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VALIDITY OF DATA ON SELF-REPORTED HIV STATUS IN MALAWI AND UGANDA AND IMPLICATIONS FOR MEASUREMENT OF ARV COVERAGE

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Validity of Data on Self-reported HIV Status in Malawi and Uganda and Implications for Measurement of ARV Coverage

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Preface

The Demographic and Health Surveys (DHS) Program is one of the principal sources of international data on fertility, family planning, maternal and child health, nutrition, mortality, environmental health, HIV/AIDS, malaria, and provision of health services.

One of the objectives of The DHS Program is to continually assess and improve the methodology and procedures used to carry out national-level surveys as well as to offer additional tools for analysis. Improvements in methods used will enhance the accuracy and depth of information collected by The DHS Program and relied on by policymakers and program managers in low- and middle-income countries.

While data quality is a main topic of the DHS Methodological Reports series, the reports also examine issues of sampling, questionnaire comparability, survey procedures, and methodological approaches. The topics explored in this series are selected by The DHS Program in consultation with the U.S. Agency for International Development.

It is hoped that the DHS Methodological Reports will be useful to researchers, policymakers, and survey specialists, particularly those engaged in work in low- and middle-income countries, and will be used to enhance the quality and analysis of survey data.

Sunita Kishor
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Abstract

Objective: To assess the validity of self-reported HIV status in two population-based surveys—the 2010 Malawi DHS and the 2011 Uganda AIS—to determine whether self-reported HIV status can be used as a basis for measuring indicators of use of services such as ART and PMTCT by people living with HIV (PLHIV).

Methods: Self-reported HIV status was compared with HIV serostatus obtained from blood test results. Among HIV-positive respondents with HIV-negative self-reports a simulation was conducted using estimates of HIV incidence and time since last HIV test to predict the percentage of respondents likely to have seroconverted since their last test. Finally, the impact of the validity of data on self-reported HIV status on service coverage indicators is assessed.

Results: A total of 40 percent of HIV-positive women and 36 percent of HIV-positive men in Malawi and 32 percent of HIV-positive women and 24 percent of HIV-positive men in Uganda reported that they had been tested for HIV, had received the result, and the result was HIV-negative. Among respondents who were HIV-positive on the survey blood test, the percentage likely to have seroconverted since their last HIV test was estimated at 1 percent or lower among women and men in both surveys.

Conclusions: There is evidence of substantial underreporting of positive HIV status among respondents who are likely to know they have HIV. The low validity of data on self-reported HIV status will affect indicators of service use by PLHIV and estimates of eligibility for ART based on CD4 testing.

1. Introduction

The 2011 United Nations Political Declaration on HIV and AIDS set a goal of reaching 15 million people with antiretroviral (ARV) treatment by 2015, and as of 2012 an estimated 9.7 million people in low- and middle-income countries were being treated with ARVs (UNAIDS, 2013). Monitoring the achievement of this goal has given rise to an increasing demand for data on ARV use. Performance of care and treatment programs is usually measured through service statistics, but there are limitations to this data source, including incomplete reporting and the challenge of estimating the population in need of services. Population-based surveys are another potential data source for measuring the coverage of services for people living with HIV (PLHIV) such as the provision of ARVs, CD4 testing, and services for the elimination of mother-to-child transmission of HIV. ARV use can be measured by self-reported information or by means of a blood test. The blood test, however, requires high-performance liquid chromatograpy, a technology not widely available in sub-Saharan Africa and for which capacity is very limited in African settings. This means that in most countries it is more feasible to estimate ARV coverage in a survey is through the collection of self-reported information during the individual interview. In order to measure use of these services in a survey, respondents must first disclose their HIV status to the interviewer so that the questions on service use can be asked of those who know they are HIV-positive. *Underreporting of positive serostatus among respondents who know they have HIV can bias the service use indicators.*

There is little evidence on the validity of self-reported HIV status in sub-Saharan Africa. Most studies in this region have focused on comparing biological measures of HIV infection to perceived risk of HIV infection among populations with low coverage of HIV testing. Studies on perceived risk have found that respondents tend to overestimate their risk of HIV infection (Anglewicz and Kohler 2009; Bignami-Van Assche et al. 2007; Chintu et al. 1997; Fagbamigbe et al. 2011; Quigley et al. 1997; Stringer et al. 2004). Only a few published studies have compared biological measures of HIV status with respondents' self-reports of HIV status based on their prior testing history. Most of these studies have been conducted in the United States, Europe, and Australia and have focused on key populations such as people who inject drugs and men who have sex with men. These studies tend to show a high degree of agreement between self-reported HIV status and the results of HIV testing among all respondents—between 89 and 99 percent—but less valid reporting is seen among respondents who are HIV-positive (Harrington et al. 2001; Latkin and Vlahov 1998; Lima et al. 1994; McCusker and Stoddard 1993; McCusker et al. 1992; Origer and Schmit 2012; Ross et al. 1993; Salani Mota et al. 2011; Strauss et al. 2001; Thornton et al. 2000). *Sensitivity*, that is, the percentage of HIV-positive respondents who reported they were HIV-positive in each of the studies was calculated for respondents who had been tested for HIV and received the result. Sensitivity generally ranged from 50 to 82 percent, but reached 93 percent in one study of people who inject drugs in Australia (McCusker and Stoddard 1993). In the 2012 Kenya AIDS Indicator Survey (KAIS), a nationally-representative household survey including both self-reported and biological tests of HIV status, 47 percent of respondents who were HIV-positive on the biological test had been tested for HIV prior to the survey and reported that they were HIV-positive (Ng'ang'a et al. 2014).

The specific reasons for underreporting of positive HIV status in the studies cited above are not known but a number of possible explanations were noted; these include: 1) seroconversion since last HIV test, 2) untruthful reporting, 3) failure to understand the test result, and 4) misunderstanding the interview question on self-reported status. Unbiased measurement of indicators of coverage of services for PLHIV requires valid reporting by respondents who know they are HIV-positive because it can be assumed that HIV-positive respondents who are truly unaware of their status will not be receiving these services. This analysis has two main objectives: first, to assess the validity of the data on self-reported HIV status among HIV-positive respondents in the 2010 Malawi Demographic and Health Survey (MDHS) and the 2011 Uganda AIDS Indicator Survey (UAIS), and second, to examine how data quality problems with self-reported HIV status can affect the accuracy of program coverage indicators measured by these surveys. The findings provide information to guide decisions about whether indicators of use of services by PLHIV based on respondent-reported data should be measured in population-based surveys.

2. Methods

2.1. Data

The 2010 MDHS and 2011 UAIS are cross-sectional household surveys with nationally representative samples. In Malawi, all women age 15-49 and all men age 15-54 in selected households were eligible for the individual interview. In Uganda, all women and men age 15-59 were eligible for the individual interview. For simplicity, we restricted all analyses to women and men age 15-49. In a standard Demographic and Health Survey (DHS) or AIDS Indicator Survey (AIS), all respondents to the Woman's Questionnaire and the Man's Questionnaire are asked if they have ever been tested for HIV; if they answer yes, they are asked whether they received the result of their last HIV test. Before being asked if they received the result of the HIV test, respondents are first informed that they will not be asked to report the test result. In the 2010 Malawi DHS and the 2011 Uganda AIS, the part of the question indicating that they would not be asked to report the result was removed. In both surveys, women were asked separate questions about HIV testing in the context of antenatal care services and in the context of HIV testing in general. In the Malawi survey, after this sequence of testing questions, women who reported that they had received the result to any of their HIV tests were asked, "What was the result of your last HIV test?" In the Uganda survey, by contrast, after each question about being tested for HIV, women who said they received the result for that test were immediately asked, "What was the result of the test?" Male respondents in both surveys were asked only one question about whether they had ever been tested for HIV. Those who reported that they had been tested for HIV and received the result of their last HIV test were asked, "What was the result of the test?"

The response options for the question on result of HIV test differed slightly between the two surveys. Both surveys included response codes of positive, negative, and refused to answer. In addition, the 2011 UAIS included a response code for not knowing the test result (although respondents reported receiving their HIV test result in the previous question). The 2010 MDHS included a response code for an indeterminate test result; it also included a filter for privacy—specifically for the HIV test result question—and respondents were not asked this question if privacy could not be obtained.

Women and men who reported that the result of their last HIV test was positive were then asked questions about the use of ARVs and other services for PLHIV. In both the 2010 MDHS and the 2011 UAIS, self-reported ARV use was ascertained by asking "Are you taking ARVs, that is, antiretroviral medications daily?" In the 2011 UAIS, the response options were limited to yes, no, and don't know. In the 2010 MDHS response codes included: "Yes, taking ARVs daily," "Yes, taking medicine daily, not sure what kind," and "No."

The collection of data on use of PMTCT services differed slightly between the two surveys. In the 2010 MDHS, separate questions on ARVs during pregnancy, single-dose nevirapine (sdNVP) during labor, and postnatal administration of NVP to their children were asked of women who reported they were HIV-positive, had a birth in the two years preceding the survey, and who said they knew that they were HIV-positive before their last birth. In the 2011 UAIS, women were asked the result of the HIV test they received during ANC. Women who responded that the result of their ANC HIV test was positive were asked a single question on ARV use: "During pregnancy or labor and delivery were you offered antiretroviral drugs to reduce the risk of passing on the AIDS virus to your unborn baby?" Both surveys asked about HIV testing for children of mothers who reported they were HIV-positive; however, the 2011 UAIS asked this information only for children who were alive at the time of the survey.

All interviewed women and men in the Uganda households and in a one-third subsample of the Malawi households were eligible for the survey HIV test. In Malawi, the blood sample for the HIV test was taken from a finger prick and collected in the form of dried blood spots on a filter paper card. Blood samples were transported to the Community Health Sciences Unit of the Ministry of Health in Lilongwe for testing. In Uganda, serum samples were obtained via venous blood draw and were tested at the Uganda Virus Research Institute. Dried blood samples were obtained from a finger prick for a few respondents who declined the venous blood draw.[1]

The protocol for the blood sample collection and testing for HIV for the 2010 MDHS was reviewed and approved by the Malawi Health Sciences Research Committee. The protocol for the 2011 UAIS was reviewed and approved by the Uganda Virus Research Institute Science and Ethics Committee. Both surveys were reviewed and approved by the Centers for Disease Control and Prevention (CDC) in Atlanta and the Institutional Review Board of ICF Macro.

The number of eligible respondents and the sample size of women and men interviewed, tested for HIV, and found to be HIV-positive in the two surveys is shown in Table 1. Response rates for the interview and HIV testing all exceeded 90 percent, except for men in Malawi, among whom 84 percent of those eligible participated in the interview and HIV testing.

Table 1 Sample size among respondents in Malawi and Uganda who were eligible for interview and HIV testing, Malawi 2010 and Uganda 2011

	Women		Men	
	Unweighted	Weighted	Unweighted	Weighted
Malawi				
Eligible	8,174	na	7,391	na
Interviewed	7,911	7,830	6,818	6,805
Tested for HIV	7,398	7,091	6,179	6,497
HIV-positive	890	913	492	529
Uganda				
Eligible	11,353	na	9,080	na
Interviewed	11,148	11,160	8,718	8,735
Tested for HIV	10,986	10,883	8,542	8,673
HIV-positive	873	907	500	529

na=not applicable

2.2 Data Analysis

The validity of the data on self-reported HIV status was examined by comparing respondents’ HIV testing history and the reported result of their most recent HIV test prior to the survey with the result of the survey blood test using bivariate cross tabulation. Additionally, among respondents who were HIV-positive in the survey blood test and who reported that they had been tested for HIV prior to the survey but that their test result was negative, the reasons for discordance were explored. Discordance between self-reported status and survey blood test results among HIV-positive persons who are likely to have known their current HIV status is due mainly to one of two major factors: 1) seroconversion since the respondent’s last HIV test or 2) intentional misreporting of HIV status. The greater the number of respondents who can be shown to have seroconverted between their last test and the survey test, the greater the validity of self-reported data. Therefore, the paper developed estimates of the percentage of HIV-positive respondents with HIV-negative self-reports *who are likely to have seroconverted since their*

[1] Further information about the HIV testing algorithms used in the two surveys can be found in the final reports for the surveys: NSO and ICF Macro 2011 (Malawi); MOH et al. 2012 (Uganda).

last HIV test. The estimates were arrived at through a simulation using information on HIV incidence and exposure time since the last test.

The HIV incidence rates used in the simulation were those for the adult population age 15-49, disaggregated by sex, from Spectrum version 5.51 for the year 2010 for Malawi and for the year 2011 for Uganda. For most female respondents and all male respondents, information on time since last HIV test is available from a direct question. Responses were recorded categorically with codes corresponding to less than 12 months, 12-23 months, and 24 or more months before the interview. The direct question on time since last HIV test was not asked for women who had a birth in the two years (Malawi) or five years (Uganda) preceding the survey and whose last HIV test was during antenatal care (ANC). For these women, a range for the possible time of the last test was calculated based on the timing of the pregnancy relative to the interview (see the Methodological Appendix for further details).

All respondents in each category of *time since last test* were assigned a length of exposure time equal to the number of months at the midpoint of the interval of time since last test. To calculate the percentage who could have seroconverted since their last HIV test—among women and men who tested positive in the 2010 MDHS or 2011 UAIS HIV test but who self-reported as HIV-negative—the following steps were taken. First, the number of respondents in each category for time since last test is multiplied by the number of months of exposure assigned to that group to generate the total person-years of exposure in that category. Second, the person-years of exposure for each category are then multiplied by the incidence rate, resulting in the number of seroconversions for each category of time since last test. Finally, the numbers of seroconversions in each of the categories are added together and the sum is divided by the total number of respondents to generate the percentage of respondents likely to have seroconverted. Calculations were carried out separately for women and men in order to apply sex-specific incidence rates.

For respondents who were last tested for HIV more than 24 months ago it is not possible to calculate an average time since last test. Instead, an assumption is made regarding the average amount of exposure time to assign to respondents in this category. Three scenarios were developed using different assumed values for average time since last test for respondents in the 24+ months category. Scenario A assumes that these respondents were tested between 2 and 5 years before the survey, yielding an average exposure time since last test of 3.5 years. Scenario B assumes that these respondents were tested between 2 and 10 years before the survey, yielding an average exposure time since last test of 6 years. Scenario C assumes that these respondents were tested between 2 and 15 years before the survey, yielding an average exposure time since last test of 8.5 years.

This analysis first presents the survey results on HIV testing history and self-reported HIV status for all survey respondents; then it presents these results for the respondents who tested positive for HIV in the survey blood test. This discussion is followed by the results of the simulation estimating the percentage of HIV-positive respondents with negative self-reported HIV status who are likely to have seroconverted since their last test. Next, these results are incorporated into the self-reported HIV data for all HIV-positive respondents to assess the validity of self-reported HIV status for the group of HIV-positive respondents as a whole. The report then lists various indicators of service coverage and examines the potential bias that inaccurate self-reports of HIV status can have on estimates of these indicators. Finally, the report examines issues of sample size that affect how well population-based surveys can estimate coverage of PMTCT services. The report concludes with recommendations regarding the inclusion of questions on self-reported HIV status and on use of services for PLHIV in population-based surveys.

3 Results on Self-reported HIV Status

Table 2 presents the data on HIV testing history and self-reported HIV status for all respondents who participated in the survey HIV test. In both countries, at least two-thirds of women and around half of men had been tested for HIV prior to the survey and had received the test result. This is the population for which self-reported HIV status is available. In Malawi, 5 percent of women and 2 percent of men reported being HIV-positive, as did 4 percent of women and 2 percent of men in Uganda; however, HIV prevalence according to the survey blood test is 13 percent among women and 8 percent among men in Malawi, and 8 percent among women and 6 percent among men in Uganda.

Table 2 Self-reported HIV status among women and men age 15-49, Malawi 2010 and Uganda 2011

	Malawi		Uganda	
	Women	Men	Women	Men
Previously tested and received HIV result	**71.9**	**51.5**	**65.8**	**44.8**
Self-reported HIV positive	5.2	2.2	3.9	2.2
Self-reported HIV negative	64.4	49.1	61.5	42.3
Reported HIV result was indeterminate	0.5	0.2	na	na
Don't know result	na	na	0.4	0.3
Refused to disclose result	0.4	<0.1	<0.1	<0.1
No privacy during interview to disclose result/missing	1.4	0.3	na	na
Previously tested and did not receive result	**1.5**	**1.4**	**4.3**	**2.3**
Not previously tested	**26.1**	**46.8**	**29.9**	**52.8**
Prior test history missing	**0.5**	**0.0**	**0.0**	**0.0**
Total	100.0	100.0	100.0	100.0
Number	7,091	6,497	10,883	8,673
HIV positive from survey blood test	12.9	8.1	8.3	6.1

Note: Table includes men and women age 15-49 with a valid HIV test result from the 2010 MDHS or 2011 UAIS.

One concern about the introduction of the question on self-reported status has been whether asking respondents to disclose their HIV status during the interview will affect participation in HIV testing in a DHS or AIS. Box 1 provides an analysis of whether participation in the HIV testing in the 2010 MDHS and 2011 UAIS varied by prior testing history and self-reported HIV status.

Box 1
Did introducing a question on self-reported status affect participation in the 2010 MDHS and 2011 UAIS HIV testing?

In DHS or AIS surveys that include collection of blood samples for HIV and other testing, one concern about asking respondents to disclose their HIV status is that respondents who report their status may be less willing to provide a blood sample for HIV testing. Individuals who have said they are positive may wonder why the survey would need to take a blood sample to find out their HIV status. Respondents who know they are positive but choose to report they are HIV-negative may not want to give a blood sample for fear that their false report will be detected. Differences in the response rates for the HIV test by self-reported status would bias the HIV prevalence estimate derived from the survey.

To examine whether self-reported HIV status affects blood collection response rates, the table below shows how response rates to the HIV blood collection in the 2010 MDHS and the 2011 UAIS varied according to prior testing history of the respondent and self-reported HIV status. Response rates are high for both women and men across all categories. Further, response rates do not differ by self-reported status. Thus, data from these two surveys suggest that asking respondents to disclose the result of their last HIV test does not affect participation in the survey HIV testing.

Table 3 Response rates to the survey HIV test according to prior testing history and self-reported HIV status (unweighted), Malawi 2010 and Uganda 2011

Prior HIV testing history and self-reported HIV status	Percentage tested for HIV	Number eligible for HIV test	Percentage tested for HIV	Number eligible for HIV test
		Malawi		
	Women 15-49		Men 15-54	
All interviewed	94	7,911	91	7,175
All previously tested	94	5,611	92	3,719
Self-reported positive	96	397	93	166
Self-reported negative	94	5,148	92	3,536
Other[1]	89	66	88	17
Never tested	92	2,300	90	3,456
		Uganda		
	Women 15-59		Men 15-59	
All interviewed	98	12,153	98	9,588
All previously tested	98	8,295	98	4,546
Self-reported positive	99	470	100	212
Self-reported negative	98	7,240	98	4,082
Other[1]	99	585	99	252
Never tested	98	3,858	98	5,042

[1] “Other” includes those who had been tested for HIV but who said the result of their last HIV test was indeterminate, who refused to disclose their test result, who lacked privacy to report their test result, who said they never received their test result, who said they did not know their test result, and whose prior testing history was missing.

4 Evaluating the Quality of Data on Self-reported HIV Status

To capture use of HIV-related services in a survey, it is first necessary to attempt to identify respondents who know they are HIV-positive. As a practical matter, it does not make sense to ask respondents whether they are taking ARVs if they are HIV-negative or if they have HIV but do not know it. Further, identification of respondents who know they are HIV-positive provides information useful for programs. For example, this information enables calculation of the percentage of the HIV-positive population that is aware of their status, an important indicator of the performance of counseling and testing interventions. In addition, the population of HIV-positive individuals who know they are positive is a meaningful denominator for indicators of coverage of HIV-related services—individuals who know they are HIV-positive can be reached directly with care and treatment services whereas individuals who are positive but do not know it must first be identified through testing services.

Population-based surveys can measure respondents' reported HIV status but it is important to recognize that respondents may not accurately report what they know their HIV status to be. It is important that the data on self-reported status be as accurate as possible because misreporting can result in biased measurement of coverage indicators. If respondents who know they are HIV-positive report that they are HIV-negative, no data will be collected about their use of ARVs or PMTCT services. Further, HIV-positive respondents who choose to disclose their status may differ from those who choose to hide their status in ways related to their probability of using HIV-related services. For example, respondents who choose to disclose that they have HIV may have been infected for a longer period of time and thus may be more likely to have come to terms with their HIV-positive status. Also, those who have been infected longer are more likely to have progressed to a point where they are eligible for treatment. In addition, being on treatment itself requires individuals to discuss their status with others, including health care providers, and in most cases friends and family. This communication may make individuals more comfortable discussing their status openly with a survey interviewer as well. Accordingly, this section of the report attempts to evaluate the validity of the self-reported HIV status information from the 2010 MDHS and 2011 Uganda AIS.

4.1 Comparing Self-reported HIV Status with HIV-positive Status Determined by the Survey HIV Test

Table 4 shows the testing history and self-reported HIV status of respondents who were HIV-positive according to the survey blood test. Among respondents who were HIV-positive, coverage of prior HIV testing is high in both countries, especially among women. Less than one in five HIV-positive women in both Malawi and Uganda and around two in five HIV-positive men in both countries reported never having been tested for HIV prior to the survey. While these respondents, presumably, did not know about their positive HIV status, even among those who said they had been tested prior to the survey, reporting of HIV-positive status during the interview was low. In Malawi, 39 percent of HIV-positive women and 26 percent of HIV-positive men reported that they had been tested for HIV prior to the survey and that the result of their last HIV test was positive; in Uganda, the corresponding proportions were 44 percent of HIV-positive women and 32 percent of HIV-positive men.

Table 4 Self-reported HIV status among women and men age 15-49 with positive HIV survey blood test result, Malawi 2010 and Uganda 2011

Self-reported HIV status	Malawi		Uganda	
	Women	Men	Women	Men
Ever-tested				
Report positive	38.6	26.1	44.2	31.8
Report negative	40.4	36.2	31.6	24.2
Never tested	17.3	35.7	18.6	39.7
Other	3.7	2.0	5.6	4.3
Total	100.0	100.0	100.0	100.0
Number	913	529	907	529

Note: "Other" includes those who had been tested for HIV but who said the result of their last HIV test was indeterminate, who refused to disclose their test result, who lacked privacy to report their test result, who said they never received their test result, who said they did not know their test result, and whose prior testing status was missing.

Among all HIV-positive respondents, 40 percent of women and 36 percent of men in Malawi and 32 percent of women and 24 percent of men in Uganda said they had been tested for HIV, had received their test result, and reported that the test result was negative. Three explanations have been proposed for why such large proportions of respondents who tested positive on the survey HIV test self-report as HIV-negative, and each may contribute to some portion of the difference:

a) The respondent was truly negative at the time she/he was last tested for HIV but has since seroconverted.

b) The respondent knowingly misreported his/her HIV status as negative during the interview.

c) The respondent's last HIV test result and the survey HIV test result were discordant.

Regarding the third explanation (c above), the likelihood of receiving discordant results on the respondent's HIV test through the health care system and the survey HIV test depends both on the quality of the testing and the diagnostic procedures themselves. While HIV Testing and Counseling (HTC) services usually rely on rapid diagnostic tests, the HIV result for these two surveys was obtained via third-generation ELISA tests, with Western Blot used as a tie-breaker. Nevertheless, the proportion of the difference due to discrepant test results is likely to be relatively small.[2] The next section focuses on understanding the relative contribution of the other two potential explanations for the difference between the survey HIV test result and the self-reported HIV test result: seroconversion and misreporting. The quality of the data on self-reported HIV status depends on the relative size of these two groups. If almost all of the difference between positive HIV status, as measured by the survey HIV test, and negative self-report is due to seroconversion and not to false reporting, then the questions on self-reported status can be considered a valid measure of what respondents know their status to be. However, the proportion of these respondents who are likely to have seroconverted since their last HIV test must be very low for the data on self-reported HIV status to be considered valid. The higher the level of misreporting, the stronger the bias in coverage indicators will be.

[2] There is evidence that rapid HIV tests are used effectively in service settings. An investigation of the use of rapid HIV testing in service settings in Botswana, Kenya, Rwanda, and Zimbabwe found a median concordance between rapid test results from service sites and reference laboratory results of 99 percent (Plate 2007). Where problems with the quality of rapid HIV testing in service sites exist, false positives are more common than false negatives (Aghokeng et al. 2009; Gray et al. 2007; Klarkowski et al. 2009; Plate 2007). However, isolated cases of low sensitivity of rapid tests in service settings (resulting in false negatives) have been documented (Wolpaw et al. 2010).

4.2 Validity of Self-reported HIV Status in the 2010 MDHS and 2011 UAIS

In a population-based survey it is impossible to determine the exact proportion of respondents who gave false information when asked about the result of their last HIV test. However, a reasonable estimate of those providing false information can be obtained if the proportion who could be expected to have seroconverted is known. The latter figure can be estimated by simulating the number of seroconversions that are likely to have occurred by using existing information on HIV incidence and the duration of time since the last test. Such a simulation has been undertaken using the data from the 2010 MDHS and 2011 UAIS. An overview of the methods is described in the Data Analysis section above, and more details on the methods and calculations can be found in the Methodological Appendix.

As explained above, the simulation uses average exposure time since last test and HIV incidence rates from Spectrum software for the year 2010 for Malawi and for 2011 for Uganda, disaggregated by sex. The incidence rate is 1.10/100 person-years for women in Malawi, 0.87/100 person-years for women in Uganda, 0.80/100 person-years for men in Malawi, and 0.63/100 person-years for men in Uganda. The actual HIV incidence rate among the group of HIV-positive respondents in these two surveys is unknown but it is likely that this group has a higher risk profile and a higher HIV incidence rate than the general population. With no way of knowing how much higher, we chose to use a standard, general population estimate. The Spectrum incidence estimates were chosen partly because they were higher than other published estimates including the Malawi government estimate of 0.54/100 person-years (GOM 2012).

Having set the assumptions for HIV incidence, the next step in the simulation was to estimate the exposure time since last HIV test. For most female respondents and all male respondents, information on time since last test is available from a direct question with precoded responses of less than 12 months, 12-23 months, and 24 or more months preceding the interview (see the Methodological Appendix for further detail). The unweighted distribution of time since last test for women and men is shown in Table 5. There were 333 women and 176 men in Malawi and 90 women and 44 men (unweighted) in Uganda who tested positive in the survey HIV test but who reported they were HIV-negative during the interview. At least 60 percent of women and around 70 percent of men in both countries received their last HIV test in the two years preceding the survey.

Table 5 Distribution of women and men age 15-49 who tested positive in the survey HIV test but reported they were HIV negative, by time since last HIV test (unweighted), Malawi 2010 and Uganda 2011

Time since last HIV test[1]	Malawi		Uganda	
	Percent	Number	Percent	Number
Women				
<12 months	37.2	124	34.4	90
12-23 months	16.8	56	15.7	41
3-20 months[2]	6.6	22	10.7	28
24+ months	30.6	102	30.9	81
15-32 months[2]	8.4	28	8.4	22
Missing	0.3	1	100.0	262
Total	100.0	333	34.4	90
Men				
<12 months	50.0	88	38.6	44
12-23 months	19.9	35	33.3	38
24+ months	30.1	53	28.1	32
Missing	0.0	0	100.0	114
Total	100.0	176	38.6	44

[1] All categories are mutually exclusive, i.e., a respondent can be in only one category.
[2] Women in these categories all gave birth in the two (Malawi) or five (Uganda) years preceding the survey. The possible range for the date of the last HIV test was estimated from the date of their last birth. See the Methodological Appendix for further detail.

A summary of the results of the simulation is presented in Table 6. A detailed presentation of the calculations for the number of seroconversions for each of the three scenarios is included in the Methodological Appendix. As shown in Table 6, the percentage of respondents in the group who tested positive in the survey HIV test and reported that they were HIV-negative who are likely to have seroconverted since their last HIV test is less than 4 percent across all four populations in all three of the scenarios. According to Scenario B, only 3 percent of women and 2 percent of men in Malawi, and 2 percent of women and men in Uganda, are likely to have seroconverted since their last HIV test. This means that the rest of the respondents who tested positive in the survey HIV test but who reported they were negative in the interview were likely to have been positive at the time of their last HIV test and should have received a positive test result. The most probable explanation for the discrepancy between their serostatus and self-report is that they intentionally gave false information about their HIV test result during the interview. Scenarios B and C are likely to be high estimates of exposure because testing programs in Malawi and Uganda have rapidly expanded in recent years; nonetheless, they are considered for the sake of generating a conservative (i.e., higher) estimate of the number of seroconversions. The findings of the simulation provide strong evidence of substantial deliberate underreporting of positive HIV status in both the 2010 MDHS and 2011 UAIS.[3]

Table 6 Results of a simulation to estimate the proportion of HIV-positives who reported they were negative who are likely to have seroconverted since their last HIV test, Malawi 2010 and Uganda 2011

	Malawi		Uganda	
	Number of serocon-versions	Percentage serocon-verting	Number of serocon-versions	Percentage serocon-verting
Women				
Scenario A	6	1.9	4.0	1.5
Scenario B	9	2.8	5.8	2.2
Scenario C	12	3.6	7.5	2.9
Total number of respondents		333		262
Men				
Scenario A	2	1.3	1.2	1.1
Scenario B	3	1.9	1.7	1.5
Scenario C	4	2.5	2.2	1.9
Total number of respondents		176		114

Note: Scenario A assumes that respondents who said they were tested for HIV at least two years before the survey were tested between 2 and 5 years before the survey; Scenario B assumes these respondents were tested between 2 and 10 years before the survey; Scenario C assumes these respondents were tested between 2 and 15 years before the survey.

To understand the potential impact of the misreporting of HIV status on estimates of service coverage, we incorporated the results of the simulation into the data on self-reported HIV-status among all HIV-positive respondents. Table 7 shows the results when Scenario B in the simulation is applied to the population of all respondents who tested positive for HIV in the two surveys. As shown above in Table 6, 3 percent of HIV-positive women in Malawi who reported they were negative are likely to have seroconverted since their last HIV test and to have accurately reported that the result to their last HIV test was negative. Three percent of the 40 percent of women who claimed to be HIV-negative amounts to a little over 1 percent of all HIV-positive women in the 2010 MDHS being likely to have seroconverted since their last HIV test and to have accurately reported that their last HIV test result was negative. Using

[3] Allowing an extra three months of exposure time for each respondent to take into account the window period for many HIV tests has no notable impact on the results. Further, since the incidence rate is likely higher for individuals in the group of respondents who tested positive than for the general population, another simulation was run applying an incidence rate of 2/100 person-years for both women and men to Scenario B. Even this much higher incidence rate resulted in only 5 percent of women and men in both countries being likely to have seroconverted since their last test.

these same calculations, the proportions of HIV-positive men in the 2010 MDHS and of HIV-positive women and men in the 2011 UAIS who are likely to have seroconverted since their last HIV test is less than 1 percent.

Table 7 Self-reported HIV status among women and men age 15-49 accounting for possible seroconversion, Malawi 2010 and Uganda 2011

	Malawi		**Uganda**	
Self-reported HIV status	Women	Men	Women	Men
Report positive	38.6	26.1	44.2	31.8
Negative misreport	**39.3**	**35.5**	**30.9**	**23.8**
Negative report - possible seroconversion	**1.1**	**0.7**	**0.7**	**0.4**
Never tested	17.3	35.7	18.6	39.7
Other	3.7	2.0	5.6	4.3
Total	100.0	100.0	100.0	100.0
Number	913	529	907	529

Note: "Other" includes those who had been tested for HIV but who said the result of their last HIV test was indeterminate, who refused to disclose their test result, who lacked privacy to report their test result, who said they never received their test result, who said they did not know their test result, and whose prior testing status was missing.

According to the findings presented in Table 7, seroconversion cannot account for the discordance between current HIV status and self-reported HIV status among those who have been tested and received their result. Even accounting for seroconversion, notable percentages of HIV-positive respondents in both surveys are likely to have known they were HIV-positive but intentionally misreported their HIV status as negative: over one-third of HIV-positive respondents in Malawi, and 31 percent of HIV-positive women and 24 percent of HIV-positive men in Uganda. In Malawi the percentage of HIV-positive respondents who are likely to have falsely reported their status as HIV-negative is higher than the percentage who truthfully reported their status as HIV-positive, for both women and men.

This misreporting of HIV status has implications for the measurement and interpretation of all indicators based on the self-reported status questions. Data from the 2010 MDHS show that 39 percent of HIV-positive women reported they were positive. However, applying the results of the simulation, the percentage of HIV-positive women who know they are HIV-positive could be as high as 78 percent. Likewise, this percentage could increase from 26 percent to 62 percent among men in Malawi, from 44 percent to 75 percent among women in Uganda, and from 32 percent to 56 percent among men in Uganda. Thus, it is clear that the questions on self-reported status in the two surveys provide substantial underestimates of the percentage of individuals with HIV who are aware of their status.[4]

[4] The group of people who are aware that they are HIV-positive but who did not accurately report their status may also include respondents who claim they have not been tested or did not receive the test results, who refuse to disclose status, and who report their test result as indeterminate. In Table 7, the latter three of these four groups are included in the "other" category and are extremely small.

5 Assessing the Validity of Coverage Indicators Derived from Data on Self-reported HIV Status

The purpose of this report is not only to assess the validity of self-reported HIV status but also to explore the implications of that validity for the quality of the estimates of coverage indicators based on self-reported HIV status. Thus, the next section of the report explores specific indicators of coverage of services for people living with HIV that can be measured in a population-based survey when the survey includes questions on self-reported HIV status. There is also an assessment the potential impact of self-reporting bias on the measurement and interpretation of these indicators.

5.1 ARV Coverage Indicators

At least three different ARV coverage indicators can be defined based on different denominators.

- The percentage of self-reported positive individuals using ARVs
- The percentage of HIV-positive individuals using ARVs
- The percentage of eligible HIV-positive individuals using ARVs

The first two indicators can be estimated using results from the individual interviews, but the third—which is the optimal indicator for assessing program performance—requires information on CD4 cell counts. All three of the indicators require valid information on HIV testing prior to the survey, the reported result of the last HIV test, and reported ARV use. There may be some additional validity issues with self-reported ARV use, depending on the degree of knowledge respondents have about ARVs. It is not possible to assess the quality of the data on ARV use without a biomarker, but we do not expect misreporting of ARV use to have as strong an effect on these indicators as the effect of misreporting of HIV status. The following discussion explores how data quality issues regarding self-reporting of HIV status affect the measurement of each of these indicators.

5.1.1 Percentage of Self-Reported HIV-Positive Individuals Taking ARVs

Table 8 ARV coverage among self-reported HIV-positive respondents, Malawi 2010 and Uganda 2011

	Malawi		Uganda	
ARV use	Women	Men	Women	Men
Yes, taking ARVs daily	62.2	58.0	47.0	43.0
Yes, taking medicine daily, not sure what kind	2.7	2.3	na	na
Don't know	na	na	0.4	0.0
No	33.9	39.4	52.6	57.0
Missing	1.3	0.3	0.0	0.0
Total	100.0	100.0	100.0	100.0
Number	370	145	419	190

Table 8 shows that, among women who tested positive for HIV and also reported that they were HIV-positive, 62 percent in Malawi and 47 percent in Uganda reported they were taking ARVs. Among self-reported HIV-positive men, the proportion reporting they were taking ARVs was slightly lower (58 percent in Malawi and 43 percent in Uganda) than for self-reported HIV-positive women. An additional 3 percent of women and 2 percent of men in Malawi said they were taking medicine daily but they did not know what kind. These individuals cannot be included in ARV coverage rates because of the possibility they may be taking cotrimoxazole (or some other medication or supplement) and not ARVs. To the extent that these individuals were taking ARVs but did not know it, the coverage rates would be slightly underestimated. At the same time, there could be some individuals taking other medications but who reported them as ARVs, which would result in an overestimate.

However, it is the denominator of this indicator—self-reported positives—that presents the greatest challenge for interpretation. The group, self-reported positives, is not a meaningful population for analysis unless it closely represents the population of individuals who know they are HIV-positive. As shown in section 4.2, the data from the 2010 MDHS and 2011 UAIS suggest that the self-reported positives include only about half of the women and less than half of the men in the Malawi survey and slightly more than half of the women and men in the Uganda survey who know they are HIV-positive. The population of those who know they have HIV but report they are HIV-negative is not likely to exhibit the same treatment-seeking behavior as the population of those who know they have HIV and report they are HIV-positive, so the use of ARVs in these two groups will differ. Thus, the percentage of self-reported positives who are taking ARVs cannot serve as a valid proxy for ARV coverage among all PLHIV who are aware of their status. If treatment levels are lower among the positives who report a negative status than among the self-reported positives—as is likely if given that the former group also conceals their HIV status in situations outside the survey—then ARV coverage among self-reported positives could considerably overestimate the coverage level among all those who know they are positive.

5.1.2 Percentage of HIV-Positive Individuals Using ARVs

This indicator uses as the denominator all individuals who participated in the HIV test in the survey and whose result was positive. The numerator includes only individuals who reported that they are HIV-positive during the interview and who said they "were taking ARVs daily." One advantage of this indicator is that it is comparable over time even as eligibility criteria for treatment change. As shown in Table 9, using this approach, ARV coverage among the group who tested positive is estimated at 24 percent of women and 16 percent of men in Malawi and 21 percent of women and 15 percent of men in Uganda. However, respondents who knew they were HIV-positive but reported they were negative were not asked if they were taking ARVs. Presumably, some of these respondents were taking ARVs, but for the purpose of determining ARV coverage, they were considered to be nonusers. Thus, false reporting of a negative HIV status could result in a large underestimate of this ARV coverage indicator.

Table 9 Percentage of all HIV-positive individuals who are taking ARVs, Malawi 2010 and Uganda 2011

Self-report of HIV status and ARV use	Malawi		Uganda	
	Women	Men	Women	Men
Self-reported positives	38.6	26.1	44.2	31.8
Yes, taking ARVs daily	**24.1**	**15.6**	**21.2**	**15.3**
Yes, taking medicine daily, not sure what kind	1.0	0.6	na	na
Don't know	na	na	0.2	0.0
No	13.1	9.8	22.8	16.5
Missing	0.4	0.1	0.0	0.0
Self-reported negatives/never tested[1]	61.4	73.9	55.8	68.2
Total	100.0	100.0	100.0	100.0
Number	913	529	907	529

[1] This category also includes those who had been tested for HIV but who said the result of their last HIV test was indeterminate, who refused to disclose their test result, who lacked privacy to report their test result, who said they never received their test result, who said they did not know their test result, and those whose prior testing status was missing.

5.1.3 Percentage of Those Eligible for ARVs Who are Using ARVs

From a program performance perspective, knowing the percentage of the HIV-positive population on ARVs is of limited use when many HIV-positive people are not eligible to receive the treatment. Eligibility for ARV treatment is generally defined by an individual's CD4 count in combination with various clinical criteria. The World Health Organization (WHO) currently recommends that individuals with a CD4 count of 500 cells/mm^3 or below should be considered eligible to begin treatment (WHO 2013); however, at the time the Malawi and Uganda surveys were conducted, the recommended cutoff for eligibility was 350 cells/mm^3 (WHO 2010). So, in order to define the eligible population, information on individuals' CD4 cell count is needed.

Even when a survey includes CD4 testing, there are still challenges to defining the population eligible to receive ARVs. An individual's current CD4 level alone is not sufficient to classify her/him as eligible to receive ARVs. A person who had a CD4 level below the cutoff in the past and who started taking ARVs could have a CD4 count above the cutoff at the time of the survey. This person should be considered eligible for treatment even though their current CD4 cell count would classify them as ineligible if they had not already initiated ARVs. Thus, valid data on current ARV use is needed for each HIV-positive respondent in order to correctly interpret her/his current CD4 level and eligibility for treatment. For example:

- If respondents know they are HIV-positive, declare negative status, have a *low* CD4 cell count, and are taking ARVs, they should be classified as eligible and using. However, they are counted as eligible but not using in this coverage indicator because they were not asked about ARV use. This type of error would bias the coverage estimate lower because all such individuals are included in the denominator of the coverage indicator, and none are included in the numerator.

- If respondents know they are HIV-positive, declare negative status, have a *high* CD4 cell count, and are taking ARVs, they should be classified as eligible and using. However, they are counted as not eligible and not using in this coverage indicator because once again they were not asked about ARV use. This type of error would also bias the coverage estimate lower, though to a lesser extent than the previous misclassification error. These individuals should be included in both the numerator and denominator of the coverage percentage, but they are excluded from both.

The 2011 UAIS included CD4 testing for respondents who tested positive for HIV. As shown in the last column of Table 10, among all respondents who had a positive result on the survey HIV test and a valid CD4 test, 23 percent were found to be using ARVs, 24 percent were found to be eligible but not using ARVs, and 54 percent were found to be ineligible.[5] Among those found to be eligible for treatment, about half were taking ARVs.

One-quarter of the respondents in Table 10 said they had been tested for HIV and that the test result was negative (292 of 1,144); it is assumed that none of these individuals is taking ARVs. However, the results of the simulation show that a large proportion of these respondents are likely to know that they are HIV-positive, and some of them may be taking ARVs. Such individuals would be misclassified in either the "eligible and not using" category or the "not eligible" category, depending on their CD4 cell count.

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[5] CD4 cell counts are available for only 1,144 of the 1,436 women and men found to be HIV-positive according to the laboratory blood test. Most of the shortfall consists of respondents who tested HIV-negative on the home-based rapid test and HIV-positive in the central laboratory, for whom samples were unavailable for CD4 testing. Other reasons for the missing results include samples reaching the central laboratory too late for CD4 testing and other logistical problems.

Table 10 Percent distribution of women and men age 15-49 who are HIV positive and had a CD4 test result by ARV use and eligibility, according to self-reported HIV status, Uganda 2011

ARV use and eligibility	Self-reported HIV status: Report HIV positive	Report HIV negative	Never tested/other[1]	Total
Using ARVs	48.4	0.0	0.0	22.5
Eligible and not using[2]	15.6	29.3	31.6	23.6
Not eligible	35.9	70.7	68.4	53.9
Total	100.0	100.0	100.0	100.0
Number	532	292	321	1,144

Notes: Eligibility for ARV therapy is defined as having a CD4 cell count of ≤ 350.
[1] "Other" includes those who had been tested for HIV but who said the result of their last HIV test was indeterminate, who refused to disclose their test result, who lacked privacy to report their test result, who said they never received their test result, who said they did not know their test result, and those whose prior testing status was missing.
[2] Not using includes those who responded that they did not know if they were taking ARVs, and those with missing responses on ARV use.

Misclassifications of ARV use and eligibility status in self-reported negatives could have a large impact on the overall survey estimate of percentage of eligible respondents using ARVs. To understand the potential magnitude of bias that could result from misreporting of HIV status, assume a simple scenario in which all of the self-reported negative respondents knew they were HIV-positive, and their ARV use and eligibility profile were the same as those who reported they were HIV-positive. The resulting proportion of eligible respondents using ARVs in the 2011 UAIS would rise from 49 percent to 63 percent.

5.2 Indicators of Coverage of PMTCT Services

Several indicators of coverage of services for prevention of mother-to-child transmission of HIV (PMTCT) have been proposed for measurement in population-based surveys. At the time the 2010 MDHS and 2011 UAIS were conducted, both countries were still using single-dose nevirapine (sdNVP) for the mother during labor and the newborn (if the mother was not eligible to take ARVs for her own health). Some of the proposed indicators are:

- Percentage of HIV-positive pregnant women who took ARVs during the pregnancy or sdNVP during labor for their most recent birth

- Percentage of children born to HIV-positive mothers who received postnatal NVP

- Percentage of children born to HIV-positive mothers who have been tested for HIV

- Percentage of HIV-positive children who are currently on ARVs

A major advantage that comes with using data from population-based surveys to measure these coverage indicators is the ability to capture the entire population at risk, not just those receiving antenatal or delivery care. However, indicators on coverage of PMTCT services suffer from all of the same sources of bias caused by underreporting knowledge of positive HIV status as do coverage indicators for ARV use. Measuring PMTCT indicators is complicated by two additional challenges. First, the woman's HIV status at the time of the birth of her child may differ from her current HIV status. Second, these indicators suffer from sample size limitations because PMTCT services are only relevant for the subsample of HIV-positive women who have had a recent birth.

5.2.1 Coverage of ARVs or Single-Dose Nevirapine among HIV-Positive Pregnant Women and Their Children and HIV Testing among Children Born to HIV-Positive Mothers

The target population for these four indicators is women who have had a recent birth and who knew they were HIV-positive at the time of the birth. This population will differ from the population of women who know they are *currently* HIV-positive. In addition, although an objective measure of a respondent's current HIV status can be obtained from the survey test result, the surveys can provide no objective measure of a respondent's HIV status at the time of her last birth. The respondent's report is the only information available on her knowledge of her HIV status at the time of the birth. The standard DHS/AIS questionnaires include questions about HIV testing during pregnancy for women who had a live birth in the two years preceding the survey.

The sample sizes for measuring the PMTCT indicators for the 2010 MDHS and the 2011 UAIS are shown in Figures 1a and 1b below. In the MDHS, 1,067 women (unweighted) reported they were HIV-positive, 296 of them had a birth in the two years preceding the survey, and 192 said they were HIV-positive before the last birth (Figure 1a). The total sample size for the MDHS was 23,020 women, HIV prevalence was 13 percent among women age 15-49, and the total fertility rate was 5.7 children per woman. Thus, even in a country with a relatively high HIV prevalence and high fertility, a very large sample size is needed to capture enough cases of HIV-positive mothers to show PMTCT service coverage indicators, even at the national level. With fewer than 200 cases, it is not possible to produce reliable estimates for urban and rural areas, geographic regions, or by other background characteristics. The UAIS (Figure 1b) has a smaller sample size than the MDHS and Uganda has a lower HIV prevalence than Malawi. Of the 418 women who reported they were HIV-positive at the time of the UAIS, only 89 had had a child in the two years preceding the survey. Sixty-nine of these said that they were tested during ANC and the test result was positive.

Figure 1a Sample size for PMTCT indicators in the 2010 Malawi DHS (unweighted)

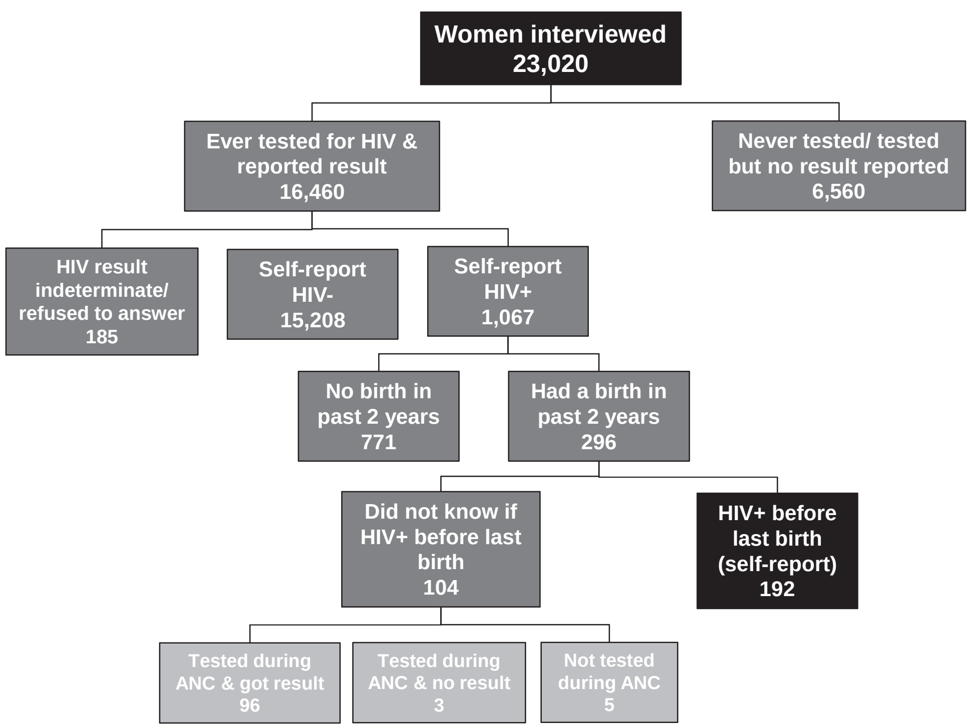
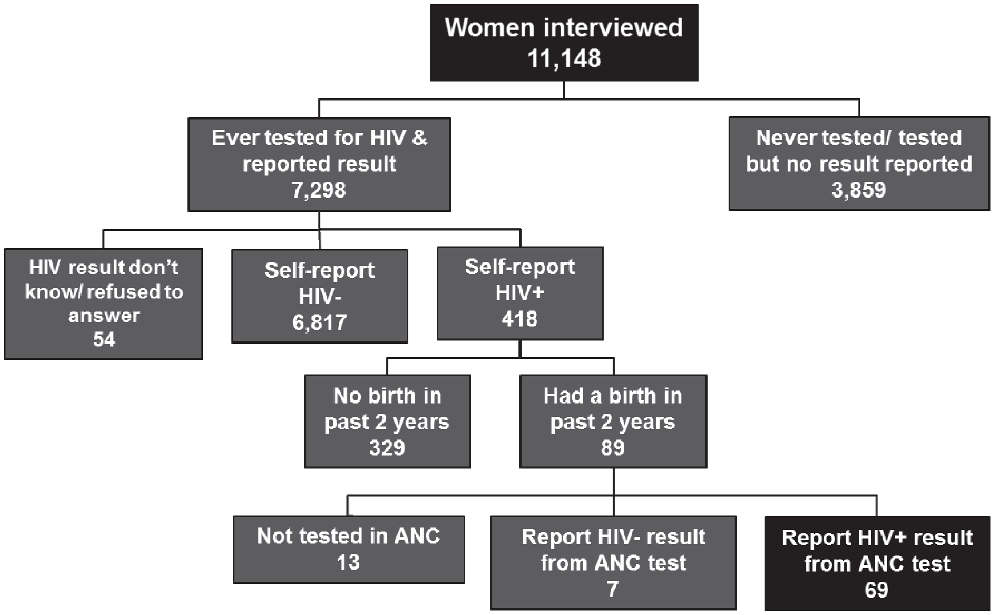


Figure 1b Sample size for PMTCT indicators in the 2011 Uganda AIS (unweighted)



The quality of data on self-reported HIV status affects these indicators as well as the indicators on ARV coverage. In Figures 1a and 1b, the 1,067 women in Malawi and 418 women in Uganda who reported they were HIV-positive may in fact underrepresent the total number of respondents who knew they were HIV-positive at the time of the survey. However, all subsequent PMTCT coverage indicators are based on this group of self-reported positives.

Finally, the data from the Malawi survey indicate there may be an additional source of reporting bias for PMTCT coverage indicators based on the self-reporting of HIV status at the time of the last birth. In the 2010 MDHS, women were not asked specifically for the result of their HIV test during ANC. Current HIV status was assessed by asking a question about the result of their most recent HIV test. Women who reported that the result of their most recent HIV test was positive and who had a child in the two years preceding the survey were asked "Did you know you were positive before you gave birth to (NAME)?" Among the 296 women who reported that they are currently HIV-positive and had a birth in the past two years, only 192 (65 percent) reported that they knew they were HIV-positive before the birth. Further investigation suggests that this figure may be too low. Of the 104 women who had a birth in the two years preceding the survey, reported that they were HIV-positive at the time of the survey, and said that they did not know they were HIV-positive before their last birth, 92 percent were tested for HIV during ANC and received the result. As indicated by the results of the simulation earlier in this report, only a few of these women are likely to have seroconverted in less than two years. Thus, although it is possible that some received an incorrect HIV test result during ANC, it is likely that the vast majority of these women received a positive HIV test result during ANC, and yet reported in the interview that they did not know they were HIV-positive before the child was born. Therefore, it appears that even among women who are willing to disclose that they are currently HIV-positive there may be additional underreporting of HIV-positive status at the time of their last birth. The effect of this underreporting is to compound the bias in the denominator for the population of women and children eligible to receive PMTCT services. The strategy used in the 2011 UAIS, to ask for the test result each time the questionnaire asks about an HIV test, appears to be a stronger approach for establishing HIV status during the most recent pregnancy.

Table 11 shows the data from the 2010 MDHS and 2011 UAIS for basic PMTCT coverage indicators for women and their last births. According to these results, the coverage appears to be quite high. However, for the reasons detailed above, the denominators for these PMTCT coverage indicators are not likely to be representative of all women and children at risk for mother-to-child transmission of HIV. As noted in the Data section (2.1 above), women in the 2010 MDHS were asked separate questions about being on ART during pregnancy and taking sdNVP during labor. In the 2011 UAIS, women were asked only one question about ARV use during pregnancy or labor. The response codes included an option to identify women who were already taking ART. However, some women who were taking ART could have simply answered "Yes" to this question, so Table 11 does not attempt to separate women in the 2011 UAIS as users of ART during pregnancy or sdNVP during labor.

Table 11 Coverage of PMTCT services

Among women who reported being HIV-positive and reported being HIV-positive before the birth of their last child in the past two years, percentage who reported receiving various PMTCT services for themselves and their babies, and the percentage of children ever tested for HIV, Malawi 2010 and Uganda 2011

PMTCT indictor	Percent	Number
Malawi		
ARV use by the mother		
Percentage who were offered nevirapine during pregnancy or labor and delivery[1]	50.3	198
Percentage who took nevirapine[1]	50.2	198
Percentage who were taking ARVs daily when they gave birth	43.5	198
Percentage who took nevirapine or were taking ARVs daily	93.7	198
Nevirapine use by the child		
Percentage who received nevirapine to give to their child	68.8	198
Percentage whose child took nevirapine during the first few days of life[1]	80.7	198
Percentage of children ever tested for HIV	55.6	198
Uganda		
ARV use by the mother		
Percentage who took nevirapine or were taking ARVs daily[1]	80.0	65
Nevirapine use by the child		
Percentage whose child took nevirapine during the first few days of life[1]	50.2	65
Percentage of children ever tested for HIV	46.7	58

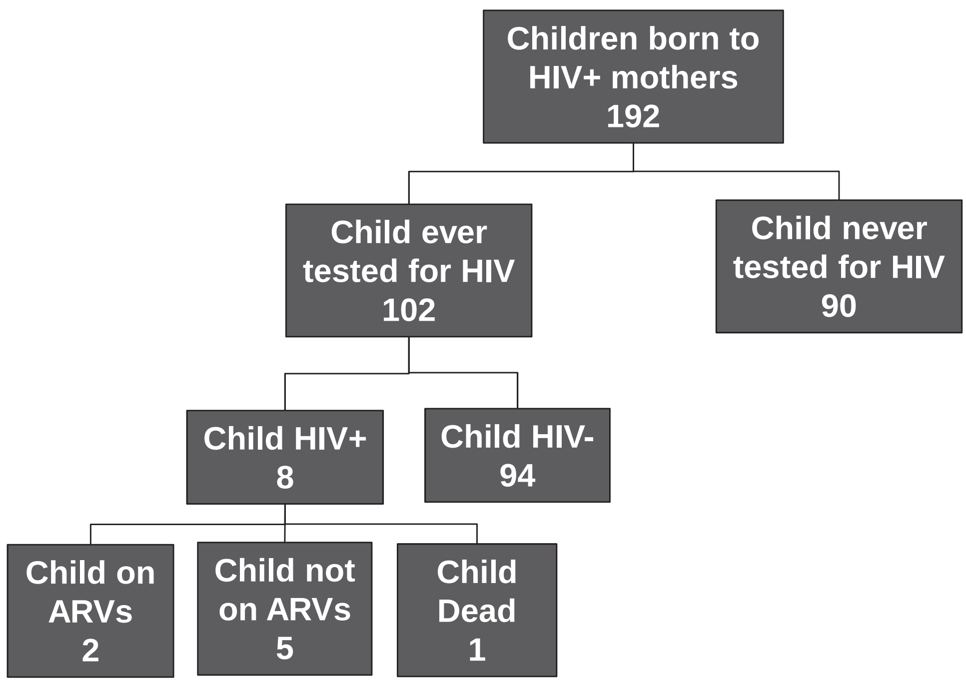
ARV = antiretroviral
[1] Women were not asked about nevirapine by name. They were asked whether they were given "medicine to reduce the risk of passing the AIDS virus to [their] baby."

5.2.2 *Percentage of HIV-Positive Children Who are Currently on ARVs*

This indicator focuses on an even smaller and more restricted denominator: HIV-positive children born to mothers who reported they were HIV-positive before the birth of the child. The denominator of HIV-positive children for this indicator is defined as those children reported by their mothers to be HIV-positive. Children were not tested in the 2010 MDHS. The 2011 UAIS did include HIV testing of children, but the ARV information is not recorded for all HIV-positive children, only the woman's youngest child. Further, information reported by the mother about her "youngest child" cannot be linked to the HIV status of a specific child from the survey blood test.[6]

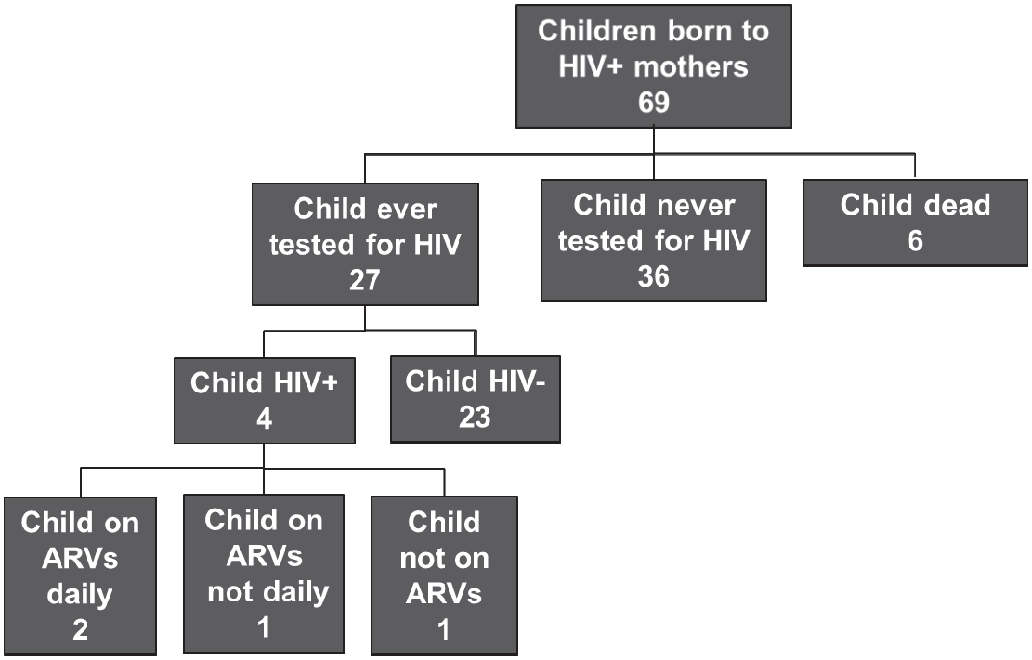
Figure 2a shows that for the 2010 MDHS, among the 192 last births (unweighted) in the two years preceding the survey to women who reported that they knew they were HIV-positive before their last birth, only 8 children were reported by their mothers to have ever been tested for HIV and to have received a positive result, 1 of whom died prior to the survey. In the 2011 UAIS, the numbers are even lower. Among children born in the two years preceding the survey to women who reported they were HIV-positive during the pregnancy, there were only 27 children tested for HIV, and only 4 HIV-positive children (Figure 2b). Single-digit numbers of cases are insufficient for estimating ARV coverage among HIV-positive children.

Figure 2a Number of children (unweighted) born to women who reported they were HIV-positive before their last birth in the 2010 Malawi DHS, by survival status of the child, current HIV status, and ARV use



[6] In the 2011 UAIS, it is possible to link the HIV status of a child who participated in the survey HIV test with the HIV status and interview information of his or her mother based on relationship information collected in the household questionnaire. However, when questions about the testing history, HIV status, and ARV use of the respondent's "youngest child" were asked in the woman's questionnaire, there was no unique identifier recorded for this child. From among the woman's sons and daughters with a result for the survey HIV test, it is difficult to determine which of them corresponds to the "youngest child" discussed in the questionnaire, if any. If the number of children tested in the survey is less than the number of surviving children reported by the woman, it is impossible to know whether the "youngest child" is even among those who participated in the survey HIV test.

Figure 2b Number of children (unweighted) born to women who reported they were HIV-positive before their last birth in the 2011 Uganda AIS, by survival status of the child, current HIV status, and ARV use



5.2.3 Other Indicators: Effectiveness of PMTCT Coverage

Relying on self-reported data on HIV status and PMTCT coverage to measure the effectiveness of PMTCT interventions in preventing mother-to-child transmission of HIV presents even more challenges. As Figures 3a and 3b show, the number of children born to HIV-positive mothers is not high, certainly not high enough to measure indicators for several subgroups. In addition, the numbers of HIV-positive mothers and their children reported as having no exposure to ARVs are extremely low, thereby preventing comparisons among the different exposure groups and the measurement of indicators such as infections averted.

Figure 3a Sample size for PMTCT effectiveness indicators from the 2010 Malawi DHS

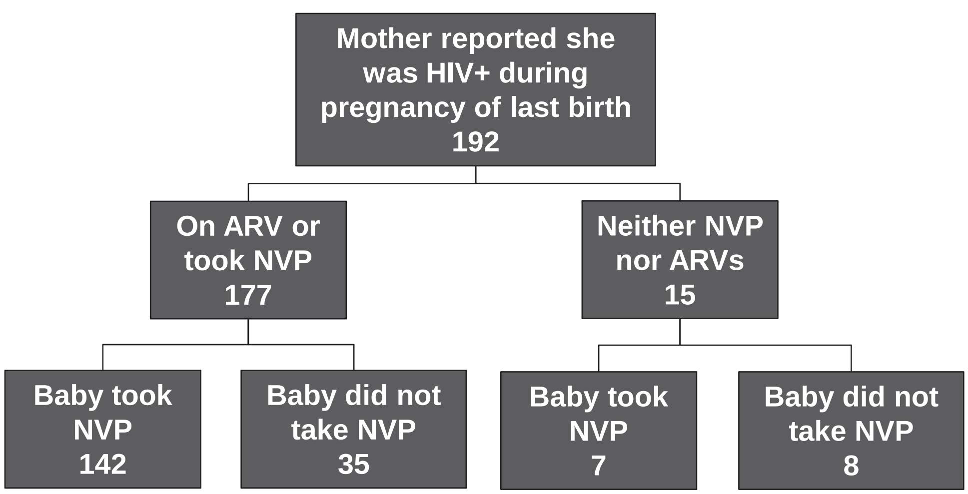
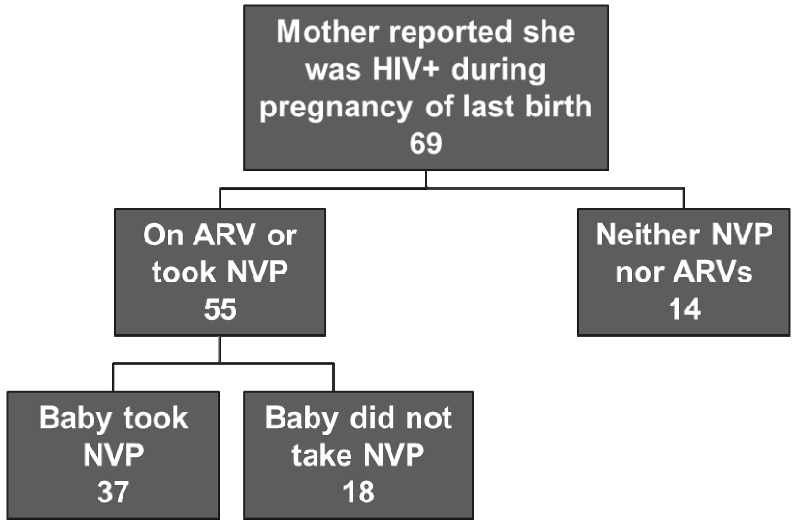


Figure 3b **Sample size for PMTCT effectiveness indicators from the 2011 Uganda AIS**



6 Conclusions and Recommendations

The results of this analysis indicate that there is likely to have been substantial underreporting of positive HIV status among respondents who were asked to self-report HIV status in the 2010 Malawi DHS and the 2011 Uganda AIS. Forty percent of HIV-positive women and 36 percent of HIV-positive men in the 2010 MDHS reported that they had been tested for HIV prior to the survey and their test result was negative, as did 32 percent of HIV-positive women and 24 percent of HIV-positive men in the 2011 UAIS. The results of a simulation to estimate the rate of seroconversion in this group indicate that only a small portion of these individuals is likely to have seroconverted between their most recent HIV test and the date of interview, with intentional misreporting of HIV status being the most likely explanation for the remaining discrepancy between self-reported HIV status and the results of the survey HIV test. Notably, a side analysis found no evidence in either the 2010 MDHS or the 2011 UAIS of differential participation in the survey HIV test by self-reported status that would bias the survey HIV prevalence estimate. Participation rates in the survey HIV test were similar for respondents who reported they were HIV positive, HIV negative, or did not know their HIV status.

We have focused on seroconversion and false reporting as the two major causes of differences between self-reported and observed HIV status; however, it is also possible that some percentage of the discordance is due to a combination of false negative results on the prior tests or false positive results on the survey blood test. Nonetheless, testing-quality issues are unlikely to explain the majority of the remaining difference between prevalence measured by the survey HIV test and by self-report. Further, social desirability may lead respondents to report they received an HIV test when they did not. If they reported that the result of the test they did not actually receive was negative, this would be another cause of underreporting of HIV infection among people who reported they knew their status.

The low validity of data on self-reported HIV status observed in the 2010 MDHS and 2011 USAIS, which is likely to occur in similar surveys, has implications for the measurement and interpretation of all indicators based on the self-reported status questions, including self-reported use of ARVs. In addition, problems measuring ARV use based on self-reported information present a serious challenge for interpreting CD4 data in population-based surveys, where collected. For indicators on coverage of PMTCT services, problems with self-reported HIV status are not the only challenge. Even in countries with relatively high HIV prevalence, very large sample sizes are required in order to produce enough cases to measure these indicators at the national level.

In conclusion, the evidence provided by these two population-based surveys in Malawi and Uganda raises serious concerns about the validity of self-reported HIV status. The low validity of these data implies that estimates of coverage of ARVs and other services for people living with HIV (PLHIV) based on these data are inaccurate and likely to be misleading. Hence, this research strongly suggests that including questions on self-reported status in population-based surveys—which is necessary in order to ask questions about use of HIV-related services—is not recommended. Measurement of ART coverage through a biomarker to test for metabolites of ARV medications among individuals found to be HIV-positive on the survey blood test should prove a more accurate method of estimating ART coverage, although this testing procedure is expensive and the capacity to conduct the testing in Africa is limited. If questions on self-reported HIV status and ARV use are included in population-based surveys, the quality of data must be carefully examined before the survey results on coverage of services for PLHIV can be considered valid.

Methodological Appendix

Tables A.1 and A.2 show the details for calculating the number of estimated seroconversions among female respondents in the 2010 Malawi DHS and the 2011 Uganda AIS, respectively, who tested HIV-positive in the survey HIV test but reported they were HIV-negative. Scenarios A, B, and C allow for different assumptions regarding the time since last test for the respondents who reported their most recent HIV test occurred more than 24 months prior to the survey, as explained in the Methods section.

Table A.1 Results of a simulation estimating the number of seroconversions between the interview date and the date of the last HIV test among women who tested HIV-positive in the 2010 MDHS HIV test but reported they had been tested prior to the survey and were HIV-negative at the time of the last test, Malawi 2010

Time since last HIV test	Number of respondents who tested positive but reported negative	HIV incidence (in per person-years)	Average exposure time per person (in years)	Number of women serocon-verting	Percentage of women serocon-verting
			Scenario A		
<12 months	124	0.0110	0.5	0.7	
12-23 months	56	0.0110	1.5	0.9	
3-20 months	22	0.0110	1.0	0.2	
24+ months (2-5 years)	102	0.0110	3.5	3.9	
15-32 months	28	0.0110	2.0	0.6	
Missing	1	0.0110	2.0	0.0	
Total	333			6.4	1.9
			Scenario B		
<12 months	124	0.0110	0.5	0.7	
12-23 months	56	0.0110	1.5	0.9	
3-20 months	22	0.0110	1.0	0.2	
24+ months (2-10 years)	102	0.0110	6.0	6.7	
15-32 months	28	0.0110	2.0	0.6	
Missing	1	0.0110	2.0	0.0	
Total	333			9.2	2.8
			Scenario C		
<12 months	124	0.0110	0.5	0.7	
12-23 months	56	0.0110	1.5	0.9	
3-20 months	22	0.0110	1.0	0.2	
24+ months (2-15 years)	102	0.0110	8.5	9.5	
15-32 months	28	0.0110	2.0	0.6	
Missing	1	0.0110	2.0	0.0	
Total	333			12.0	3.6

The direct question on time since last HIV test was not asked for women who had a birth in the two years (Malawi) or five years (Uganda) preceding the survey and whose last HIV test was during antenatal care (ANC). For these women, a range for the possible time of the last test was calculated based on the timing of the pregnancy relative to the interview date, and was then recoded as follows: Women whose entire nine-month pregnancy fell within one of the standard coding categories for time since last test (<12, 12-23 and 24+ months) were recoded into that category. This left two groups of women, those whose pregnancies straddled the point in time 12 months before the survey (i.e., pregnancies that ended at least 3 completed months preceding the survey and started less than 21 completed months preceding the survey), and those whose pregnancies straddled the point in time 24 months before the survey (i.e., pregnancies that ended at least 15 completed months preceding the survey and started less than 33 completed months preceding the survey). All women in each of the two new categories were assigned a length of exposure time equal to the number of months at the midpoint of the interval of the category, regardless of the exact timing of each birth. This resulted in an exposure time of 12 months for women in the 3-20 month category and 24 months for women in the 15-32 month category.

Table A.2 Results of a simulation estimating the number of seroconversions between the interview date and the date of the last HIV test among women who tested HIV-positive in the 2011 Uganda HIV test but reported they had been tested prior to the survey and were HIV-negative at the time of the last test, Uganda 2011

Time since last HIV test	Number of respondents who tested positive but reported negative	HIV incidence (in per person-years)	Average exposure time per person (in years)	Number of women serocon-verting	Percentage of women serocon-verting
Scenario A					
<12 months	90	0.0087	0.5	0.4	
12-23 months	41	0.0087	1.5	0.5	
3-20 months	28	0.0087	1.0	0.2	
24+ months (2-5 years)	81	0.0087	3.5	2.5	
15-32 months	22	0.0087	2.0	0.4	
Missing	0	0.0087	2.0	0.0	
Total	262			4.0	1.5
Scenario B					
<12 months	90	0.0087	0.5	0.39	
12-23 months	41	0.0087	1.5	0.54	
3-20 months	28	0.0087	1.0	0.24	
24+ months (2-10 years)	81	0.0087	6.0	4.23	
15-32 months	22	0.0087	2.0	0.38	
Missing	0	0.0087	2.0	0.00	
Total	262			5.78	2.2
Scenario C					
<12 months	90	0.0087	0.5	0.4	
12-23 months	41	0.0087	1.5	0.5	
3-20 months	28	0.0087	1.0	0.2	
24+ months (2-15 years)	81	0.0087	8.5	6.0	
15-32 months	22	0.0087	2.0	0.4	
Missing	0	0.0087	2.0	0.0	
Total	262			7.5	2.9

Table A.1 is interpreted as follows: as shown in the first column, there were 124 women who were last tested for HIV in the 0-12 months before the survey. To get the person-years of exposure, the number of women is multiplied by 6 months, i.e., the average number of months since the last test, for a total person-years of exposure of 62. Then the 62 person-years is multiplied by the incidence rate of 1.10/100 person-years to obtain the number of women expected to have seroconverted between their last HIV test and the interview, i.e., 0.7 women in the 0-12 months category. Through a similar process, 0.9, 0.2, and 0.6

seroconversions are estimated for the 12-23 month, 3-20 month, and 15-32 month categories, respectively. In Scenario A, an average exposure time of 3.5 years is assigned to the 102 women in the 24+ months category, yielding 357 person-years of exposure and 3.9 seroconversions, for a total of roughly 6 seroconversions across all five categories of time since last test. Six seroconversions divided by 333 (the total number of women who tested positive in the 2010 MDHS HIV test but reported they were HIV-negative during the interview) is 1.9 percent, as shown for Scenario A for women in Table A.1.

This analysis did not use a life-table approach to estimate seroconversion, in part because the number of seroconversions was so low that applying this more complex methodology would be unlikely to yield different results. In addition, the method applied here would produce a more conservative (i.e., higher) estimate of seroconversion relative to a life-table approach.

Tables A.3 and A.4 show the details for calculating the number of estimated seroconversions among male respondents in Malawi and Uganda, respectively, who tested HIV-positive in the survey HIV test but reported they were HIV negative.

Table A.3 Results of a simulation estimating the number of seroconversions among men who tested HIV-positive in the 2010 MDHS HIV test but reported they were HIV-negative, Malawi 2010

Time since last HIV test	Number of men who tested positive but reported negative	HIV incidence (in per person-year)	Average exposure time per person (in years)	Number of men seroconverting	Percentage of men seroconverting
Scenario A					
<12 months	88	0.0080	0.5	0.4	
12-23 months	35	0.0080	1.5	0.4	
24+ months (2-5 years)	53	0.0080	3.5	1.5	
Total	176			2.3	1.3
Scenario B					
<12 months	88	0.0080	0.5	0.4	
12-23 months	35	0.0080	1.5	0.4	
24+ months (2-10 years)	53	0.0080	6.0	2.5	
Total	176			3.3	1.9
Scenario C					
<12 months	88	0.0080	0.5	0.4	
12-23 months	35	0.0080	1.5	0.4	
24+ months (2-15 years)	53	0.0080	8.5	3.6	
Total	176			4.4	2.5

Table A.4 Results of a simulation estimating the number of seroconversions among men who tested HIV-positive in the 2011 UAIS HIV test but reported they were HIV-negative, Uganda 2011

Time since last HIV test	Number of men who tested positive but reported negative	HIV incidence (in per person-year)	Average exposure time per person (in years)	Number of men seroconverting	Percentage of men seroconverting
		Scenario A			
<12 months	44	0.0063	0.5	0.1	
12-23 months	38	0.0063	1.5	0.4	
24+ months (2-5 years)	32	0.0063	3.5	0.7	
Total	114			1.2	1.1
		Scenario B			
<12 months	44	0.0063	0.5	0.1	
12-23 months	38	0.0063	1.5	0.4	
24+ months (2-10 years)	32	0.0063	6.0	1.2	
Total	114			1.7	1.5
		Scenario C			
<12 months	44	0.0063	0.5	0.1	
12-23 months	38	0.0063	1.5	0.4	
24+ months (2-15 years)	32	0.0063	8.5	1.7	
Total	114			2.2	1.9

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