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## Offering Counselling and HIV Test Results at Home in a Survey: The Experience of Uganda

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Based on further analysis of the 2004-05 Uganda  
HIV/AIDS Sero-Behavioural Survey

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**Offering Counselling and HIV Test Results at Home in a Survey:  
The Experience of Uganda**

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## **ABSTRACT**

This paper summarizes the results from a qualitative study that examined how respondents participated in a population-based survey that offered free test results for syphilis and HIV in Uganda. The survey asked potential respondents to give blood for testing, whether they wanted to receive their test results or not, and where (at home or elsewhere) they wanted to learn their results. The survey, called the home-based voluntary counselling and testing survey, was conducted in 2005 by the Ministry of Health (MOH) in three regions of central and western Uganda to test the feasibility and implications of offering HIV test results at home as part of a population-based survey.

The qualitative study was conducted by the Child Health and Development Centre (CHDC) of Makerere University, with technical assistance from Macro International. The CHDC study observed key events in the survey process (administration of the informed consent statement, the actual drawing of blood for testing, and delivery of test results at home) and interviewed survey respondents about their experience with the survey team. The study sought to understand how and why respondents accepted the blood draw and consented to a home visit by a counselor to learn their test results. A return visit several months later sought to discover any effects on social relations from receiving HIV test results at home.

Overall, this study found that survey participants welcomed the opportunity to get tested and counselled at home. Respondents readily accepted testing because it was an official operation of the government, introduced by local political officials, with a focus on households instead of individuals, and conducted by people outside the community, with confidential results. From the perspective of respondents, the survey provided a good opportunity to receive test

results without social or economic costs. From a programmatic standpoint, this method of getting individuals as part of a survey presented some disadvantages as well.

## INTRODUCTION

This document summarizes the results from a qualitative study that examined how respondents participated in a population-based survey that offered free test results for syphilis and HIV in three regions of Uganda<sup>1</sup>. The survey asked potential respondents to give blood for testing, whether they wanted to receive their test results or not, and where (at home or elsewhere) they wanted to learn their results. The qualitative study asked a sample of the survey respondents how and why they decided to participate in the blood draw, how they came to receive their test results, and where they wanted to receive those test results. Since the practice of offering HIV tests and test results as part of a survey is relatively new, it is important to learn how respondents understand the choices they are offered and the basis for their choices.

The survey in question, called the home-based voluntary counselling and testing survey, was conducted in 2005 by the Ministry of Health (MOH) in 33 clusters in three regions of central and western Uganda to test the feasibility and implications of offering HIV test results at home as part of a population-based survey. Some HIV/AIDS specialists 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. Also, it was thought that if respondents were offered a free HIV test result 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 survey questionnaire used was the same one used in late 2004 in the national survey on sexual practices and HIV/AIDS, known as the 2004-05 Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS).

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<sup>1</sup> A full report of the qualitative study is available elsewhere (Yoder et al. 2006).

The qualitative study reported here was conducted by the Child Health and Development Centre (CHDC) of Makerere University, with technical assistance from Macro International. The study observed key events in the survey process (administration of the informed consent statement, the actual drawing of blood for testing, and delivery of test results at home) and interviewed survey respondents about their experience with the survey team. The CHDC study sought to understand how and why respondents accepted the blood draw and consented to a home visit by a counselor to learn their test results. A return visit several months later sought to discover any effects on social relations from receiving HIV test results at home.

### **Context of Uganda**

In the last decade of HIV/AIDS programmatic scale-up, consensus in public health circles has grown on the importance of getting as many people as possible tested for HIV infection. HIV testing presents an opportunity for prevention counselling and also serves as an entry point to social support and medical care and treatment. The Government of Uganda and non-governmental agencies have been expanding voluntary counselling and testing centres (VCT) around the country over the past 15 years and have promoted HIV testing as a means of HIV prevention and access to care (Garbus and Marseille 2003). The AIDS Information Centre (AIC), an indigenous non-governmental organization (NGO), has provided over 1 million HIV tests to Ugandans at VCT centres throughout the country since 1990 (Alwano-Edyegu and Marum 1999). Routine counselling and testing is now provided at several large and district hospitals (Wanyenze 2005), and in several districts in the country home-based HIV testing is now being offered through door-to-door testing by donors.

Despite increased access to VCT, most people (85%) in Uganda have never been tested for HIV. One way to increase the proportion of individuals tested would be to offer HIV testing as part of a national or regional survey. From 2001-2005, national sero-surveys in over 15 countries, including Mali, Kenya, Zambia, Malawi, and now Uganda, have collected blood for anonymous HIV testing to assess HIV prevalence in the adult population. The surveys have also provided vouchers for free HIV tests for participants who want to learn their HIV test results at local health facilities (cf. Yoder and Konaté 2002). Although not formally studied, the rates of voucher utilization are thought to be very low in most countries.

One potential way to increase the number of those tested who learn their HIV status is to provide testing and results in homes of survey participants. High uptake of VCT has been documented in several population-based surveys and interventions in Uganda (Were et al. 2006; Wolff et al. 2005). Offering immediate or next day HIV test results in a survey context is similar to such studies in that test results are delivered at home, but different in that only sampled households are eligible for HIV testing. However, while offering test results in the home might increase the proportion of survey participants who obtain their HIV results, it may also affect survey participation rates or lead to negative social outcomes.

In 2004 the MOH implemented the Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS) that included taking blood for anonymous HIV testing. This national survey provided respondents with vouchers to obtain a free HIV test at a health facility. As mentioned, the national survey was followed by the home-based voluntary counselling and testing survey, known in Uganda as a “nested survey” and conducted in three regions. This smaller survey was designed to test the feasibility of offering HIV test results at home as part of a population-based survey, and to assess the impact of an offer of home-based provision of HIV test results on

survey participation rates. The qualitative study whose findings are reported here was conducted to follow the process of conducting this smaller survey.

## **STUDY METHODS**

### **Design**

The qualitative study originally 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 three decisions as separate and sequential. Observations and interviews revealed that in the field, however, these decisions were largely collapsed into one main decision: whether or not to cooperate with the survey teams. Thus the analysis of study results focused less on the three individual 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.

### **Sample**

For both logistical and linguistic reasons, the CHDC study team worked in the Central and Western regions only, rather than including the West Nile region, the third region in which the MOH survey was conducted. These two regions were chosen because they were more accessible from the capital, and it was assumed that nearly everyone could speak either Luganda (central) or Runyoro/Rutooro (western) respectively.

Two four-person teams were trained to conduct fieldwork to follow the MOH survey: one team who worked in Luganda, and one who worked in Runyoro/Rutooro. In the end, the two qualitative study teams worked in 10 clusters in seven districts, conducted 328 observations of the informed consent process and interviewed more than 280 survey respondents before and after they received their HIV test results. In its demographic characteristics, the sample population for

the qualitative study was roughly the same as the sample for the 33-cluster MOH survey in the Central and Western regions.

### **Instruments**

The study directors, assisted by the training participants, developed three separate instruments during training for data collection: 1) an observation form that was primarily a check list with spaces for comments; 2) a short conversation guide to use in talking to survey respondents after they had seen the lab technician for a blood draw; and 3) another short conversation guide for an interview several months later after respondents had learned of their own HIV status.

The observation guide served as a form for recording what happened between the lab technician and survey respondents during the administration of informed consent. 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. The check list showed which topics from the protocol were actually mentioned in the informed consent presentation and the questions asked by survey respondents.

Guided by the main research questions, the group in training formulated a short series of questions in Luganda and Runyoro/Rutooro to guide the conversations with respondents. In the first questioning guide used right after the blood draw and the pre-test counselling, respondents were asked what they recalled 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: if they wanted to learn their test results and where they would receive their results. The second questioning guide focused on their experience in being counseled after they had learned

their test results. Field workers asked about the questions respondents may have asked during the counselling session, the advice given, and their overall impression of the experience.

About three months after the first phase of interviews of survey respondents, two field workers returned to the Luganda-speaking clusters and interviewed 61 of the respondents interviewed earlier. Since the second phase sought information about repercussions in a household after a person received their HIV test results, the study teams chose three kinds of households—those where someone had tested HIV positive, those where there was a discordant couple, and those where one person was tested and another was not. The main purpose of these return visits was to find out if the revelation of peoples' sero status had caused any social conflict within the households visited by the survey teams. The study's field workers asked the survey respondents about what had happened in the village after the survey team had passed through, about their experience in getting their test results and sharing those results with others, and about how friends and family reacted to the news of their test results.

### **Data collected**

The data from the observation of the informed consent statement came from the check lists of structured observations made during the administration of consent statements. Also, the individual interviews with respondents were tape recorded, transcribed and typed in Luganda and Runyankole/Rutooro, and then translated into English and typed in Microsoft Word. The findings draw on all of these data sources.

## **Data analysis**

The data from the structured observations in the form of check lists were entered into SPSS for analysis. The data base in SPSS was used to examine the frequencies of the mentioning of certain key topics such the confidentiality of the results, the voluntary nature of participation, HIV testing, and home delivery of HIV test results. The texts in English from the interviews were manually coded to identify certain themes: reasons given for participating in the survey and for giving blood, concerns about privacy, and comments on receiving HIV test results at home. One-page summaries of each interview citing these and other themes were prepared for use in the analysis and writing process.

## **FINDINGS**

### **Participation rates in the blood draw**

The offer of providing free HIV test results did not change the rates of participation in the 33-cluster survey or the blood draw for women, but participation rates dropped slightly for men with this approach. In all, 86% of respondents in the 33-cluster survey accepted their HIV test results (83% of men and 88% of women). Most respondents said they were pleased to receive their test results for syphilis and for HIV at home. The qualitative study provides explanations for the high rates of participation in the blood draw and in acceptance of HIV test results at home.

The observations of the informed consent process made it clear that respondents were expected to participate in the blood draw. In cases of initial refusal, the lab technician would explain everything again and try to persuade the person to participate. No relationship was found between the topics mentioned in the consent process and whether or not an individual agreed to participate in the blood draw.

### **Rationale for participation in the nested survey**

Respondents in the qualitative study cited several main issues that affected their participation in the MOH nested survey. First, the survey was conducted by the Government of Uganda: the survey team members were there as representatives of the MOH and they wore the white coats of government health care providers. Second, in their visits to selected households, the survey team members were accompanied by local leaders who not only helped in identifying the selected households but also formally introduced the teams and asked household members to cooperate. Third, those conducting the survey were outsiders to the communities where the survey was conducted and thus did not know the respondents personally. Fourth, the households included in

the survey were randomly selected and listed before the survey so that people in the community were not sure of the selection process.

Each of these reasons deserves some elaboration:

1. The survey was an official government-sponsored exercise.

A number of respondents in the qualitative study 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 survey teams were accompanied by community leaders (Local Council Chairpersons).

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

3. The survey team members were outsiders to the communities involved.

The fact that the interviewers and lab technicians were outsiders 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 HIV and the syphilis tests did not know them personally and thus would not talk about them to their neighbors or anyone else. One reason respondents mentioned for not getting tested locally is that health care providers who knew them might talk about them to others in the neighborhood.

4. The randomness of the household selection process and criteria for participation.

The selection procedure seems to have removed stigma from getting an HIV test. Many of the study respondents assumed that their decision to participate or not in the blood draw part of the survey 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 on a household basis more than individually, for in most cases, all the eligible adults in the household were tested for HIV and syphilis.

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. This concern did not apply in the survey context. It seems important to take note of this key difference, for survey-based testing offers one way to test individuals for HIV in a context with little or no stigma attached. Whether home-based VCT is offered as part of a survey or in some other context, the effect of designating a group of persons rather than an individual for testing may offer a way for programs to encourage HIV testing.

### **Receiving HIV test results at home**

Nearly all survey participants interviewed said they preferred to receive their test results at home rather than elsewhere. This finding must be, in part, a result of the way the options were presented, since lab technicians sometimes just told people that a counselor would come to the house the next day. However, respondents said they welcomed the test results at home because it was free, and no one could see what happened inside the household. To 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.

When asked what they thought about getting tested at home, respondents often responded with comments such as these:

- *I am happy to be tested at home because it does not involve movement.*
- *It is good to get them at home, because I do not want people to interpret things because my children will get worried.*
- *He said he will come back tomorrow and bring me my results here so I should not move away.*
- *At home, because it does not cost me anything.*
- *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 rumour mongering...*

Almost all the respondents who participated in the blood draw considered their homes as places where they could receive their test results privately and confidentially. Spaces were found within the homes where the presentation of the results and the counselling process could be done without any witnesses, and people found this arrangement satisfactory. The fact that the testing and counselling were being conducted by people from outside the community, and by people who did not know them personally, further reinforced respondents' perceptions that their test results would be kept private, since the survey teams were unlikely to disclose people's test results. This concern for confidentiality can be seen in the comments below:

- *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.*
- *Nobody was seeing not even hearing.*
- *At home others have no way of finding out unless you tell them.*

For married persons, both husbands and wives, the survey offered 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, which might be necessary if they sought an HIV test at a health unit or a VCT facility. A person observed visiting a health unit where HIV testing takes place would be considered as someone who was worried about possibly being HIV positive.

The response to getting tested at home differs somewhat by gender. The interviews conducted after the blood draw revealed that couples, especially those who did not fully trust their partners, perceived the survey 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 women. Given the gender and power relations that often exist within households in Uganda, women are often reluctant to go on their own for an HIV test.

### **Social consequences of home visits**

As mentioned earlier, the second phase of the qualitative study consisted of follow-up conversations with a sample of the persons who had been interviewed three-months earlier by the qualitative study team tracking the nested survey. The purpose was to determine if the visit of the survey team and the delivery of HIV test results had any social repercussions in the households concerned. Those conversations confirmed the findings of the first phase of the

qualitative study that showed a general preference for receiving HIV tests at home rather than elsewhere. Also discussed were the HIV test results and the disclosure of the test results to others. Among the 34 individuals who were married, 21 (62 percent) had disclosed their HIV test results to their spouse, while 13 individuals had not done so.

The conversations with respondents in phase two focused on their impressions of the visit of the MOH survey team, on family events since the team's visit, and on other social contacts since that time. The respondents did not mention examples of social problems that followed 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 that in one case a wife decided to leave her husband after she discovered that she was HIV infected. However, we had expected to find evidence of social tension or disruptions in families where someone had been found HIV positive.

The research team expected to find evidence of negative reactions to finding someone HIV positive, and particularly in situations where a married woman is found HIV positive. However, phase two found only 9 of 58 individuals (16%) HIV positive: six men and three women. Two of these men were married while four were single or divorced. 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 and the inclusion of married women who are found HIV positive. Thus the evidence available does not allow us to say for certain that there are few social disruptions after delivery of HIV test results at home.

## **DISCUSSION**

Overall, this study found that survey participants welcomed the opportunity to get tested and counselled at home within a survey organized by the government. From the perspective of respondents, the survey provided a good opportunity to receive test results without social or economic costs. When done in a household context, getting tested did not seem to be stigmatized. Respondents accepted testing readily because it was an official operation of the government, introduced by local political officials, with a focus on households instead of individuals, and conducted by people outside the community, with confidential results. These reasons were cited over and over again by respondents to explain why they accepted an HIV test along with the results.

Getting tested in the privacy of one's home meant that they could confirm their HIV status without the risk of being seen at an HIV testing center. It should be noted that many respondents explained that receiving an HIV test result at home was totally different from getting an HIV test in a facility, where others could see you and might wonder why you needed to be tested for HIV. In such a survey context with a sample selected randomly, there was no sense of stigma attached to being tested for HIV. Thus most of the individuals in the sample learned their sero status.

A major limitation of this study is that it did not see a large enough sample of respondents in the second phase to properly evaluate the social consequences of home delivery of HIV test results. It is true that the study was designed with other objectives in mind (to understand decisions around participation in the survey, the blood draw, and home test results), and the study found that respondents participated readily more because the survey was a government exercise than because of the choices offered by the survey team. Nevertheless, this

was an opportunity missed, given the importance of evaluating the social consequences of being found HIV positive.

From the standpoint of survey respondents, this approach to HIV testing—offering VCT at home as part of a population-based survey—was welcome, since it provided them with an opportunity to check their sero-status without raising questions about why they might need testing. From a programmatic standpoint, however, several drawbacks must be considered. First, offering HIV testing increases the survey costs because of the materials to be purchased, the extra time and personnel involved, and the training of counsellors and support staff. Second, the survey process itself becomes cumbersome, because three to four counsellors and three laboratory technicians need to be added to the interviewing survey team.

In addition, while learning one's HIV status may be beneficial, the benefits of that knowledge may be wasted if no follow-up service, whether social or medical, is available. Where counsellors receive specialized and extensive training, and where social support and medical services can be made available, it makes sense to consider home visits to offer HIV testing and counselling. In situations without such training and support, home visits are more difficult to justify. While the disadvantages cited above suggest that a large sample survey is not the ideal mechanism for home delivery of HIV test results, other mechanisms should be explored to offer free HIV testing at home to increase awareness of sero-status and facilitate access to services.

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