Accuracy of self-reported HIV testing history and awareness of HIV-positive status among people living with HIV in four Sub-Saharan African countries

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Abstract

Background: In many countries in Sub-Saharan Africa, self-reported HIV testing history and awareness of HIV-positive status from household surveys are used to estimate the percentage of people living with HIV (PLHIV) who know their HIV status. Despite widespread use, there is limited empirical information on the sensitivity of those self-reports, which can be affected by non-disclosure.

Methods: Bayesian latent class models were used to estimate the sensitivity of self-reported HIV testing history and awareness of HIV-positive status in four *Population-based HIV Impact Assessment* surveys in Eswatini, Malawi, Tanzania, and Zambia. Antiretroviral (ARV) metabolites biomarkers were used to identify persons on treatment who did not accurately report their status. For those without ARV biomarkers, the pooled estimate of non-disclosure among untreated persons was 1.48 higher than those on treatment.

Results: Among PLHIV, the sensitivity of self-reported HIV testing history ranged 96% to 99% across surveys. Sensitivity of self-reported awareness of HIV status varied from 91% to 97%. Non-disclosure was generally higher among men and those aged 15-24 years. Adjustments for imperfect sensitivity did not substantially influence estimates of of PLHIV ever tested (difference <4%) but the proportion of PLHIV aware of their HIV-positive status was higher than the unadjusted proportion (difference <8%).

Conclusions: Self-reported HIV testing histories in four Eastern and Southern African countries are generally robust although adjustment for non-disclosure increases

43 estimated awareness of status. These findings can contribute to further refinements in
44 methods for monitoring progress along the HIV testing and treatment cascade.

45 **Keywords:** Sensitivity; Bayesian latent class; self-report; testing behaviors; HIV
46 disclosure; HIV/AIDS

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INTRODUCTION

Monitoring the HIV treatment and care cascade is central to the *Joint United Nations Programme on HIV/AIDS'* (UNAIDS) objective of ending the AIDS epidemic as a public health risk by 2030 (1). Routine tracking of population-level progress towards the UNAIDS' 2020 90-90-90 and 2030 95-95-95 diagnostic, treatment, and viral load suppression targets can guide public health initiatives and improve programmatic efficiencies (2). However, estimating progress towards the first pillar of the targets –the percentage of people living with HIV (PLHIV) who know their HIV status– is challenging. In sub-Saharan Africa (SSA), where 67% of the 38 million PLHIV were estimated to reside in 2019 (3), measures of awareness are typically constructed from data about self-reported HIV testing behaviour or reported directly from nationally representative household surveys (4-8).

Consideration of the potential for measurement bias is needed when interpreting self-reported survey data. Studies have shown that self-reporting about sensitive information, such as an individual's HIV testing history and HIV status, could be affected by non-disclosure (6, 9, 10). For example, inconsistencies have been documented in Kenya and Malawi between an individual's self-reported data and biomarkers for metabolites of antiretrovirals (ARVs) and viral load suppression (5, 10). While previous studies have sought to validate the accuracy of self-reported HIV status (10-12), analyzing recent data on both non-disclosure of self-reported HIV testing history and HIV status among PLHIV is key to improving the validity of these estimates.

Surveys that collect both self-reported information and ARV biomarkers can be used to assess the accuracy of self-reported HIV testing histories and HIV awareness status. In this study, Bayesian latent class models are used to estimate the sensitivity of self-reported HIV testing history and awareness of HIV status among PLHIV based on the presence of detectable ARVs (13).

Methods

Study population

The *Population-based HIV Impact Assessment* (PHIA) surveys are nationally representative multistage household-based surveys designed to provide population-level information on the burden of HIV disease and to document the progress of HIV programs (14-17). All four PHIA surveys with available microdata on PLHIV aged 15+ years of age were included in our analysis: *Swaziland (Eswatini) HIV Incidence Measurement Survey 2* (2015-2016), *Malawi PHIA* (2015-2016), *Tanzania HIV Impact Survey* (2016-2017), and *Zambia PHIA* (2016).

Self-reports and antiretroviral (ARV) status

Participants who reported having ever received the results of any HIV test were classified as *ever tested and received results* (hereafter referred to as *"ever tested"*; *see Table S1)*. Participants who reported having received a positive test result after any HIV test, were classified as *aware of HIV-positive status*. The specific laboratory algorithms used to detect ARVs varied across surveys, although all were analyzed in the same

laboratory, and included drugs in the nationally recommended first- and second- line regimens: efavirenz, lopinavir, and nevirapine (14-17).

Bayesian latent class models

Bayesian latent class models (18) were used to quantify the sensitivity of both self-reported HIV testing history and HIV status awareness among PLHIV. Cross-tabulations of self-reports with ARV biomarkers provide empirical information on their sensitivity among those with detectable ARVs (Figure 1A).

With regard to participants with detectable ARVs, we assumed that: (1) they had been tested for HIV, received their results, and were aware of their status; and (2) there were no false positives in the detection of ARV metabolites, self-reported HIV testing history, or awareness of HIV status.

As ARV metabolite data only provide information about the sensitivity of self-reports among participants on ARVs, the ratio of non-disclosure for PLHIV without detectable ARVs versus those with detectable ARVs was given a log-normal prior distribution with a mean of *log(1.48)* (standard error: 4) to estimate the sensitivity of self-reports for people without detectable ARVs. This prior was elicited by reviewing available studies an meta-analyzing the evidence. The pooling of two studies conducted in rural Mozambique and Malawi (19, 20) suggests that people not receiving ARVs are 1.48 more likely to not disclose their diagnosis. Additional analyses were conducted to investigate the influence of this prior on our results. Equations and prior distributions are presented in the *Supplementary Materials (Table S2 and Text S1)*.

Given known biases in self-reported estimates of HIV status awareness, analysts often manually reclassify individuals not aware of their status but with detectable ARVs –as in published PHIA reports. Most surveys, however, do not collect ARV biomarkers and only rely on self-reported information. To examine the impact of this partial adjustment, we compared the unadjusted, ARV-reclassified (as in PHIA reports), and Bayesian-adjusted estimates of PLHIV aware.

Models were run separately for each country and for subgroup analyses (i.e. age, sex, urban/rural and socio-economic status). Bayesian hierarchical models using Markov Chain Monte Carlo (MCMC), implemented through the JAGS software (21) and the *rjags* packages, were used to approximate the posterior densities (22, 23).

Ethics

Ethics approval for secondary data analyses was obtained from McGill University's Faculty of Medicine Institutional Review Board (A10-E72-17B).

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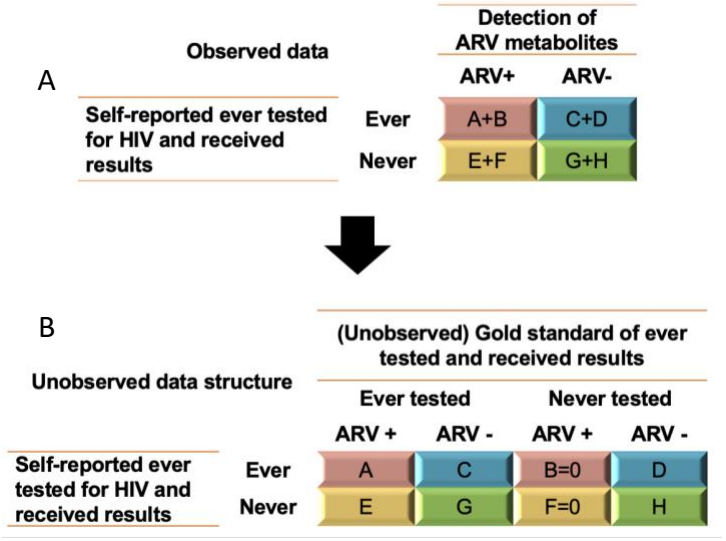

Definitions for A to H			
	(Unobserved) Gold Standard	ARV Status	Self-report
A	Ever	ARV+	Ever
B	Never	ARV+	Ever
C	Ever	ARV-	Ever
D	Never	ARV-	Ever
E	Ever	ARV+	Never
F	Never	ARV+	Never
G	Ever	ARV-	Never
H	Never	ARV-	Never

126

127 **Figure 1.** Observed and unobserved data structure of self-reported *ever tested and*
128 *received results*, and antiretroviral (ARV) metabolites status. Definitions for cells A to H
129 are listed in the table. As it was assumed that participants with detectable ARV must
130 have been tested, cells B and F are *de facto* equal to zero. The same technique was
131 applied to the self-reported awareness of HIV status and was applied to all four Sub-
132 Saharan African countries.

133

Results

Overall, 3,003 PLHIV from Eswatini, 2,227 PLHIV from Malawi, 1,831 PLHIV from Tanzania, and 2,467 PLHIV from Zambia were included in the analyses. In all countries, a high fraction of PLHIV reported having ever been tested and the proportion of PLHIV reporting being aware of their status ranged from 68.0% in Tanzania to 86.5% in Eswatini. The proportion of PLHIV with detectable ARV metabolites was highest in Eswatini (76.0%), followed by Malawi (68.1%), Zambia (61.5%), and Tanzania (53.9%).

Sensitivity of self-report

Self-reported testing history

Among participants with detectable ARVs, the estimated sensitivity was highest in Eswatini at 99.5% (95% credible interval [95%CrI]: 99.2-99.8%), followed by Malawi (98.2%; 97.5-98.8%), Zambia (97.4%; 96.5-98.1%), and Tanzania (96.6%; 95.3-97.6%) (Figure 2). For people without ARV metabolites, the estimated sensitivity was 2.4% points (0.1-11.4%) lower than those with detectable ARVs in Tanzania.The differences were smaller elsewhere. Detailed values can be found in *Supplementary Table 3*.

Self-reported awareness of HIV status

The sensitivity of self-reported awareness of HIV-positive status among participants with ARV metabolites was 97.4% (96.7-98.0%) in Eswatini, 94.2% (93.0-95.4%) in Malawi, 92.3% (90.5-93.8%) in Tanzania, and 91.6% (90.1-92.9%) in Zambia (Figure 2A). The estimated differences in sensitivity between PLHIV with ARV metabolites and those

without were 1.8% points (0.1-8.5%), 4.2% points (0.2-19.6%), 5.7% points (0.3-26.7%) and 6.2% points (0.3-29.0%) in Eswatini, Malawi, Tanzania, and Zambia respectively.

Differences by gender, age, rural/urban, and socioeconomic status

Among participants with detectable ARVs, women had 0.9-2.4% points higher sensitivities of self-reported HIV testing history and HIV status awareness than men (Figure 2B). The estimated sensitivities were the lowest at age 15-24 years (94.7-97.2% for HIV testing history and 83.9-91.9% for HIV status awareness) in all of the countries (Figure 2C). Participants residing in urban and rural areas had similar sensitivities (*Figure S1A*) and variations by socio-economic status (SES) were also small (*Figure S1B and Figure S2*).

Adjusted proportion of PLHIV ever tested and PLHIV aware of their status

Adjusting for imperfect sensitivity influenced the estimates of the self-reported proportion ever tested for HIV less (largest difference between the adjusted and the self-reports was 3.9% points in Tanzania) than the estimates of self-reported proportion of PLHIV aware of their status (largest difference was 7.2% points in Zambia) (Figure 2D). Results were less affected by the assumed non-disclosure ratio for PLHIV without detectable ARV metabolites when antiretroviral therapy (ART) coverage is high (*Figure S3*).

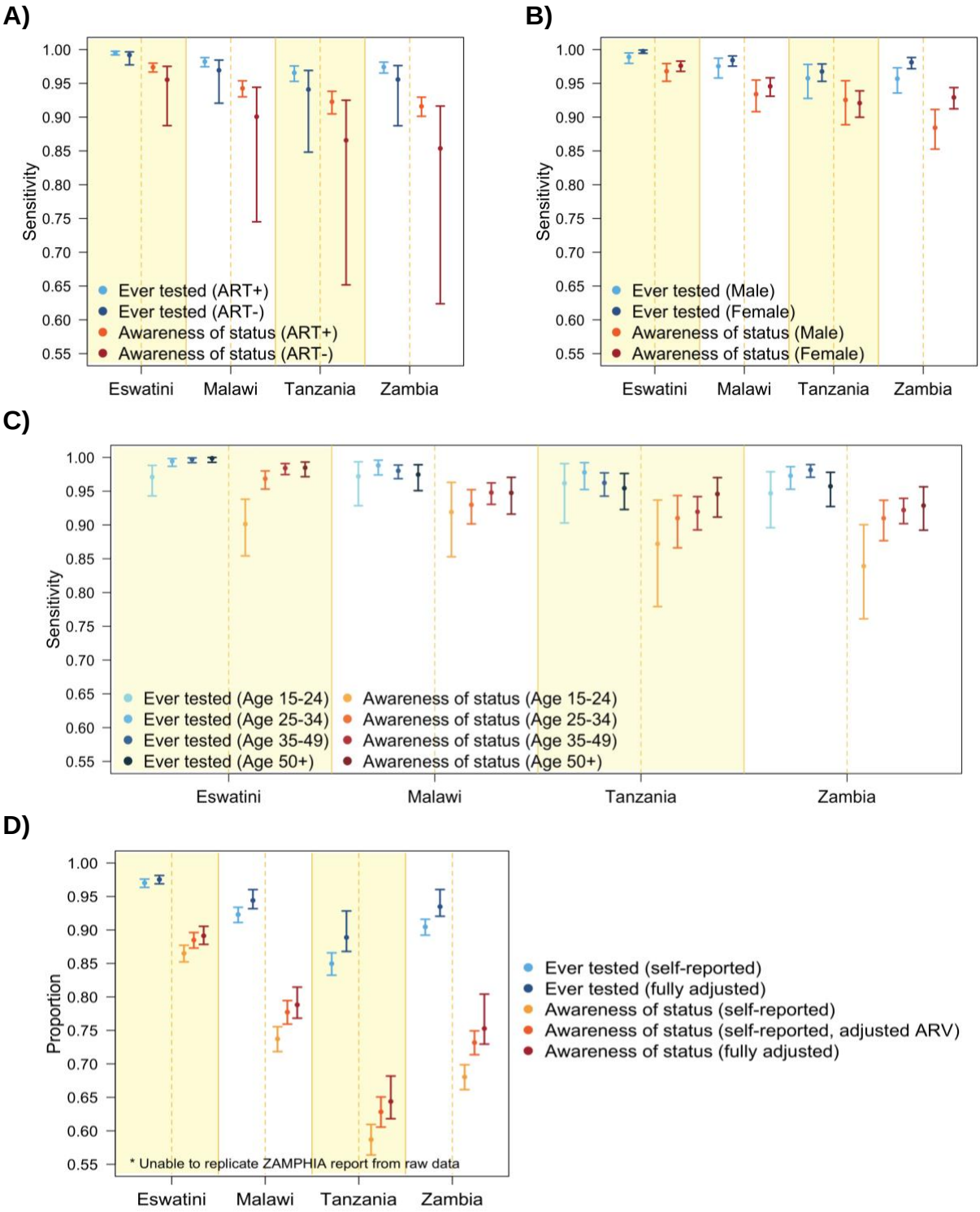

Figure 2. Marginal posterior medians and 95% credible intervals for selected outcomes. Sensitivity of self-reported ever tested and received results, and awareness of HIV-positive status among people living with HIV (PLHIV) by: (A) antiretroviral (ARV) metabolites status, (B) gender (ARV+), and (C) age groups (ARV+). Panel D portrays the overall proportion of PLHIV ever tested who received results and the awareness of HIV-positive status (self-reported vs. adjusted ARV metabolites status vs. fully adjusted).

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Discussion

Self-reported information on HIV testing and diagnosis are primary data sources used to monitor trends in the HIV treatment and care continuum (2, 9). These same data have also been proposed to estimate cross-sectional HIV incidence (24). In this study, we leveraged ARV biomarkers from four household representative surveys in Eswatini, Malawi, Tanzania and Zambia to estimate the sensitivity of self-reported HIV testing history and awareness of HIV status among PLHIV. We found that self-reports of HIV testing history have a high sensitivity (>96%) among PLHIV with detectable ARVs across these settings. Self-reported awareness of HIV status had a marginally lower sensitivity (>91%) in these same countries.

Subgroup analyses revealed nonnegligible lower sensitivities of both self-reported HIV testing history and awareness of status among male PLHIV and those aged 15-24 years which could result from social desirability bias (25). Additionally, differences in survey instruments could result in higher sensitivities for women. For example, in the PHIA survey, women are asked about HIV testing up to 4 times (before pregnancy, during pregnancy, during labor, and at their last HIV test), while men were asked only once. As women were classified based on the positive response to any of the 4 questions, this increased the probability of women disclosing their true status.

In this study, we estimated the sensitivity of the self-reports alone but when ARV biomarkers are available, presentation of cascade results from the surveys usually adjust these self-reports by reclassifying PLHIV that do not disclose their status but for which ARV metabolites are detected as “aware”. We have found that this partial

196 adjustment may be insufficient, especially if ART coverage is low in the surveyed
197 population and the ratio of non-disclosure among those not on ART is high (26-29). To
198 accurately estimate awareness of status, results must also be adjusted for non-
199 disclosure among PLHIV with undetectable ARVs.

200 Our results need to be interpreted considering certain study limitations. First, only four
201 PHIA surveys have publicly available micro-data, none of which are located in the West
202 and Central African regions, where non-disclosure could be higher (30). The PHIA
203 included here had some of the lowest levels of non-disclosure of these reviewed studies
204 suggesting that other settings could have lower sensitivities. Second, our study design
205 limited our assessment of the sensitivity of testing history to PLHIV, and findings should
206 not be extrapolated to people not living with HIV. Third, it is not possible to empirically
207 validate the sensitivity of self-reports among PLHIV without ARV metabolites. As such,
208 we had to use information from two previous studies that used medical records to inform
209 the non-disclosure ratio. Results could be sensitive to this non-disclosure ratio but the
210 high ART coverage in the four countries mitigates this influence (*Figure S3*). Finally, the
211 specificity of self-reports was assumed to be 100% which could lead to overestimating
212 the proportion of PLHIV ever tested / aware of HIV-positive status. However, previous
213 study has shown a high specificity of self-reported HIV testing results (11) implying that
214 this assumption will likely have little impact on the outcomes.

215 Strengths of this study include the use of standardized survey and laboratory data (i.e.
216 detection of ARV metabolites). Second, the Bayesian latent class models propagate
217 uncertainty to our results by assuming prior distributions and generating posterior

credible intervals. Finally, we examined sex, age, urban/rural, and SES differences in the sensitivity of self-reports.

In conclusion, self-reported HIV testing histories have high sensitivities in the four countries examined but self-reported awareness of HIV status are lower. Whenever available, ARV biomarkers data can be used to adjust self-reports but such adjustments may still underestimate diagnosis coverage, especially if ART coverage is low in that population. Future research should extend this work in other regions and populations.

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