

Evaluation of a Home-Based Tracing Study of Patients Lost to Follow-Up from HIV Care in Rural Mozambique

Student: Paula Ruiz-Castillo Rojas

Supervisors: Denise Naniche (Associate Research Professor, ISGlobal),
Elisa López-Varela (Medical research fellow, ISGlobal) &
Laura de la Fuente Soro (Pre-doctoral fellow, ISGlobal)

Date of submission, June 20th 2018
MFP Thesis: 8256 words

Table of contents

1. Executive Summary

2. Background

3. Problem statement

4. Objectives

5. Methods:

- Study setting and participants
- Data collection
- Data management
- Data analysis
- Definitions
- Ethical considerations

6. Results

7. Discussion & limitations

8. Conclusion & recommendations

9. References

List of abbreviations

AIDS: Acquired immune deficiency syndrome

ART: Antiretroviral treatment

CDC: Center for Disease Control

CI: Confidence interval

CISM: Centro de Investigação em Saúde de Manhiça

ePTS: electronic Patient Tracking System

HBT: home-based testing

HDSS: Health and demographic surveillance system

HIV: Human immunodeficiency virus

HR: Hazard ratio

HTC: HIV testing and counseling

IQR: Interquartile range

LTFU: Lost to follow-up

MDH: Manhiça District Hospital

MoH: Ministry of health

ODK: Open data kit

PICT: provider-initiated counseling and testing

PLHIV: People living with HIV/AIDS

REDCap: Research electronic data capture

RIC: Re-engagement in care

SSA: Sub-Saharan Africa

TB: Tuberculosis

UNAIDS: Joint United Nations Programme on HIV/AIDS

VCT: Voluntary counseling and testing

WHO: World Health Organization

1. Executive Summary

In response to the HIV epidemic, UNAIDS has established the 90-90-90 targets of 90% of all people living with HIV (PLHIV) knowing their HIV status; 90% of all people diagnosed with HIV receiving sustained antiretroviral therapy (ART); and 90% of all people on treatment having viral suppression by 2020. Such an ambitious objective will require first, a comprehensive understanding of the barriers faced by the patients to get diagnosed and treated; and second, a constant evaluation of strategies to re-engage patients in care. This study performed home-visits to a cohort of HIV patients in southern Mozambique considered LTFU one year after their diagnosis. The aim of the visit was to determine patient outcomes, to encourage re-engagement in care (RIC), and to understand the main reasons for non-adherence to HIV care.

We found that the vast majority of the patients visited (93%) were LTFU from care before starting treatment. More specifically, 52% of the participants had not even enrolled in care prior to the home visit. After the visit, one third of the patients visited returned to care within 90 days, whereas only 4% of spontaneous returns occurred in a group of non-visited patients. Participants who were visited were 10 times more likely to re-engage in care. Having enrolled in care prior to the visit played a crucial role in the chances of RIC since patients enrolled were 4,71 times more likely to return to care than those who never enrolled in care. Among the most frequent reasons for LTFU reported by participants were a self-perception of good health and a discouraging social environment. Regarding barriers to retention associated with the relationship with the health system, patients declared having lost their hospital identification card, not believing the HIV test results, and/or having to wait too long at the clinic.

In addition to maintaining patients in care, it is key to develop outreach strategies to re-engage LTFU, as these patients suffer from high rates of morbidity and mortality. A home-visit 12 months post diagnosis had a positive effect on the rates of RIC, but mostly on patients who had at least enrolled in care. This is a resource-intensive intervention and therefore might be best applied in the context of a differentiated care model for those patients LTFU after enrollment in care. In addition, given the high proportion of patients LTFU who had not enrolled in care at the time of the visit, and who are less likely to re-engage, alternative interventions must be tailored for this group. Lastly, improvements on the logistics of HIV care, as well as in patient-provider communication are key to reduce patient attrition. Larger societal changes such as strong social and family support, and non-discriminating attitudes towards patients will also contribute to increase patients in care.

2. Background

The 90-90-90 targets

The UNAIDS has set the ambitious goal of ending the AIDS epidemic by 2030.¹ Although the response against HIV has seen significant progress in the past decades, the 90-90-90 target has been established to accelerate advancement. By 2020, 90% of all people living with HIV (PLHIV) should know their HIV status; 90% of all people diagnosed with HIV should receive sustained antiretroviral therapy (ART); and 90% of all people on treatment should have viral suppression. Achieving these figures will result in at least 73% of all PLHIV worldwide to be virally suppressed, which will lead to extensive health improvements and reduced transmission as well as economic and societal benefits.¹

There are multiple strategies aiming at ending the HIV epidemic that focus on prevention, diagnosis, and treatment. The 2017 UNAIDS report on progress towards the 90-90-90 targets showed that the first 90 has the lowest rates of the three objectives.² In 2017, an estimated 70% (51-84%) of PLHIV knew their status, whereas 77% (57-89%) of those who knew their status were under ART, and of those, 82% (60-89%) were virally suppressed. ART has revolutionized the management of the HIV epidemic, greatly increasing life expectancy and averting new cases.³⁻⁶ In an effort to enhance treatment uptake worldwide, the recent “test and treat all” guidelines recommend ART for every patient regardless of his or her CD4 count.⁷⁻⁹ Previous to these guidelines, ART was provided based on the CD4 count, or clinical monitoring of the patient.¹⁰ One of the expected benefits of the new model is that by skipping steps of care, the number of patients linked to HIV care will increase due to a simplification of the overall process.¹¹ In order to achieve the third target, high retention rates on treatment as well as access to viral load monitoring will be required.²

An important challenge: patients lost-to follow up (LTFU)

Despite massive advancements in treatment scale up and coverage, in 2016 it was estimated that only 53% of all PLHIV were receiving ART, with the majority of the untreated patients living in sub-Saharan Africa (SSA).² One of the biggest challenges is retaining PLHIV in care throughout the different stages of the cascade of HIV care. LTFU is particularly severe in low-income countries, where the barriers to access to care are considerably high and individuals are hard to reach.¹²⁻¹⁴ Patient losses to follow-up are a threat to the success of ART programs, since they represent a source of HIV transmission, and a cause of high mortality and morbidity. Although there is not a universal definition, generally a patient is considered LTFU if he or she has stopped attending clinical appointments at any of the steps of the continuum of HIV care.¹⁵ The essential stages of the HIV care pathway prior to the “test and treat”

guidelines include pre-ART phases: enrollment in care, linkage to care, assessment of ART eligibility (i.e.; obtaining a CD4 count and return to receive results), and post-ART phases: ART initiation, and ART retention in care. However, a new model has been proposed under the universal ART policies, in which the pre-ART period only consists of enrollment in care and linkage to ART initiation, whereas in the post-ART stage we can differentiate between early retention and lifelong retention in care.⁹ Accurate monitoring of the losses along the cascade is crucial to develop targeted interventions, yet it is challenging due to the poor quality of health information systems, as well as the dynamic nature of patient behavior. LTFU is often overestimated because of difficulties documenting migrations, transfers to other facilities and deaths. In addition, the pathway of HIV care is not the linear sequence presented by the 90-90-90 targets, but a more complex process in which patients might cycle in and out the subsequent steps.^{15,16}

There is a substantial amount of research focusing on patient linkage and retention in care.^{13,17-18} On the other hand, long-term retention in ART programs and RIC of those LTFU has received comparatively less attention.¹³ In addition, studies on rates and risk factors for LTFU have shed little light on potential interventions to re-engage patients.^{15,19} A few examples of outreach programs encouraging patients to return to ART via phone calls, letters, or visits, both in high and low income countries have been evaluated in the literature.²⁰⁻²³ Such examples have demonstrated that program attrition can be reduced through active tracking of patients. Although most countries recommend the tracing of LTFU patients, context-specific strategies have still to be defined and implemented. In addition, evidence on specific populations who could benefit more from RIC interventions is currently lacking. Given the importance of re-engaging patients in the overall success of ART programs, intensified efforts and improved intervention strategies are necessary.

Barriers to treatment adherence

Improvements of ART programs could contribute to maintaining patients in care, avoiding much of the post-LTFU interventions. However, to prevent patient attrition, first it is necessary to understand its root causes. In an effort to identify key problematic aspects, multiple studies have documented patient narratives of self-perceived barriers to care.^{12,24-25} Specifically, studies in SSA have identified societal and individual factors, as well as weak health systems as leading causes.²⁶⁻²⁹ Stigma and lack of spouse or family support are typically a common impediment for patients.^{12,30} HIV positive individuals are often afraid to disclose their serostatus, and concerned to be seen while seeking care due to potential social isolation.¹³ Additionally, other themes related with the individual, such as financial problems, perception of wellness, drug adverse effects, or poor health have been described.^{12,13} Lastly, healthcare systems with low coverage, overburden, administrative problems,

and/or inefficient delivery of services contribute to patient attrition.¹³ Nevertheless, further understanding of the location- or population-specific barriers would help to better tailor programs for each context.³¹ For instance, knowing if the barriers perceived by LTFU patients vary along the different steps of the cascade, could guide targeted interventions for each group of patients.

3. Problem statement

Retention in care of PLHIV is one of the main challenges impeding halting the HIV epidemic. Efforts to decrease patient attrition are key but so are strategies to recapture those who have abandoned the continuum of HIV care. However, there seems to be a research gap in the identification of population-specific reasons for LTFU as well as the description of best practices to re-engage patients LTFU at different stages of the cascade, especially in areas of high endemicity and low resources such as SSA.

4. Objectives

Primary objective

The primary objective of this study was to evaluate outcomes of LTFU patients of a cohort in southern Mozambique who had a home-visit 12 months post-diagnosis, and to assess the effect of this visit on re-engagement in HIV care.

Secondary objectives

- To describe sociodemographic characteristics of individuals LTFU
- To identify the main steps in the cascade in which patients were lost from HIV care
- To compare the rates of RIC of the patients receiving a home visit with spontaneous RIC in a group of non-visited patients.
- To explore the perceived barriers to retention in care for patients considered LTFU

5. Methods

Study setting and participants

The study was performed in the Manhiça District, a semi-rural area in Maputo province (southern Mozambique) served by the Manhiça District Hospital (MDH) and 11 peripheral health posts. Free HIV services are offered in the facilities, including HTC (HIV testing and counseling) and ART treatment following the WHO recommended criteria to start care. In this area, since 1996, the Centro de Investigação em Saúde de Manhiça (CISM) runs continuous health and demographic surveillance system (HDSS) for vital events including births, deaths, and migrations which in 2015, at the time of the study, covered a total district population of nearly 174,000 individuals.³² This is a high HIV burden setting, with an estimated community based prevalence of 39.7% among adults in 2012.³³

This study was embedded in a larger prospective cohort referred to as the Tesfam cohort which consecutively enrolled patients with a new HIV diagnosis from three different testing modalities: voluntary counseling and testing (VCT), provider-initiated counseling and testing (PICT) and home-based testing (HBT).³⁴⁻³⁵ The inclusion criteria consisted of being eighteen years old or older, residing in the MDH catchment area, and receiving a first HIV positive result. Exclusion criteria were being co-infected with tuberculosis, pregnancy at the time of diagnosis, or having a HIV test performed in the previous 3 months. After recruitment in the study, the newly diagnosed HIV positive patients were referred to the MDH reception for enrollment in care, assignment of a hospital identification number, and scheduling of the first clinical visit for the same or next day. The clinic-based testing venues (VCT and PICT) typically had staff members who guided patients from the testing unit to the MDH reception whereas for community testing, the individual was referred to the hospital at their own convenience. The study procedures did not influence the linkage to care beyond the HTC and facility-based guidance to the reception. HTC was performed individually, unless the participant requested to be tested with other family members or friends. At first clinical consultation, CD4 testing was scheduled to be performed at the MDH laboratory and the patient collected the results prior to the next consultation. ART eligibility determination typically involved 2-3 additional hospital visits. Patients eligible for ART ($CD4 < 350$ cells/mm³ in 2015 and 500 cells/mm³ in 2016) received three-month clinical evaluations plus CD4 testing. Patients not eligible also had follow-up consultations every three months.³⁶ Routine patient-level HIV clinical data were recorded in a Ministry of Health managed electronic Patient Tracking System (ePTS), which allows monitoring of the HIV population registered in the facility, the quality of care provided as well as the retention in care. In particular, this tracing study involved those patients of the Tesfam cohort who, twelve months after initial diagnosis

were identified as LTFU through the ePTS system. Patients were retrospectively considered LTFU if they had more than 180 days without clinical consultation prior to the home-visit or if they had never enrolled in care.

Data collection

Home visits were performed for patients who received a HIV positive result between May 2014-June 2015 and who were identified as LTFU 12 months after diagnosis according to definition below. The visits occurred between July 2015-July 2016.

Generation of lists for home-visit: the lists of LTFU patients were generated every two months by merging the database of Tesfam cohort patients with the ePTS. Patients were classified as:

1. Primary LTFU: patients with no documentation of having enrolled in care.
2. Secondary LTFU:
 - Patients who enrolled in care and had a first clinical visit. They were registered in the ePTS system but did not return in the 180 days prior to the 12-month home visit.
 - Patients who attended more than one clinical/laboratory visit after the first visit but missed or defaulted in follow up visits in the 180 days prior to the 12-month home visit.

A quality control cross-check of those secondary LTFU was conducted by consulting their patient paper-based chart before visiting their homes (to exclude problems of missing data or incorrect data entry). Lastly, the list was merged with the HDSS database in order to identify those migrations and deaths and to locate the houses.

Home-visit 12 months after HIV positive diagnosis: Two experienced counselors identified the residence of each participant and performed the home-visit. If the person was not at home, the counselor returned two additional times to locate the person. One additional visit was performed on Saturday if a family member indicated that the participant might be at home.

The coordinator was responsible for reviewing the questionnaires and logs daily, entering the enrollment statistics in the main study excel document for monitoring. The study coordinator supervised and ensured the correct implementation of all activities.

Questionnaire (see Annex 1): the main objective of the questionnaire for the home-visit was to ascertain if the patient was truly LTFU and if so, in which step of the cascade the patient was lost and which were his or her self-reported reasons for LTFU. All patients were asked to show their hospital identification card provided by the MDH, or other possible health facilities. If the patient had a hospital identification card, the information was recorded in the questionnaire. If the patient denied having had a previous HIV test or HIV positive result, he/she was offered the opportunity to perform the test (HTC was offered to all household members). Then, the interviewer asked the patient about each stage of the cascade of care (enrollment in care, place of HIV care, CD4 testing, initiation of ART...etc.) regardless of their identified LTFU status. The patient was first asked if he or she had accomplished a specific step of care. If an individual responded not having accomplished certain step, the interviewer asked the reason and then marked within a list of approximately 25 potential self-perceived barriers in his notes those which applied. In addition, the counselor wrote a summary of the open narrative of the patient if the answer did not correspond to any of the predetermined responses. For those patients who were not in follow up at the MDH, nor at any other ART clinic inside or outside of the Manhiça district, the interviewer conducted a counseling session in order to re-engage the patient in care in the health facility of her/his choice.

Data management

All information regarding each participant's visit was recorded digitally in Open Data Kit software 1.4 (ODK) and uploaded into a database in REDCap (Research Electronic Data Capture). At the end of each day, the counselors returned to the CISM and reviewed the visits for accuracy of data with the transcriber and/or study coordinator.

The database from the home-visit was cleaned and merged with data from the ePTS, HDSS and Tesfam cohort to obtain relevant variables. Information gathered in the visit made possible to identify silent transfers, system failures, and errors on the ePTS database. To evaluate the potential reengagement of patients, we obtained data of clinical consultations from the administrative censoring until January 27th 2017.

All open narratives were digitally recorded in Portuguese and then, tabulated into a matrix format using MS Excel. This matrix was pre-designed in advance to classify the barriers of each step in the HIV cascade of care: (i) enrolment in care, (ii) first clinical visit, (iii) CD4 count, (iv) clinical follow up and (v) treatment adherence.

Data analysis

STATA® was used to perform descriptive and inferential statistics. To assess the impact of the home-based visit in patient re-engagement in care, we defined a control group of patients LTFU who did not receive the intervention. For these patients, a hypothetical date of home-visit was assigned. This date was estimated first by calculating the average number of days between the diagnosis and the home-visit for those patients visited, and then adding that number of days to the date of recruitment of non-visited patients. Descriptive analysis of the categorical variables of the study population was performed and Chi-square test was used to assess significant differences between the visited and non-visited groups. Continuous variables were expressed as median and interquartile range (IQR) and the p-value corresponded to the Kruskal Wallis test. Univariate and multivariate survival analysis using Cox proportional hazards model was conducted to determine the association between the explanatory variables and the study outcome, RIC. All baseline population characteristics (e.g.; gender, age, occupation, etc.) were included in the model. We categorized patients in two groups following the abovementioned definition: those primary LTFU and secondary LTFU. After performing the univariate analysis, those variables that showed significant association ($p < 0,2$) with the outcome or that were considered potential confounders (i.e.; age and gender) were retained in the multivariate model.

The perceived barriers to retention in care were extracted from the questionnaire used in the home-visit and grouped into 13 categories that were then classified in 4 main themes: “social climate”, “determinants at the individual level”, “relationship with the health system”, and “related to medication” (see Annex 2). Open text responses were manually coded either as one or more of the predetermined barriers provided in the questionnaire, or as a new type of barrier. Two people performed the analysis, and in case of disagreement it was brought to discussion. Only the barriers reported by patients primary LTFU are presented in this document (the analysis of the barriers for the remaining steps is work in progress). To extract the most frequent barriers, we listed the them in order of most to least reported by patients, and selected the top 8 barriers.

Definitions

Cascade steps:

- *Enrollment in care:* registration at the MDH or any other health facility as a new HIV patient and assignment of a hospital identification number.

- *First consultation*: first medical assessment of the patient after he/she has enrolled in care
- *CD4*: obtaining a CD4 count to assess ART eligibility
- *Follow up (ART eligible)*: attendance to the corresponding clinical consultations after being classified as ART eligible according to WHO recommendations
- *Follow up (ART not eligible)*: attendance to the corresponding clinical consultations after being classified as not eligible for ART according to WHO recommendations
- *On treatment*: pick up of medicines for ART treatment every month

Lost to follow-up (LTFU): patients who did not have a clinical consultation in the 180 prior to the home visit (i.e.; if patients have appointments every 3 months, and a patient is at least 3 months late to this appointment, then he or she is considered LTFU)

Primary LTFU: patients with no documentation of having enrolled in care

Secondary LTFU: patients who enrolled in care but missed or defaulted in follow up visits in the 180 days prior to the 12-month home visit

Patient migrated: patient who is residing outside of the Manhica District for at least 3 months at time of visit.

Patient visited: patient considered LTFU who was visited 12 months after being diagnosed, was found, and accepted the visit

Patient traced: patient considered LTFU whose house was located

Re-engagement in care (RIC): return to HIV care within 90 days after the home visit. We considered two types of RIC. First, patients who had not enrolled in care (i.e.; primary LTFU) before the visit and come back to start the process of care; and second, patients that had enrolled in care before the visit (i.e.; secondary LTFU) and return to a clinical consultation.

Date of RIC: For those who were considered primary LTFU before the visit, the date of RIC was the date in which they came back to enroll in care at the health facility within 90 days after the visit. For secondary LTFU patients, the date of RIC was established as the date of the first available consultation at the health facility within a period of 90 days after the home visit.

Ethical considerations

This study was approved by the Mozambican National Bioethics Committee as well as by the Institutional Review Boards at the Centers for Disease Control and Prevention, the Barcelona Institute

of Global Health and the Centro de Investigação em Saúde de Manhiça. All participants provided written informed consent.

6. Results

Study profile

Among the total 1122 participants recruited in the Tesfam cohort,³⁴⁻³⁵ 691 were identified as LTFU at the time of the analysis according to the definition in methods. Figure 1 shows the study profile. Out of those LTFU, 134 patients were not listed as LTFU in the real-time generation of lists and thus, they were not visited. These patients were later identified with the final databases, but since no visit information was available for these individuals, they were excluded from the analysis (Figure 1). In addition, the houses of 18 patients were not found because the location of the house was not accurate or the house had been demolished, so there was no outcome registered for those patients. Thus, a total of 539 (78,1%) patients were actually traced and their houses were located but out of these, 218 (40,4%) were not found. Of this group, 43 (7,9%) were dead, 69 (12,8%) were absent, 94 (17,4%) had migrated, and 12 (2,2%) were not found for other motives. Out of the 321 (59,5%) patients that were successfully located, 69 (21,5%) were not visited and 252 (78,5%) were visited and completed the interview. Of those not visited, 15 (4,6%) rejected the visit, whereas 18 (5,6%) patients initially accepted but then refused to undergo another HIV test after declaring themselves HIV negative or not having a previous test. Lastly, 20 (6,2%) patients who showed a new hospital identification card as a written proof of having relocated to another sanitary unit were identified as silent transfers. Moreover, 16 (4,9%) individuals were incorrectly classified as being secondary LTFU (i.e.; not having enrolled in care) due to a probable failure of the ePTS system in patient registration. However, during the visit these patients demonstrated that they were actually on care by showing their corresponding hospital identification card and follow up consultation dates.

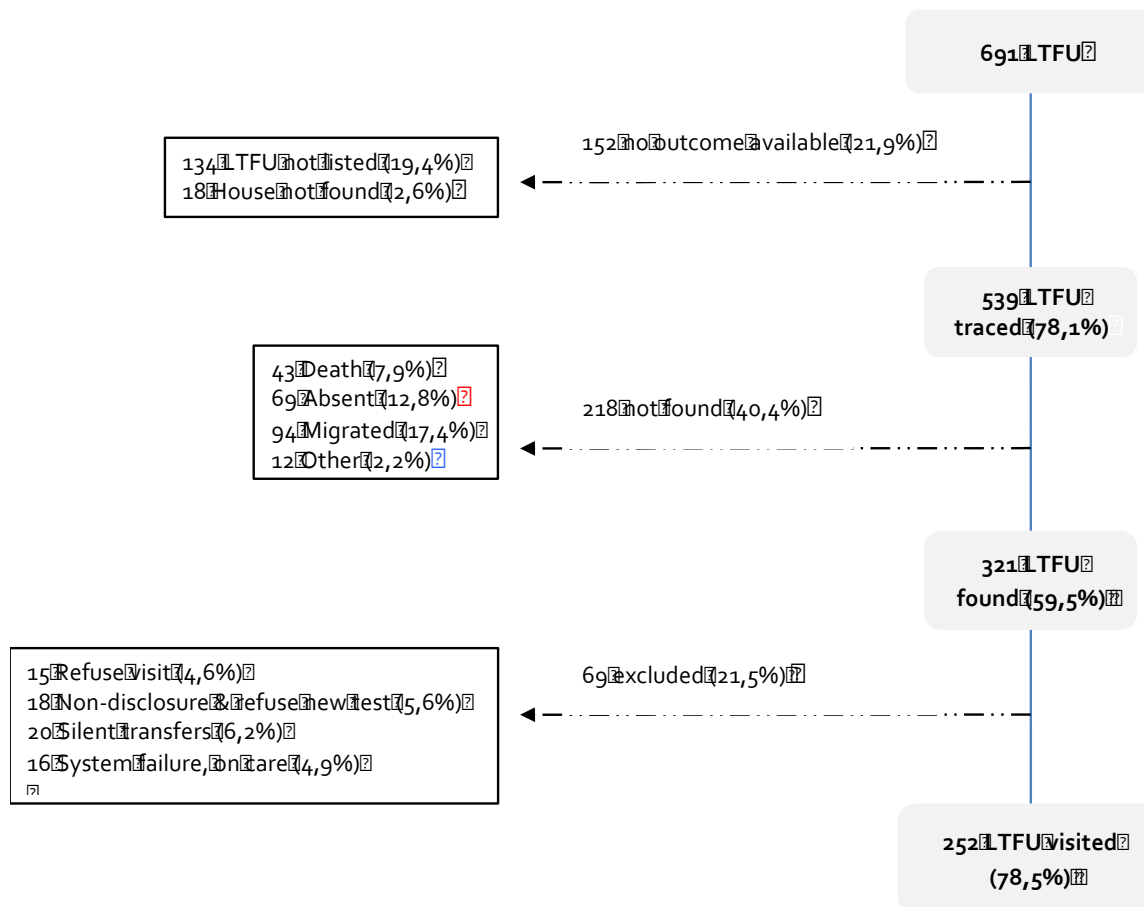


Figure 1. Study profile for patients of the Tesfam cohort who were identified as LTFU and who received a home-based visit. Percentages are calculated over the previous step.

Identification of a control group of non-visited patients

To assess the impact of the home visit in patient re-engagement in care, we defined a control group of patients LTFU who did not receive the home visit. We excluded patients without an outcome of the home-based visit (i.e.; LTFU not listed and houses not found), as well as patients who had no possibility of returning to care (i.e.; dead, migrated, silent transfers, and on care). Therefore, the final group of non-visited patients consisted of 69 patients that were absent at the time of the home-visit, plus the 33 individuals who refused to be visited. Baseline population characteristics including sex, age, occupation, having a cellphone, and test group ($p > 0,179$) of these two groups were comparable (data not shown), so they were combined into one control group ($N=102$).

Baseline characteristics of study populations

When comparing the non-visited (N=102) and the visited (N=252) groups, we found no significant statistical differences for any of the variables examined (Table 1). The gender distribution was 50,9% and 51,6% female for the non-visited and the visited groups respectively. The median age was 30,9 yr for the non-visited and 33,9yr for the visited group. Patients were classified into three types of occupation, and there were slightly more individuals in the service sector than in the rural sector or without occupation. The majority of the patients owned a cellphone in both groups (67,6% of non-visited and 71,4% of those visited, Table 1). Enrollment and initial retention in care was higher in patients that were diagnosed at a clinical setting and thus, the majority of LTFU patients had received HBT (56,9% from the control group and 59,9% from the visited group).

Table 1. Baseline characteristics between non-visited and visited lost to follow-up patients

		LTFU non-visited N = 102, n(%)	LTFU visited N = 252, n(%)	Total N = 354, n(%)	p-value
Sex	Female	52 (50,9)	130 (51,6)	182 (51,4)	0,918
	Male	50 (49)	122 (48,4)	172 (48,5)	
Age, median (IRQ)		30,9 (24,9-43,5)	33,9 (26,3-43,5)	32,9 (25,8-43,5)	0,228
Occupation	Services	47 (46,1)	110 (43,6)	157 (44,4)	0,663
	Rural	19 (18,6)	58 (23)	77 (21,7)	
	Domestic/No occupation	36 (35,3)	84 (33,3)	120 (33,9)	
Has cellphone	Yes	69 (67,6)	180 (71,4)	249 (70,3)	0,481
	No	33 (32,3)	72 (28,6)	105 (29,6)	
Test group	VCT	17 (16,7)	37 (14,7)	54 (15,2)	0,846
	PICT	27 (26,5)	64 (25,4)	91 (25,7)	
	HBT	58 (56,9)	151 (59,9)	209 (59)	
Primary LTFU	No	50 (49,02)	120 (47,6)	170 (48)	0,811
	Yes	52 (50,9)	132 (52,4)	184 (51,9)	

Attrition along the HIV continuum of care

More than half of the individuals visited, 132 (52%) were primary LTFU since they had not enrolled at the health facility (Figure 2). A total of 20 (8%) patients who did enroll in care, failed to attend the first clinical consultation, and 37 (15%) subjects who fulfilled the two first steps did not obtain a CD4 count. A group of 21 (8%) patients who met ART eligibility criteria according to the WHO recommendations never started treatment, whereas 25 (10%) patients non-eligible due to high CD4 counts did not

continue with clinical visits. Lastly, only 17 (7%) patients out of the 252 visited had initiated treatment but missed pharmacy pickups and were thus LTFU post-ART initiation.

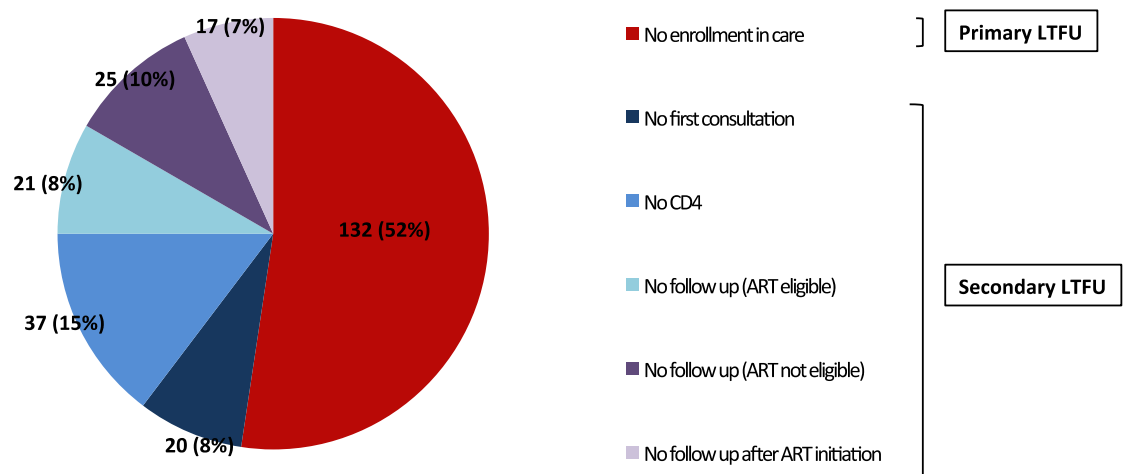


Figure 2. Distribution of visited patients (N=252) according to step of the continuum of care where they were lost (results are shown as n (%))

Re-engagement in care (RIC)

We next assessed re-engagement in care among groups of visited and non-visited individuals. A total of 83 patients returned to care. Among visited participants 79 (31,3%) returned to care whereas among non-visited, only 4 (3,9%) returned ($p < 0,0001$). These 4 individuals corresponded to people who had been absent at the time of the home visit. None of the 33 who actively rejected the visit returned to care. In addition, 62 patients who re-engaged in care were secondary LTFU so they returned to a follow up clinical consultation, whereas 21 patients were primary LTFU and returned to enroll in care for the first time.

Table 2 shows the results of the univariate and multivariate survival analysis using Cox proportional hazards model to examine potential factors associated with RIC. According to the univariate model, having a cellphone, having received HBT, having received home visit, and being secondary LTFU was associated with increased likelihood of RIC. The multivariate model was constructed by including those variables that had a p-value, $p < 0,2$ in the univariate model plus adjusting by age and gender. Only the home-visit and type of LTFU remained significantly associated with increased RIC in the multivariate model with adjusted hazard ratios of 10,0 (CI 95% 3,65-27,36, $p < 0,0001$) and 4,71 (CI 95% 2,51-8,86, $p < 0,0001$) respectively. Figure 3 displays the Kaplan-Meier survival curve estimates of

cumulative incidence of RIC over 90-days after the visit for the visited group and the non-visited group.

Table 2: Univariate and multivariate analysis of factors associated with RIC

			Univariate			Multivariate		
		RIC, n(%)	SHR	95% CI	p	aSHR	95% CI	p
Gender	Male	40 (23,3)	Ref		-	Ref	-	-
	Female	43 (23,6)	1,00	0,65-1,54	0,992	0,99	0,62-1,59	0,993
Age		32,7	1,00	0,98-1,01	0,712	1	0,98-1,02	0,482
Occupation	Services	38 (24,2)	Ref			-	-	-
	Rural	20 (25,9)	1,09	0,63-1,88	0,598	-	-	-
	Domestic/no occupation	25 (20,8)	0,82	0,49-1,35		-	-	-
Has cellphone	No	16 (15,2)	Ref		-	Ref	-	-
	Yes	67 (26,9)	1,86	1,08-3,21	0,025	1,47	0,82-2,62	0,190
Test group	VCT	19 (35,2)	Ref			Ref	-	-
	PICT	26 (28,6)	0,77	0,42-1,39	0,014	0,84	0,46-1,54	0,579
	HBT	38 (18,2)	0,47	0,26-0,81		1,22	0,61-2,43	0,572
Home-visit	No	4 (3,9)	Ref		-	Ref	-	-
	Yes	79 (31,3)	9,49	3,47-25,9	<0,0001	10,0	3,65-27,36	<0,0001
Enrolled in care	No	21 (11,4)	Ref		-	Ref		
	Yes	62 (36,5)	3,62	2,21-5,96	<0,0001	4,71	2,51-8,86	<0,0001

Cox proportional hazard model analysis estimating determinants of re-engagement in care within 90 days after the home-visit among visited patients (N=252) and non-visited patients (N=102).

n: number of individuals re-engaged in care and % of individuals from each category who re-engage in care

Abbreviations: RIC: re-engagement in care; SHR: subdistribution hazard ratio; CI: confidence interval; aSHR: adjusted subdistribution hazard ratio

We also examined the time to RIC, defined as number of days between the date of the home visit and the return of the patient to the health facility (Figure 4). More than half of the patients (47 patients, 56,6%) re-engaged in care within the first ten days after the home visit. The remaining patients re-engaged in care during the period between the 10th day after the home visit and the 90th day.

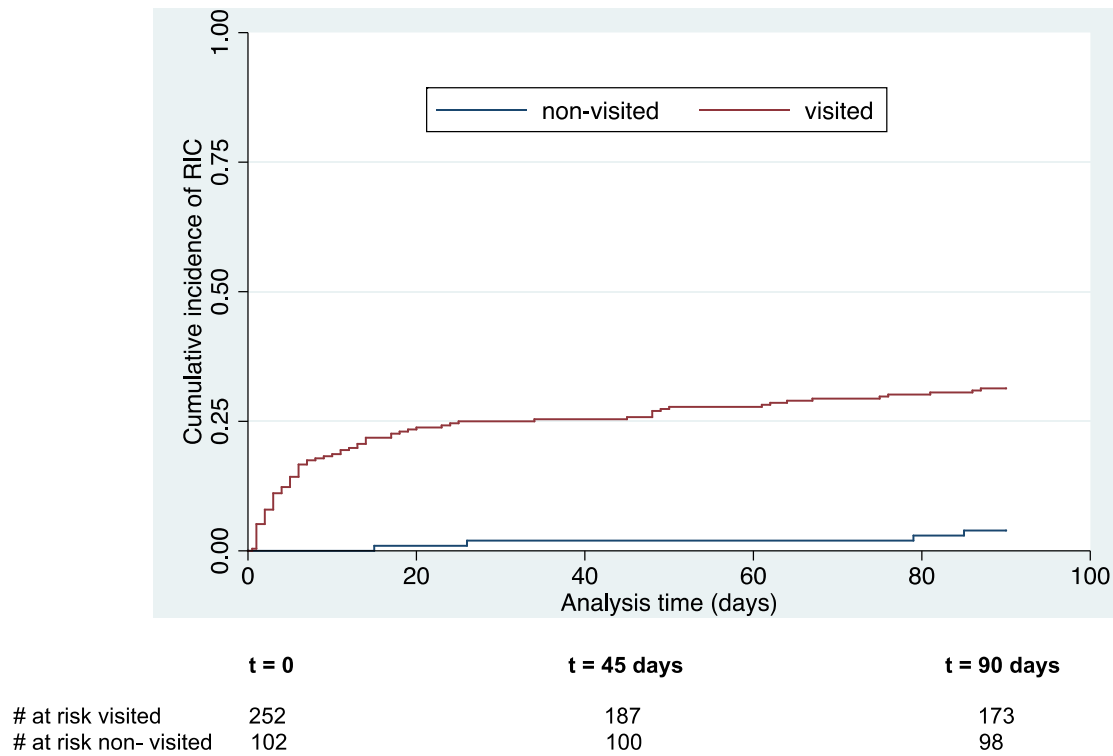


Figure 3. Cumulative incidence in RIC for patients visited and non-visited.
Number at risk are shown below the Kaplan Meier survival estimates

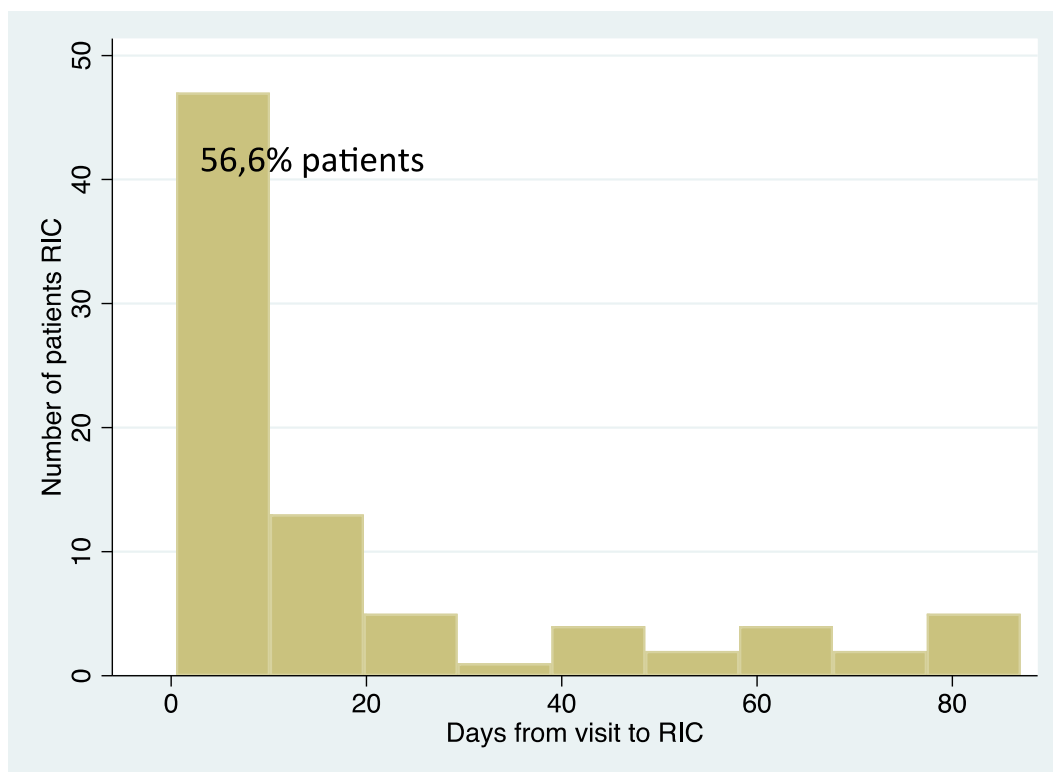


Figure 4. Time to RIC for visited and non-visited patients who returned to care (n=83). Data was shown as number of patients re-engaged in care. For non-visited patients, a hypothetical date of home-visit was created (described in *Methods*)

Patient self-reported barriers to care

Figure 5 shows the distribution of the 322 barriers reported by 121 participants who self-reported being primary LTFU. The barriers were classified into four established themes (see *Methods*), but since we only analyzed the answers of patients who are not enrolled in care, none of the barriers reported corresponded to the theme “related to medication”. Almost half of the responses (48,9%) registered were associated with determinants at the individual level; this is, personal circumstances that prevent the patient from seeking care. Specifically, the most frequent barriers cited were related to a self-perception of being in good health and thus, not requiring treatment, as well as to work responsibilities. The remaining half of the responses was divided between 26,7% barriers associated with the relation between the patient and the health system, and 24,3% with the current social climate. For the compliance with the health system, the most frequent barrier was associated with the loss of the hospital identification card given to the patients the day of the HIV positive diagnosis and which allows them to enroll in care at the hospital. Several patients explained having been tested for HIV multiple times in the past years with varying outcomes each time, which led them to not longer believe any result or been confused about their serostatus (*“Disse o paciente que fez teste quando queria fazer circuncisao e disseram que era negativo e fez duas semanas depois em casa fez deu positivo e veio fazer deu negativo.”*[Men, 21, HBT]). Lastly, having to wait long time at the reception of the hospital due to lengthy lines was another prevalent reason. Regarding a discouraging social climate, several patients did not disclose being HIV positive or did not recognized having been tested before.

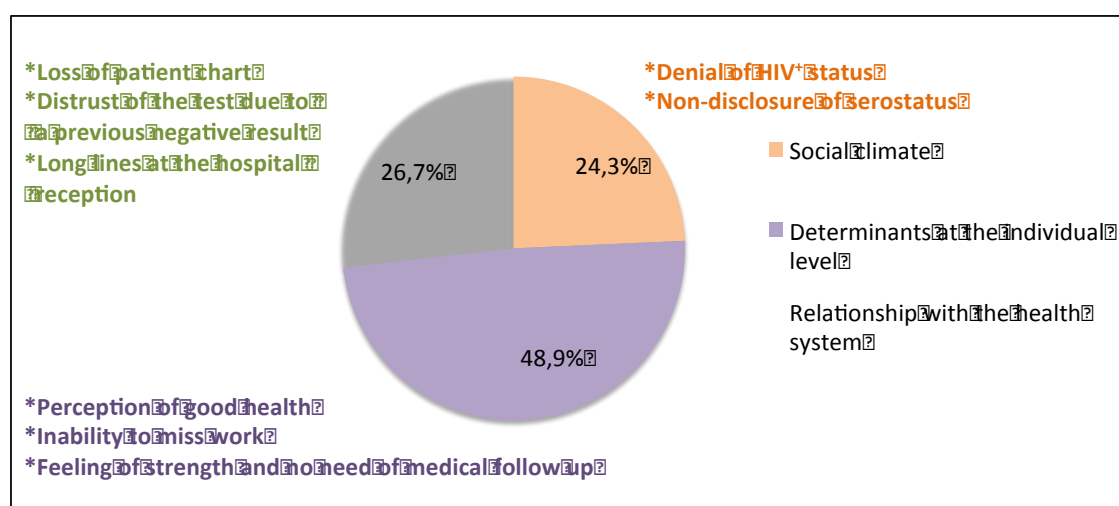


Figure 5. Top barriers described by patients who did not enroll in care and main themes identified. Percentages are calculated from a total of N=322 barriers referred by 121 patients who self-reported not being enrolled in care (primary LTFU). Most frequent barriers displayed were extracted by selecting the top 8 most reported barriers.

7. Discussion & limitations

The present study provides a comprehensive characterization of potential drivers of LTFU and RIC in patients 12 months after HIV diagnosis in a rural area of southern Mozambique. The RIC was assessed after a home-visit in which a counselor documented the patient's self-perceived reasons for LTFU and encouraged re-engagement in care. From 691 patients identified as LTFU, we located 321, and 78% accepted the visit. Among the patients visited, over half had not enrolled in care. The home-visit had a positive effect on RIC since one third of the patients visited returned to care, compared to only 4% of spontaneous return from those individuals non-visited. Those visited were 10 times more likely to re-engage in care as compared to those not visited (adjusted HR of 10, 95% CI 3,65-27,36; $p < 0,0001$) and those who had previously enrolled in care were nearly 5 times more likely to re-engage in care. Frequent reasons for disengagement in care reported by the patients were a perception of good health, a denial of serostatus, or inability to miss work. In addition, several participants declared having lost their hospital identification cards, mistrusting the HIV test results, and having to wait too long at the clinic.

After 12 months of follow up, we found that only 7% of the patients visited were on ART whereas 93% were in pre-ART stages of care. A recent systematic review on retention in HIV care in SSA determined that retention rates among pre-ART patients fell within the range of 23-88%.³⁷ In Nigeria, it was reported that approximately half of the patients enrolling in pre-ART programs during almost a decade (i.e.; 2004-2012), had not started ART by 2013.³⁸ Another study in Malawi compared the rate of LTFU patients in pre-ART and ART care. The rate of pre-ART attrition was almost the double (48 per 100 person-years) that of the ART patients (26 per 100 person-years).³⁹ One of the main reasons described for low retention on pre-ART is the patient self-perception of good health and the idea that treatment will be required only when symptoms of sickness appear.⁴⁰ Another cause of pre-ART losses might be the lack of comprehensive HIV care services for the patients. Nevertheless, the recently rolled out "test and treat" guidelines will likely decrease the number of individuals facing the issue of pre-ART retention. For instance, since a CD4 count will no longer be required prior to ART initiation, the technical laboratory difficulties that might account for the high proportion of patients in our study without CD4 criteria (15%), may no longer represent a problem. However, the new policy may shift LTFU downstream to the post-ART phase of the cascade of care.⁹

Despite the importance of re-engaging LTFU patients in care, most of the recent studies on HIV care in SSA focus on preventing patient attrition.^{13, 17-18} However, as increasing numbers of PLHIV initiate lifelong ART, their life expectancy is prolonged leading to a higher risk of falling out of the cascade, suffering high mortality and morbidity, and moreover, representing a significant source of HIV transmission.² There are few tracing studies to understand the drivers of the attrition and to encourage patient return to the clinic, both in high and low income countries, but the modest number of reports indicates there is a research gap on this topic.⁴¹ For instance, a recent review on evidence-informed (EI) or evidence-based interventions (EBI) for increasing linkage, retention, and re-engagement of PLHIV in the US identified 10 best practices, but the authors were not able to find any EI nor EBI which solidly informed best practices in re-engagement in care.⁴¹ In addition, the Center for Disease Control (CDC) offers recommendations for linkage to, retention in, and re-engagement in HIV care (LRC),⁴² but in practice these are not standardized across the US.⁴³ The Mozambican Ministry of Health (MoH) and CDC Mozambique currently recommend active tracing of LTFU patients using routine data collection systems.³⁶ However, with already strained resources, many health facilities do not systematically adhere to the recommendations. The Mozambican MoH is currently developing guidelines for addressing LTFU and RIC which may include internal triangulations (e.g.; patient files, pharmaceutical records), external triangulations (i.e.; demographic data compared to the registry of nearby clinics) to identify LTFU patients, as well as phone calls and home-visits from peer educators.⁴⁴

The observed 31,3% RIC of our study was slightly lower compared to other studies employing phone calls and/or home-visits, although surprisingly low rates of RIC are found even in high-income countries. In a study of 409 PLHIV in New York city, 57% patients returned to care after receiving phone calls, a mail letter, or a visit.²² In another study in Malawi called "Back to care" (B2C), health workers traced adults and children LTFU and documented the reasons for missing appointments, achieving a 74% rate of RIC.²³ The fact that the counselor arranged the new clinical appointment right at the time of the visit might have significantly contributed to the success of this intervention compared to our study, where patient return was self-driven. Moreover, in the Malawi "Back to care" study, all patients were LTFU post-ART whereas in our study 93% of participants were LTFU in pre-ART stages. Another example, also carried out in the same community of rural Mozambique, assessed active mobile tracing to re-engage LTFU children.⁴⁵ In this case, 37 out of the 144 children identified as LTFU were successfully reached by telephone. Re-engagement in care was 57% among contacted children compared to 18% of those not reached.

Being enrolled in care has an important impact on the likelihood of RIC. Out of those visited, 58 (73%) had previously enrolled in care (secondary LTFU), and they were almost 5 times more likely to RIC (aHR 4.71; 95% CI 2.51-8.86; $p < 0.0001$) than those primary LTFU. Patients who had at least enrolled in care at the health facility may denote an initial self-motivation to seek care, may feel sicker, or may have better access, so their return to the clinic might be more likely than for those who never started. We were not able to find any additional predictive factors of RIC among our patients. However, we cannot exclude that other variables not included in our analysis such as distance to the hospital, level of education, or marital status could impact RIC.

Patient re-engagement occurred promptly after the home-visit. More than 50% of the patients returned to the clinic within the first 10 days. Such a short time between the visit and the RIC increases the likelihood that the RIC was due to the intervention. For the purpose of this analysis, we set a 90-day limit from the home-visit in defining RIC. Later re-engagement could be due to the visit, but also to other intercurrent process such as disease progression or pregnancy, not directly attributable to the home visit.

LTFU in HIV care is a growing problem as we strive towards the 90-90-90 targets. Reaching the third 90 of viral suppression is not the end of the 90-90-90 initiative since patients must be retained in care for life both for the patient's benefit and to prevent transmission. It is thus crucial to understand the drivers of LTFU to guide future interventions. In our study, we found common barriers previously described in the literature at three different levels: individual, societal, and related to the health system.¹² The first issue identified was that patients claimed not having enrolled in care yet because of a lack of symptoms and a self-perceived good health, as abovementioned in the discussion of causes of pre-ART losses. This is a common theme in both high and low-income countries. For instance, in a tracing study of patients living in New York the most commonly reported reason for abandonment of care was "felt well".²² In our case, the majority of the patients LTFU had been tested in a home-based testing campaign, where low levels of uptake in care have been described by our group.⁷ Patients who were tested in their homes lacked a reason to attend the clinic in the first place, so it is likely that they had a sense of wellness and failed to seek care. In addition, enrollment in care is self-driven for those tested outside of the clinic, so they require a stronger motivation than patients tested at the health unit. Alternative approaches such as community linkage for HBT patients, in which patients can enroll in care right after being diagnosed in community testing campaigns, could increase the rates of enrollment. Notably, the frequent changes in the ART criteria during the past years, might have led to certain misconceptions among the patients. Initially, only those with severe disease were eligible for treatment, then, higher CD4 thresholds increased the number of treatable

patients, and currently, all patients can receive ART.⁷⁻⁹ Therefore, communication between health workers and the community needs to be reinforced, and efforts to better convey the correct messages about the disease should be prioritized.

Another frequent issue we observed was the participant's denial of serostatus, which is often encountered in the literature.³⁵ For instance, the Kenya AIDS Indicator Survey revealed that among diagnosed HIV-positive individuals, 56% reported they did not know their status, 28% mistakenly thought they were HIV-negative, and only 16% actually knew their HIV-positive status.¹⁵ Common arguments for this scenario are the stigma that is still associated with the disease, the fear of social rejection and discrimination, or negative outcomes after past disclosures.⁴⁶ In addition, such lack of awareness from the patients may indicate insufficient or inadequate counseling from the health workers. Patients are not fully accepting and understanding the consequences of their status, which results in higher losses to follow-up rates at the early stages of the continuum of care.¹³ Lastly, we identified that confusion during the diagnosis process led to several patients mistrusting the results of the test. Individuals reported having had multiple tests with varying outcomes, and thus not achieving any definite conclusion. Suboptimal conditions during HIV testing or counseling, in addition to low levels of acceptance of a positive diagnosis might contribute partially to the misunderstanding.

The third factor that we identified was a clear fear to return to the hospital. Many patients that had missed appointments or had lost the hospital identification card, expressed being afraid to be scolded at the healthcare center upon return. Although less often, similar narratives have been reported in other settings, such as in Iringa, Tanzania, where participants showed a desire to restart care but worried about the harsh treatment by the clinic staff.⁴⁷ Researchers found that only the patients with strong social support networks were able to re-engage in care, and even they felt shame and guilt for having discontinued care. As abovementioned, strategies to improve patient-provider relationships as well as outreach and support for patients LTFU are key to facilitate the return. In addition, patient empowerment and individual education on the right to health could play a key role in their interactions with the health system. Village health committees and community participation should be promoted to raise patient complaints and provide support when individuals desire to come forward.⁴⁸

A recurrent debate in studies of PLHIV is the heterogeneity of the LTFU definition.⁴⁹ The lack of consensus on the criteria to define patients LTFU hinders possible comparisons among studies or countries and the extraction of definitive conclusions. In addition, the high variability in estimations of LTFU patients can significantly affect the outcomes of research studies and program evaluations.

When HDSS or census data does not exist, migrations and transfers may be considered as LTFU.⁵⁰⁻⁵² Specifically, the main components of the LTFU definition that should be standardized are: length of time without a visit or number of missed consecutive visits; what counts as a visit (e.g.: clinical appointment, laboratory visit, drug pickup); and from which date to start counting (e.g., time from last visit or from missed visit).⁴⁹ In this study, LTFU was defined as not having a visit in the 180 days previous to the home-visit following the Mozambican MoH definition. This is a retrospective definition of LTFU that corresponds to patients being at least 90 days late for a clinical visit.

This study has several limitations. First, the analysis was embedded in a larger prospective linkage to care cohort study and as such, it did not incorporate a prospective randomized control group to compare the effect of the home-visit in RIC. In order to estimate the effect of the intervention, we retrospectively identified a group of patients who did not receive the home-visit as a comparison group. To avoid an overestimation of the effect of the home-visit, we restricted this group to those patients with accurate follow-up information and no evidence of migration, death, or potential silence transfers. Our baseline comparison including important variables such as sex, age, occupation, etc. did not show any differences between the visited and non-visited groups but we cannot exclude differences between the groups in variables that were not examined, such as distance to the hospital or level of studies. Furthermore, the study sample size was not determined a priori and was a result of the number of LTFU patients available from in the main linkage cohort study. Although the final populations of the visited and non-visited group were small and the 95%CI for the RIC estimates was wide, the lower bound of the 95%CI would show at least a minimum of 3 times more RIC after the home-visit.

Another limitation was that the lists of LTFU patients generated for the visits in real time had discrepancies with the final cleaned database for the analysis. This discrepancy led to 134 patients classified as LTFU in the final analysis but not listed in real time and thus, not visited. The ePTS is a ministry-managed database and data exported into Open Access format was used to generate LTFU lists in real time. The MoH staff manually transcribes data from paper charts to the ePTS and this often leads to missing or incomplete information that was only corrected at a later time after the 12-month home-visits had been conducted. The 134 individuals were mainly from VCT and PICT modality of testing and many lacked a HDSS permanent-identification number. Therefore, they were excluded from the analysis, as they were not given a chance to accept or decline the home-visit. Since HIV testing modality did not differ between visited and non-visited patients in our baseline analysis and

was not associated with RIC in multivariate analysis, it is unlikely that this exclusion has biased the RIC results.

The home-visit allowed identification of 36 misclassified patients. This is likely to be an underestimate since we could only correct those cases in which a written proof of the actual status was shown by the patient. For example, we excluded from the analysis the silent transfers who showed a hospital identification card from a different sanitary unit (N=20), but not those who verbally claimed to have relocated. This could have led to misclassification of LTFU as silent transfers but the number is likely too small to have influenced the results. Similarly, we identified individuals who were misclassified as primary LTFU but had a hospital identification card with upcoming clinical consultations, so they demonstrated to be on care (N=16). Unfortunately, we could not discern patients LTFU for the downstream steps of the cascade such as CD4 or ART initiation (secondary LTFU) due to the lack of a written proof. This might lead first, to an overestimation of the number of patients LTFU, and second, to lower rates of RIC (e.g.: some of the patients LTFU might actually be in care or in other sanitary unit). However, these findings are considered as part of the results of the study, and as an indication of the limitations of the ePTS system.⁵³

8. Conclusion & Recommendations

LTFU patients are at a high risk of morbidity and mortality, and treatment interruption reduces much of the ART benefits, both for the individual and the surrounding community. Besides efforts to maintain patients in care, it is crucial to develop strategies to promote their return once they have disengaged. Active tracing of patients, and outreach programs to re-engage LTFU patients play a key role in improving their survival and quality of life but cannot be applied in a blanket one-size-fits-all manner.

A home-based visit 12 months after a positive HIV diagnosis had a positive impact on the rate of RIC among participants who were LTFU. However, this visit benefited mostly PLHIV who were secondary LTFU and therefore, had already had an initial contact with health facility. Given the time- and staff-intensive nature of this intervention, further economic analysis should be performed to assess its cost-effectiveness in this specific population in the context of a differentiated care service delivery model. Although modeling studies have shown that outreach strategies to recapture patients in the pre-ART and on-ART phases are cost-effective in terms of DALYs averted,⁵⁴ the applicability of this visit to

secondary LTFU patients in Mozambique specifically, should be examined. RIC of patients with longer follow-up periods could be also analyzed since the rates of LTFU have been shown to increase over the years after diagnosis.⁵⁵ Alternatively, less costly methods, such as performing phone calls could be tested, although it has been shown that mobile tracing is often a less effective strategy. In addition, the fact that more than half (52%) of the patients visited were primary LTFU and they are particularly less likely to RIC cannot be ignored. Additional resources should be devoted to initially engage these patients, who may be less motivated to seek care. However, with the advent of the “test and treat all” guidelines, a collapse of the steps in the cascade is likely to lead to increased rates of enrollment in care, but also shift LTFU to later steps.¹¹ Given the importance of being primary vs. secondary LTFU for the rate of RIC, elevated numbers of patients LTFU in post-ART stages will probably affect the success of RIC interventions; therefore careful monitoring of patient distribution along the cascade will be key for future strategy design.

The barriers reported by patients revealed deep-rooted problems at the individual, societal and health system levels. The individual process of accepting a HIV positive result might be lengthy and challenging for the patients. Thus, it is as important to simplify the logistics of seeking and remaining in care to prevent patient attrition, as it is to combine the process with effective counseling and social support. Tools and evaluation methods may be necessary to improve patient-provider communication on the chronic and long-life nature of the disease, as well as the type of care required by the individual. Trainings for health workers should highlight the importance of establishing interactions with the patients based on respect and kindness. Lastly, measurements to facilitate the navigation of the health system could prevent much patient abandonment. For instance direct electronic patient tracking instead of paper-based and secondarily digitized patient information, or permit flexible appointment systems (e.g.; “drop ins” available for patients who miss a visit) would avoid frequent losses. Fortunately, the public health approach to HIV care is undergoing changes in order to incorporate flexibility and tailor HIV care to individual needs. Several differentiated care models of health care delivery are in various stages of testing in SSA.⁵⁶ These would allow more intensive linkage and retention interventions for those PLHIV who need it, and less for those who have fewer obstacles to care.

9. References

1. 90-90-90: An ambitious treatment target to help end the AIDS epidemic. Joint United Nations Programme on HIV/AIDS (UNAIDS). 2014
2. Ending AIDS. Progress towards the 90–90–90 targets. Joint United Nations Programme on HIV/AIDS (UNAIDS). Global AIDS update, 2017
3. Samji H, Cercon A, Hogg RS, Modur SP et al. Closing the Gap: Increases in Life Expectancy among Treated HIV-Positive Individuals in the United States and Canada. PLoS ONE. 2013, 8: e81355
4. Karim SAS, Karim QA. Antiretroviral prophylaxis: a defining moment in HIV control. Lancet. 2011, 378:e23-e25
5. Rodger A, Bruun T, Cambiano V, Vernazza P et al. HIV transmission risk through condomless sex if HIV+ partner on suppressive ART: PARTNER study. 21st Conference on Retroviruses and Opportunistic Infections, Abstract number 153LB, Boston, USA, 2014.
6. Editorial. U=U taking off in 2017. The Lancet HIV. 2017, 4 (11), 475
7. Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV: Early release. September 2015. World Health Organization.
8. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Recommendations for a public health approach. Second edition 2016. World Health Organization
9. Fox MP, Rosen S. A new cascade of HIV care for the era of “treat all.” PLoS Med. 2017;14(4):4–11
10. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Recommendations for a public health approach. June 2013. World Health Organization
11. Fox MP. Are we shifting attrition downstream in the HIV cascade? Lancet HIV. 2016;3(12):e554–e555
12. Brinkhof MWG, Pujades-Rodriguez M, Egger M. Mortality of Patients Lost to Follow-Up in Antiretroviral Treatment Programmes in Resource-Limited Settings: Systematic Review and Meta-Analysis. Plos One. 2009, 4 (6), e5790
13. Fox MP, Rosen S. Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007-2009: Systematic review. Trop Med. Int Heal. 2010;15 (SUPPL. 1):1–15
14. Outcomes of HIV-positive patients lost to follow-up in African treatment programmes. Systematic review of tracing and LTFU from 32 studies
15. Kranzer K, Govindasamy D, Ford N, Johnston V, et al. Quantifying and addressing losses along the continuum of care for people living with HIV infection in sub-Saharan Africa: a systematic review. Journal of the International AIDS Society. 2012, 15:17383
16. Kranzer K, Ford N. Unstructured treatment interruption of antiretroviral therapy in clinical practice: a systematic review. Trop Med Int Health. 2011, 16:1297313


17. Genberg BL, Naanyu V, Wachira J, Hogan JW, et al. Linkage to and engagement in HIV care in western Kenya: an observational study using population-based estimates from home-based counseling and testing. *Lancet HIV*. 2015; 2(1): e20–e26.
18. Elul B, Lahuerta M, Abacassamo F, Lamb MR et al. A combination strategy for enhancing linkage to and retention in HIV care among adults newly diagnosed with HIV in Mozambique: study protocol for a site-randomized implementation science study. *BMC Infectious Diseases*. 2014, 14, 1, 1-9
19. Weigel R, Hochgesang M, Brinkhof MWG, Hosseinipour MC, et al. Outcomes and associated risk factors of patients traced after being lost to follow-up from antiretroviral treatment in Lilongwe, Malawi. *BMC Infectious Diseases*. 2011, 11:31
20. Buchacz K, Chen M-J, Parisi MK, YoshidaCervantes M, et al. Using HIV Surveillance Registry Data to Re- Link Persons to Care: The RSVP Project in San Francisco. *PLoS One*. 2015, 10(3): e0118923
21. Magnus M, Herwehe J, Gruber DA, Willbright W, et al. Improved HIV-related outcomes associated with implementation of a novel public health information exchange. *International Journal of Medical Informatics*. 2012, 81 (10), e30-e38
22. Udeagu CCN, Webster TR, Bocour A, Michel P et al. Lost or just not following up: public health effort to re-engage HIV-infected persons lost to follow-up into HIV medical care. *AIDS* 2013, 27, (14), 2271-79
23. Tweya H, Gareta D, Chagwera F, Ben-Smith A, et al. Early active follow-up of patients on antiretroviral therapy (ART) who are lost to follow-up: The “Back-to-Care” project in Lilongwe, Malawi. *Trop Med Int Heal*. 2010;15(SUPPL. 1):82–9.
24. Yehia BR, Stewart L, Momplaisir F, Mody A, Holtzman CW et al. Barriers and facilitators to patient retention in HIV care. *BMC Infectious Diseases* (2015) 15:246
25. Mills EJ, Nachega JB, Bangsberg DR, Singh S et al. Adherence to HAART: A Systematic Review of Developed and Developing Nation Patient-Reported Barriers and Facilitators. *PLoS Medicine*. 2006, 3 (11), e438
26. Knight LC, Van Rooyen H, Humphries H, Barnabas R V, Celum C. Empowering patients to link to care and treatment: qualitative findings about the role of a home-based HIV counselling, testing and linkage intervention in South Africa. *AIDS Care*. 2015, 1–6
27. Hladik W, Benech I, Bateganya M, Hakim AJ. The utility of population-based surveys to describe the continuum of HIV services for key and general populations. *Int J STD AIDS*. 2015
28. Camlina CS, Neilands TB, Odenyc TA, Lyamuyad R, et al. Patient-reported factors associated with reengagement among HIV-infected patients disengaged from care in East Africa Carol. *AIDS*. 2016; 30(3): 495–502
29. Tomori C, Kennedy CE, Brahmbhatt H, Wagman JA, Mbwambo JK, Likindikoki S, et al. Barriers and facilitators of retention in HIV care and treatment services in Iringa, Tanzania: the importance of socioeconomic and sociocultural factors. *AIDS Care*. 2014;26(7):907–13.
30. Klopper C, Stellenberg E, van der Merwe A. Stigma and HIV disclosure in the Cape Metropolitan area, South Africa. *African J AIDS Res*. 2014, 13(1): 37–43

31. Colvin CJ, Konopka S, Chalker JC, Jonas E, et al. A Systematic Review of Health System Barriers and Enablers for Antiretroviral Therapy (ART) for HIV-Infected Pregnant and Postpartum Women. *PLoS One*. 2014, 9 (10), e108150
32. Sacoer C, Nhacolo A, Nhalungo D, Aponte JJ, Bassat Q, Augusto O, et al. Profile: Manhica Health Research Centre (Manhica HDSS). *Int J Epidemiol*. 2013, 42(5):1309–18
33. González R, Munguambe K, Aponte J, Bavo C, Nhalungo D, Macete E, et al. High HIV prevalence in a southern semi-rural area of Mozambique: a community-based survey. *HIV Med*. 2012, 13(10):581–8
34. Lopez-Varela E, Fuente-Soro L, Augusto OJ, Sacoer C, et al. The Continuum of HIV Care in Rural Mozambique: The Implications of HIV Testing Modality on Linkage and Retention. *AIDS Journal of Acquired Immune Deficiency Syndrome*. Published Ahead-of-Print - Last Updated: June 15, 2018
35. Fuente-Soro L, Lopez-Varela E, Augusto OJ, Sacoer C et al. Monitoring progress towards the first UNAIDS target: understanding the impact of people living with HIV who re-test during HIV-testing campaigns in rural Mozambique. *Journal of the International AIDS Society* 2018, 21:e25095
36. Guia de tratamento antiretroviral e infeções oportunistas no adulto, adolescente, grávida e criança. 2013. Republica do Moçambique. Ministerio da saúde. Direcção nacional de assistência médica
37. Plazy M, Orne-Gliemann J, Dabis F, Dray-Spira R. Retention in care prior to antiretroviral treatment eligibility in sub-Saharan Africa: a systematic review of the literature. *BMJ Open*. 2015;5:e006927
38. Agolory SG, Auld AF, Odafe S, Shiraishi RW, et al. High rates of loss to follow-up during the first year of pre-antiretroviral therapy for HIV patients at sites providing pre-ART care in Nigeria, 2004–2012. *PLoS One*. 2017, 12(9): e0183823
39. Tweya H, Oboho IK, Gugsu ST, Phiri S, et al. Loss to follow-up before and after initiation of antiretroviral therapy in HIV facilities in Lilongwe, Malawi. *PLoS ONE*. 2018, 13(1): e0188488
40. Boyles T, Wilkinson L. How should we care for patients who are not yet eligible for ART? *South Afr J HIV Med* 2011;12:11–13
41. Higa DH, Crepaz N, Mullins MM. Identifying Best Practices for Increasing Linkage to, Retention, and Re-engagement in HIV Medical Care: Findings from a Systematic Review, 1996–2014. *AIDS Behav*. 2016, 20:951–966
42. <https://www.cdc.gov/hiv/research/interventionresearch/compendium/lrc/index.html>),
43. Grimes RM, Hallmark CJ, Watkins KL, Agarwal S, et al. Re-engagement in HIV Care: A Clinical and Public Health Priority. *J AIDS Clin. Res*. 2016, 7(2)
44. Personal communication, Elisa Lopez-Varela
45. Luis S, Fuente-Soro L, Augusto O, Bernardo E, et al. Re-engagement of HIV-infected children lost to follow up after active mobile phone tracing in a rural area of Mozambique. *J Trop Pediatrics*. 2018 (in press)

46. Chaudoir SR, Fisher JD, Simoni JM. Understanding HIV disclosure: a review and application of the disclosure processes model. *Soc Sci Med*. 2011;72(10):1618–29
47. Layer EH, Brahmbhatt H, Beckham SW, Ntogwisangu J. "I Pray That They Accept Me Without Scolding:" Experiences with Disengagement and Re-Engagement in HIV Care and Treatment Services in Tanzania. *AIDS PATIENT CARE and STDs*. 2014; 28 (9), 483
48. Feingalss E. Spring 2015 Program Update: Realizing the Right to Health. 2015. Available at: <https://namati.org/news/spring-2015-program-update-realizing-the-right-to-health/>
49. Shepherd BE, Blevins M, Vaz, LME, Moon TD, et al. Impact of Definitions of Loss to Follow-up on Estimates of Retention, Disease Progression, and Mortality: Application to an HIV Program in Mozambique. *Am J Epidemiol*. 2013;178(5):819–828
50. Marson KG, Tapia K, Kohler P, McGrath CJ, et al. Male, Mobile, and Moneyed: Loss to Follow-Up vs. Transfer of Care in an Urban African Antiretroviral Treatment Clinic. *PLoS One*. 2013;8(10):2–9
51. Self-transfer and death: Self-transfer and mortality amongst adults lost to follow-up in ART programmes in low- and middle-income countries: systematic review and meta-analysis.
52. Difficulties con LTFU: Are they really lost? "true" status and reasons for treatment discontinuation among HIV infected patients on antiretroviral therapy considered lost to follow up in Urban Malawi.
53. Bernardo EL, Fuente-Soro L, Lopez-Varela E, Naniche D. Anonymity in HIV testing: Implications for Public Health. *Lancet*. 2017; 390(10112):2546.
54. Olney JJ, Braitstein P, Eaton JRW, Sang E, et al. Evaluating strategies to improve HIV care outcomes in Kenya: a modelling study. *Lancet HIV*. 2016; 3: e592–600
55. Auld AF, Shiraishi RW, Couto A, Mbofana F, et al. A Decade of Antiretroviral Therapy Scale-up in Mozambique: Evaluation of Outcome Trends and New Models of Service Delivery Among More Than 300,000 Patients Enrolled During 2004–2013. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2016. 73(2):e11–e22
56. Davis N, Kanagat N, Sharer M, Eagan S, et al. Review of differentiated approaches to antiretroviral therapy distribution. *Psychological and socio-medical aspects of AIDS/HIV*. 2018, 30 (8), 1010-1016

ANNEX 1. Questionnaire

CÓPIA

SSP_TESFAM_002_A01_v01_PT		Visita campo	
 cism centro de investigação em saúde de manhiça	Estudo: TESFAM Inquérito: Patient 12 month follow-up		Serial Number

Informação do participante																					
1.	Perm_id	_ _ _ _ - _ _ _ - _ _																			
2.	Digito check	_																			
3.	Numero TESH -	_ _ _ _																			
4.	Tem Numero HdD	<input type="checkbox"/> Sim <input type="checkbox"/> Não																			
4.1	Se sim: numero	_ _ / _ _ _ / _ _ / _ _ _ _ _																			
5.	Casa localizada	<input type="checkbox"/> Sim <input type="checkbox"/> Não																			
5.1	Se não, por quê?	<input type="checkbox"/> Casa não encontrada <input type="checkbox"/> Casa destruída <input type="checkbox"/> Outro _ _ _ _ _ _ _ _ _																			
6.	Participante localizado	<input type="checkbox"/> Sim <input type="checkbox"/> Não																			
6.1	Se não, por quê?	<input type="checkbox"/> Ausente <input type="checkbox"/> Óbito <input type="checkbox"/> Emigração <input type="checkbox"/> Outro _ _ _ _ _ _ _ _ _ <i>(só preencher "Ausente" se a pessoa já foi visitada 3 vezes)</i>																			
7.	A pessoa aceita ser visitada?	<input type="checkbox"/> Sim <input type="checkbox"/> Não <i>Se a pessoa recusa ser visitada, terminar aqui o inquérito</i>																			
Dados de diagnostico																					
8.	Alguma vez a pessoa fez teste de HIV?	<input type="checkbox"/> sim <input type="checkbox"/> não <input type="checkbox"/> não sabe																			
9.	Se 8 é sim, qual foi o resultado do teste?	<input type="checkbox"/> Positivo <input type="checkbox"/> Negativo <input type="checkbox"/> Não sabe																			
10.	Se 8 é sim, onde que a pessoa refere ter feito o teste?	<input type="checkbox"/> Casa <input type="checkbox"/> GATV/SAAJ <input type="checkbox"/> Triagem/contentores <input type="checkbox"/> Maternidade <input type="checkbox"/> B. socorro <input type="checkbox"/> não sabe <input type="checkbox"/> outro, especificar _ _ _ _ _ _ _ _ _																			
11.	<i>Se a pessoa refere não conhecer o seu estado ou diz que é negativo, tentar lembrar quando fez o teste HIV e em último recurso, depois do aconselhamento, oferecer o teste</i> <input type="checkbox"/> Recusa fazer teste <input type="checkbox"/> Aceita fazer teste <input type="checkbox"/> Reconhece ter feito teste anteriormente 11.1 Se a pessoa reconhece ter feito o teste, qual foi o resultado? <input type="checkbox"/> Positivo <input type="checkbox"/> Negativo <input type="checkbox"/> Não sabe 11.2 Onde que a pessoa refere ter feito o teste? <input type="checkbox"/> Casa <input type="checkbox"/> GATV/SAAJ <input type="checkbox"/> Triagem/contentores <input type="checkbox"/> Maternidade <input type="checkbox"/> B. socorro <input type="checkbox"/> não sabe <input type="checkbox"/> outro, especificar _ _ _ _ _ _ _ _ _																				
Acesso e Adesão aos cuidados de HIV																					
12.	A pessoa já abriu processo de consultas de HIV no C.S? <input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe 12.1 Se sim, aonde? <table style="width: 100%; border: none;"> <tr> <td><input type="checkbox"/> CS Manhiça</td> <td><input type="checkbox"/> CS Maragra</td> <td><input type="checkbox"/> CS Palmeira/Nwamatibjana</td> </tr> <tr> <td><input type="checkbox"/> Xinavane</td> <td><input type="checkbox"/> Maputo</td> <td><input type="checkbox"/> Xai-Xai</td> </tr> <tr> <td><input type="checkbox"/> Munguini</td> <td><input type="checkbox"/> Calanga</td> <td><input type="checkbox"/> 3 Fevereiro/Taninga</td> </tr> <tr> <td><input type="checkbox"/> Ilha Josina</td> <td><input type="checkbox"/> Xibukutsu</td> <td><input type="checkbox"/> Malavel</td> </tr> <tr> <td><input type="checkbox"/> Maluana</td> <td><input type="checkbox"/> Marracuene</td> <td></td> </tr> <tr> <td><input type="checkbox"/> Outro</td> <td colspan="2"> _ _ _ _ _ _ _ _ _ </td> </tr> </table>			<input type="checkbox"/> CS Manhiça	<input type="checkbox"/> CS Maragra	<input type="checkbox"/> CS Palmeira/Nwamatibjana	<input type="checkbox"/> Xinavane	<input type="checkbox"/> Maputo	<input type="checkbox"/> Xai-Xai	<input type="checkbox"/> Munguini	<input type="checkbox"/> Calanga	<input type="checkbox"/> 3 Fevereiro/Taninga	<input type="checkbox"/> Ilha Josina	<input type="checkbox"/> Xibukutsu	<input type="checkbox"/> Malavel	<input type="checkbox"/> Maluana	<input type="checkbox"/> Marracuene		<input type="checkbox"/> Outro	_ _ _ _ _ _ _ _ _	
<input type="checkbox"/> CS Manhiça	<input type="checkbox"/> CS Maragra	<input type="checkbox"/> CS Palmeira/Nwamatibjana																			
<input type="checkbox"/> Xinavane	<input type="checkbox"/> Maputo	<input type="checkbox"/> Xai-Xai																			
<input type="checkbox"/> Munguini	<input type="checkbox"/> Calanga	<input type="checkbox"/> 3 Fevereiro/Taninga																			
<input type="checkbox"/> Ilha Josina	<input type="checkbox"/> Xibukutsu	<input type="checkbox"/> Malavel																			
<input type="checkbox"/> Maluana	<input type="checkbox"/> Marracuene																				
<input type="checkbox"/> Outro	_ _ _ _ _ _ _ _ _																				
13.	Se 12 não, por quê? (varias respostas) <input type="checkbox"/> Não acreditou o resultado <input type="checkbox"/> Esta forte, não precisa seguimento <input type="checkbox"/> Vergonha de ser visto <input type="checkbox"/> Medo a ser visto <input type="checkbox"/> Prefere consultar ao curandeiro	<input type="checkbox"/> Precisava ao parceiro/familiar <input type="checkbox"/> Recusa do parceiro/familiar <input type="checkbox"/> Não tinha com quem deixar as crianças <input type="checkbox"/> Hospitalizado, não pôde vir as consultas/farmácia																			

Protocolo

CÓPIA

	<input type="checkbox"/> A pessoa diz estar bem de saúde <input type="checkbox"/> Receio de mau trato do pessoal de hospital <input type="checkbox"/> Distancia ao hospital <input type="checkbox"/> Larga bicha na recepção <input type="checkbox"/> Mandaram voltar num outro dia <input type="checkbox"/> Tinha presa <input type="checkbox"/> Dinheiro transporte <input type="checkbox"/> Não pode faltar ao trabalho	<input type="checkbox"/> Muito doente para vir ao hospital <input type="checkbox"/> Algum familiar ao seu cargo doente <input type="checkbox"/> Falta de transporte disponível <input type="checkbox"/> Perda de dinheiro se faltar ao trabalho <input type="checkbox"/> Não sabe por que <input type="checkbox"/> Não sabia onde era a recepção <input type="checkbox"/> Não sabia que tinha que abri-lo <input type="checkbox"/> Outro _____
14.	Pedir a pessoa para mostrar o cartão de seguimento A pessoa mostrou o cartão de seguimento? <input type="checkbox"/> Sim <input type="checkbox"/> Não	
15.	Se 14 é não, por quê? <input type="checkbox"/> Recusa <input type="checkbox"/> Perdeu <input type="checkbox"/> Não tem <input type="checkbox"/> Outro _____	
16.	Se 14 é sim, o numero de cartão bate com o numero HDD da lista ? <input type="checkbox"/> Sim <input type="checkbox"/> Outro (C.S.Manhiça) _____ <input type="checkbox"/> Fora da Manhiça _____ Se os números não batem, escrever no cartão a caneta os dois números	
17.	Se 14 é sim, preencher as seguintes perguntas 17.1 Data da primeira consulta _____ <input type="checkbox"/> Não tem data <input type="checkbox"/> Assegura ter consulta feita mas sem cartão, não tem prox data escrita no cartão 17.2 Data da penúltima consultas 1. _____ <input type="checkbox"/> Não tem data <input type="checkbox"/> Assegura ter consulta feita mas sem cartão, não tem prox data escrita no cartão 17.3 Data da última consulta 2. _____ <input type="checkbox"/> Não tem data <input type="checkbox"/> Assegura ter consulta feita mas sem cartão, não tem prox data escrita no cartão	
18.	A pessoa chegou a fazer uma primeira consulta com o clinico? <input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe	
19.	Se 18 não, por quê? (varias respostas) <input type="checkbox"/> Não acreditou o resultado <input type="checkbox"/> Esta forte, não precisa seguimento <input type="checkbox"/> Vergonha de ser visto <input type="checkbox"/> Medo a ser visto <input type="checkbox"/> Prefere consultar ao curandeiro <input type="checkbox"/> A pessoa diz estar bem de saúde <input type="checkbox"/> Receio de mau trato do pessoal de hospital <input type="checkbox"/> Distancia ao hospital <input type="checkbox"/> Larga bicha na recepção <input type="checkbox"/> Mandaram voltar num outro dia <input type="checkbox"/> Tinha presa <input type="checkbox"/> Dinheiro transporte <input type="checkbox"/> Não pode faltar ao trabalho <input type="checkbox"/> Precisava ao parceiro/familiar	<input type="checkbox"/> Recusa do parceiro/familiar <input type="checkbox"/> Não tinha com quem deixar as crianças <input type="checkbox"/> Hospitalizado, não pôde vir as consultas/farmácia <input type="checkbox"/> Muito doente para vir ao hospital <input type="checkbox"/> Algum familiar ao seu cargo doente <input type="checkbox"/> Falta de transporte disponível <input type="checkbox"/> Perda de dinheiro se faltar ao trabalho <input type="checkbox"/> Não sabe por que <input type="checkbox"/> Não encontraram o processo <input type="checkbox"/> Não sabia que tinha que vir ao hospital <input type="checkbox"/> Outro _____
20.	Chegaram de tirar sangue? <input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe	
21.	Se 20 não, por quê? (varias respostas) <input type="checkbox"/> Não acreditou o resultado <input type="checkbox"/> Esta forte, não precisa seguimento <input type="checkbox"/> Vergonha de ser visto <input type="checkbox"/> Medo a ser visto <input type="checkbox"/> Prefere consultar ao curandeiro <input type="checkbox"/> A pessoa diz estar bem de saúde <input type="checkbox"/> Receio de mau trato do pessoal de hospital <input type="checkbox"/> Distancia ao hospital <input type="checkbox"/> Larga bicha na recepção <input type="checkbox"/> Mandaram voltar num outro dia <input type="checkbox"/> Tinha presa <input type="checkbox"/> Dinheiro transporte <input type="checkbox"/> Não pode faltar ao trabalho <input type="checkbox"/> Precisava ao parceiro/familiar	<input type="checkbox"/> Muito doente para vir ao hospital <input type="checkbox"/> Algum familiar ao seu cargo doente <input type="checkbox"/> Falta de transporte disponível <input type="checkbox"/> Perda de dinheiro se faltar ao trabalho <input type="checkbox"/> Não sabe por que <input type="checkbox"/> Não encontraram o processo <input type="checkbox"/> Não sabia que tinha que vir ao hospital <input type="checkbox"/> Não explicaram na consulta que tinha que fazer a proba <input type="checkbox"/> Não preciso fazer nenhuma proba <input type="checkbox"/> Igreja não permite <input type="checkbox"/> Não podiam fazer as probas no laboratório <input type="checkbox"/> Pediram dinheiro no laboratório <input type="checkbox"/> Medo a tirar sangue

CÓPIA

	<input type="checkbox"/> Recusa do parceiro/familiar <input type="checkbox"/> Não tinha com quem deixar as crianças <input type="checkbox"/> Hospitalizado, não pôde vir as consultas /farmácia	<input type="checkbox"/> No hospital depois vendem a sangue <input type="checkbox"/> Outro _____
Seguimento HIV e tratamento		
	A pessoa continua a fazer seguimento nas consultas? <input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe	
22.	22.1 Se sim, onde? <input type="checkbox"/> CS Manhiça <input type="checkbox"/> CS Maragra <input type="checkbox"/> CS Palmeira/Nwamatibjana <input type="checkbox"/> Xinavane <input type="checkbox"/> Maputo <input type="checkbox"/> Xai-Xai <input type="checkbox"/> Munguini <input type="checkbox"/> Calanga <input type="checkbox"/> 3 Fevereiro/Taninga <input type="checkbox"/> Ilha Josina <input type="checkbox"/> Xibukutsu <input type="checkbox"/> Malavel <input type="checkbox"/> Maluana <input type="checkbox"/> Marracuene <input type="checkbox"/> Outro _____	
23.	Se 22 não, por quê? (varias respostas) <input type="checkbox"/> Não acreditou o resultado <input type="checkbox"/> Esta forte, não precisa seguimento <input type="checkbox"/> Vergonha de ser visto <input type="checkbox"/> Medo a ser visto <input type="checkbox"/> Prefere consultar ao curandeiro <input type="checkbox"/> A pessoa diz estar bem de saúde <input type="checkbox"/> Receio de mau trato do pessoal de hospital <input type="checkbox"/> Distancia ao hospital <input type="checkbox"/> Larga bicha na recepção <input type="checkbox"/> Mandaram voltar num outro dia <input type="checkbox"/> Tinha presa <input type="checkbox"/> Dinheiro transporte <input type="checkbox"/> Não pode faltar ao trabalho <input type="checkbox"/> Precisava ao parceiro/familiar <input type="checkbox"/> Recusa do parceiro/familiar <input type="checkbox"/> Não tinha com quem deixar as crianças	<input type="checkbox"/> Hospitalizado, não pôde vir as consultas/farmácia <input type="checkbox"/> Muito doente para vir ao hospital <input type="checkbox"/> Algum familiar ao seu cargo doente <input type="checkbox"/> Falta de transporte disponível <input type="checkbox"/> Perda de dinheiro se faltar ao trabalho <input type="checkbox"/> Não sabe por que <input type="checkbox"/> Não encontraram o processo <input type="checkbox"/> Não sabia que tinha que vir ao hospital <input type="checkbox"/> Não marcaram na recepção a seguinte consulta <input type="checkbox"/> Perderam o processo/cartão <input type="checkbox"/> Pediram dinheiro nas consultas <input type="checkbox"/> Perdeu o cartão HIV <input type="checkbox"/> Larga demora em começar tratamento <input type="checkbox"/> Consultas muito rápidas <input type="checkbox"/> Outro _____
24.	Se 22 sim, a pessoa refere ter faltado alguma vez às consultas? <input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe	
	24.1 Se sim, por quê? (varias respostas) <input type="checkbox"/> Não acreditou o resultado <input type="checkbox"/> Esta forte, não precisa seguimento <input type="checkbox"/> Vergonha de ser visto <input type="checkbox"/> Medo a ser visto <input type="checkbox"/> Prefere consultar ao curandeiro <input type="checkbox"/> A pessoa diz estar bem de saúde <input type="checkbox"/> Receio de mau trato do pessoal de hospital <input type="checkbox"/> Distancia ao hospital <input type="checkbox"/> Larga bicha na recepção <input type="checkbox"/> Mandaram voltar num outro dia <input type="checkbox"/> Tinha presa <input type="checkbox"/> Dinheiro transporte <input type="checkbox"/> Não pode faltar ao trabalho <input type="checkbox"/> Precisava ao parceiro/familiar <input type="checkbox"/> Recusa do parceiro/familiar <input type="checkbox"/> Não tinha com quem deixar as crianças	<input type="checkbox"/> Hospitalizado, não pôde vir as consultas/farmácia <input type="checkbox"/> Muito doente para vir ao hospital <input type="checkbox"/> Algum familiar ao seu cargo doente <input type="checkbox"/> Falta de transporte disponível <input type="checkbox"/> Perda de dinheiro se faltar ao trabalho <input type="checkbox"/> Não sabe por que <input type="checkbox"/> Não encontraram o processo <input type="checkbox"/> Não sabia que tinha que vir ao hospital <input type="checkbox"/> Não marcaram na recepção a seguinte consulta <input type="checkbox"/> Perderam o processo/cartão <input type="checkbox"/> Pediram dinheiro nas consultas <input type="checkbox"/> Perdeu o cartão HIV <input type="checkbox"/> Larga demora em começar tratamento <input type="checkbox"/> Consultas muito rápidas <input type="checkbox"/> Outro _____
25.	Alguma vez os clínicos disseram que precisava começar a tomar comprimidos contra o HIV? <input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe	
25.1	Se sim, chegou a iniciar? <input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe	

ORIGINAL

CÓPIA

26.	<p>Se 25.1 é sim, atualmente continua a vir à farmácia a levantar os medicamentos?</p> <p><input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe</p> <p>Se a pessoa refere vir a farmácia a levantar medicamentos, pedir para mostrar os comprimidos</p> <p>26.1 Se 26 sim, mostrou os comprimidos <input type="checkbox"/> Sim <input type="checkbox"/> Não</p> <p>26.2 Se 26.1 é não, porque <input type="checkbox"/> acabou <input type="checkbox"/> perdeu <input type="checkbox"/> alguém levou <input type="checkbox"/> Partilha com familiar <input type="checkbox"/> Não sabe <input type="checkbox"/> Outro _____</p>
27.	<p>Se 26 não, por quê? (varias respostas)</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 48%;"> <input type="checkbox"/> Não acreditou o resultado <input type="checkbox"/> Esta forte, não precisa seguimento <input type="checkbox"/> Vergonha de ser visto <input type="checkbox"/> Medo a ser visto <input type="checkbox"/> Prefere consultar ao curandeiro <input type="checkbox"/> A pessoa diz estar bem de saúde <input type="checkbox"/> Receio de mau trato do pessoal de hospital <input type="checkbox"/> Distancia ao hospital <input type="checkbox"/> Larga bicha na recepção <input type="checkbox"/> Mandaram voltar num outro dia <input type="checkbox"/> Tinha presa <input type="checkbox"/> Dinheiro transporte <input type="checkbox"/> Não pode faltar ao trabalho <input type="checkbox"/> Precisava ao parceiro/familiar <input type="checkbox"/> Recusa do parceiro/familiar <input type="checkbox"/> Não tinha com quem deixar as crianças <input type="checkbox"/> Sensação de cura <input type="checkbox"/> Hospitalizado, não pôde vir as consultas/farmácia </div> <div style="width: 48%;"> <input type="checkbox"/> Muito doente para vir ao hospital <input type="checkbox"/> Algum familiar ao seu cargo doente <input type="checkbox"/> Falta de transporte disponível <input type="checkbox"/> Perda de dinheiro se faltar ao trabalho <input type="checkbox"/> Não sabe por que <input type="checkbox"/> Não explicaram quando tinha que començar <input type="checkbox"/> Perderam o processo/cartão <input type="checkbox"/> Pediram dinheiro na farmácia <input type="checkbox"/> Os comprimidos fazem mal (efeitos secundários) <input type="checkbox"/> Ficaram sem comprimidos na farmácia <input type="checkbox"/> Recomendação curandeiro <input type="checkbox"/> Não precisa TARV, toma medicamento tradicional <input type="checkbox"/> Preciso comer bem para tomar os comprimidos, mas não tinha comida <input type="checkbox"/> Muitos comprimidos <input type="checkbox"/> Outro _____ </div> </div>
28.	<p>Se 26 e sim, alguma vez deixou de vir a levantar medicamentos?</p> <p><input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe</p>
29.	<p>Se 28 sim, por quê? (varias respostas)</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 48%;"> <input type="checkbox"/> Não acreditou o resultado <input type="checkbox"/> Esta forte, não precisa seguimento <input type="checkbox"/> Vergonha de ser visto <input type="checkbox"/> Medo a ser visto <input type="checkbox"/> Prefere consultar ao curandeiro <input type="checkbox"/> A pessoa diz estar bem de saúde <input type="checkbox"/> Receio de mau trato do pessoal de hospital <input type="checkbox"/> Distancia ao hospital <input type="checkbox"/> Larga bicha na recepção <input type="checkbox"/> Mandaram voltar num outro dia <input type="checkbox"/> Tinha presa <input type="checkbox"/> Dinheiro transporte <input type="checkbox"/> Não pode faltar ao trabalho <input type="checkbox"/> Precisava ao parceiro/familiar <input type="checkbox"/> Recusa do parceiro/familiar <input type="checkbox"/> Não tinha com quem deixar as crianças <input type="checkbox"/> Sensação de cura <input type="checkbox"/> Hospitalizado, não pôde vir as consultas/farmácia </div> <div style="width: 48%;"> <input type="checkbox"/> Muito doente para vir ao hospital <input type="checkbox"/> Algum familiar ao seu cargo doente <input type="checkbox"/> Falta de transporte disponível <input type="checkbox"/> Perda de dinheiro se faltar ao trabalho <input type="checkbox"/> Não sabe por que <input type="checkbox"/> Não explicaram quando tinha que començar <input type="checkbox"/> Perderam o processo/cartão <input type="checkbox"/> Pediram dinheiro na farmácia <input type="checkbox"/> Os comprimidos fazem mal (efeitos secundários) <input type="checkbox"/> Ficaram sem comprimidos na farmácia <input type="checkbox"/> Recomendação curandeiro <input type="checkbox"/> Não precisa TARV, toma medicamento tradicional <input type="checkbox"/> Preciso comer bem para tomar os comprimidos, mas não tinha comida <input type="checkbox"/> Muitos comprimidos <input type="checkbox"/> Outro _____ </div> </div>
FIM	
30.	<p>No ultimo ano teve que tomar tratamento contra tuberculose?</p> <p><input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe</p>
31.	<p>Se mulher, ficou grávida no ultimo ano?</p> <p><input type="checkbox"/> Sim <input type="checkbox"/> Não <input type="checkbox"/> Não sabe</p>
<p>Código conselheiro _____ Data _____-201____</p> <p>32. Agradecer ao participante a sua participação, terminar a sessão de aconselhamento positivo e</p> <p style="text-align: center;">ENTREGAR GUIA REFERENCIA ABANDONO</p>	

ANNEX 2. Classification of self-reported barriers

BARRIER	CATEGORY	THEME
Vergonha de ser visto	Aceitação de apoio comunitário	Clima Social
Medo de ser visto	Aceitação de apoio comunitário	Clima Social
Medo de ser rejeitado	Aceitação de apoio comunitário	Clima Social
Precisava do parceiro/familiar	Aceitação de apoio familiar	Clima Social
Recusa do parceiro/familiar	Aceitação de apoio familiar	Clima Social
Disclosure do parceiro	Aceitação de apoio familiar	Clima Social
Não acreditou no resultado	Empoderamento das pessoas que vivem com HIV	Clima Social
Non-disclosure	Empoderamento das pessoas que vivem com HIV	Clima Social
Prefere consultar o curandeiro	Medicina Tradicional	Clima Social
Esta forte, não precisa de seguimento	Health literacy	Condicionantes de nível individual
A pessoa não está bem de saúde	Health literacy	Condicionantes de nível individual
Conhecimento em saúde (falta de)	Health literacy	Condicionantes de nível individual
Outros familiares com HIV	Health literacy	Condicionantes de nível individual
Crenças espirituais: religião	Religião	Condicionantes de nível individual
Não pode faltar ao trabalho	Responsabilidades competentes	Condicionantes de nível individual
Algum familiar do seu cargo doente	Responsabilidades competentes	Condicionantes de nível individual
Perdida de dinheiro e faltar ao trabalho	Responsabilidades competentes	Condicionantes de nível individual
Migração	Responsabilidades competentes	Condicionantes de nível individual
Responsabilidade: trabalho	Responsabilidades competentes	Condicionantes de nível individual
Responsabilidade: morte de um familiar	Responsabilidades competentes	Condicionantes de nível individual
Distância do hospital	Situações incapacitantes	Condicionantes de nível individual
Dinheiro transporte	Situações incapacitantes	Condicionantes de nível individual
Não venho porque estava doente	Situações incapacitantes	Condicionantes de nível individual
Hospitalizado, não pode vir às visitas/farmácia	Situações incapacitantes	Condicionantes de nível individual
Falta de transporte disponível	Situações incapacitantes	Condicionantes de nível individual
Muito doente para vir ao hospital	Situações incapacitantes	Condicionantes de nível individual
Enfermedade mental	Situações incapacitantes	Condicionantes de nível individual
Inhalação	Valor do estado de saúde	Condicionantes de nível individual
Não inala com quem deixar as crianças	Valor do estado de saúde	Condicionantes de nível individual
Não sabe porque	Valor do estado de saúde	Condicionantes de nível individual
Falta de interesse na sua saúde	Valor do estado de saúde	Condicionantes de nível individual
Medo da doença	Valor do estado de saúde	Condicionantes de nível individual
Falta de tempo/presa	Valor do estado de saúde	Condicionantes de nível individual
Recusa	Valor do estado de saúde	Condicionantes de nível individual
Falta de esperança	Valor do estado de saúde	Condicionantes de nível individual
Receio de inalação do pessoal de hospital	Autoridade do SS/Compliance	Relação com o sistema sanitário
Hospital: má qualidade da atenção	Autoridade do SS/Compliance	Relação com o sistema sanitário
Gravidez	Autoridade do SS/Compliance	Relação com o sistema sanitário
Medo de ser apreendido no hospital	Autoridade do SS/Compliance	Relação com o sistema sanitário
Sentimento de culpa	Autoridade do SS/Compliance	Relação com o sistema sanitário
Distrust do teste devido a prior negative result	Estratégias da US para melhorar a adesão	Relação com o sistema sanitário
Hospital: descentralização da atenção	Estratégias da US para melhorar a adesão	Relação com o sistema sanitário
Larga fila na recepção	Problemas de circuito/circuitos complicados	Relação com o sistema sanitário
Mandaram voltar num outro dia	Problemas de circuito/circuitos complicados	Relação com o sistema sanitário
Não sabia onde era a recepção	Problemas de circuito/circuitos complicados	Relação com o sistema sanitário
Não sabia que tinha que brilhar	Problemas de circuito/circuitos complicados	Relação com o sistema sanitário
Perda de HDD/ruído/cartão	Problemas de circuito/circuitos complicados	Relação com o sistema sanitário
Má informado por parte do pessoal sanitário/falta de informação sobre procedimentos	Problemas de circuito/circuitos complicados	Relação com o sistema sanitário