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Research Material

Collecting data on HIV/AIDS mortality during household surveys: A randomized validation study in Malawi

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Collecting data on HIV/AIDS mortality during household surveys: A randomized validation study in Malawi

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Abstract

BACKGROUND
In countries with limited civil registration, household surveys do not include questions on HIV-related mortality.

OBJECTIVE
We aim to test whether accurate data on the HIV status of the deceased siblings of survey respondents could be collected during household surveys conducted in low- and middle-income countries.

METHODS
We added HIV questions to the standard module on adult and maternal mortality used in household surveys. We compared the data generated by these questions to data collected by the Karonga Health and Demographic Surveillance System in Malawi. We randomly assigned men and women aged 15–59 years to face-to-face (FTF) interviewing or the more confidential method of audio computer-assisted self-interviewing (ACASI). We compared survey reports of adult deaths to prospective reference data on mortality and HIV status.

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RESULTS
The added HIV questions yielded nearly complete data on the HIV status of deceased siblings, particularly those who had died recently. The sensitivity of survey data on the HIV status of the deceased was high in both study groups, even after accounting for partial verification bias (>0.75). There were few false negative reports of the HIV status of deceased siblings (specificity > 0.95). ACASI did not improve the accuracy of survey data, but it required extensive training of respondents, and more time to collect mortality data.

CONCLUSIONS
Adding HIV questions to instruments used to measure mortality in LMICs is feasible and generates accurate data on the HIV status of deceased adults.

CONTRIBUTION
The data generated by these new HIV-related questions might help to better track progress towards global HIV elimination targets.

1. Introduction

Despite the rollout of antiretroviral treatment (ART) and effective prevention methods (e.g., male circumcision, pre-exposure prophylaxis), HIV/AIDS remains a leading cause of adolescent and adult mortality in many countries (Masquelier et al. 2017). Reaching “zero AIDS-related deaths” or stopping “preventable deaths from HIV-related causes” are key goals of HIV prevention and treatment programs (Croxford et al. 2023; Ford et al. 2013).

In high-income countries, the data required to monitor progress towards these objectives come from health information systems, and civil registration and vital statistics (CRVS) systems (e.g., Bhaskaran et al. 2021; Sellier et al. 2023). In the low- and middle-income countries (LMIC) most affected by HIV, the coverage of these data systems is often low (Mikkelsen et al. 2015). In many countries in eastern and southern Africa, a large proportion of deaths occur at home (Adair 2021; Chisumpa, Odimegwu, and De Wet 2017). After a death, family members must contact administrative offices to notify them of the event and fill in administrative paperwork, but few families complete these steps due to a lack of knowledge about procedures, high transportation costs, and/or limited perceived benefits associated with the registration of deaths (Mathenge et al. 2013). Even when deaths are registered with the competent administrative authority, their cause(s) may not be included, or may be misclassified, on death certificates (Adair et al. 2020; Bradshaw et al. 2016; Burger et al. 2012; Groenewald et al. 2025).

Reliable data on HIV-related mortality in African countries are thus often only available for small and highly selective populations. Clinical cohorts document causes of death among ART patients (Haas et al. 2018), but they rarely measure mortality among persons with HIV (PHIV) who are not receiving ART, and they do not provide data on the survival of HIV-negative individuals. Health and demographic surveillance systems (HDSS) regularly visit households to gather population-based data on causes of death (Bangha et al. 2010; Sankoh and Byass 2012). They determine if a death is related to HIV through biological testing (Reniers et al. 2016) and/or linkages with data from health facilities (Rentsch et al. 2017). They might also identify deaths due to HIV/AIDS through detailed post-mortem interviews with relatives, called 'verbal autopsies' (Streatfield et al. 2014). However, HDSS often cover small and rural localities within African countries. HDSS have also served as platforms for trials of HIV interventions, such as the use of ART or male circumcision to prevent HIV transmission (Gray et al. 2007; Iwuji et al. 2018). Thus most HDSS might not be representative of other populations affected by HIV in a country.

National and sub-national estimates of HIV/AIDS mortality in most African countries are developed primarily by UNAIDS (Case et al. 2019) and the Institute for Health Metrics and Evaluation (IHME) (GBD 2017 HIV collaborators 2019). These organizations derive their figures by combining information on HIV prevalence from periodic surveys of clinic attendees or the general population, counts of PHIV who receive ART, and/or available estimates of all-cause mortality (Maheu-Giroux et al. 2019; Masquelier et al. 2017). The likely number of HIV-related deaths is then inferred from epidemiological projections (van Schalkwyk et al. 2024; Stover et al. 2019). These models can yield discrepant estimates (Hallett et al. 2014), which might lead to (a) conflicting assessments of the impact of HIV/AIDS in a country, and (b) biased evaluations of the effectiveness of interventions that seek to address HIV epidemics.

The data on all-cause mortality used by UNAIDS and IHME in their models of HIV-related mortality usually come from household surveys. Over the past decades, such surveys have been conducted periodically in many LMICs. They are designed to be representative at national or sub-national levels (Corsi et al. 2012; Khan and Hancioglu 2019). They measure mortality retrospectively (Hill, Choi, and Timaeus 2005) by asking a random sample of respondents about the survival of their close relatives, such as their children, siblings, and household members. They also frequently include assessments of pregnancy-related and accidental/violent deaths (Hill et al. 2006; Obermeyer, Murray, and Gakidou 2008).

Household surveys such as the Demographic and Health Surveys (DHS), Multiple Indicator Cluster Surveys (MICS), and the Population-based HIV Impact Assessment (PHIA) have so far not collected data on HIV-related mortality. This omission stems from concerns that survey respondents do not know whether their relatives were infected with

HIV and possibly died of HIV-related causes. However, these concerns might have receded following the expansion of HIV testing services across the African continent (Johnson et al. 2015; Maman et al. 2016). Whereas only 1 in 20 PHIV residing in African countries were aware of their infection in 2000, this was the case for more than 4 in 5 PHIV in 2020 (Giguère et al. 2021). This trend has been accompanied by increased disclosure of HIV status to family members (Maman, van Rooyen, and Groves 2014; Tam, Amzel, and Phelps 2015) and frequent conversations in social networks to determine if an individual's death can be attributed to HIV/AIDS (Watkins 2004). Survey respondents may now have sufficient knowledge of the HIV status of their deceased relative(s) to answer interview questions on that subject.

We therefore developed new questions that can be incorporated into the survey module commonly used in household surveys to document adult and maternal mortality, i.e., the survival history of a respondent's siblings (Timæus and Jasseh 2004). Due to time limitations in survey interviews, these new questions do not document the circumstances of deaths as extensively and precisely as verbal autopsies. They do not allow coding the cause of a death using the international classification of diseases (ICD), nor do they permit assessing whether a death can be attributed to HIV infection (Croxford et al. 2023; Mollel et al. 2022). Instead, the new questions aim to determine the HIV status of a respondent's deceased sibling(s). If accurate, the data generated might then help measure the proportion of adult deaths that occur among PHIV, an important parameter to calibrate epidemiological and statistical models used to estimate HIV-related deaths in countries affected by the pandemic.[6]

The current lack of questions on HIV-related mortality in household surveys can also be linked to the potential sensitivity of the topic. Respondents may perceive such questions as intrusive and may not be willing to disclose information about the HIV status of their deceased relative to a survey interviewer, due to various forms of stigma linked to the disease (Bonnington et al. 2017). For example, they might fear negative reactions or discrimination from being associated with recently deceased PHIV (Bogart et al. 2008).

Several factors may alleviate these concerns. First, there have been recent declines in HIV stigma in African countries, possibly related to increased access to ART (Chan, Tsai, and Siedner 2015; Stangl et al. 2020; Tsai and Venkataramani 2015). This trend is limited (Chan and Tsai 2016), but it may have improved respondents' willingness to report HIV-related information about deceased relatives during a survey interview. Second, household surveys already collect data on several sensitive HIV-related topics, such as the sexual behaviors that might have led to the transmission of HIV (Blanc and

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[6] In conjunction with survey data on the prevalence of HIV among surviving family members, the data generated by the newly added questions might also help assess whether PHIV experience 'excess mortality' relative to other population members. We do not detail this possibility further in this paper.

Way 1998; Doyle et al. 2012). In the countries most affected by the HIV pandemic, survey respondents have also been asked to report the results of their own most recent HIV test, and to undergo HIV testing at the time of the interview (Johnston et al. 2015; Mishra et al. 2006). Initially believed to be too intrusive, these questions and procedures have been well accepted by participants (Brumfield et al. 2020). Third, techniques exist that facilitate the collection of survey data on sensitive topics. Most household surveys conduct interviews using a face-to-face (FTF) interviewing approach, in which an interviewer meets the respondent in person, asks questions, and records answers. In order to minimize non-response to possibly sensitive questions, aspects of informed consent, privacy, confidentiality, and non-judgmental attitudes are emphasized during training of interviewers (Jansen et al. 2004). To further increase confidentiality and privacy when inquiring about sensitive topics, researchers have also developed and tested Audio Computer-Assisted Self-Interviewing (ACASI) methods. ACASI entails equipping respondents with headsets through which they hear pre-recorded questions, and instructing them about how to enter answers on their own, using a tablet or keypad (Mensch, Hewett, and Erulkar 2003). The use of ACASI ensures that questions are asked in a consistent manner, whereas interviewers might be tempted to paraphrase questions on sensitive topics during FTF interviews. It also enhances privacy because only respondents hear the questions they are being asked and see the answers they provide. ACASI has been used to improve the reporting of sexual behaviors, drug use, and experiences of domestic and gender-based violence (van der Elst et al. 2009; Falb et al. 2017; Kane et al. 2016; Mensch et al. 2008; Rathod et al. 2011). Systematic reviews of ACASI trials indicate that this method consistently improves the reporting of particularly sensitive topics, such as the respondents' experience of forced sex and other forms of domestic violence (Langhaug, Sherr, and Cowan 2010; Phoo et al. 2022). The benefits of ACASI for reporting less sensitive items (e.g., ever having had sex) are smaller, and may only apply to urban areas and the more-educated segments of local populations (Phillips et al. 2010).

In this study, we evaluated the addition of HIV-related questions to the standard survey module on adult and maternal mortality. We worked in a northern district of Malawi, where HDSS have been collecting reference data on HIV prevalence and family relations for several decades. We conducted a randomized trial of two approaches to collecting such potentially sensitive data: FTF and ACASI. We hypothesized that (1) the new questions would generate accurate data on the HIV status of a respondent's deceased sibling(s), and (2) the use of ACASI might further increase the accuracy of survey data on the mortality of PHIV compared to the standard practice of collecting survey data via FTF.

2. Data and methods

2.1 Study setting

Malawi is a low-income country in East Africa, with an estimated life expectancy of 63.3 years and an annual GDP per capita of 389.4 USD in 2018. We worked in the Karonga district of the Northern region of Malawi. According to a representative survey of HIV prevalence, 4.9% of men and 8.8% of women were infected with HIV in this region in 2015/16 (Ministry of Health, Malawi 2018). In that survey, two-thirds of the men and 4 out of 5 women interviewed in the Northern region reported that they had ever been tested for HIV. More than a quarter of PHIV remained unaware of their infection.

Karonga district is bordered by Tanzania to the north and Lake Malawi to the east. This area of Malawi has been the site of epidemiological studies since the 1970s, focusing initially on leprosy (e.g., Fine et al. 1986), then on tuberculosis (e.g., Crampin, Glynn, and Fine 2009) and HIV (e.g., Crampin et al. 2003; Glynn et al. 2001), and more recently on non-communicable diseases (e.g., Chilunga et al. 2019). Since 2002, a HDSS has been implemented in the southern part of Karonga district (Crampin et al. 2012; Jahn et al. 2007), covering an area of approximately 135 square kilometers with a predominantly rural population. The HDSS also includes a semi-urban trading center located on the main road to Tanzania and a port village where the ferry that connects towns along the shores of Lake Malawi docks once a week. The local economy is thus centered on subsistence agriculture, small-scale trading, and fishing.

A complete description of the procedures of the Karonga HDSS is available elsewhere (Crampin et al. 2012). Briefly, after a baseline census, key informants recruited from villages covered by the HDSS continuously record the births and deaths that occur among the population. Key informants also report migrations into and out of the HDSS area. Every year a new census is conducted to record new households, as well as births and deaths that have been missed by key informants. Each HDSS resident is attributed a unique identification (ID) number that s/he keeps even after moving between households. When feasible, parental ID numbers are added to an individual's HDSS record. This information allows rapidly listing the known siblings of HDSS residents by looking up HDSS records that share the same maternal and/or paternal ID numbers.

Extensive HIV-related information has been collected over the years in Karonga district. Several studies of the risk factors of leprosy and tuberculosis conducted in the 1980s and 1990s included HIV testing (Crampin et al. 2003; Shaw et al. 1991). Biomarkers of HIV infection were collected among all residents of the HDSS in 2005–2006, and every year between 2007 and 2011. These serosurveys achieved participation rates between 73% and 83%, and the vast majority of participants learned their HIV status following rapid tests (Molesworth et al. 2010). Since 2011, no other serosurveys have been conducted, but the HDSS has continued to collect HIV-related data from clinical registers at health facilities serving the HDSS population (Houben et al. 2012; Koole et al. 2014; Price et al. 2014). These clinical data have been linked to HDSS datasets via the system of unique identifiers referenced above. Ancillary studies conducted within the HDSS have asked selected residents to self-report the results and date of their most recent HIV test (Chilunga et al. 2019; Nakanga et al. 2019).

2.2 Questionnaire development

To develop survey questions assessing the HIV status of a respondent's deceased sibling, we emulated instruments used during large-scale household surveys to ascertain the respondents' own HIV status (Johnston et al. 2015). These surveys ask respondents to state if they have ever been tested for HIV, and if so, to indicate the results of their most recent HIV test. However, solely asking similar questions about deceased siblings might yield missing data on HIV status, due to incomplete or selective disclosure of HIV test results within families. We therefore also added a question that asked respondents to evaluate the likelihood that their deceased sibling was infected with HIV. Respondents were presented with a 5-point Likert scale, with categories ranging from 'highly likely' to 'highly unlikely'. This question was not applicable if the respondent stated that their deceased sibling had received positive results at his/her most recent HIV test. Other questions relating to aspects of siblings' survival histories remained similar to the standard adult and maternal mortality module used in household surveys: respondents were asked to list all their maternal siblings, state whether they were still alive, and report their current age (live siblings) or their age at death and time since death (deceased siblings). If their deceased sibling was a woman who had died when of reproductive age, they were also asked if the death occurred while she was pregnant, at the time of delivery, or within 6 weeks of childbirth. Finally, they were asked if their deceased sibling died after an accident or external injury. The HIV-related questions were only applicable for the siblings reported to have died in adulthood (i.e., at ages 15 and over).

Both the FTF and ACASI versions of the questionnaire were implemented in Open data Kit or ODK (Hartung et al. 2010), a tablet-based application commonly used for surveys conducted in LMICs. In the FTF version, interviewers used the tablet to read questions and record answers. For the ACASI version, a team member pre-recorded detailed instructions, as well as the interview questions pertaining to (1) the HIV status of deceased siblings, (2) whether the death of a woman of reproductive age occurred while pregnant, during pregnancy, or within 42 days of childbirth, and (3) whether the death was due to an accident or injury. For these subsets of questions, the respondents were handed the tablet and were equipped with a headset through which they could hear the pre-recorded questions. We used color-coded shapes and symbols and high-contrast color schemes to indicate where ACASI respondents should push on the tablet screen if they wanted to enter a specific answer. For example, respondents were instructed to "press the blue circle for yes" or, if they refused to answer a question, to "press the cross". As in other implementations of ACASI, this was necessary due to low literacy levels in some segments of the HDSS population (Mensch, Hewett, and Erulkar 2003). It also helped ensure that color-blind participants could use ACASI (Lor 2020). Finally, unlike the FTF version, the ACASI version of the questionnaire included a training section, where respondents were presented with simple questions (e.g., whether it was raining at the time of the interview) so that they could become familiar with the process of self-interviewing.

We pre-tested the study instruments with data collectors and potential survey participants recruited from HDSS communities. We used their feedback to refine interview procedures and develop training instructions about how to conduct interviews in each study group. For example, we expanded ACASI training to ensure a high level of competency with this modality among participants.

2.3 Data collection

We conducted a validation study of the data generated by the new HIV-related questions. We used information from the Karonga HDSS as (1) a sampling frame to identify and recruit participants, and (2) a reference dataset against which to compare the information reported by survey respondents. The study protocol was approved by Institutional Review Boards at Johns Hopkins University, the London School of Hygiene and Tropical Medicine, and the Malawi National Health Science Research Committee. The protocol was also pre-registered at ISRCTN (Protocol number 15197669).

To identify 'sibships', i.e., groups of HDSS members who have the same biological mother, we looked up maternal ID numbers compiled by the HDSS. We also constituted a reference classification of the HIV status of deceased adult members of the HDSS population. To do so, we used only pre-mortem data collected by the HDSS through serosurveys and record linkages. Deaths of PHIV were defined as deaths for which a clinical record or self-report of an HIV-positive test was available in the HDSS datasets. Deaths of persons who were HIV-negative were defined as deaths for which there was a clinical record or self-report of an HIV-negative test within 5 years of the death (Byass et al. 2013; Reniers et al. 2017).

This classification of deaths obtained from HDSS data is not a gold standard measure of the HIV status of the deceased, because (1) some linkages to clinical records might have been made to the wrong person, (2) some self-reports of HIV test results might be inaccurate, and (3) the 5-year window we used to identify HIV-negative deaths might misclassify recent seroconversions, i.e., individuals who acquired HIV within a few months/years of their death. In addition, this classification is only available for some of the deaths recorded by the HDSS. For others, the data available through the HDSS are not sufficient to determine their HIV status at the time of death.

We selected a stratified random sample of HDSS residents aged 15 to 59 years as of June 1st, 2018. We oversampled individuals who had experienced an adult death among their known siblings according to the HDSS datasets. We oversampled at a higher rate the individuals whose deceased sibling was classified as PHIV by HDSS data. We selected at most one respondent per sibship. Selected participants were randomized in a 1:1 ratio to an interview by FTF (control group) or ACASI (treatment group). We stratified the randomization by gender of the participant and by the composition of his/her sibship (i.e., whether he/she had a sibling who was PHIV and died when an adult). All sampling and randomization procedures were conducted on lists of HDSS residents, using random number sequences generated using Stata 14.1.

To calculate the required sample size of the randomized trial, we focused on two primary outcomes: the sensitivity and specificity of survey data in determining whether a deceased sibling was infected with HIV. Sensitivity is defined as the proportion of deaths that occurred among PHIV according to the HDSS that are classified as such by survey data, whereas specificity is the proportion of deaths among siblings who were HIV-negative according to the HDSS that are classified as such by survey data. We hypothesized that the sensitivity of survey data on the HIV status of deceased siblings was 0.77 when administered using FTF techniques, similar to the accuracy obtained during verbal autopsies of close relatives (Mclean et al. 2016). By comparison, we hypothesized that the sensitivity would increase to 0.90 through ACASI. To test the hypothesis of the superiority of ACASI over FTF using a two-sided chi-square test, with 80% power and $\alpha = 0.05$, we required 127 participants with a deceased sibling who was PHIV in each study group. To investigate the specificity of survey data, we planned a non-inferiority approach. We assumed that both interview modes have a specificity equal to 0.95, and we set a non-inferiority limit of $\delta = 0.08$. We required 82 participants per study group with a deceased sibling whose HIV status was negative according to the reference HDSS data. Finally, we aimed to recruit 72 participants among the remaining residents of the Karonga HDSS, i.e., those without a sibling who had died when adult, or those with a sibling who died when adult but whose HIV status could not be ascertained according to the reference HDSS classifications. We thus required a total of 490 participants in this study. Assuming an 80% participation rate, we selected 613 potential participants from the HDSS lists of residents.

In total, we trained 5 interviewers in data collection procedures, for 1 week. All study participants were recruited during household visits. Contact information for each participant and assignments to the ACASI or FTF groups were pre-loaded into ODK. Respondents assigned to ACASI were automatically switched to FTF if they reported vision problems, i.e., not being able to see the screen of the tablet in order to answer questions. To prevent selective manipulation of study group assignments, interviewers learned the allocation of respondents to ACASI or FTF only after a selected individual had consented to participate and his/her vision had been assessed. All interviews were conducted in Chitumbuka, the local language in the study area. We also collected metadata on the interview process. We used the audit feature in ODK to record the date of the interview, start and end times, and overall duration, as well as the time spent on each question and the occurrence of errors during the interview.

Following data collection, we manually linked the lists of maternal siblings reported by respondents to the lists of their maternal siblings contained in the HDSS database. Two reviewers had access to the list of siblings' names collected during the survey, as well as their sex. They also had access to the expected list of each respondent's siblings according to the HDSS, the sex of each of these siblings, and their ID number in the HDSS datasets. Then, for each match between the two lists, they linked the reported sibling to his/her HDSS ID number. When reviewers disagreed in their matching outcomes, a third reviewer adjudicated. None of the reviewers had access to data on siblings' vital status, age, HIV status, or cause and circumstance of death, from either the survey or the HDSS. Not all of the siblings reported during the survey could be linked to their HDSS record because some of them never resided in the HDSS area (and thus did not have a HDSS record), or because respondents reported insufficient or inaccurate information to establish a link. Furthermore, among linked deaths, only a subset had reference data on the HIV status of the deceased in the HDSS database.

2.4 Data analysis

First, we described the characteristics of study participants by study group, including their gender, age group, educational level, ownership of a mobile phone, and prior use of the internet. These latter variables were included to assess respondents' familiarity with digital tools similar to those used in ACASI interviews. Second, we described the distribution of answers to each HIV-related question asked during the survey interview, by study group. We used χ^2 tests to evaluate the null hypothesis that there were no differences between the FTF and ACASI groups in the distribution of (1) background characteristics, and (2) answers to HIV-related questions.

Third, we classified deaths reported during the survey interview as deaths of PHIV whenever respondents stated that the deceased had either received an HIV positive test result or was reported as 'likely' or 'highly likely' to have been infected with HIV. The

HIV status of the deceased was coded as ‘missing’ if the respondent stated that he/she did not know how likely it was that his/her deceased sibling was infected with HIV. All other deaths were coded as deaths of HIV-negative persons. We assessed the proportion of reported deceased adult siblings whose HIV status could not be ascertained from data generated by the HIV questions. We investigated whether this proportion varied by study group. Analysts often only use data on recent deaths to produce estimates of adult/maternal mortality (Reniers, Masquelier, and Gerland 2011). We thus assessed whether the extent of missing data on HIV status varied by reported timing of the death. We classified reported deaths as having occurred during an 8-year reference period prior to the survey (‘recent deaths’), or during an earlier period (‘distant deaths’).

Fourth, we measured the sensitivity and specificity of survey data in recording the HIV status of deceased siblings by cross-tabulating the HIV status of linked siblings according to the reference HDSS classification and according to the survey data. True positives (TP) were deaths where the deceased was classified as PHIV by the HDSS and by the survey data; false positives (FP) were deaths where the deceased was classified as HIV-negative by the HDSS but as PHIV according to survey data; true negatives (TN) were deaths where the deceased was classified as HIV-negative by the HDSS and by the survey data; and false negatives (FN) were deaths where the deceased was classified as PHIV by the HDSS but as HIV-negative by the survey data.

Basic estimates of the sensitivity of survey data in determining the HIV status of deceased adult siblings were obtained as $\frac{TP}{(TP+FN)} \times 100$, whereas basic estimates of specificity were obtained as $\frac{TN}{(TN+FP)} \times 100$. We also used logistic regression models to compute adjusted estimates of sensitivity and specificity. In these models, the dependent variable was the HIV status of the deceased as obtained from survey data, and the main independent variable was a binary variable denoting the study group (ACASI vs. FTF). Models for sensitivity were estimated among siblings who were PHIV according to the HDSS, whereas models for specificity were estimated among siblings who were HIV-negative according to the HDSS. We accounted for the stratified randomization by including binary variables denoting the composition of the respondent’s sibship, and the timing of death (Kahan and Morris 2012). In sub-group analyses, we also included an interaction term between the study group (ACASI vs. FTF) and the timing of the death (recent vs. distant). Our adjusted estimates of the sensitivity and specificity of survey data are predicted values from the logistic regression models described above.[7]

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[7] All analyses of sensitivity and specificity use unweighted data because these two measures are intrinsic to the measurement tool being assessed, i.e., they do not depend on the prevalence of a specific condition (i.e., HIV) in the population/sample. The fact that we oversampled sibships/families where deaths of PHIV occurred thus does not affect our estimates of sensitivity/specificity. Using weighted data would be required for investigations of other indicators of survey data quality, such as the positive and negative predictive values, which depend on

Reference HDSS data on HIV status were only available for a subset of respondents' deceased adult siblings, due to limited linkage with HDSS data or because of incomplete/missing HDSS data on HIV status. We thus computed corrected estimates of sensitivity and specificity which account for such partial verification bias (O'Sullivan et al. 2018). We conducted multiple imputations of missing reference HDSS data on HIV status, as recommended (de Groot et al. 2008, 2011). In doing so, we assumed that reference HDSS data on the HIV status of the deceased were missing at random (MAR), i.e., their availability depends on a number of reported/observed characteristics of the respondent and his/her deceased siblings. We created 10 imputed datasets through chained equations (Little and Rubin 2019; Rubin 1976). In these datasets, reference HIV status was predicted for cases with missing HDSS data from logistic regression models fitted on the subset of observations with complete data. The predictors included in such models were (1) characteristics of respondents such as gender, educational attainment, ownership of a mobile phone, and prior use of the internet, and (2) characteristics of the deceased siblings, such as their gender, age at the time of death, time elapsed since the death, and HIV status, as reported during the survey interview. In each of the 10 imputed datasets, we measured sensitivity and specificity using logistic regression methods with controls for the stratification variables (i.e., gender of the respondent and sibship composition). The corrected estimates of sensitivity and specificity were then obtained by averaging results across imputed datasets (Freedman and Wolf 1995). Analyses accounting for partial verification bias were not pre-specified when we registered the study protocol.

All comparisons of sensitivity and specificity between study groups were conducted on an intention-to-treat basis, i.e., with participants included in their randomly assigned study group (ACASI or FTF). During the course of the study, some participants assigned to FTF were interviewed using ACASI, and vice-versa, either by error or due to vision problems. To assess the robustness of our findings, we thus also conducted an as-treated analysis of our primary outcomes, with participants classified according to the interview mode they received.

Finally, to assess the feasibility of including HIV-related modules into standard survey modules on adult and maternal mortality, we described the amount of time (in minutes) required to complete several survey components. In the ACASI group, we measured the duration of ACASI training. In both the FTF and ACASI groups, we measured the total amount of time used to (a) collect the entire siblings' survival history, and (b) complete the HIV-related questions. For comparison, we also computed the amount of time required to administer questions used to determine whether deaths were pregnancy-related and/or linked to accidents and injuries. We used non-parametric

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the prevalence of a particular condition in a population/sample and are thus affected by stratified sampling schemes. However, we do not consider such indicators in this paper.

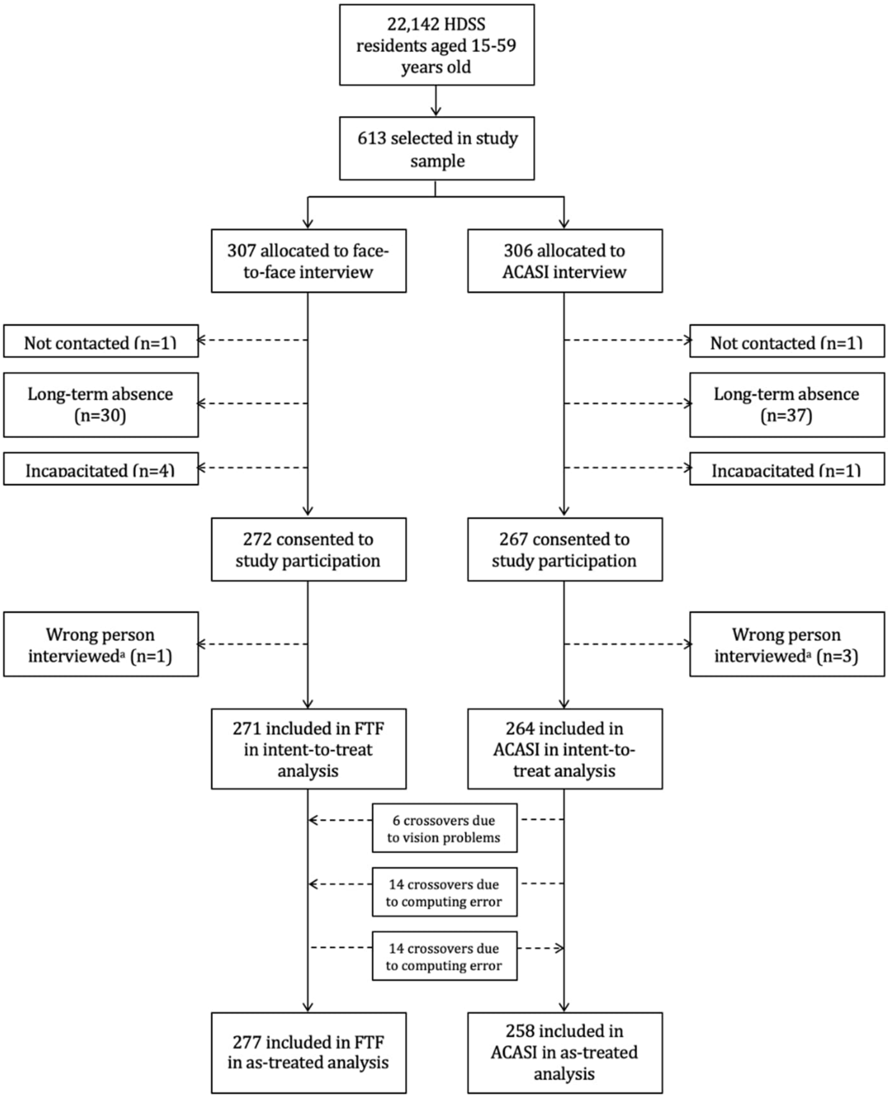
Wilcoxon tests to assess the null hypothesis of no difference in interview duration between the FTF and ACASI groups.

3. Results

The study was conducted between October 12th, 2018 and January 14th, 2019. Among selected HDSS residents, 307 were allocated to FTF and 306 were allocated to ACASI (Figure 1). Participation rates were 88.6% in the FTF group (272/307) and 87.3% in the ACASI group (267/306). Long-term absence was the most common reason for non-participation in each group. We excluded 4 participants after their enrollment, because we did not interview the selected person. Twenty participants were switched from ACASI to FTF, and 14 were switched in the opposite direction. Six of those who switched from ACASI to FTF did so due to reported vision problems. The other 28 respondents were automatically switched due to a computing error that occurred after one of the interviewers went on leave, and her work was reassigned to other interviewers.

In each study group, there were slightly more female participants than male participants (Table 1). The educational level of participants was low, with more than a third of respondents not having pursued education beyond primary school. Only a limited number of respondents had prior experience of digital tools: more than a third of respondents did not own a mobile phone, and only slightly more than 1 in 10 respondents had ever used the internet. We did not detect differences between the ACASI and FTF groups in the distribution of respondents' characteristics (Table 1).

Figure 1: Enrollment process



Note: [a] These errors were first detected at the data-editing stage, due to large age discrepancies for the respondent between the survey and the HDSS data (>20 years); they were subsequently confirmed during household re-visits.

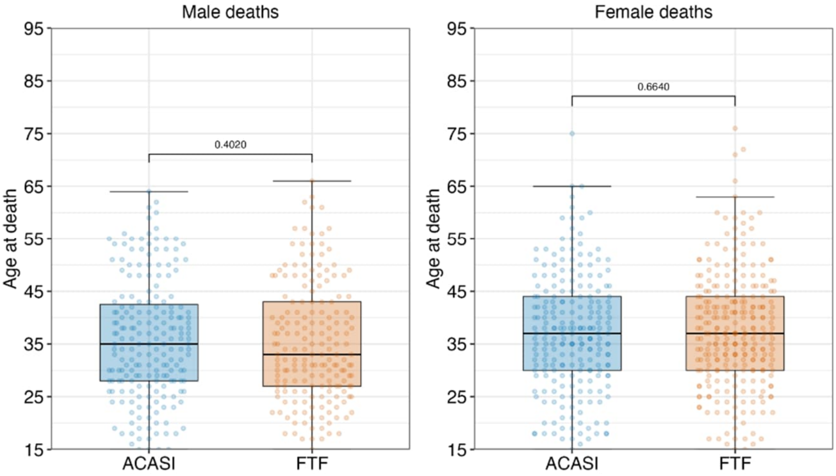
Table 1: Characteristics of study participants, by assigned study group

Characteristic	**ACASI** N = 264	**FTF** N = 271	**p-value** [b]
Sex			0.90
male	130 (49%)	132 (49%)	
female	134 (51%)	139 (51%)	
Educational level			0.16
No schooling/Primary level	163 (62%)	157 (58%)	
Secondary level	99 (38%)	106 (39%)	
Higher education	2 (0.8%)	8 (3.0%)	
Age group			0.29
15–24	40 (15%)	30 (11%)	
25–34	60 (23%)	68 (25%)	
35–44	69 (26%)	85 (31%)	
45 and older	95 (36%)	88 (32%)	
Mobile phone ownership [a]			0.56
Yes	163 (62%)	174 (64%)	
No	101 (38%)	97 (36%)	
Internet usage			0.80
Yes, has used internet	31 (12%)	37 (14%)	
No, has not used internet	103 (39%)	102 (38%)	
No, does not know what the internet is	130 (49%)	132 (49%)	

Notes: [a] mobile phone ownership was defined as 'personal ownership' rather than 'household ownership';
[b] p-values were obtained from a chi-square test of the null hypothesis of no difference in the distribution of respondents' characteristics between study groups (ACASI vs. FTFI).

Respondents listed 3,414 maternal siblings during survey interviews: 1,766 brothers and 1,648 sisters. In total, 1,497 siblings listed during the survey interviews were reported to have died. Forty-nine reported deaths had missing data on age at death (3.3%) and 885 deaths were reported to have occurred at adult ages (15 years and older). Among this latter subset, the distributions of ages at death did not differ between study groups (Figure 2).

Figure 2: Age distributions of reported deaths, by assigned study group and gender of the deceased



Note: Each dot represents an adult death. The box plots represent summary measures of the distribution of ages at death, including median and inter-quartile range. The p-values reported above the brackets are derived from non-parametric Wilcoxon tests assessing differences between assigned study groups in the distribution of age at death.

The answers generated by the 3 HIV-related questions asked about deceased siblings differed between study groups (Table 2). ACASI respondents were more likely than FTF respondents to state that their sibling had never been tested for HIV (33% vs. 19%, $p < 0.001$). By comparison, ACASI respondents were less likely to state that they did not know if their deceased sibling had ever been tested for HIV (14% vs. 24%). In both study groups, the proportion of deceased siblings reported to have ever been tested for HIV was higher for recent deaths than for distant deaths (for example 67% vs. 43% in the ACASI group).

Table 2: Distribution of answers to HIV-related questions about deceased siblings, by study group and timing of death

	All deaths			Distant deaths			Recent deaths		
	ACASI N = 427	**FTF** N = 458	**p-value**[1]	**ACASI** N = 237	**FTF** N = 283	**p-value** [a]	**ACASI** N = 190	**FTF** N = 175	**p-value**[1]
Sibling ever tested for HIV?			<0.001			<0.001			0.01
Yes	228 (53%)	258 (56%)		101 (43%)	128 (45%)		127 (67%)	130 (74%)	
No	141 (33%)	89 (19%)		105 (44%)	75 (27%)		36 (19%)	14 (8.0%)	
Don't know	58 (14%)	111 (24%)		31 (13%)	80 (28%)		27 (14%)	31 (18%)	
Sibling's most recent HIV test results			0.05			0.10			0.20
Positive	123 (54%)	142 (55%)		56 (55%)	80 (63%)		67 (53%)	62 (48%)	
Negative	81 (36%)	104 (40%)		31 (31%)	41 (32%)		50 (39%)	63 (48%)	
Don't know	24 (11%)	12 (4.7%)		14 (14%)	7 (5.5%)		10 (7.9%)	5 (3.8%)	
Likelihood that sibling had HIV			<0.001			0.006			0.004
Highly likely	45 (15%)	18 (5.7%)		35 (19%)	18 (8.9%)		10 (8.1%)	0 (0%)	
Likely	27 (8.9%)	21 (6.6%)		18 (9.9%)	14 (6.9%)		9 (7.3%)	7 (6.2%)	
Unlikely	79 (26%)	71 (22%)		38 (21%)	47 (23%)		41 (33%)	24 (21%)	
Highly unlikely	124 (41%)	140 (44%)		71 (39%)	73 (36%)		53 (43%)	67 (59%)	
Don't know	29 (9.5%)	66 (21%)		19 (10%)	51 (25%)		10 (8.1%)	15 (13%)	

Note: Column percentages are in parentheses. Recent deaths are deaths that occurred during the past 8 years according to reports from survey respondents. Distant deaths are deaths that occurred more than 8 years ago according to reports from survey respondents.
[1] p-values were obtained from a chi-square test of the null hypothesis of no difference between study groups (ACASI vs. FTFI) in the distribution of answers to HIV-related questions.

ACASI respondents were more likely to state that they did not know the status of their deceased sibling(s) who had been tested prior to death (11% vs. 4.7%, $p = 0.05$). When asked to assess the likelihood that their deceased sibling was infected with HIV, the patterns of answers provided by ACASI and FTF respondents differed (Table 2, $p < 0.001$). ACASI respondents were more likely than FTF respondents to state that it was 'highly likely' that their deceased sibling was HIV-infected (15% vs. 5.7%). ACASI respondents were less likely to state that they did not know how likely it was that their deceased sibling had been infected with HIV (9.5% vs. 21%). In both study groups, the proportion of respondents who stated that it was highly likely that their deceased sibling had HIV was lower in recent than in distant deaths (for example, 8.1% vs. 19% in the ACASI group).

Based on answers to these 3 questions, the HIV status of the deceased sibling could not be determined for 6.8% of deaths reported by ACASI respondents, vs. 14.4% of deaths reported by FTF respondents (Table 3, $p = 0.003$). The proportion of missing data on HIV status varied by reported time since the death. Among distant adult deaths, ($n = 520$), the proportion of siblings whose HIV status could not be ascertained was 8.0% in the ACASI group, vs. 18.0% in the FTF group ($p = 0.007$). Among the 365 recent deaths (i.e., those that had occurred within the 8 years before the survey), the extent of missing data on HIV status of the deceased was lower, and there were no differences in completeness between ACASI and FTF (5.3% missing in the ACASI group vs. 8.6% missing in the FTF group, p = 0.25).

Table 3: Availability of survey data on HIV status of deceased siblings, by selected characteristics and timing of death

	All deaths			Distant deaths			Recent deaths		
	Available N = 790	**Missing** N = 95	**p-value**[1]	**Available** N = 450	**Missing** N = 70	**p-value**[1]	**Available** N = 340	**Missing** N = 25	**p-value**[1]
Assigned study group			0.003			0.007			0.25
ACASI	398 (93.2%)	29 (6.8%)		218 (92.0%)	19 (8.0%)		180 (94.7%)	10 (5.3%)	
FTF	392 (85.6%)	66 (14.4%)		232 (82.0%)	51 (18.0%)		160 (91.4%)	15 (8.6%)	
Sibling's gender			0.61			0.55			0.56
Female	345 (89.8%)	39 (10.2%)		215 (87.4%)	31 (12.6%)		130 (94.2%)	8 (5.8%)	
Male	445 (88.8%)	56 (11.2%)		235 (85.8%)	39 (14.2%)		210 (92.5%)	17 (7.5%)	
Sibling's reported age at death			0.47			0.29			0.65
15–24	114 (91.9%)	10 (8.1%)		75 (89.3%)	9 (10.7%)		39 (97.5%)	1 (2.5%)	
25–34	244 (90.0%)	27 (10.0%)		164 (88.7%)	21 (11.3%)		80 (93.0%)	6 (7.0%)	
35–44	252 (86.3%)	40 (13.7%)		139 (81.8%)	31 (18.2%)		113 (92.6%)	9 (7.4%)	
45–54	130 (90.3%)	14 (9.7%)		56 (86.2%)	9 (13.8%)		74 (93.7%)	5 (6.3%)	
55–64	42 (91.3%)	4 (8.7%)		15 (100%)	0 (0%)		27 (87.1%)	4 (12.9%)	
65+	8 (100.0%)	0 (0%)		1 (100%)	0 (0%)		7 (100%)	0 (0%)	

Note: Row percentages are in parentheses. Recent deaths are deaths that occurred over the past 8 years according to reports from survey respondents. Distant deaths are deaths that occurred more than 8 years ago according to reports from survey respondents. [1] p-values were obtained from chi-square tests of the null hypothesis of no difference between categories of a selected variable in the availability of survey data on HIV status.

According to survey data, 414 deceased adult siblings of respondents were classified as HIV-negative at the time of death, whereas 376 were classified as PHIV (Table 4). Reference HDSS data on HIV status were unavailable for approximately 4 out of 5 deceased siblings classified as HIV-negative by survey data. This proportion did not vary between the FTF and ACASI groups (p > 0.9). Reference HDSS data on HIV status were more frequently available for deceased siblings who were classified as PHIV according to survey data. A clinical record of an HIV test was thus available for 155 out of 376 (41%) of deceased siblings who were PHIV, and an additional 1.3% of these siblings (5 out of 376) had a self-report of an HIV test in their HDSS records. Based on a chi-square test, we could not reject the null hypothesis that there were no differences between ACASI and FTF groups in the availability of reference HDSS data on HIV for deceased siblings classified as PHIV by survey data (p = 0.11).

Table 4: Availability of reference HDSS data on HIV status of deceased siblings, by assigned mode of interview and survey-based classification of HIV status

	HIV status of deceased adult sibling according to survey data							
	HIV-negative				HIV-positive			
	TOTAL N = 414	ACASI N = 203	FTF N = 211	p-value[1]	TOTAL N = 376	ACASI N = 195	FTF N = 181	p-value[1]
Status of linkage with HDSS records				>0.9				0.11
Unlinked	326 (79%)	160 (79%)	166 (79%)		216 (57%)	122 (63%)	94 (52%)	
Linked to clinical records	71 (17%)	34 (17%)	37 (18%)		155 (41%)	71 (36%)	84 (46%)	
Linked to self-reported data	17 (4.1%)	9 (4.4%)	8 (3.8%)		5 (1.3%)	2 (1.0%)	3 (1.7%)	

Note: Column percentages are in parentheses. [1] p-values were obtained from a chi-square test of the null hypothesis of no difference between study groups (ACASI vs. FTFI) in the linkage of survey data to HDSS records.

Basic estimates indicated that the sensitivity of survey data was 89.9% in the ACASI group and 90.3% in the FTF group (Table 5), whereas basic estimates of specificity in these groups were 94.6% and 92.3%, respectively. Adjusted estimates yielded similar assessments. After accounting for partial verification bias through multiple imputations, corrected estimates of the sensitivity of survey data declined to 79.4% in the ACASI group and 75.9% in the FTF group. Corrected estimates of the specificity of survey data were 97.4% in the ACASI group and 96.3% in the FTF group. The sensitivity of survey data in recording the HIV status of deceased siblings was higher in recent deaths than in distant deaths: for example, in the ACASI group, corrected estimates of sensitivity were 67.6% for distant deaths vs. 96.0% for recent deaths. Based on logistic regression models, we could not reject the null hypotheses that there were no differences in sensitivity and specificity between ACASI and FTF, including for sub-groups of most recent deaths. An as-treated analysis, in which respondents are analyzed according to their actual (rather than assigned) mode of interview, yielded similar results (Table A-1).

Table 5: Sensitivity/specificity of survey data in recording HIV status of deceased adult siblings, by assigned mode of interview and reported timing of the death

	Available data[1]						Sensitivity				Specificity			
	N	**Ref**	**TP**	**FP**	**TN**	**FN**	**Basic[2]**	**Adjusted[3]**	**Corrected[4]**	**p-value[5]**	**Basic[2]**	**Adjusted[3]**	**Corrected[4]**	**p-value[5]**
All deaths										0.511				0.713
ACASI	398	116	71	2	35	8	89.9%	90.4%	79.4%		94.6%	94.8%	97.4%	
FTF	392	132	84	3	36	9	90.3%	91.1%	75.9%		92.3%	94.4%	96.3%	
Distant deaths										0.980				--[6]
ACASI	218	36	21	1	7	7	75.0%	77.6%	67.6%		87.5%	--[6]	--[6]	
FTF	232	53	40	0	9	4	90.9%	91.9%	67.5%		100%	--[6]	--[6]	
Recent deaths										0.401				--[6]
ACASI	180	80	50	1	28	1	98.0%	97.9%	96.0%		96.6%	--[6]	--[6]	
FTF	160	79	44	3	27	5	89.8%	89.0%	92.2%		90.0%	--[6]	--[6]	

Note: All results in this table were obtained from an intent-to-treat analysis, with respondents included in their assigned study group.

[1] Ref = Reference data available from the HDSS. TP = True positives, FP = False positives, TN = True negatives, FN = False negatives.

[2] Basic estimates of sensitivity were obtained by dividing TP by (TP+FN), and basic estimates of specificity were obtained by dividing TN by (TN + FP).

[3] Adjusted estimates are obtained from logistic regressions estimated among deaths for which reference data are available. These models also include controls for randomization strata.

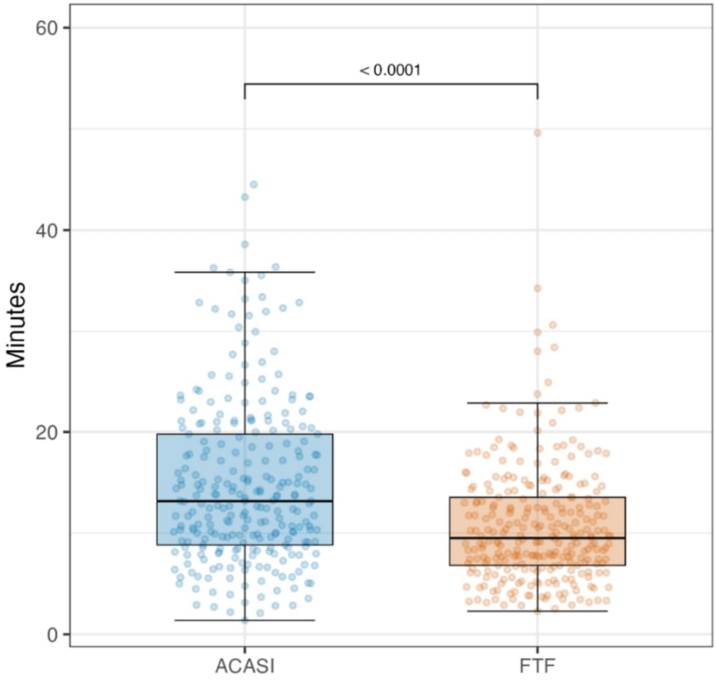
[4] Corrected estimates were obtained from similar logistic regression models, but they were based on datasets in which missing reference data on HIV status were imputed from multiple iterated chained equations.

[5] The P-values reported in the table were obtained from logistic regression models used to compute corrected estimates.

[6] Estimates of specificity are only reported for 'all deaths', and not for sub-samples defined by the reported timing of death, because of limited sample size and empty cells.

ACASI training lasted a median time of 7.4 minutes (inter-quartile range = 5.7 to 11.2 minutes, Figure A-1), with 4 participants requiring more than 20 minutes to complete ACASI training. ACASI also increased the time required to collect sibling survival histories (Figure 3) from a median time of 9.5 minutes using FTF to 13.1 minutes using ACASI ($p < 0.001$). Close to 25% (64/264) of respondents assigned to the ACASI group required more than 20 minutes to complete the sibling survival history, whereas this was the case for only 17 out of 271 (6.3%) of respondents assigned to FTF.

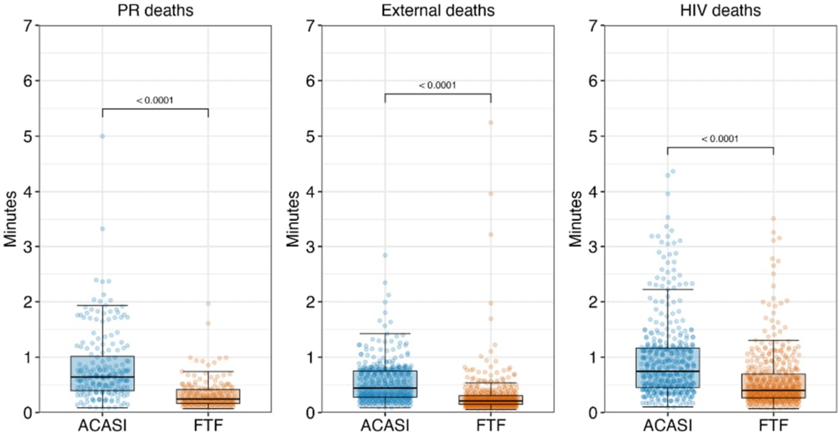
Figure 3: Duration of sibling survival histories, by assigned study group



Note: Each dot represents an adult death. The box plots represent summary measures of the distribution of interviewing times, including median and inter-quartile range. The p-value listed above the bracket is derived from a non-parametric Wilcoxon test of the null hypothesis of no difference in duration between ACASI and FTFI groups.

The collection of the 3 HIV questions required a median time of 0.4 minutes per deceased adult sibling in the FTF group and 0.7 minutes in the ACASI group (Figure 4, $p < 0.001$). This is comparable to the median time required to collect information on pregnancy-related deaths (0.6 minute in the ACASI group and 0.4 minutes in the FTF group, $p < 0.001$) and on accidental/external deaths (0.5 minute in the ACASI group and 0.2 minute in the FTF group, $p < 0.001$).

Figure 4: Distributions of interviewing time, by assigned study group and type of question



Note: PR deaths = Pregnancy-related deaths. Each dot represents an individual interview. The box plots represent summary measures of the distribution of interviewing times, including median and inter-quartile range. The p-values reported above the brackets are derived from non-parametric Wilcoxon tests assessing differences between assigned study groups in distributions of interviewing times.

4. Discussion

In this study we tested whether accurate data on the HIV status of deceased siblings could be collected during household surveys. Such surveys constitute the main sources of representative data on all-cause mortality in most African countries. They already provide data on some important causes and circumstances of death, e.g., external and pregnancy-related causes, but they do not collect data on mortality associated with HIV/AIDS. We thus added HIV questions to the standard adult and maternal mortality module and we conducted a validation study of these data in the Karonga HDSS in northern Malawi.

Adding HIV questions yielded largely complete data on the HIV status of respondents' deceased siblings, particularly among the subset of deaths that had occurred within the 8 years prior to the survey. This is important because when calculating estimates of adult/maternal mortality rates, often most survey programs (e.g., DHS) only consider recent deaths and person-years from such a reference period.

The classification of deceased siblings according to their HIV status generated by these survey questions was often accurate. In analyses that accounted for partial verification bias, slightly more than 3 out of 4 siblings who were PHIV according to reference HDSS data were also correctly classified as such by survey respondents. There were also very few false negative reports, i.e., siblings who did not have HIV according to reference HDSS data but who were reported as PHIV during the survey. Our estimates of the specificity of survey data in recording HIV status were thus >0.95 in corrected analyses. These accuracy levels are comparable to estimates of the sensitivity/specificity of survey data in recording pregnancy-related and injury-related deaths obtained in prior studies (Helleringer et al. 2013, 2014, 2015; Pison et al. 2018; Shahidullah 1995b, 1995a). Whereas questions about these latter circumstances of deaths are included in virtually all household surveys that have recently collected data on maternal and adult mortality, HIV questions have not yet been included. This is a missed opportunity because collecting these additional data requires very limited time: in face-to-face interviews, asking the 3 HIV questions required on average 0.4 minute (i.e., 25 seconds) per deceased adult sibling. By comparison, questions about pregnancy-related deaths require on average 20 seconds per woman who died at reproductive age.

We found limited support for the use of ACASI in collecting data on HIV-related deaths. The data collected using ACASI were more complete than FTF data, but only for the deaths that occurred more than 8 years prior to the study. Overall, ACASI data did not have higher sensitivity/specificity than the data collected via FTF. However, ACASI also required significantly more time than FTF to collect mortality data. Training ACASI respondents took an average of 7.4 minutes, and close to 4 additional minutes per respondent (relative to FTF) were needed to collect the siblings' survival history using ACASI. Shifting to ACASI would thus place an excessive burden on interviewers and respondents. Our study does not justify recommending ACASI over FTF for the collection of data related to HIV mortality in household surveys.

Our study has several limitations. First, the reference HDSS dataset does not constitute a gold standard in ascertaining the HIV status of deceased siblings. On the one hand, it relies partly on record linkage with clinical registers from health facilities to establish the HIV status of the deceased. These linkages might occasionally be made erroneously, e.g., in the case of two persons with similar names. Such instances might lead to estimates of sensitivity and specificity that are too low. On the other hand, the HIV status of some deceased siblings was occasionally assessed by the HDSS on the basis of self-reports. This was rare among siblings who were classified as HIV-positive but more common among those who were classified as HIV-negative. Since self-reported data on HIV test results might be affected by social desirability bias, our reference classification might include a number of false negatives (Johnston et al. 2015). This would lead to estimates of the specificity of survey data that might also be too low. Finally, we classified deceased siblings as HIV-negative if they had received negative test results in the 5 years before their death. This definition might systematically miss a number of individuals who had seroconverted within a few months/years prior to death.

However, given the low (recent) levels of HIV incidence in Malawi (Ministry of Health, Malawi 2018) and patterns of disease progression, false negatives due to recent seroconversions might be rare in our reference HDSS data.

Second, reference data on HIV status were only available for a subset of the deaths reported during the survey interview. We addressed this partial verification bias through multiple imputations. This approach led to overall estimates of sensitivity that were lower than those obtained for the subset of deaths for which reference data were available, and to estimates of specificity that were higher than those obtained for that subset. Multiple imputations, however, assume that reference data are missing at random (MAR) among reported deaths, i.e., the likelihood of data availability only depends on a few reported characteristics of respondents and the deaths they reported (e.g., age at death, gender of deceased, time since death). If data availability is determined by other unobserved factors, then reference data are not missing at random and multiple imputation procedures might not adequately correct estimates of sensitivity/specificity.

Third, our study focused on participants who were residents of the HDSS area, and whose siblings had died when they were also residents of the HDSS area. Furthermore, the Karonga HDSS in Malawi covers a predominantly rural population, where family ties might be stronger than in more urban areas. Due to this increased geographic and social proximity, our validation sample might have included individuals who had better knowledge about the medical history of their deceased siblings than others. The accuracy of survey data in recording the HIV status of deceased siblings might be lower among family members who migrated, or who resided further away from the deceased. However, this might not necessarily be the case, since migrants are often closely involved in providing the financial support required to care for relatives who are PHIV. They might also return home to visit sick relatives and might otherwise remain in touch with their siblings through phone calls and text messages. The accuracy of survey data on the HIV status of recently deceased individuals might also be more limited in cities and areas where family ties are weaker than in the area of Karonga district covered by the HDSS. Future validation studies of the HIV-related questions should include some of the urban HDSS located in eastern and southern Africa (Adedini et al. 2021; Beguy et al. 2015; Geubbels et al. 2015; Leyna et al. 2017; Oduor et al. 2023).

Fourth, due to limited sample size, we did not conduct further sub-group analyses of our study outcomes. We thus did not test whether the sensitivity/specificity of survey data in recording the HIV status of deceased siblings might vary according to (a) the characteristics of the respondents (e.g., gender, educational level) or (b) the characteristics of the deceased siblings (e.g., gender, age at death). We also did not investigate whether ACASI might help improve the accuracy of survey data for some population groups, e.g., those with secondary schooling and/or prior experience of digital tools.

Finally, our study might have limited external validity, i.e., its results might not reflect the levels of sensitivity/specificity that might be expected if HIV questions were systematically included in national household surveys. This is because in Karonga HDSS, the scale-up of HIV-related services occurred earlier than in other similar settings in Malawi and other African countries. Indeed, over the course of several years (2007–2011), the HDSS population was targeted by several HIV serosurveys, during which most adult residents were offered the opportunity to access home-based HIV testing services (Molesworth et al. 2010). As a result, a large fraction of the PHIV in the area became aware of their own HIV status and might subsequently have disclosed this information to siblings and other relatives (Price et al. 2017). In other settings where HIV testing was not scaled-up in a similar manner, fewer PHIV may be aware of their infection, and the sensitivity/specificity of survey data in recording the HIV status of deceased siblings might be lower. Additional studies should be conducted to confirm the validity of survey data generated by these HIV questions in populations with varying levels of access to HIV-related services. This is particularly important at a time when recent funding cuts might precipitate rapid declines in the availability of HIV testing services throughout the LMICs most affected by HIV (Powers et al. 2025; Ratevosian et al. 2025).

In conclusion, our study suggests a simple strategy for further improving the measurement and tracking of HIV-related mortality in LMICs with limited health information and CRVS systems. Instead of relying solely on statistical models and projections, adding a few simple questions to data collection tools already widely used by household surveys might help generate data on the mortality of persons with HIV in a particular country or population. Such questions require limited additional time to collect, but they might help better calibrate and test the statistical models and procedures used by UNAIDS and IHME to track HIV epidemics. If these findings are replicated in additional validation studies in other settings, their inclusion in large scale household surveys conducted in LMICs will be warranted.

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Appendix

Table A-1: Sensitivity/specificity of survey data in recording HIV status of deceased adult siblings, by actual mode of interview and reported timing of the death (as-treated analyses)

	Available data[1]						Sensitivity				Specificity			
	N	**Ref**	**TP**	**FP**	**TN**	**FN**	**Basic[2]**	**Adjusted[3]**	**Corrected[4]**	**p-value[5]**	**Basic[2]**	**Adjusted[3]**	**Corrected[4]**	**p-value[5]**
All deaths										0.928				0.729
ACASI	390	114	69	2	34	9	88.5%	89.3%	77.5%		94.4%	94.8%	97.3%	
FTFI	490	134	86	3	37	8	91.5%	92.1%	77.8%		92.5%	94.5%	96.4%	
Distant deaths										0.425				--[6]
ACASI	215	39	23	1	7	8	74.2%	77.0%	64.5%		87.5%	--[6]	--[6]	
FTFI	235	50	38	0	9	3	92.7%	93.6%	70.3%		100%	--[6]	--[6]	
Recent deaths										0.784				--[6]
ACASI	175	75	46	1	27	1	97.9%	93.6%	95.9%		96.4%	--[6]	--[6]	
FTFI	165	84	48	3	28	5	90.6%	89.7%	92.6%		90.3%	--[6]	--[6]	

Note: All results in this table were obtained from an as-treated analysis, with respondents included according to their actual mode of interview.

[1] Ref = Reference data available from the HDSS. TP = True positives, FP = False positives, TN = True negatives, FN = False negatives.

[2] Basic estimates of sensitivity were obtained by dividing TP by (TP+FN), and basic estimates of specificity were obtained by dividing TN by (TN + FP).

[3] Adjusted estimates were obtained from logistic regressions estimated among deaths for which reference data were available. These models also include controls for randomization strata.

[4] Corrected estimates were obtained from similar logistic regression models, but they were based on datasets in which missing reference data on HIV status were imputed from multiple iterated chained equations.

[5] The P-values reported in the table were obtained from logistic regression models used to compute corrected estimates.

[6] Estimates of specificity are only reported for 'all deaths' and not for sub-samples defined by the reported timing of death, because of limited sample size and empty cells.

Figure A-1: Distribution of ACASI training time