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

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1 INTRODUCTION

Programs that offer services to individuals living with HIV and AIDS are expanding. As a result, the demand for data to monitor these programs has increased, as has the interest in using population-based surveys to collect these data. Two key indicators for program monitoring are (1) use of antiretroviral (ARV) medications and (2) coverage of services for the prevention of mother-to-child transmission (PMTCT). Both of these indicators require identifying the population potentially “in need” of these services, that is, the population that is HIV positive. Using service statistics to measure these coverage indicators requires a separate data source to measure the population in need, which may bias coverage estimates when the two data sources are not comparable. By contrast, population-based surveys have the potential to provide answers to both of these questions because a survey can collect information from the same respondent on both HIV status and, if applicable, use of services.

Despite increased interest in using population-based surveys to measure coverage of HIV-related services, the validity of such estimates has not been examined. The need for such an examination arises because, before questions about use of ARVs or PMTCT services can be asked, respondents must disclose their HIV-status to the interviewer. Little is known about the willingness of respondents to speak candidly about their HIV-status in a face-to-face survey interview setting. If the information on self-reported status is inaccurate, because respondents either misreport or refuse to report their HIV status, then the resulting estimates of the coverage indicators will not be representative of those who are in need of the relevant service. Another challenge in using population-based surveys to measure the coverage of services needed by only a relatively small sub-group within the population—HIV-positive individuals in this case—is that the sample size required to obtain even rough estimates of the indicators of interest is very large and could cause surveys to become too expensive and unwieldy.

To investigate these issues, this report examines in detail data from the 2010 Malawi Demographic and Health Survey (MDHS), which collected information on self-reported HIV-status and use of HIV program services in the survey interviews. Also included in the survey was an HIV testing component. The objectives are two-fold: first to assess the validity of the data on self-reported HIV status, and second, to examine how data quality problems with self-reported HIV status could affect the accuracy of program coverage indicators measured by population-based surveys. The report first discusses the data collected on self-reported HIV status in the 2010 MDHS and then compares these data with the results from the MDHS HIV test. Next, the report assesses the accuracy of the self-reported HIV status information by presenting the results of a simulation, which calculates the likelihood that differences between self-reported HIV status and HIV status measured from the 2010 MDHS HIV test are due to seroconversion. The report then lists various indicators of service coverage and examines the potential bias that inaccurate self-reports of HIV status could have on the 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 HIV-positive individuals in population-based surveys.

2 DATA SOURCE

The 2010 MDHS sample was selected using a stratified, two-stage cluster design. In the first stage of sampling, 849 clusters were selected. After a listing of households was completed in all clusters, a representative sample of 27,345 households was selected. All women age 15-49 were eligible for interview in every sample household. Interviews with men age 15-54 and HIV testing of both men and women was conducted in a subsample consisting of one-third of sample households.

2.1 Measurement of Self-reported HIV Status and Use of Services

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, and if they answer yes, they are asked whether they have received the result of their last HIV test. Before they are asked if they have received the result of the HIV test, respondents are first informed that they will not be asked to report the test result. In contrast, the 2010 MDHS also asked respondents the standard set of questions about whether or not they had ever been tested for HIV; however, when asked about receiving the result of the HIV test, the part of the question stating they would not be asked to report the result was removed. Instead, respondents who answered that they had been tested for HIV and received the result of their last HIV test, were asked what the result of their most recent HIV test was. Then, women and men who reported that the result of their last HIV test was positive were asked questions about ARV use. Further, women who reported that the result of their last HIV test was positive and who had a birth in the two years preceding the survey were also asked if they knew they were HIV-positive before their most recent birth. Women who said "yes" were asked a series of questions about their use of PMTCT services and about HIV testing, HIV status, and ARV use of their last-born child.

2.2 HIV Testing

In households in the subsample selected for HIV testing, consent to participate in an HIV test was requested of women age 15-49 and men age 15-54. Respondents were informed that the testing would be anonymous and that they would not receive the result of the laboratory test. They were provided information on nearby facilities where they could later obtain free HIV testing and counseling services, if desired. 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. The protocol for the blood sample collection and testing for HIV was reviewed and approved by the Malawi Health Sciences Research Committee, the Institutional Review Board of ICF Macro, and the Centers for Disease Control and Prevention (CDC) in Atlanta. For further information, see NSO and ICF Macro, 2011.

In the subsample in which HIV testing was carried out, 8,174 women age 15-49 and 7,783 men age 15-54 (7,391 men age 15-49) were identified as eligible for interview and testing. Interviews were completed with 7,911 women age 15-49 and 7,175 men age 15-54 (6,818 men age 15-49). The response rate for HIV testing was 91 percent among eligible women age 15-49 and 84 percent among eligible men age 15-54. Overall, a total of 7,398 women age 15-49 and 6,512 men age 15-54 (6,179 men age 15-49) were interviewed and participated in the HIV testing. A total of 890 women and 530 men age 15-54 (492 men age 15-49) were HIV-positive in this group. (All numbers are unweighted.)

3 RESULTS ON SELF-REPORTED HIV STATUS

Table 1 presents the data on self-reported HIV status collected in the 2010 MDHS for all MDHS respondents included in the HIV testing component of the survey. A total of 72 percent of women and 52 percent of men reported that they had been tested for HIV prior to the survey and had received the test result.[1] This is the population for which self-reported HIV status is available. Five percent of women and 2 percent of men reported that they were HIV-positive during the interview.

Table 1 Self-reported HIV status among women and men age 15-49, Malawi 2010

	Women	Men
Previously tested and received HIV result:	**71.9**	**51.5**
Self-reported HIV-positive	5.2	2.2
Self-reported HIV-negative	64.4	49.1
Reported HIV result was indeterminate	0.5	0.2
Refused to disclose result	0.4	<0.1
No privacy during interview to disclose result/missing	1.4	0.3
Previously tested and did not receive result	**1.5**	**1.4**
Not previously tested	**26.1**	**46.8**
Prior test history missing	**0.5**	**0.0**
Total	100.0	100.0
Number	7,091	6,497

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

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 a brief analysis of whether participation in the HIV testing in the MDHS varied by knowledge of and self-reported HIV status.

[1] Results on history of HIV testing and self-reported HIV status are similar in the subsample of those with a valid HIV test in the 2010 MDHS (shown in Table 1) and in the full interviewed sample for the 2010 MDHS. In the full sample, 71 percent of women and 51 percent of men had been tested for HIV prior to the survey and had received the test result.

Box 1

Did introducing a question on self-reported status affect participation in the 2010 MDHS 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 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 the 2010 MDHS suggest that asking respondents to disclose the result of their last HIV test does not affect participation in the survey HIV testing. More research is needed before we can determine whether this finding for Malawi can be generalized to other settings.

Table 2. Response rates to the HIV test in the 2010 MDHS according to prior testing history and self-reported HIV status (unweighted), Malawi 2010

Prior HIV testing history and self-reported HIV status	Women 15-49		Men 15-54	
	Percentage tested for HIV	Number eligible for HIV test	Percentage tested for HIV	Number eligible for HIV test
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

[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, 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 that they are HIV-positive. As a practical matter, it does not make sense to ask respondents whether or not 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, 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. In addition, this information enables a 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.

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. Thus, the population of self-reported positives may differ from the population that actually knows they are HIV-positive. It is important that the data on self-reported status be as accurate as possible, as misreporting could result in biased measurement of coverage indicators. If respondents who know that 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 time and may have had time to come to terms with their status. 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 an interviewer as well. For these reasons, estimates of coverage of services measured among self-reported positives may not be valid for the whole population of those who know they have HIV. Accordingly, this section of the report considers several measures of the quality of the self-reported HIV status information from the 2010 MDHS.

4.1 How Does Self-reported HIV Status Compare with HIV-positive Status Determined by the 2010 MDHS HIV Test?

The MDHS results allow one to investigate how the results of the HIV test conducted in the survey compare with respondents' self-reported HIV status. The top panel in Table 2 shows the HIV prevalence as measured by the 2010 MDHS HIV test and the HIV prevalence as measured by self-reports for all respondents age 15-49 who participated in the HIV testing and had a valid result. The overall HIV prevalence as measured by the 2010 MDHS HIV test is 13 percent among women and 8 percent among men. The self-reported HIV prevalence is much lower, only 5 percent among women and 2 percent among men.[2]

However, many women and men do not know their HIV status, mainly because they have never been tested. Thus it is more valid to compare the prevalence estimates from the two sources (self-reports and the 2010 MDHS HIV test) based only on the sample of those who had been tested for HIV prior to the survey and received the result, as shown in the lower panel of Table 3. Even when the sample is restricted in this way, there is a large difference between HIV prevalence as measured by the 2010 MDHS HIV test and HIV prevalence as measured by self-report. Among women and men who had been tested for HIV prior to the

[2] Although, as shown in Table 3, many respondents who tested positive for HIV in the 2010 MDHS HIV test reported they were negative, there were very few cases of respondents who tested negative but reported they were HIV-positive (23 women and 10 men, unweighted).

survey and received the test result, HIV prevalence measured by the 2010 MDHS HIV test is 15 percent for women and 10 percent for men. By contrast, the self-reported HIV prevalence in this population is 7 percent for women and 4 percent for men.

Table 3 HIV prevalence as measured by the blood sample taken in the 2010 MDHS and self-report, among women and men age 15-49, Malawi 2010

	Women		Men	
	Percent	Number	Percent	Number
Among all respondents				
Percentage HIV-positive according to:				
2010 MDHS HIV test	12.9	7,091	8.1	6,497
Self-report	5.2	7,091	2.2	6,497
Among respondents who had ever been tested for HIV prior to the survey and received the result				
Percentage HIV-positive according to:				
2010 MDHS HIV test	14.5	5,099	9.9	3,368
Self-report	7.3	5,099	4.3	3,368

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

4.2 What are the Possible Reasons for the Difference between Self-reported HIV Status and HIV Status from the 2010 MDHS HIV Test?

To identify the reasons for the discrepancy between the two measures of HIV status, it helps to examine participation in HIV testing prior to the survey and self-reported HIV status among respondents who tested HIV-positive in the 2010 MDHS HIV test. Figures 1a and 1b provide further detail on the testing history and self-reported status of HIV-positive individuals in the 2010 MDHS. As shown in the figures, only 39 percent of women and 26 percent of men who tested positive in the 2010 MDHS HIV test reported that they were positive during the interview.

Figure 1a **Self-reported HIV status among HIV-positive women age 15-49**

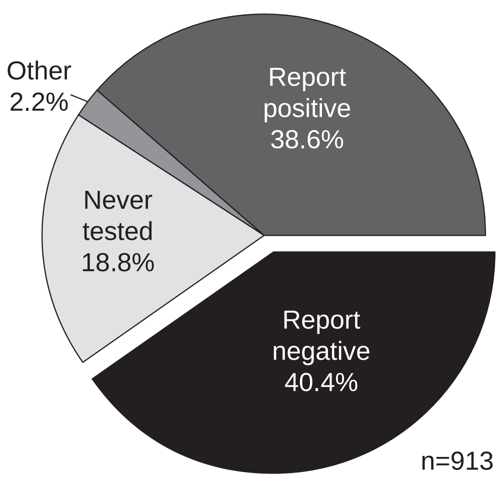
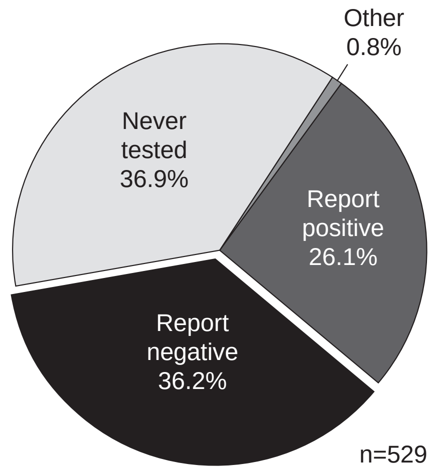


Figure 1b **Self-reported HIV status among HIV-positive men age 15-49**



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, and whose prior testing status was missing.

Substantial proportions of the respondents who were HIV-positive in the 2010 MDHS—19 percent of women and 37 percent of men—did not report their HIV status because they said they had never been tested, or had been tested but said they did not receive the result of their last test. It is possible that some of these respondents had been tested and knew their status but chose to conceal that information. Accepting the responses at face value, however, it is clear that a sizeable proportion of respondents could not report their HIV status because they had not been tested. It should be noted that coverage of HIV testing in Malawi is relatively high. In countries with lower coverage of HIV counseling and testing, this problem is expected to be even greater.

Figures 1a and 1b also show that many HIV-positive respondents who had been tested prior to the survey reported that the result of their last HIV test was negative. Among HIV-positive women, 40 percent reported that they were HIV-negative. Among HIV-positive men, the percentage who claimed to be HIV-negative is 36 percent. There are three possible explanations for why such large proportions of respondents who tested positive on the MDHS HIV test self-report as negative:

a) The respondent received a false negative result at their last HIV test.

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

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

The percentage of people given a false HIV test result depends on the quality of counseling and testing services in the country, but it is likely to be small[3] and unlikely to explain the large difference between HIV status according to the 2010 MDHS HIV test and status by self-report. Therefore, the next section focuses on understanding the relative contribution of the other two potential reasons for the difference: seroconversion and misreporting.

If almost all of the difference between positive HIV status, as measured by the 2010 MDHS 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, if the proportion of these respondents who are likely to have seroconverted since their last HIV test is below the vast majority, then the population of self-reported positives is not representative of those who know they are HIV-positive. The higher the level of misreporting, the stronger the bias in coverage indicators will be.

4.3 Is Self-reported Status a Good Measure of What HIV-positive Respondents Know Their Status to Be?

In a population-based survey, it is impossible to determine exactly what proportion of respondents have given false information when asked about the result of their last HIV test. It is possible, however, to get a reasonable estimate 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 2010 MDHS data. An overview of the methods and results are presented below, and a more detailed presentation of the calculations is included in the Methodological Appendix.

[3] 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; and 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).

This section describes how the simulation parameters of HIV incidence and time since the last test were defined, and how the number of estimated seroconversions was calculated. The HIV incidence rates used for the simulation were taken from Spectrum version 5.51 for Malawi for the year 2010, disaggregated by sex. The incidence rate for women is 1.10/100 person-years and for men is 0.80/100 person-years. It should be noted that these general population incidence rates may underestimate the incidence for this group of HIV-positive respondents, who may have a higher-risk profile than the general population. Nonetheless, the general incidence rate is applied here because (1) the risk profile of the group is difficult to measure in a survey because many stigmatized behaviors are under-reported and (2) little data are available on incidence rates among high risk groups in Malawi. 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).

For most female respondents and all male respondents, information on time since last test is available from a direct question. Responses were recorded categorically with codes corresponding to less than 12 months ago, 12-23 months ago, and 24 or more months ago. For women who had a birth in the two years preceding the survey and whose last HIV test was during ANC, the question on time since last HIV test was not asked. However, a range for the possible time of their last test can be established using the date of their last birth. The unweighted distribution for time since last test for women and men is shown in Table 3. In the 2010 MDHS, there were 333 women and 176 men (unweighted) who tested positive in the survey HIV test but who reported they were HIV-negative during the interview. Most respondents in this group were tested for HIV recently, with at least 60 percent of women and 70 percent of men receiving their last HIV test within the two years preceding the survey.

Table 4 Distribution of women and men age 15-49 who tested positive in the 2010 MDHS HIV test but reported they were HIV-negative by time since last HIV test, Malawi 2010 (unweighted)

	Women		Men	
Time since last HIV test[1]	Percent	Number	Percent	Number
<12 months	37.2	124	50.0	88
12-23 months	16.8	56	19.9	35
3-20 months[2]	6.6	22	na	na
24+ months	30.6	102	30.1	53
15-32 months[2]	8.4	28	na	na
Missing	0.3	1	0.0	0
Total	100.0	333	100.0	176

[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 years preceding the survey. The possible range for the date of the last HIV test was estimated from the date of their last birth.
na = not applicable

All respondents in each category of time since last test were assigned an 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 the women and men who tested positive in the 2010 MDHS 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 in order to generate the percentage of respondents likely to have seroconverted. The calculations are conducted separately for women and men to apply the different incidence rates estimated for the two sexes.

However, for respondents who were last tested more than 24 months ago, it is not possible to calculate an average time since last test. Instead an assumption must be 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. Scenario B and C are high estimates of exposure since testing programs in Malawi 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. Across the three scenarios, the only group for which average time since last test differs is the 24+ month group. For the other testing categories, the exposure time is set to the midpoint of the stated time since last test, as explained earlier.

A summary of the results of the simulation is presented in Table 5. The percentage of respondents in the group who tested positive in the 2010 MDHS HIV test, but who reported that they were HIV-negative, and who are likely to have seroconverted since their last HIV test, is extremely low in all three of the scenarios. According to the middle estimate, only 3 percent of women and 2 percent of men are likely to have seroconverted since their last HIV test. This means that the rest of the respondents who tested positive in the 2010 MDHS HIV test but who reported they were negative in the interview were positive at the time of their last HIV test and should have received a positive test result; they most likely inaccurately reported their test result during the interview. The findings of the simulation provide strong evidence of substantial underreporting of positive HIV status in the 2010 MDHS.[4]

Table 5 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

	Women		Men	
	Number of seroconversions	Percentage seroconverting	Number of seroconversions	Percentage seroconverting
Scenario A	6	1.9%	2	1.3%
Scenario B	9	2.8%	3	1.9%
Scenario C	12	3.6%	4	2.5%
Total number of respondents		333		176

Note: Estimates for incidence taken from Spectrum for the year 2010. The incidence rate for women is 1.10/100 person-years and for men is 0.80/100 person-years.

[4] 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. The number of seroconversions for Scenario B increases to 10 women and 4 men, and the percentage of respondents likely to have seroconverted is still 3 percent for women and 2 percent for men. Further, since that 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 being likely to have seroconverted since their last test.

Figures 2a and 2b show results when Scenario B in the simulation is applied to the population of respondents who tested positive for HIV in the 2010 MDHS. As shown in Table 5, 3 percent of HIV-positive women 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 translates to a little more than 1 percent of all HIV-positive women being likely to have seroconverted since their last HIV test and to have accurately reported that their last HIV test result was negative. Similarly, 2 percent of the 36 percent of the HIV-positive men who reported they were negative equals a little less than 1 percent of all HIV-positive men.

Figure 2a **Self-reported HIV status accounting for HIV seroconversion, women age 15-49**

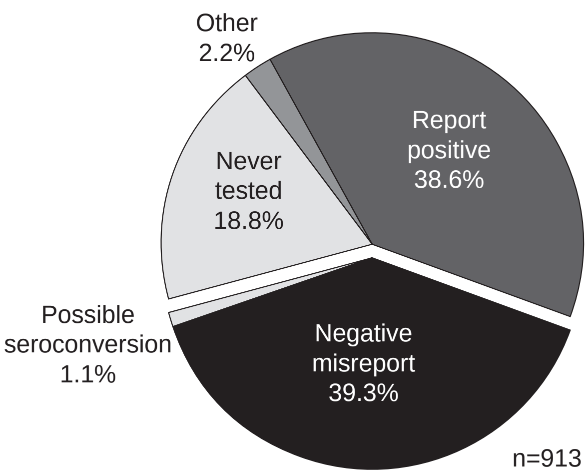
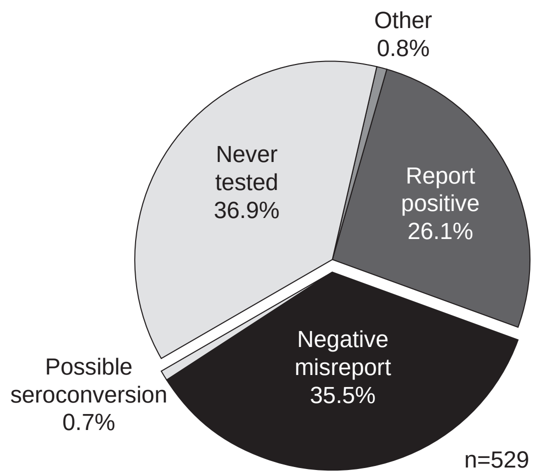


Figure 2b **Self-reported HIV status accounting for HIV seroconversion, men age 15-49**



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, and whose prior testing status was missing.

In summary, we conclude that more than one-third of HIV-positive women and men in the 2010 MDHS are likely to have knowingly misreported their HIV status. It is possible that some percentage of the respondents who were HIV-positive at the time of their last HIV test received a false negative result at that time (either due to testing error or being too recently infected to be detected by the test), and honestly reported in the survey that they believe they are negative. The size of this group is expected to be small and is unlikely to explain much of the remaining difference between prevalence measured by the 2010 MDHS HIV test and by self-report.

This misreporting of HIV status has implications for the measurement and interpretation of all indicators based on the self-reported status questions. The data from the 2010 MDHS show that 39 percent of HIV-positive women report they are positive. However, applying the results of the simulation, we conclude that the percentage of HIV-positive women who know they are HIV-positive may be as high as 78 percent. For men, the percentage of positives that are aware of their status was reported as 26 percent in the 2010 MDHS, but may be as high as 62 percent. Thus it is clear that the questions on self-reported status provide a substantial underestimate of the percentage of individuals with HIV who are aware of their status.[5]

[5] 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 Figures 2a and 2b, 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 this report explores specific indicators of coverage of services for people living with HIV and AIDS that can be measured in a population-based survey when the survey includes questions on self-reported status. The impact that self-reporting bias on these questions may have on the measurement and interpretation of these indicators is assessed.

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 population surveys, but the third—which is the optimal indicator for assessing program performance—requires information on CD4 counts, which generally is not collected in population surveys.

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. The indicators also depend on the effective measurement of ARV use from a survey, which additionally requires respondents to have knowledge of ARVs.

The following discussion explores how data quality issues regarding self-reporting of HIV status affect the measurement of each of these indicators. It is not possible to assess the quality of the data on ARV use (i.e., the numerator), but we do not expect misreporting of ARV use to be great enough to have as strong an effect on the indicators as the effect of misreporting of HIV status.

5.1.1 Percentage of self-reported HIV-positive individuals taking ARVs

Table 5 shows, among the women in the Malawi 2010 survey who tested positive for HIV and also reported that they were HIV-positive, 62 percent reported they were "taking ARVs, that is, antiretroviral medicines, daily." Among self-reported HIV positive men, the proportion reporting that they were taking ARVs was slightly lower (58 percent). An additional 3 percent of women and 2 percent of men said they were taking medicine daily, but they did not know what kind. These individuals cannot be included in ARV coverage rates due to the possibility that they could 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.

Table 6 ARV coverage among self-reported HIV-positive respondents, Malawi 2010

ARV use	Women	Men
Yes, taking ARVs daily	62.2	58.0
Yes, taking medicine daily, not sure what kind	2.7	2.3
No	33.9	39.4
Missing	1.3	0.3
Total	100.0	100.0
Number	370	145

Note: This table is based on women and men who reported they were HIV-positive and who also participated in the HIV test in the 2010 MDHS. Results, including respondents not in the subsample of the survey selected for HIV testing, are very similar. See National Statistical Office (NSO) and ICF Macro, 2011.

However, it is the denominator of this indicator, which consists of self-reported positives, that presents the greatest challenge for interpretation. The group of self-reported positives is not a meaningful population for analysis unless it very closely represents the population of individuals who know they are HIV-positive. As shown in section 4.2, the data from the 2010 MDHS suggest that the self-reported positives may include only about one-half of women and less than one-half of men in the survey who know they are HIV-positive. The population of those who know they have HIV but claim to be 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 also differ. Thus, the percentage of self-reported positives who are taking ARVs cannot serve as a valid proxy for ARV coverage among all known positives. If treatment levels are lower among the positives who report a negative status than among the self-reported positives (as is likely given that the former group may be concealing their status in situations beyond the survey), then ARV coverage among self-reported positives potentially represents a considerable overestimate of the coverage level among all 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." As shown in Table 6, using this approach, ARV coverage among the group who tested positive is estimated at 24 percent of women and 16 percent of men. However, the numerator clearly poses a problem in accurately estimating this indicator. Any 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 also taking ARVs, but for the purpose of determining ARV coverage, they are all nonusers. Based on the results of the simulation in section 4.2, more than one-third of all HIV-positive respondents could have reported they were HIV-negative but likely knew they were positive. These respondents should have been asked the question on ARV use but were not. This is equivalent to having missing information for over one-third of the population of interest. Thus, false reporting of a negative HIV status could result in a large underestimate of this ARV coverage indicator.

Table 7 Percentage of all HIV-positive individuals who are taking ARVs

Self-report of HIV status and ARV use	Women	Men
Self-reported positives	38.6	26.1
Yes, taking ARVs daily	**24.1**	**15.6**
Yes, taking medicine daily, not sure what kind	1.0	0.6
No	13.1	9.8
Missing	0.4	0.1
Self-reported negatives/never tested[1]	61.4	73.9
Total	100.0	100.0
Number	913	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, 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, it is not very useful to know the percentage of the HIV-positive population on ARVs 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. WHO currently recommends that individuals with a CD4 count of 350 cells/mm^3 or below should be considered eligible to begin treatment (WHO, 2010). So, in order to define the eligible population, information on individuals' CD4 count is needed, which is usually not available in population-based surveys.

Even if 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 them as eligible to receive ARVs or not. 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 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 his or her current CD4 level and eligibility for treatment. For example:

- If respondents know they are HIV-positive, declare negative status, have a *low* CD4 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 percentage, and none are included in the numerator.

- If respondents know they are HIV-positive, declare negative status, have a *high* CD4 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.

5.2 Indicators of Coverage of PMTCT Services

Several indicators of coverage of PMTCT services have been proposed for measurement in population-based surveys.

- Percentage of HIV-positive pregnant women who took ARVs during the pregnancy or a single dose of nevirapine during labor for their most recent birth
- Percentage of children born to HIV-positive mothers who received postnatal nevirapine
- Percentage of children born to HIV-positive mothers who have been tested for HIV
- Percentage of HIV-positive children born to HIV-positive mothers who are currently on ARVs

The major advantage in using population-based surveys to measure these indicators is 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 of current HIV-positive status as do coverage indicators for ARV use. In addition, these indicators also suffer sample size limitations because PMTCT services are only relevant for the subsample of HIV-positive women who have had a recent birth.

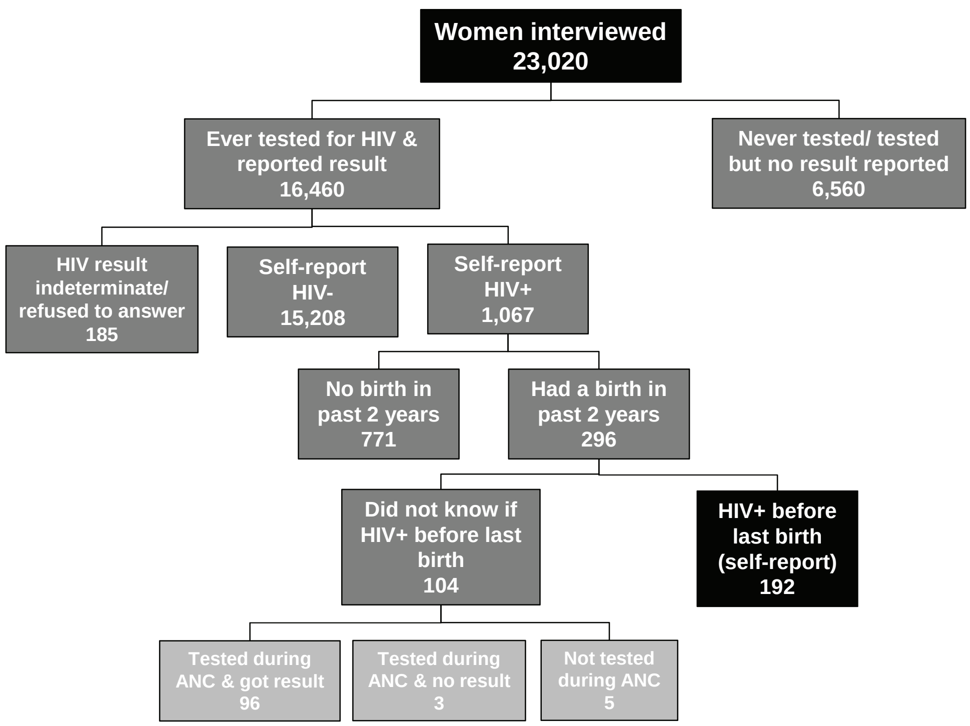
5.2.1 Coverage of ARVs or single-dose nevirapine among HIV-positive pregnant women and their children and HIV testing among children born to HIV-positive mothers

The target population for these three 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 those who know that they are currently HIV-positive. In addition, although a respondent's current HIV status is known from her survey test result, there is no way of knowing which respondents were HIV-positive at the time of their last birth. We must rely only on their reported information. 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. In the 2010 MDHS, the questions on ARVs during pregnancy, single-dose nevirapine during labor, and postnatal administration of nevirapine 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.

Sample size is also an issue for these indicators. In the 2010 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 that they were HIV-positive before the last birth (Figure 3). The total sample size for the MDHS was 23,020 women, HIV prevalence was measured at 13.3 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 relatively 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 will usually be impossible to produce reliable estimates for urban and rural areas, geographic regions, or other background characteristics.

Figure 3 **Sample size (unweighted) for PMTCT indicators in the 2010 Malawi DHS**



In addition, the indicators are affected by the problem with the quality of data on self-reported HIV status mentioned earlier. In Figure 3, this indicates that the 1,067 women who reported that they were HIV-positive may in fact underrepresent all respondents who knew they were HIV-positive at the time of the survey, introducing a bias into the estimates for the indicators on coverage of PMTCT services.

Finally, as Figure 3 indicates 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 Malawi DHS, women were not asked specifically for the result of their HIV test during ANC. Rather, women who reported that they are currently HIV-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 also had received a positive HIV test result during ANC, and yet they reported that they did not know they were HIV-positive at that time. 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.

Table 8 shows the data from the 2010 MDHS 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 denominator for these PMTCT coverage indicators is highly unlikely to be representative of all women/babies who were at risk for mother-to-child transmission of HIV.

Table 8 Coverage of PMTCT services

Among women who reported that they are HIV-positive and who said they knew they were 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, by residence and region, Malawi 2010

ARV or single-dose nevirapine use by the mother	
Percentage who were given nevirapine during pregnancy or labour[1]	50.3
Percentage who took nevirapine[1]	50.2
Percentage who were taking ARVs daily when they gave birth	43.5
Percentage who took nevirapine or were taking ARVs daily	93.7
Nevirapine use by the baby	
Percentage who received nevirapine to give to their baby[1]	68.8
Percentage whose baby took nevirapine during the first few days of life[1]	80.7
Percentage of children ever tested for HIV	55.6
Number of women who reported that they were HIV-positive before their last birth	198

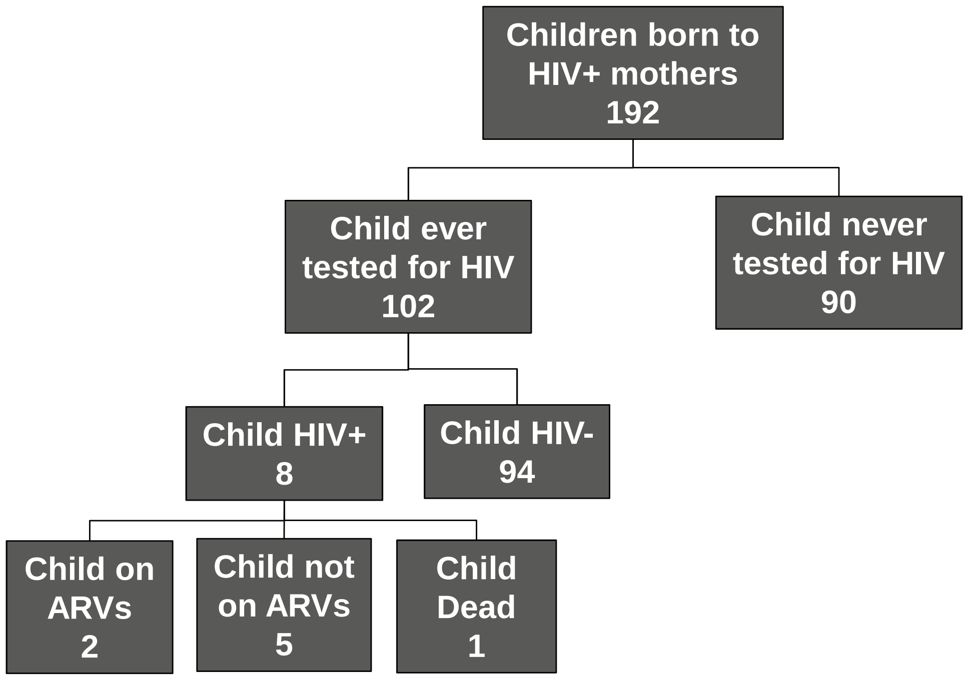
ARV = antiretroviral
[1] Women were not asked about nevirapine by name. They were asked whether they were given 'medicine to reduce the risk of passing the AIDS virus to [their] baby.'

5.2.2 Percentage of HIV-positive children born to HIV-positive mothers who are currently on ARVs

This indicator focuses on an even smaller and more restricted denominator: HIV-positive children born to mothers who reported themselves to be HIV-positive. Children were not tested in the 2010 MDHS. Therefore, the denominator of HIV-positive children for this indicator is defined as those children reported by their mothers to be HIV-positive.

Figure 4 below shows that 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 eight 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. Seven unweighted cases are insufficient for estimating ARV coverage among HIV-positive children. Although the number of HIV-positive children is likely to be grossly underreported, with accurate reporting the number of cases would still be insufficient to analyze. To obtain enough cases of HIV-positive children, all else being the same, the sample size of the survey would need to be much larger than even the 23,020 included in the 2010 MDHS.

Figure 4 **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, current HIV status, and ARV use**

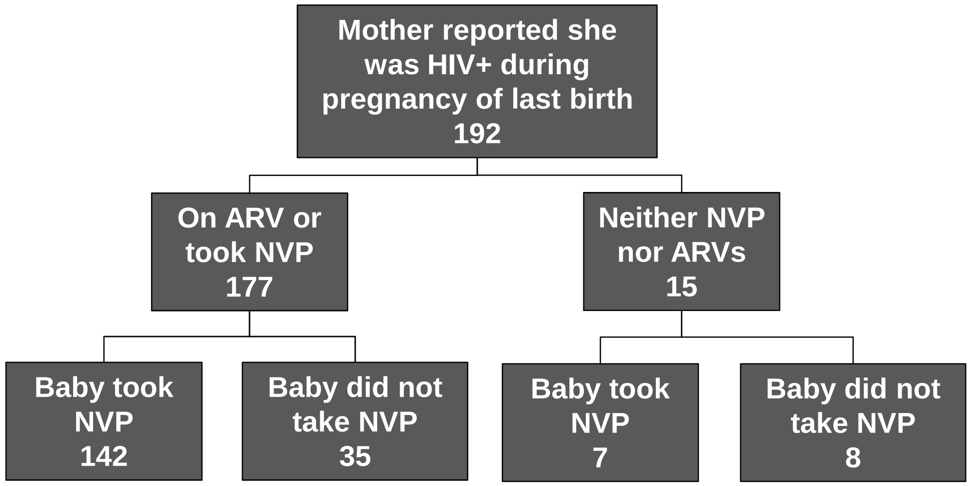


5.2.3 Other indicators: effectiveness of PMTCT coverage

Not much interest has been expressed in using self-reported data on HIV status and PMTCT coverage from population-based surveys to measure the effectiveness of PMTCT interventions in preventing mother-to-child transmission. Data from the 2010 Malawi DHS can also be used, however, to assess the feasibility of measuring program effectiveness.

As shown in Figure 5, the overall number of children born to HIV-positive mothers is not high enough to assess indicators based on several sub-groups. In addition, the numbers of HIV-positive mothers and their children who are unexposed to ARVs are extremely low, and comparisons among the different exposure groups cannot be made to measure indicators such as infections averted.

Figure 5 **Sample size for PMTCT effectiveness indicators from the 2010 Malawi DHS**



6 Conclusions and Recommendations

The 2010 Malawi DHS included questions on self-reported HIV status so respondents who knew they were positive could be asked a series of questions to derive population-based estimates of coverage of ARV and PMTCT services.

HIV prevalence based on self-reports was much lower than HIV prevalence based on the 2010 MDHS HIV test, even among respondents who had ever been tested for HIV and had received the result of the test. Forty percent of HIV-positive women and 36 percent of HIV-positive men reported their HIV status as negative. The results of a simulation to estimate the rate of seroconversion in this group indicate that very few individuals could have seroconverted and, consequently, most of the discrepancy between self-reported HIV status and status based on the survey HIV test is likely due to underreporting of HIV-positive status among respondents who report being tested before the survey.

The degree of misreporting of self-reported HIV status that is observed in the 2010 MDHS and is likely to occur in any other similar survey introduces substantial bias in all indicators that require the collection of additional data from HIV-positive individuals during the interview, including all indicators on coverage of ARVs and PMTCT services. In addition, problems in measuring ARV use present a serious challenge for interpreting CD4 data in population-based surveys, where collected.

For indicators on coverage of PMTCT services, problems in 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.

At least for the Malawi 2010 DHS, this analysis found that concerns that introducing questions on self-reported HIV status may reduce participation in the survey HIV test appear to be unfounded. There is no evidence of any differential participation in the HIV test by self-reported status that would bias the survey HIV prevalence estimate. However, this finding is unrelated to the problems with the data on self-reported HIV status.

Based on this investigation of the 2010 MDHS survey data, we conclude that, while questions on self-reported HIV status do not have adverse effects on respondent participation in HIV testing, they do not produce valid data on the number of HIV-positives, and, thus, the results could not be used to generate valid measures of the coverage of services offered to people living with HIV and AIDS. Therefore, based on the data from the 2010 Malawi DHS, we recommend against including questions on self-reported HIV status in population-based surveys.

METHODOLOGICAL APPENDIX

Table A.1 shows the details for calculating the number of estimated seroconversions among female respondents who tested HIV-positive in the 2010 MDHS HIV test but reported they were HIV-negative for Scenarios A, B, and C. Table A.2 shows the same for male respondents.

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-year)	Average exposure time per person (in years)	Number of women sero-converting	Percentage of women sero-converting
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

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 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.

Table A.2 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 sero-converting	Percentage of men sero-converting
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

REFERENCES

Aghokeng, A. F., E. Mpoudi-Ngole, H. Dimodi, A. Atem-Tambe, M. Tongo, C. Butel, E. Delaporte, and M. Peeter. 2009. "Inaccurate diagnosis of HIV-1 group M and O is a key challenge for ongoing universal access to antiretroviral treatment and HIV prevention in Cameroon." 2009. *Plos One* 4(11).

Government of Malawi (GOM). 2012. *2012 Global AIDS Response Progress Report: Malawi Country Report for 2010 and 2011*. Lilongwe, Malawi: Government of Malawi.

Gray, R. H., F. Makumbi, D. Serwadda, T. Lutalo, F. Nalugoda, P. Opendi, G. Kigozi, S. J. Reynolds, N. K. Sewankambo, and M. Wawer. 2007. "Limitations of Rapid HIV-1 Tests during Screening for Trials in Uganda: Diagnostic Test Accuracy Study." *BMJ* 335(188).

Klarkowski, D., J, M, Wazome, K. M. Lokuge, L. Shanks, C. F. Mills, and D. P. O'Brien. 2009. "The Evaluation of Rapid In Situ HIV Confirmation Test in a Programme with a High Failure Rate of the WHO HIV Two-Test Diagnostic Algorithm." *Plos One* 4(2).

National Statistical Office (NSO) and ICF Macro. 2011. *Malawi Demographic and Health Survey 2010*. Zomba, Malawi, and Calverton, Maryland, USA: NSO and ICF Macro.

Plate, D. K., for the Rapid HIV Test Evaluation Working Group. 2007. "Evaluation and Implementation of Rapid HIV Tests: The Experience in 11 African Countries." *AIDS Research and Human Retroviruses* 23(12): 1491-1498.

Wolpaw, B. J., C. Mathews, M. Chopra, D. Hardie, V. de Azevedo, K. Jennings, and M. N. Lurie. 2010. "The Failure of Routing Rapid HIV Testing: A Case Study of Improving Low Sensitivity in the Field." *BMC Health Services Research* 10(73).

WHO. 2010. Antiretroviral Therapy for HIV Infection in Adults and Adolescents: Recommendations for a Public Health Approach, 2010 revision. Geneva: WHO.