; to learn their HIV test results or not; and the place (home or elsewhere) to learn those results. Fieldworkers for the qualitative study also expected that respondents would make a sequence of choices. In fact, respondents talked about ‘getting tested at home’ and receiving the test results at home as equivalent.

In these Phase II conversations, all those who gave blood at home also received their test results at home. The way they all talked about their interactions with the survey team indicates that in their minds, giving blood, having it tested, and getting the results all went together; either it was a single event with several parts, or the parts of a series of events were so closely linked that it amounted to the same thing.

#### **9.4 Receiving HIV Test Results at Home**

The CHDC study team was unsure of what reaction to expect from respondents when they were given the options of getting HIV test results at home. We wondered if the counsellors would be able to find a private space where results could be given confidentially. We also thought that individuals with higher social status (older, male) would be more willing to accept home visits since they would feel less of an obligation to share their test results with others. None of those expectations were borne out in our conversations with respondents.

Respondents were asked what they thought about getting their test results at home, and what problems they saw in receiving their results at home. Nearly everyone (59 of 61) said it was good to receive their test results at home. About half of them just said it was a good thing to do, or that there was no problem at all, or that they were happy with the home visits. About half the respondents explained why they liked receiving HIV test results at home and tended to cite one of three reasons for preferring home VCT as opposed to going to a hospital: 1) there was no need to pay money for transport; 2) it was easy, one did not have to go anywhere; and 3) it was more secret than going for testing in a hospital where people saw you going for a test. The reason mentioned most often was that it was free.

About one-fourth of the respondents mentioned that getting tested and counselled at home was good because they did not need to pay anything. For example, a married woman who had borne 11 children said:

*I was so happy, because I had really wanted to be tested but did not have the money.*

An older man who tested positive for HIV said that home testing presented no problem:

*I have not spent transport, and transport money for testing can be used to buy something else.*

Another older man who was divorced and who tested positive for HIV said:

*It's good, because the blood is drawn free of charge just like they say over the radio.*



A widow with five children said:

*The good part is the free testing and no transport.*

Although the opinions expressed above may duplicate those found in Phase I (Chapter 8) it seems important to note that three months after the survey, respondents still found that home testing and counselling was the preferred strategy for them. About one-fourth of respondents mentioned the advantage they saw in staying at home and having the ‘doctors’ come to them. For example, a widow with many children said:

*It is good because you have not gone anywhere, you stay home doing your work, and the doctor finds you at home.*

A married woman with seven children remarked:

*It is good because I did not have to go anywhere, I did not go through a queue.*

A young woman separated from her husband said:

*It is good to get results at home without going anywhere.*

A young married woman with two children had this to say:

*It's good, you stay in your house, they come and ask you questions, that's the good in it.*

A small number of respondents (seven) compared being tested at home with going for testing at a health care facility, each one mentioning that being tested at home is better. They consider that home VCT allows them to get tested without others really knowing what occurred. For example, a married woman with four children said she was very happy to get tested at home, because:

*It is good because you know the results for the two of you (her and her husband), be they good or bad, and no one gets to know them and start spreading rumours about you that you have this or that disease.*

The husband of this woman expressed a similar sentiment:

*Depending on the team and how they prepare you, you can be confident, for even if you have AIDS, you don't fear as much as you would if you have gone to test at the hospital.*

A woman who was one of three wives said:

*If they test you at the hospital everyone may get to know, but if you are tested at home, only you get to know and perhaps the health worker.*

In the same vein, an older married man with six children said:

*The importance I see is that it's only you who gets to know. Outsiders don't know it.*

A married man with two children who did not give blood observed:

*It is good, because there is no one from the outside around who may find out.*

An older married man with six children remarked:

*The good thing is that you get to know how your life is. They come and tell you (at home) without others knowing your secret. But if you go to the hospital and someone sees you, you will hear rumours that they saw so-and-so.*

A few others expressed similar opinions. For these respondents, being seen going to the hospital for an HIV test means that others will see them and talk about how they were seen getting tested. When they are tested at home, they have more control over who sees them getting tested, for only family members know for sure who gets tested. Perhaps more importantly, as the Phase I discussions showed, being identified by a government team and asked to test for HIV is essentially different from going to a hospital, for anyone going to a hospital must have reasons for getting tested.

We found several exceptions to the positive response toward home testing. Three respondents who found that home VCT was a good thing observed that it could cause problems. A young married woman with four children said that getting tested at home was fine unless the children overhear the discussion. An older man with six children said he was very happy that the team came to his house, but then remarked:

*The problem would be testing and finding out that we are positive, and each one would blame the other for causing the problem.*

Finally, an older (62 years old) widow who tested positive for HIV, noted:

*The problem is, even if you get tested, you get no help.*

This comment raises an issue to which we return in the conclusion, namely, that those who were tested and counselled were not likely to find social or medical services available. We interviewed nine individuals who indicated that they tested positive for HIV; each of them had received a card that they were told could be used to obtain free services at a hospital, but so far none of them had used the card, perhaps because they had no symptoms of illness.

Judging from these conversations, most survey respondents were grateful for the opportunity to be tested for syphilis and HIV and receive results at home. The procedure demands little effort and no money on their part, and they can keep the results to themselves if they wish. Several respondents said that friends or neighbours asked about their results and they declined to tell them. In addition, no one interviewed had elected to receive their HIV test results in a place other than their home. Although some respondents were given options for where to receive their results, all accepted the home VCT option.

## **9.5 Disclosure of HIV Test Results**

Fieldworkers interviewed 25 men and 33 women whose blood was tested for HIV and who received their results (one respondent did not give blood and two respondents were tested for syphilis only). Most respondents said they had told someone or several people about their results, or that they told their spouse only. However, when asked if others had learned about their test results, a small number of respondents (seven) said that another person had read the form that showed their results. Most likely, respondents were thinking about the syphilis results, for counsellors were not supposed to write down HIV test results.

The study team assumed that whether an individual discussed their HIV test results with someone else (or not) may play a role in the consequences of getting tested. When a person tells both family and friends their HIV test results, they may receive encouragement and support, or they may be criticized. If a person tells no one, there can be no support or recognition of HIV status. If a person tells only a spouse, at least the person with the greatest need to know will have been informed. We expected to find at least two factors that would influence disclosure of test results to others: 1) the family situation, particularly marital status, and 2) the test results.

Among the 61 respondents interviewed, 37 were married (17 men and 20 women), 16 were no longer married (five men and 11 women), and 8 had never married. The category 'no longer married' includes separated, divorced and widowed. Among the women, five were widowed, four divorced, and two separated, which makes up one-third of the women interviewed. The information on marital status is presented as background to the discussion of disclosure: to no one, to a spouse only, or to others.

Table 9.1 classifies married respondents by whether or not they disclosed their HIV test results to their spouse. Disclosure of HIV status to a spouse is critical for prevention of HIV infections as well as for behaviour change. Among men, 10 men disclosed to their spouse and six did not. Among women, 11 shared their HIV test results with their husband and seven did not. There is no difference in disclosure by sex apparent with these small numbers. Both men and women are more likely to tell their spouse their test results than keep results to themselves.

Table 9.1 Disclosure of HIV test results to spouse					
	No one	Spouse only	Spouse and others	Others only	Total
Men	2	4	6	4	16
Women	4	8	3	3	18
Total	6	12	9	7	34

There is no discernable pattern for disclosure among the nine individuals (six men and three women) who tested positive for HIV. Three of the six men told no one, and three told others. On the women's side, all three women who tested positive told others about their test results. None of the three women were married: two were widows and one was divorced. As for the men, two of the six who tested positive were married, while four were either single or divorced.

## 9.6 Social Consequences of Home Delivery of HIV Test Results

While the guided conversations of Phase II covered a variety of topics, one of the most important reasons for returning to the homes of respondents two to three months after the survey was to look for possible negative consequences that might follow the survey team's visit. We thought that if an event such as a lot of quarrelling or fighting in one household or a spouse leaving home had occurred after the HIV test results were received at home, respondents would mention such events if they occurred in their home or in a nearby home. We thought that if a wife tested positive for HIV and the husband and family find out, she may be blamed for being positive and be asked to leave the household. We also thought that the visit of a counsellor might touch off arguments or disputes about the HIV test results of a family member.

Fieldworkers asked about the impact of the survey team's visit in various ways. They asked what respondents remembered from the visit of the survey team, how they benefited from the team's visit, what happened in the village in the past three months, what changes they noticed since the survey team was around, and if their relationship with their family, their friends, and their neighbours had changed recently. In seeking to find out what had happened since the survey team's visit, the interviewers used follow-up questions such as: Has anything changed between you and your: a) family; b) friends; c) neighbours; or d) relatives?

In response to being asked about what had happened in the past two to three months, the majority of respondents mentioned an event that had occurred such as a wedding or a funeral, or they said they or their family members had become ill. More than one-fourth of respondents said their children had become ill, often with a fever. Listed below are a few typical examples of such responses:

A 27-year-old married man explained what happened in the neighbourhood:

Respondent: *There was a wedding at Mr. Sembuya's place...*

Interviewer: *What changes have taken place in your life since our visit?*

Respondent: *Nothing associated with people; we are the way we were.*

A 39-year-old married woman had this to say about her relationship with household members since the first visit:

Respondent: *Still the same, that is all.*

Interviewer: *I mean the changes among the people in the home.*

Respondent: *Still the same, no change. The way we were is how we are still, except for the malaria that I got.*

A 19-year-old single man living with his parents said:

*There was a death, my paternal grandfather.*

When asked about what had happened recently, a 40-year-old man said:

*Nothing much, except for people getting sick, like my wife, and our neighbour down the way lost her husband, and there was lots of sickness by the time you came. I had thought that you had brought medicine.*

A 20-year-old woman separated from her husband, when asked about the relationships among neighbours, said:

Respondent: *There are some relationships that are not good.*

Interviewer: *How has it been?*

Respondent: *Some are fighting each other.*

Interviewer: *What makes them fight?*

Respondent: *I do not know*

Interviewer: *But you stay in the village. Why do they fight?*

Respondent: *Those who are always fighting are drinking, and when they are drunk, they fight.*

There were other accounts of conflicts that had occurred in the past three months, but none that were related to the visit of the survey team. For example, a 50-year-old married man talked about how a son had quarrelled over land with his parents, and the case was taken to a judge for adjudication. A female shop keeper said that one of her workers had stolen money from her. In fact, there were a sufficient number of anecdotes of conflict to make us believe that respondents would have told us about conflicts provoked by the visit of the survey team had they occurred.

In most conversations with respondents, after asking what happened in the village since the team's visit, interviewers asked specifically how relationships had changed within the family, with friends, with relatives, or with neighbours. The answers given were consistently, 'Nothing has changed.' Some said, 'The way we were is the way we are.' It seems that these answers were given quickly and without reflection, which invites some scepticism. However, even the nine individuals who tested positive also said that there had been no change in their relationships with

family friends. As shown earlier, six of those nine respondents had told others of their test results, but that revelation evidently did not change anything in their relationship with others.

We did find evidence of one person who left home after discovering that she was HIV positive. This woman told the interviewer during the visit of the survey team (Phase I) that she was planning to leave her husband to stay with an aunt of hers some distance away. Thus, she was not around to be interviewed during Phase II. Her husband was interviewed in Phase II, and he said she had left to visit her aunt. He said nothing about her HIV status.

In sum, the Phase II interviews did not find evidence that receiving HIV test results at home had caused problems for those who had been tested. The concerns of the study team about women being obligated to tell their test results were not borne out by the conversations held with respondents during Phase II.

## **CHAPTER 10**

### **Conclusions and Recommendations**

#### **10.1 Study Rationale**

The home-based VCT survey conducted in 2005 was the first survey in Uganda that offered counselling and HIV testing at home. Therefore, a study was designed to follow the process of obtaining informed consent for the blood draw and the process of choosing to receive HIV test results at home. Fieldworkers were able to follow the process of drawing blood and providing HIV and syphilis test results with very few problems. Although it is possible to provide this service within a survey, there are clear costs of several kinds.

The offer of providing free HIV test results within the survey did not change the rates of participation in the survey or the blood draw for women, but participation rates for men dropped slightly with this approach. However, this approach did increase the proportion of respondents who learned their HIV status, for nearly all respondents who gave blood also received their HIV test results at home. In all, 86 percent of respondents in the 33 cluster survey accepted their HIV test results (83 percent of men and 88 percent of women). Most respondents were pleased to receive their test results for syphilis and for HIV at home. The qualitative study provides explanations for these results.

#### **10.2 Participation in the Blood Draw and Testing**

This study was designed to understand how survey respondents in the home-based VCT survey decided to participate in the blood draw or not, to learn their HIV test results or not, and to receive their test results at home or elsewhere. In the design phase we thought of these decisions as separate and sequential. In the field, however, these decisions relating to whether to give blood for an HIV test or not, whether to learn test results or not, and the venue in which to receive test results were largely collapsed into one main decision about whether to cooperate with the survey teams. Thus, the analysis focused less on those three decisions and more on the overall decision to participate in the blood draw and then receive HIV test results at home, and on the privacy afforded by the home visits.

The interviews with respondents showed that there were four issues most often cited as relevant to their decision to participate in the survey:

- 1) The high rates of participation can be explained in part by the fact that the survey was an official government-sponsored exercise. The survey team members were there as representatives of the MOH, and they wore the white coats of health care providers. A number of respondents mentioned that they felt obligated to participate in the survey and blood draw simply because it was a government exercise. A few even mentioned they might suffer consequences in the future if they refused.
- 2) The fact that the survey teams were accompanied by community leaders (LC Chairpersons) who introduced them and asked the household members to cooperate

seemed to make a great deal of difference for many respondents. In many cases, an LC Chairman came to a household and told household members to be present the next day so they could participate in the government survey. The participation of community leaders was often cited by respondents as an explanation for their participation.

- 3) The identity of the interviewers and laboratory technicians added to the anonymity of the participation in the blood draw and the testing. Respondents took comfort from the fact that those who took the blood and conducted the tests for HIV and syphilis were outsiders who did not know them personally, and who thus would not talk about them to their neighbours or anyone else.
- 4) The randomness of the selection of households and the fact that several households in each cluster were selected seems to have removed stigma from getting an HIV test. Many of the respondents assumed that their decision to participate or not in the blood draw had to some extent already been made for them by the pre-selection of their homes. Respondents talked about 'our villages and our homes were selected, so we were tested,' instead of, 'I was selected and tested.' Getting tested for HIV was something done by households more than individually. Respondents said they would not want to be seen going for an HIV test, since others would wonder why they wanted to discover their HIV status. However, the randomness of the selection of households in the 33 cluster survey seems to have removed that stigma by identifying households rather than individuals for getting tested. It seems important to note this difference, for it offers one way to get individuals tested in a context with little or no stigma attached to the action. This effect of designating a group of persons rather than an individual to be tested may offer a way for programs to encourage HIV testing.

### **10.3 Acceptance of HIV Test Results at Home**

Nearly all respondents said they preferred to receive their test results at home rather than somewhere else. This finding must be, in part, a result of the way the options were presented to respondents, since laboratory technicians sometimes just told respondents that a counsellor would come to the house the next day. However, respondents welcomed the test results at home because it was free, and no one could see what happened inside the household. In the minds of respondents, the cost in time and money to travel to a facility, and the risk of being seen by those who knew them, were the two main drawbacks to getting tested for HIV. Both of those drawbacks were removed by home counselling and testing.

Homes were perceived by almost all the respondents who participated in the blood draw as spaces where they could receive their test results in privacy and with confidentiality. Places were found within the homes where the presentation of the results and the counselling process could be done without any witnesses, and people found that satisfactory with regard to privacy and to confidentiality. The fact that the testing and counselling was being conducted by 'outsiders' further reinforced respondents' perceptions of their test results being private and



confidential. The assumption was that because the teams were outsiders to the communities, they were unlikely to disclose people's test results to others in the community.

For married persons, this was an opportunity to test for HIV without having to give an explanation to one's spouse as to why one had decided to take an HIV test, as would be the case if one decided to seek an HIV test at a health unit or a VCT facility. A person seen visiting a health unit where HIV testing takes place would be considered as someone who was worried about being HIV positive.

The study found some difference in response to getting tested at home by gender. The interviews conducted after the blood draw revealed that couples, especially those who did not fully trust their partners, perceived the study as an opportunity to learn their individual status and in some cases that of their partner as well. The opportunity provided by the survey was new and welcome, especially for the women. Given the unequal gender and power relations that often exist within households, women often find it difficult to go on their own for an HIV test, even if they are willing.

#### **10.4 Social Consequences of Home Visits**

The Phase II portion of this study consisted of conversations with respondents who had been seen by the CHDC team in Phase I to determine if the visit of the survey team and the delivery of HIV test results had any repercussions in the households concerned. Those conversations confirmed earlier findings that showed a general preference for receiving HIV tests at home rather than elsewhere. Also discussed was the disclosure of HIV test results. Among the 34 individuals who were married, 21 had disclosed their HIV test results to their spouse, while 13 had not done so.

After extensive discussion of their memories of the visit of the MOH survey team, and of family and other events since the team's visit, respondents did not give any examples of problems created by the delivery of test results at home. We did not find many examples of social or family disruption after someone learned their HIV status. We learned of one case of a wife who decided to leave her husband after she discovered that she was HIV positive.

However, this evidence does not allow us to say that there are few social disruptions after delivery of HIV test results at home, since we do not have either the numbers or the social contexts to show that. We would expect more of a reaction to finding someone HIV positive than negative, and the highest chance of disruption when a married woman is found to be HIV positive. Phase II found that nine of 61 individuals were HIV positive: six men and three women. Three of the men did not disclose their status to anyone. While all three women told their results to others, these women were not married. In order to answer the question of the social consequences of providing HIV test results at home, we would need larger numbers of HIV-infected individuals, including HIV-infected married women.

## 10.5 Advantages and Disadvantages of VCT at Home within a Survey

Overall, this study found that survey respondents welcomed the opportunity to get tested and counselled at home within a survey organized by the government. Because it was an official operation of the government, was introduced by local political officials, was free, and respondents were shielded from the eyes of others, they accepted testing readily. The main benefit of such an operation is that most of the individuals in the sample learned their sero-status.

Several drawbacks to offering VCT at home should be noted. First, the exercise is quite expensive because of the materials to be purchased, the extra time and personnel involved, and the training of counsellors and support staff. So a sizable amount of extra funds are needed to supplement survey costs. Second, the process is cumbersome, for four counsellors and three laboratory technicians are required to accompany the four interviewers and a team leader. Moving a team of 12 people around from village to village presents a challenge. Third, it is not likely that counsellors have the time for proper counselling in the field as they would have in a health facility. And fourth, devoting so much time and resources to training for drawing blood and testing may take away time and attention from training in proper survey practices. These are all drawbacks related to the functioning of a survey team.

From the standpoint of respondents, the main drawback is the lack of any services available for those who test positive for HIV. While learning one's HIV status may be beneficial, if there is no follow-up service available, either social or medical, the benefits of that knowledge may be wasted. It should also be noted that it would not be easy to explain to an ethics review board why some households should receive the service and others not in a survey context.

Considering all aspects of the home-based VCT survey in 33 clusters, we would not recommend that this approach be generally adopted in survey research in Uganda. The effect on the entire survey process is large, and those who learn their sero-status in this manner have nowhere to turn if they need assistance. The resources necessary for such an effort would be better spent elsewhere.

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**Appendix A**  
**Informed Consent Observation Form**

**Cover Sheet for Observation of Informed Consent Statement**

Name of the district: _____	___/
Name of the cluster _____	___/___/___/
Household number.....	___/___/
Line number of respondent .....	___/___/
Language used _____	___/
Sex of respondent    Female= <b>1</b> Male= <b>2</b>	___/
Date of the observation.....	___/___/05
Interviewer .....	day mo
Identity number of respondent	___/
Identity number of respondent for CHDC	___/___/___/___/___/___/___/
	___/___/___/



<p><b>III. Reaction of respondent</b></p> <p>(for each of the two questions, circle one answer)</p>	<p>A. Attention of respondent:</p> <ol style="list-style-type: none"> <li>1. Pays no attention</li> <li>2. Pays a little attention</li> <li>3. Pays close attention</li> </ol> <p>B. Respondent asks questions:</p> <p style="text-align: center;">1-Yes    2-No</p>
<p><b>Questions</b></p>	
<p><b>Comments</b></p>	
<p><b>IV. Presentation of consent form</b></p>	

## **Appendix B**

### **Questioning Guide for Phase I Interviews**

#### **Pre-test interviews:**

1. You have just finished an interview about family life and AIDS. What had you heard of the survey before we arrived? How did you hear about us?
2. Did you decide to give blood or not? What were you thinking about in deciding?
3. What did the laboratory technician tell you before the blood draw? Anything else she said?
4. Will you learn the results of your HIV test? Where will that be? Tell us about how you decided where you wanted to learn the results.
5. What did the counsellor tell you about getting your HIV test results?

#### **Post-test interviews:**

1. We would like to hear about your conversation with the counsellor. We do not want to know the results of your test, but we are interested in what you were told in general. What was your conversation like?
2. Did you ask any questions? What were they? What answers were you given?
3. What advice did the counsellor offer you? What do you think about that advice?
4. Are you pleased to get your test results at home, or would you have preferred doing it in another place? Where would that have been? Why is that?
5. What are the benefits of getting tested for HIV?

# Appendix C

## Questioning Guide for Phase II Interviews

### TOPIC GUIDE

#### I. Social Context

- A. Identity of respondent  
Name, age, marital status, education, religion, work, children
- B. Household composition  
Name, age, relation to household head
- C. Close relatives (*abenganda zo*)
- D. Close friends and confidants
- E. Associations to which s/he belongs
- F. Recent family events
- G. Health of family members
- H. Recent cases of illness

#### II. Experience with Survey Team

[Remind respondent of visit of survey team three months earlier]

- A. Interaction with survey team
  - 1. Introduction of survey team to household:
  - 2. Individual interviews
  - 3. Blood draw
  - 4. Counselling
- B. Benefits of survey team visit:
  - 1. New information learned
  - 2. Advice received
  - 3. Following advice
- C. Comments heard from others about survey team visit



### **III. Aftermath of Survey Team Visit**

- A. Family/household events since visit of survey team
- B. Events in neighbourhood since visit of survey team
- C. Changes in respondent's life
  - 1. Relations with family members
  - 2. Relations with others
- D. Knowledge of respondent's HIV test results
  - 1. Others who have heard about the test results
  - 2. Respondent discussion of test results
  - 3. Reaction of others to hearing about the test results
- E. Benefits of receiving HIV test results at home
- F. Problems in receiving HIV test results at home
- G. Desire to get tested again