Tracing people living with HIV who are lost to follow-up at antiretroviral therapy programs in Southern Africa: A sampling-based study in six countries

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Abstract

Background: Attrition threatens the success of antiretroviral therapy (ART). We examined outcomes of people living with HIV (PLHIV) who were lost to follow-up (LTFU) at ART programs in Southern Africa.

Methods: We confirmed the LTFU status by checking the medical records, and then used a standardized protocol to trace a weighted random sample of PLHIV who were LTFU in eight ART programs in Lesotho, Malawi, Mozambique, South Africa, Zambia and Zimbabwe, 2017-2019. We ascertained the vital status and identified predictors of mortality using logistic regression, adjusted for sex, age, time on ART, time since LTFU, travel time, and urban or rural setting.

Results: Among 3,256 PLHIV, 385 (12%) were wrongly categorized as LTFU and 577 (17%) had missing contact details. We traced the remaining 2,294 PLHIV (71%) by phone calls, home visits or both: 768 (34% of 2,294) were alive and in care, including 385 (17%) silent transfers to another clinic; 528 (23%) were alive without care or unknown care; 252 (11%) had died. Overall, the status of 1,323 (41% of 3,256) PLHIV remained unknown. Mortality was higher in men than women, higher in children than in young people or adults, higher in PLHIV who had been on ART <1 year, or had been lost >1 year, and higher in PLHIV living in rural areas, and living further from the clinic. Results were heterogeneous between sites.

Conclusions: Our study highlights the urgent need for better medical record systems at HIV clinics and rapid tracing of PLHIV who are LTFU.

Introduction

Mortality and retention in care are essential indicators of the success of antiretroviral therapy (ART) programs. However, obtaining accurate estimates for these indicators is challenging, given the uncertain vital and care status of people living with HIV (PLHIV) who are classified as lost to follow-up. Attrition along the care cascade is common in ART programs, as sustaining regular clinical visits can be challenging long term [1–5]. In resource-limited settings, the long distances to health clinics, direct and indirect costs of travel, long waiting times, as well as stigma and discrimination, can deter clients from attending their scheduled appointments [6–11]. Also, undocumented, silent transfers from one clinic to another can erroneously result in a client being classified as lost to care. Silent transfers are common in sub-Saharan Africa, where national and international migration is frequent, and data exchange between clinics is limited [12–14].

Tracing is an essential part of ART program activities. PLHIV who are lost to follow-up are contacted to clarify their vital and care status, and if necessary, encouraged to return to care. Yet, the implementation of effective tracing in resource-limited settings can be challenging due to organizational barriers, and the lack of adequate documentation systems, and personnel [15]. A meta-analysis of individual patient data from nine tracing studies in sub-Saharan Africa recently showed that 29% of PLHIV defined as lost to follow-up remained lost despite tracing [16]. The same study also showed the variability of outcomes across regions, with 22% of mortality overall, ranging from 9% to 50%, depending on the setting.

Most previous tracing studies used disparate protocols and were based on convenience samples, such as PLHIV living near the clinics, which were not representative for the wider group of PLHIV lost to follow-up. In this study, we used a standardized protocol to trace a weighted random sample of PLHIV who were classified as lost to follow-up at eight ART programs in Southern Africa. We report on the success of tracing, and the vital and care outcomes.

Methods

The protocol for this study is available on Open Science Framework [17].

Study setting

Eight ART programs in Southern Africa (one in Lesotho, Mozambique, South Africa and Zambia, and two in Malawi and Zimbabwe) participated in this study between October 2017 and November 2019. Participating ART programs included 73 (range 1–32) clinics, 63 (86%) rural. All ART programs reported having tracing activities in place, but their methods and the degree of implementation varied ([Table 1](#)). All programs were members of the International epidemiology Databases to Evaluate AIDS (IeDEA) consortium in Southern Africa [18,19].

Sampling

PLHIV were eligible for the study if they were classified as lost to follow-up between January 1, 2014, and June 30, 2017, based on ART programs' databases. We used a disproportional stratified random sample design. Strata were defined by sex (women and men), age at last visit (0–15, 16–25, 26–50 and ≥51 years old) and time on ART (≤30, 31–180, 181–364 and ≥365 days since ART initiation). We aimed to sample 500 PLHIV from each ART program with equal allocation within each strata. For strata containing too few patients, all patients within that strata were sampled and an equal number of additional patients was sampled from the remaining strata in order to reach the target of 500. In ART programs with less than 500 PLHIV classified as lost, all were eligible for tracing.

Tracing protocol

The standardized tracing protocol consisted of two steps: 1) confirmation of vital and care status by checking the medical records at the clinic, and 2) tracing of participants confirmed as lost. Tracing consisted of up to three phone calls and up to three home visits. Phone calls were used at all participating ART programs except in Mozambique, and home visits at all programs except in South Africa ([Table 1](#)).

Data collection

We used a questionnaire to collect data from each participant traced, including demographics, tracing methods used, whether the participant was found in person or not, vital and care outcomes. Data collection was possible in English or Portuguese, on paper or Android tablets, using REDCap (Research Electronic Data Capture) [20,21].

Definitions and outcomes

PLHIV were defined as lost to follow-up if they missed an appointment for ≥ 60 days in Malawi and ≥ 90 days at all other participating ART programs in keeping with local guidelines. We defined the age of participants as the age at their last clinic visit, and three age groups: “children” (0-9 years), “young people” (10-24 years), and “adults” (≥ 25 years). We defined time on ART as the period between the participants’ ART initiation and last clinic visit and the time since the participant was lost as the period between the last clinic visit and the study start. We defined the study start date at each program as the date when tracing activities were initiated. We determined the travel time to the clinic as the time needed for participants to travel from home to the clinic (one-way), regardless of the mean of transport. We used the following vital status categories: i) alive, ii) known to have died, or iii) unknown. Care status was categorized as follows: i) in care (participant never missed an appointment, returned to care, and documented or silent [undocumented] transfer to another clinic), ii) out of care (stopped taking ART), or iii) unknown. Process outcomes included: i) whether the medical records of the participants were found or not, ii) whether participants were found (in person or through an informant, e.g. a relative) or not, either by phone or through home visits, and iii) whether tracing was successful in ascertaining the vital status of the participant or not. We classified participants whose medical records showed that they were in fact not lost to follow-up as “false lost”, and participants whose vital and care status remained unknown after tracing as “true lost”.

Statistical analyses

We used descriptive statistics to summarize participants’ characteristics, process outcomes, and vital and care status. We compared the PLHIV who were lost and traced to those who were not traced. We used

logistic regression models to calculate odds ratios with 95% confidence intervals (CI) of mortality and being in care. We adjusted multivariable models for sex, age, time on ART, time since the participant was lost, travel time, and the clinic setting (urban or rural). A random intercept for the ART program was included in all models to account for clustering within programs. The models on mortality included all participants who were traced and for whom the vital status could be determined. The models for being in care included all patients who were traced and found alive and for whom the care status could be determined. PLHIV with incomplete data on covariates were excluded. We used weights to adjust for the sampling strategy and dropouts at the different stages of the study (see [Supplementary Text 1](#)). Analyses were performed with STATA 15 (StataCorp, College Station, TX, USA) or R v3.6 (R Foundation for Statistical Computing, Vienna, Austria).

Ethical considerations

The Ethics Committee of the Canton of Bern, the Ethics Committee of the University of Cape Town and the local ethics committees or institutional review boards all approved the contribution of each ART program to research performed within the leDEA collaboration. All PLHIV provided consent for being traced within routine care.

Results

Participant recruitment and characteristics

A total of 19,722 PLHIV from 73 clinics and eight ART programs were eligible. Most clinics were health centers in rural areas. Most programs used both phone calls and home visits to trace lost clients ([Table 1](#)). We sampled 3,256 PLHIV; 1,837 (56%) were female, the median age at the last visit was 32 years (interquartile range [IQR]: 23–44), and 1,738 (53%) were on ART for <1 year. About half of the study participants were from smaller health centers, and rural areas ([Table 2](#)). We thus reached 81% of the planned sample size. The shortfall was explained by fewer than 500 eligible PLHIV in some sites, and logistical issues in others. The selection of participants into the study and their outcomes are shown in [Figure 1](#).

Check of status in medical records

By checking the medical records, we clarified the vital and care status of 385 (12%) participants who had been erroneously classified as lost to follow-up ("false lost"): 348 (11%) were alive, 37 (1%) had died. The contact information of 577 (17%) participants was missing, including 503 (15%) for whom we could not find any medical record, and 74 (2%) for whom no contact details were available in the record ([Figure 1](#)). We traced the remaining 2,294 (71%) participants. The proportion of traced participants among those sampled varied from 38% to 99%, depending on the ART program ([Supplementary Table 1](#)). Study participants who were traced were slightly older and more likely to have been on ART for less than a year than PLHIV who were not traced ([Supplementary Table 2](#)).

Tracing process and outcomes

Of 2,294 participants, we traced 761 (33%) by phone calls, 1,096 (48%) by home visits, and 437 (19%) by a combination of both. We found 624 (27%) of them in person and spoke to 1,226 (54%) informants. We did not find the remaining 444 (19%) participants, nor any informant. Overall, 1,296 (57%) of the 2,294 participants traced were alive, 252 (11%) had died, and 746 (32%) had unknown vital status ("true lost") ([Figure 1](#)).

The detailed vital status and care outcomes among the 2,294 participants traced are summarized by ART program in [Figure 2](#). Overall, 768 (34%) participants were alive and in care, 425 (19%) were alive and out of care, and 103 (4%) were reported alive by informants with unknown care status. Among the 768 participants who were in care, 491 (64%) had transferred to another clinic. Silent transfers thus accounted for 17% (385 of 2,294) of outcomes. There was substantial variation in the distribution of outcomes across ART programs. For example, 59% of participants were found to be alive and in care in an ART program in Malawi, with only 2% not found, compared to 7% alive and in care and 53% not found in a South African program ([Figure 2](#), [Supplementary Table 1](#)).

[Figure 3](#) combines outcomes obtained from examining the medical records with those from tracing by ART program. Overall 1,112 (34%) of 3,256 participants initially identified as lost to follow-up were alive and in care, 429 (13%) were alive, but out of care, 103 (3%) were alive with unknown care status, 289 (9%) had died, and 1,323 (41%) remained lost ("true lost"). Among the latter, 577 could not be traced, and 746 were traced, but the vital status remained unknown. Again, there was substantial variation across ART programs. For example, the proportion of participants "truly lost" ranged from 20% to 71% depending on the ART program ([Supplementary Table 1](#)).

Predictors of mortality and being in care

Of the 1,548 participants for whom the vital status was clarified through tracing, 1,105 (71%) with complete data were included in analyses of mortality. Of 1,296 participants who were alive, 787 (61%) with complete data could be included in analyses of being in care. Mortality was higher in men than women, higher in children than in young people or adults, higher in PLHIV who had been on ART <1 year, or had been lost ≥ 1 year and higher in PLHIV living in rural areas, and living further from the clinic ([Figure 4](#)). For outcome being in care, most, but not all of these associations went into the opposite direction ([Figure 5](#)), with a few exceptions. There was no association with male sex or living further away from the clinic and being in care in the adjusted model. Young people were less likely to be in care than adults and children. Finally, the probability of not being in care was higher in rural clinics.

Discussion

The vital status of PLHIV who are lost to follow-up in ART programs is generally unknown but central to estimating overall program-level mortality and retention in care [1,16,22,23]. In lower-income countries, vital registration and national electronic medical record systems are often weak or absent [24–26]. In many settings, physically tracing the patients lost to follow-up is the only way to obtain reliable information on their vital and care status. This study used a standardized protocol to trace a weighted random sample of PLHIV who were classified as lost in Southern Africa. It covered the steps from identifying PLHIV lost to follow-up in clinic records to tracing and ascertaining outcomes. When combining these steps, the vital status of 41% of PLHIV lost to follow-up remained unknown. Many PLHIV were either erroneously classified as lost to care or had missing contact details so that tracing was either unnecessary or impossible. Among traced PLHIV, about a third were alive in care, a fifth were alive but out of care, and a tenth had died. Another third of patients could not be found, and hence remained lost to follow-up. Taken together, our results starkly underline the difficulty of evaluating program-level mortality of ART due to high rates of loss to follow-up [22] and the challenges of tracing PLHIV.

The outcomes differed across programs, underlining the importance of local factors that influenced the successful tracing of PLHIV lost to follow-up and the need for locally adapted interventions. The 41% unknown vital and care status hides that this percentage was 21% in a Zimbabwean but 71% in a Malawian program. The examination of medical records showed that 10% to 20% of patients were not lost to follow-up in some ART programs, whereas this was not an important issue in other programs. Similarly, in some ART programs but not in others, many medical records could not be located or did not contain the contact information required for tracing. The tracing success also varied, with the percentage of unsuccessful efforts ranging from less than 5% of PLHIV traced to over 50%. Of note, a systematic review of tracing studies from sub-Saharan Africa [2] found that compared to phone calls, home visits increased the probability of success substantially. In this study, tracing success was lowest in a program from Johannesburg, South Africa, which did not visit homes because of safety concerns. Another critical factor determining tracing success is the delay between the loss to follow-up and tracing [16]. The timely tracing of patients lost to follow-up should, therefore be a priority.

236 The mortality among the PLHIV who were traced was lower than in previous studies. The systematic
237 review of tracing studies [2] found that overall, 34% of PLHIV lost and traced had died, compared to 11%
238 in the present study. The review covered the earlier years of the scale-up of ART, i.e. the period before
239 2010. Another systematic review found a decline in mortality from 50% to 30% when comparing study
240 periods before and after December 2007 [12]. However, the studies included in these reviews are not
241 directly comparable between themselves and with the present study. For example, definitions of loss to
242 follow-up varied widely, from a single missed appointment to no visit for over six months [2,12]. Mortality
243 was higher among male PLHIV classified as lost than females, confirming the results of an individual
244 patient data (IPD) meta-analysis [16], and a recent study from Zambia [27]. Mortality was also higher
245 among participants lost for over 12 months than in those lost for less than one year. In the IPD meta-
246 analysis, mortality among PLHIV lost to follow-up plateaued at 22% four years after the last visit [16].

247 The use of a weighted random sampling approach and a standardized protocol across different ART
248 programs in Southern Africa is a strength of our study. It allowed comparing mortality between PLHIV of
249 different ages, including children and young people. Data on children and young people are scarce. The
250 IPD meta-analysis [16] included one study of adults and children [28] and one study of children only [29].
251 It showed that mortality was higher in adults older than 30 years, but lacked the power to examine
252 differences between children, adolescents and adults [16]. Compared to adults, the present study shows
253 that mortality in children was increased, and lower in young people. In contrast, the probability of being in
254 care was lower in children and young people than adults. Our study supports calls for distinguishing
255 between children and young people [30,31].

256 Silent transfers, whereby patients change facilities without notifying their original clinic, are another barrier
257 to program evaluation. These PLHIV were erroneously classified as lost to care at their original clinic,
258 although they were in care at another clinic. Seventeen per cent of the PLHIV who were traced and found
259 to be in care had silently transferred to another clinic, in line with the estimate of 19% from a systematic
260 review and meta-analysis [12]. An evaluation of the South African national electronic monitoring system
261 for HIV-positive patients showed that undocumented transfers accounted for most misclassified client
262 outcomes [26]. HIV-related laboratory records of South Africa's National Health Laboratory Service have

been used to overcome this problem and estimate retention in care, taking into account transfers between clinics [32]. The Western Cape Provincial Health Data Centre consolidates person-level clinical data across government services using patient registration systems, a unique identification number, and several administrative and clinical digital health systems [33]. The South African experience illustrates the potential and constraints of national information systems. Unfortunately, such systems are still rare in many resource-limited settings.

Our study has several limitations. Only about 80% of the planned sample size was reached, which will have reduced power, and essential data was missing in many patients, most notably the last CD4 cell count. Further, medical records and contact details were missing in some patients, which prevented their tracing. Among those traced, the vital and care status could be ascertained for two thirds only. Our study was not designed to determine barriers for remaining in long-term care, which are best addressed using qualitative methods. For example, concerns about stigma and disclosure may prevent some PLHIV from providing accurate contact details or encourage them to change clinic silently [9].

In conclusion, our study found that about a third of PLHIV considered lost to follow-up at ART programs in Southern Africa were alive and in care. About 40% remained lost due to a combination of unreliable records, missing contact information and the inability to locate patients despite intensive tracing efforts. Our study underlines the need for nationally linked medical record systems to prioritize PLHIV at high risk of death for tracing and returning to care, including children, and those who are lost after in the first year of ART and who live at a greater distance from the clinic. It illustrates the difficulties of evaluating program-level mortality in the presence of high rates of loss to follow-up [1,16,22,23]. A sampling-based approach can lead to a better understanding of the outcomes in those lost to follow-up and inform interventions tailored to the ART program.

Authors' contributions

MB, BC and ME designed the study, performed the analyses and drafted the manuscript. NA and FC performed the sampling and provided statistical support. JM, LJ, JH, JvD, MJV, MvL, CC, SJP, DO and MPF reviewed the study design and were in charge of data collection. All authors reviewed, revised and approved the final manuscript.

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Conflicts of interest

The authors declare that they have no competing interests.

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399 **Tables and figures**

400 **Table 1:** Characteristics of ART programs.

	All	SMART, Lesotho	Dignitas, Malawi	Lighthouse Trust, Malawi	SMART, Mozambique	Themba Lethu, South Africa	MoH-CIDRZ, Zambia	SMART, Zimbabwe	Newlands, Zimbabwe
Number of PLHIV classified as LTFU between 01/2014 and 06/2017	19,722	423	3,327	6,713	1,882	1,997	4,777	413 *	190
Number of clinics at ART program	73	6	22	2	7	1	2	32	1
Setting of clinics									
Rural	63 (86%)	5 (83%)	21 (95%)	0	5 (71%)	0	0	32 (100%)	0
Urban	10 (14%)	1 (17%)	1 (5%)	2 (100%)	2 (29%)	1 (100%)	2 (100%)	0	1 (100%)
Level of care of clinics									
Health center	65 (89%)	6 (100%)	21 (95%)	0	5 (71%)	0	2 (100%)	30 (94%)	1 (100%)
District hospital	7 (10%)	0	1 (5%)	2 (100%)	2 (29%)	0	0	2 (6%)	0
Regional hospital	1 (1%)	0	0	0	0	1 (100%)	0	0	0
Tracing methods in place									
Phone calls		Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Home visits		Yes	Yes	Yes	Yes	No	Yes	Yes	Yes

401 * Only PLHIV classified as lost to follow-up in 2014 were included.

402 Abbreviations: ART: antiretroviral therapy, clinics: health clinics; LTFU: lost to follow-up; MoH-CIDRZ: Ministry of Health-Centre for Infectious Disease Research in

403 Zambia; PLHIV: people living with HIV; SMART: SolidarMed-supported antiretroviral therapy program.

404

405 **Table 2:** Characteristics of all PLHIV defined as LTFU and sampled for the study, overall and by ART program.

	All	SMART, Lesotho	Dignitas, Malawi	Lighthouse Trust, Malawi	SMART, Mozambique	Themba Lethu Clinic, South Africa	MoH-CIDRZ, Zambia	SMART, Zimbabwe	Newlands, Zimbabwe
	N=3,256	N=423	N=501	N=506	N=467	N=492	N=264	N=413	N=190
Sex									
Male	1,419 (44%)	160 (38%)	230 (46%)	261 (52%)	216 (46%)	224 (46%)	137 (52%)	115 (28%)	76 (40%)
Female	1,837 (56%)	263 (62%)	271 (54%)	245 (48%)	251 (54%)	268 (54%)	127 (48%)	298 (72%)	114 (60%)
Age at last visit, in years									
0-9	327 (10%)	8 (2%)	91 (18%)	81 (16%)	69 (15%)	0	56 (21%)	19 (5%)	3 (2%)
10-24	771 (24%)	56 (13%)	134 (27%)	155 (31%)	123 (26%)	74 (15%)	88 (33%)	88 (21%)	53 (28%)
≥25	2,158 (66%)	359 (85%)	276 (55%)	270 (53%)	275 (59%)	418 (85%)	120 (46%)	306 (74%)	134 (70%)
Median (interquartile range)	32 (23-44)	35 (29-43)	27 (15-45)	26 (18-44)	27 (20-39)	39 (29-50)	24 (13-51)	32 (25-40)	33 (24-41)
Time on ART, at last visit, in months									
0-11	1,738 (53%)	145 (34%)	319 (64%)	344 (68%)	221 (47%)	297 (60%)	198 (75%)	177 (43%)	37 (19%)
≥12	1,518 (47%)	278 (66%)	182 (36%)	162 (32%)	246 (53%)	195 (40%)	66 (25%)	236 (57%)	153 (81%)
Last CD4 cell count, cells/mm³									
0-199	522 (16%)	77 (18%)	30 (6%)	63 (12%)	70 (15%)	121 (25%)	10 (4%)	102 (25%)	49 (26%)
200-349	524 (16%)	74 (17%)	48 (10%)	52 (10%)	101 (22%)	124 (25%)	12 (5%)	78 (19%)	35 (18%)
350-499	387 (12%)	53 (13%)	44 (9%)	41 (8%)	65 (14%)	95 (19%)	6 (2%)	44 (11%)	39 (21%)
≥500	551 (17%)	142 (34%)	13 (3%)	27 (5%)	122 (26%)	126 (26%)	18 (7%)	45 (11%)	58 (31%)
Median (interquartile range)	332 (191-522)	413 (228-705)	327 (209-407)	270 (144-433)	384 (221-574)	331 (194-517)	358 (219-594)	268 (143-422)	384 (185-576)
Missing	1,272 (39%)	77 (18%)	366 (73%)	323 (64%)	109 (23%)	26 (5%)	218 (83%)	144 (35%)	9 (5%)
Time since the participant was seen for the last time, in months									
0-11	462 (14%)	26 (6%)	84 (17%)	84 (17%)	179 (38%)	42 (9%)	14 (5%)	0	33 (17%)
≥12	2,638 (81%)	385 (91%)	391 (78%)	389 (77%)	213 (46%)	446 (91%)	249 (94%)	413 (100%) *	152 (80%)
Missing	156 (5%)	12 (3%)	26 (5%)	33 (7%)	75 (16%)	4 (<1%)	1 (<1%)	0	5 (3%)
Travel time from home to the clinic (one-way)									
<1 hour	1,785 (55%)	168 (40%)	472 (94%)	478 (94%)	137 (29%)	0	245 (93%)	100 (24%)	185 (97%)
≥1 hour	527 (16%)	169 (40%)	29 (6%)	4 (1%)	292 (63%)	1 (<1%)	15 (6%)	12 (3%)	5 (3%)
Missing	944 (29%)	86 (20%)	0 (0%)	24 (5%)	38 (8%)	491 (100%)	4 (2%)	301 (73%)	0
Confirmed LTFU status (from medical records)									
Yes	2,294 (71%)	248 (59%)	437 (87%)	193 (38%)	326 (70%)	464 (94%)	206 (78%)	232 (56%)	188 (99%)
No	962 (29%)	175 (41%)	64 (13%)	313 (62%)	141 (30%)	28 (6%)	58 (22%)	181 (44%)	2 (1%)
Setting of the clinic									
Rural	1,478 (45%)	391 (92%)	471 (94%)	0	203 (43%)	0	0	413 (100%)	0
Urban	1,778 (55%)	32 (8%)	30 (6%)	506 (100%)	264 (57%)	492 (100%)	264 (100%)	0	190 (100%)
Level of care of the clinic									
Health center	1,753 (54%)	423 (100%)	445 (89%)	0	203 (43%)	0	264 (100%)	228 (55%)	190 (100%)
District hospital	1,011 (31%)	0	56 (11%)	506 (100%)	264 (57%)	0	0	185 (45%)	0
Regional hospital	492 (15%)	0	0	0	0	492 (100%)	0	0	0

* Only PLHIV classified as lost to follow-up in 2014 were sampled.

Abbreviations: ART: antiretroviral therapy; LTFU: lost to follow-up; MoH-CIDRZ: Ministry of Health-Centre for Infectious Disease Research in Zambia; PLHIV: people living with HIV; SMART: SolidarMed-supported antiretroviral therapy program.

411 **Figure 1:** Study flowchart.

412
413 Abbreviations: LTFU: lost to follow-up; PLHIV: people living with HIV.

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Figure 2: Vital status and care outcomes among participants who were traced, by ART program and overall.

Abbreviations: LTFU: lost to follow-up; MoH-CIDRZ: Ministry of Health-Centre for Infectious Disease Research in Zambia; SMART: SolidarMed-supported antiretroviral therapy program.

Figure 3: Differences across ART programs in the proportions of participants confirmed lost to follow-up, medical records not found, alive or who have died, among those sampled (first bar), among the sub-group of those traced (second bar) and the combined outcomes (third bar).

Abbreviations: LTFU: lost to follow-up; MoH-CIDRZ: Ministry of Health-Centre for Infectious Disease Research in Zambia; SMART: SolidarMed-supported antiretroviral therapy program.

430 **Figure 4:** Univariable and multivariable logistic regressions of mortality, among 1,105 participants who
 431 were traced and who had complete covariate information.

432

433 Abbreviations: ART, antiretroviral therapy; CI, confidence interval; OR, odds ratio.

434

Figure 5: Univariable and multivariable logistic regressions of being in care, among 787 participants who were traced and found alive, and who had complete covariate information.

Abbreviations: ART, antiretroviral therapy; CI, confidence interval; OR, odds ratio.

439 **Supplementary Table 1:** Vital status, care status and process outcomes of participants, among those sampled, among those confirmed lost to
440 follow-up and traced, and combined, by ART program.

	All	SMART Lesotho	Dignitas, Malawi	Lighthouse Trust, Malawi	SMART, Mozambique	Themba Lethu Clinic, South Africa	MoH-CIDRZ, Zambia	SMART, Zimbabwe	Newlands, Zimbabwe
Information from medical records among sampled participants	N=3,256	N=423	N=501	N=506	N=467	N=492	N=264	N=413 *	N=190
Participants alive and in care ("false lost")	344 (11%)	73 (17%)	64 (13%)	40 (8%)	97 (21%)	18 (4%)	5 (2%)	45 (11%)	2 (1%)
Participants alive but out of care ("false lost")	4 (<1%)	0	0	0	1 (<1%)	0	0	3 (1%)	0
Participants have died ("false lost")	37 (1%)	18 (4%)	0	0	4 (1%)	0	1 (<1%)	14 (3%)	0
Medical records not found	503 (15%)	83 (20%)	0	262 (52%)	39 (8%)	0	1 (<1%)	118 (29%)	0
Medical records found, no contact details	74 (2%)	1 (<1%)	0	11 (2%)	0	10 (2%)	51 (19%)	1 (<1%)	0
Medical records found, confirmed LTFU	2,294 (71%)	248 (59%)	437 (87%)	193 (38%)	326 (70%)	464 (94%)	206 (78%)	232 (56%)	188 (99%)
Tracing outcomes among participants with confirmed LTFU status	N=2,294	N=248	N=437	N=193	N=326	N=464	N=206	N=232	N=188
Participants alive and in care	768 (34%)	83 (34%)	258 (59%)	45 (23%)	31 (10%)	32 (7%)	75 (36%)	154 (66%)	90 (48%)
Participants alive but out of care	425 (19%)	37 (15%)	21 (5%)	14 (7%)	138 (42%)	136 (29%)	6 (3%)	25 (11%)	48 (25%)
Participants alive but care status unknown	103 (4%)	28 (11%)	4 (<1%)	5 (3%)	39 (12%)	5 (1%)	9 (4%)	9 (4%)	4 (2%)
Participants have died	252 (11%)	47 (19%)	55 (13%)	40 (21%)	52 (16%)	0	20 (10%)	31 (13%)	7 (4%)
Tracing done, nobody found	444 (19%)	8 (3%)	8 (2%)	67 (35%)	16 (5%)	246 (53%)	71 (35%)	7 (3%)	21 (11%)
Tracing done, informant found, vital status unknown	302 (13%)	45 (18%)	91 (21%)	22 (11%)	50 (15%)	45 (10%)	25 (12%)	6 (3%)	18 (10%)
Combined vital status, care status and process outcomes among sampled participants	N=3,256	N=423	N=501	N=506	N=467	N=492	N=264	N=413	N=190
Participants alive and in care	1,112 (34%)	156 (37%)	322 (64%)	85 (17%)	128 (27%)	50 (10%)	80 (30%)	199 (48%)	92 (48%)
Participants alive but out of care	429 (13%)	37 (9%)	21 (4%)	14 (3%)	139 (30%)	136 (28%)	6 (2%)	28 (7%)	48 (25%)
Participants alive but care status unknown	103 (3%)	28 (7%)	4 (1%)	5 (1%)	39 (8%)	5 (1%)	9 (3%)	9 (2%)	4 (2%)
Participants have died	289 (9%)	65 (15%)	55 (11%)	40 (8%)	56 (12%)	0	21 (8%)	45 (11%)	7 (4%)
Participants "truly lost" **	1,323 (41%)	137 (32%)	99 (20%)	362 (71%)	105 (23%)	301 (61%)	148 (57%)	132 (32%)	39 (21%)

441

442 * Only PLHIV classified as lost to follow-up in 2014 were sampled.

443 ** Tracing impossible, nobody found or informant found but unknown vital status.

444 Abbreviations: ART: antiretroviral therapy; LTFU: lost to follow-up; MoH-CIDRZ: Ministry of Health-Centre for Infectious Disease Research in

445 Zambia; SMART: SolidarMed-supported antiretroviral therapy program.

446 **Supplementary Table 2:** Characteristics of the participating people living with HIV traced compared to
 447 not traced

	Traced	Not traced
	N= 2,294	N=962
Sex		
Male	1,017 (44.3%)	402 (41.8%)
Female	1,277 (55.7%)	560 (58.2%)
Age at last visit, in years		
0-9	212 (9.2%)	115 (12.0%)
10-24	538 (23.5%)	233 (24.2%)
≥25	1,544 (67.3%)	614 (63.8%)
Time on ART, at last visit, in months		
0-11	1,301 (56.7%)	437 (45.4%)
≥12	993 (43.3%)	525 (54.6%)
Time since the participant was seen for the last time, in months		
0-11	325 (14.3%)	137 (16.6%)
≥12	1,947 (85.7%)	691 (83.4%)
Setting of the clinic		
Rural	1,014 (44.2%)	464 (48.2%)
Urban	1,280 (55.8%)	498 (51.8%)
Travel time from home to the clinic (one-way) *		
<1 hour	1,301 (76.8%)	484 (78.4%)
≥1 hour	394 (23.2%)	133 (21.6%)

448

449 * Only available for 2,312 participants.

450 Abbreviation: ART: antiretroviral therapy.

451

Supplementary Text 1: Weighing of analyses

We used weights to account for the sampling strategy and dropouts at the different stages of the study (see flowchart below).

Figure S1. The different stages of sampling and dropouts for which sampling weights (w_{sampling}) and dropout weights (w_{d1} , w_{d2} , w_{d3} , w_{d4}) were calculated.

For each of the included ART programs, we accounted for the stratified random sample by calculating programme-specific sampling weights (w_{sampling}) within each of the 32 strata (2 sexes x 4 age groups x 4 days since ART initiation). These were calculated as $w_{\text{sampling}} = N_{\text{LTFU}}/N_{\text{sampling}}$ (i.e. the inverse of the sampling proportion), where N_{LTFU} is the total number of patients lost to follow-up (LTFU) within a specific program and stratum, and N_{sampling} is the total number of sampled patients within that programme and stratum.

We observed four stages of dropout/nonresponse in our study. Among all patients selected by the stratified random sample ($n=3,256$), the first stage of dropout (d_1) happened when checking medical records. Dropouts at this stage included patients wrongly defined as LTFU ($n=385$) and records that were not found ($n=503$). The second stage of dropout (d_2) was among the remaining patients confirmed LTFU ($n=2,368$), of whom 74 could not be traced due to missing contact details. Among patients who were traced ($n=2,294$), the third stage of dropout (d_3) included patients for whom nobody was found ($n=444$). Finally, the fourth and last stage of dropout/nonresponse (d_4) was among patients/informants found ($n=1850$), and included all patients for whom no vital or care status was obtained ($n=302$). To account for the different stages of dropout, we estimated the probability of non-dropout at each stage using a logistic regression model. Models included the categorical covariates sex (female, male), setting (urban, rural), level of care (health center, district hospital, regional hospital), and the continuous covariates age and time on ART, as well as all two-way interactions between covariates. Weights w_{d1} , w_{d2} , w_{d3} , and w_{d4} were then calculated as the inverse of the probability of non-dropout at the four stages.

The distribution of the derived weights is shown in the figure below. We obtained the final weights by multiplying the different weights up to the stage at which the analyses were performed. For the logistic regression of mortality and being in care, the weights were calculated as $w = w_{\text{sampling}} * w_{d1} * w_{d2} * w_{d3} * w_{d4}$.

Figure S2. The distribution (density) of the sampling weights and – for better visibility – the logarithm of the sampling weights (top 2 panels), and of the four dropout weights (w_{d1} to w_{d4}). Sampling weights varied most, median sampling weight assigned to patients sampled was 1.61 (interquartile range IQR 1.00-4.47, range 1.00-238.00). Dropout weights varied less, with medians 1.27 (IQR 1.04-1.54, range 1.01-6.41) for w_{d1} , 1.01 (IQR 1.00 – 1.03, range 1.00-1.38) for w_{d2} , 1.04 (IQR 1.03 – 1.29, range 1.01-4.42) for w_{d3} , and 1.19 (IQR 1.13 – 1.24, range 1.01-1.63) for w_{d4} .