ASSESSING LINKAGES BETWEEN HIV TESTING AND HIV CARE ENROLLMENT AND RETENTION IN CENTRAL MOZAMBIQUE
ASSESSING LINKAGES BETWEEN HIV TESTING AND HIV CARE ENROLLMENT AND RETENTION IN CENTRAL MOZAMBIQUE

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ABREVIATIONS

ANC  Antenatal care
ART  Antiretroviral therapy
CIBS  Comité Institucional de Bioética para a Saúde (Institutional Bioethics Review Board)
CIOB  Centro de Investigação Operacional da Beira (Beira Operations Research Center)
CLC  Community Leaders’ Council
CS  Centro de Saúde (Health Center)
FGD  Focus group discussion
FILA  Ficha individual de levantamento de antirretrovirais (Antiretroviral refill form)
HAI  Health Alliance International
HTC  HIV testing and counseling
IRB  Institutional review board
INS  Instituto Nacional de Saúde (National Institute of Health)
MOH  Ministry of Health
LTFU  Loss to follow-up
NGO  Non-governmental organization
PEPFAR  United States President’s Emergency Plan for AIDS Relief
PITC  Provider initiated counseling and testing
PLHIV  People living with HIV
PMTCT  Prevention of mother-to-child transmission of HIV
VCT  Voluntary counseling and testing
USAID  United States Agency for International Development
UW  University of Washington
EXECUTIVE SUMMARY

As HIV care and treatment have expanded in much of sub-Saharan Africa, concerns have mounted regarding the extent to which patients who test positive for HIV are enrolled and retained in HIV care. The 2014 UNAIDS 90-90-90 targets call for 90 percent of all people living with HIV to be diagnosed, enrolled and retained in HIV care, and virally suppressed by 2020 (UNAIDS 2014). PEPFAR 3.0 embraced these targets and called for a strengthened data-driven approach that strategically targets geographic areas and populations to achieve high impact results (PEPFAR 3.0 2014). Both of these initiatives underscore the importance of accurate data to assess linkages from diagnosis of HIV infection to enrollment and retention in HIV care. Nevertheless, there is ample evidence that current national and sub-national data for sub-Saharan Africa may substantially underestimate the true levels of enrollment and retention in ART (Rosen and Fox 2011).

This study was designed to assess these linkages in central Mozambique. It was proposed by the United States Agency for International Development (USAID) and the Mozambique Ministry of Health (MOH) to address concerns about the validity of data regarding rates of enrollment, treatment initiation, and retention among HIV-positive people. The study team worked with the MOH and USAID to develop a mixed methods approach to assess these linkages in six districts within Manica and Sofala Provinces in central Mozambique. The study was designed and conducted by HIVCore partners at the University of Washington (UW), Health Alliance International (HAI), and the Mozambique MOH Center for Operations Research in Beira (Centro de Investigação Operacional da Beira-CIOB). HIVCore is funded by USAID and led by the Population Council.

The overall study objectives were to better understand the landscape of HIV testing and enrollment in care in six districts of Sofala and Manica Provinces and to explore the linkages between enrollment and retention in HIV care in eight key health facilities offering ART in those six districts. The linkages were defined as 1) the proportion of those who tested positive for HIV who are registered in HIV care, 2) the proportion of those registered in HIV care who have evidence of initiating HIV care (both antiretroviral therapy (ART) and pre-ART), and 3) the proportion of those with evidence of initiating ART who remain in active treatment at stipulated time periods. The study was also designed to provide recommendations for the MOH and USAID in Mozambique to improve these linkages. Specific study objectives were to:

1. Identify and describe the universe of HIV testing and linkages to enrollment and retention in HIV care in the target districts.

2. Identify the major community, household, individual, and health system factors that were perceived to affect linkages to enrollment and retention in HIV care and treatment.

3. Examine how HIV-positive clients describe their experiences and perceptions of their sero-status and their health-seeking trajectory in the context of HIV, including how social and structural factors affect their utilization of health care services.
4. Assess how client perceptions of HIV testing and HIV care affect behaviors regarding enrollment and utilization of HIV care, including delayed enrollment (>1 month after testing) and loss to follow-up (LTFU) within HIV care.

5. With participation from community and health care worker representatives, identify points of intervention to improve outreach and care for HIV-positive clients.

**METHODOLOGY**

We conducted a mixed methods assessment to quantitatively describe HIV testing and linkages to enrollment and retention in HIV care, as well as to qualitatively explore issues related to these linkages.

The study began with an assessment of HIV testing and HIV care enrollment data over 12 months (between April 2012 and March 2013) in six districts of central Mozambique, including 87 health facilities. Data for people who tested for HIV and for those who tested HIV-positive were collected from HIV program registries at health facilities, at district and provincial monitoring and evaluation offices, and from the national electronic health information system. All of these data sources were cross-checked and also compared to pharmacy records of completed tests and reported positive results. Because of large amounts of missing data, especially for HIV testing, many facilities were revisited to obtain more primary data regarding testing, including cross-checking with other sources of data. If primary source data for a given month at any facility were not found, then values for the missing data points were estimated based on either (a) information from additional primary data sources (e.g., informal clinic or provider registries), (b) cross-checking with pharmacy records of HIV test distribution and positive results, or (c) by conservative imputation methods based on months where data had been reported. Revised (adjusted) estimates of HIV-positive patients and pre-ART care registries were thus generated for all but one of the 87 facilities. Imputations were conducted using R (version 3.2). We defined initial enrollment as the number of people living with HIV (PLHIV) registered in a pre-ART registry book at any one of the 34 ART facilities in the six districts.

Within these six districts, a random, systematic sample of HIV-positive patients who had enrolled in the eight selected ART health facilities during the same time period were assessed via chart review to determine their HIV care and their outcomes. We obtained initial enrollment data from the pre-ART and ART registry books at each of these eight health facilities and looked for patient charts from the randomly selected registrants. Pre-ART and ART retention data were measured by the proportion of patient charts that were found, after intensive searches at each ART facility among randomly-selected pre-ART and ART registrants. Pre-ART and ART charts were reviewed along with the individual pharmacy records to assess whether patients were effectively in treatment on the day of the study team visit. Charts were selected from patients older than 15 years given that within the Mozambique National Health System, patients older than 15 years are considered adults. Women in prevention of mother-to-child transmission of HIV (PMTCT) programs were excluded because PMTCT services are delivered in antenatal care clinics (i.e., separate from standard ART services). The data did not allow for analysis of individual linkages to HIV care since different codes were used for testing and registry in pre-ART care, and testing codes were not registered in treatment sites. Data cleaning and analysis was conducted using Stata 13.1.

To examine perceptions of factors related to enrollment and retention in HIV care and to describe HIV-positive patients experiences, we conducted in-depth interviews (IDIs) and focus group discussions (FGDs) at the same eight study health facilities and in their catchment areas. IDIs included health facility
directors (or their substitutes) and four types of PLHIV: 1) people who enrolled in HIV care within 30 days of their HIV-positive test (early enrollments); 2) people who enrolled after 30 days from their positive test result (late enrollments); 3) people who enrolled early or late but eventually dropped out of HIV care (drop-outs); and 4) people who never enrolled in HIV care after their HIV-positive test. FGD participants were health care providers, community leaders, health facility-based outreach workers, and members of patient support groups. Only people above the age of 18 who provided individual, written informed consent were interviewed or participated in FGDs. During the interviews and FGDs, study teams explored factors that participants perceived as inhibiting or facilitating the ability to enroll and be retained in HIV care. These included narratives about personal experiences or events participants had witnessed.

The IDI and FGD guides were refined after internal testing during data collectors’ training. All interviews and FGDs were audio-recorded, and notes were taken by two members of the study team to improve reliability. The recordings were used only to clarify statements and to extend notes; no transcriptions were made. Analyses explored similarities and differences in opinions and perceptions by health facility, gender, and type of participant. Preliminary results were presented to health facility, district, and provincial health providers to clarify and refine the study team’s observations and interpretations. Data were coded and analyzed using ATLAS.ti 7TM (http://atlasti.com/).

**KEY FINDINGS**

The number of people with HIV-positive tests was grossly underestimated in these six districts because of missing data from routine reports. Over 46 percent of the 1,944 monthly HIV testing reports expected from the 87 health facilities were missing. Furthermore, many of the reports that were submitted did not include data from all 13 services where HIV testing might have occurred. Thus, HIV-positive patients identified in the health system were substantially under-reported. Our aggregate imputed estimates for people tested HIV-positive during the study period (33,228) was over 35 percent greater than the number of officially reported people tested HIV positive (24,677).

**Enrollment in HIV care:** In three of the six districts, because of widespread missing data on HIV testing, reported numbers of HIV-positive clients enrolled in pre-ART or ART care exceeded, by a large margin, the reported number of people who tested HIV-positive during the same period. Missing reports for those registered in pre-ART or ART care were much less frequent, ranging from 1 percent to 15 percent in the districts. When adjustments were made to estimate the number of individuals registered in pre-ART, they changed by less than 10 percent. Using adjusted estimates for both HIV-positive patients and people registered in pre-ART, the aggregate proportion of registered HIV-positive patients in pre-ART care was reduced to 75 percent of all newly identified HIV-positive patients during the 12 month study period. We found wide variation between districts, ranging from 45 to 92 percent of newly identified HIV-positive patients who were enrolled in care.

**Retention in HIV care:** Retention was measured as the proportion of registered HIV-positive patients at a facility for whom pre-ART (or ART) charts were found. In addition, for ART patients, retention included the proportion who had evidence of having received ARVs within 90 days of the study team visit. Of the registered HIV-positive patients in the eight sites (aggregated), only 60 percent of their pre-ART patient charts and 66 percent of their ART charts were found at the facility where they had registered for care—again with wide variation between facilities (25 to 85 percent of ART charts found
and 7 to 83 percent of pre-ART charts found). A large proportion of HIV-positive patients were registered in pre-ART or ART on the same day or within a few days of their HIV test. However, for many patients, both pre-ART and ART, there was no evidence of any other interaction with the health facility after registration in pre-ART. Among the ART patients whose charts were found, only 33 percent had evidence of a clinic visit or an ART pick up at the pharmacy within 90 days of the study team visit. Variation in this retention measure between the 8 sites was between 8 percent and 62 percent.

Figure i shows a constructed cascade of HIV care for the eight facilities, starting from a theoretical cohort of 100 HIV-positive, ART-eligible individuals. The figure shows substantial losses at each step. Overall, we estimated that approximately 18 percent of the people who tested positive for HIV (and were eligible for ART) had evidence of retention within 90 days of the study team visit.

**Main factors perceived to be associated with enrollment and retention:** Qualitative results suggested that healthcare providers were aware of substantial LTFU at various stages of the cascade, from HIV testing to enrollment to retention. The majority of PLHIV reported that lack of symptoms of illness was the main barrier for enrollment in HIV care. They also identified two main barriers to retention in HIV care: disrespect by health workers and poor quality of care at the health facility.

Lack of money for food and transport was also reported as a barrier to retention. The main perceived facilitator for enrollment in HIV care was the presence of symptoms of sickness and the main perceived facilitator of retention in care was living near the health facility where one receives HIV care. This was mentioned by PLHIV who had enrolled early in HIV care and by community leaders. Table i summarizes the perceived facilitators and barriers for enrollment and retention in HIV care.
Table 1  Principal perceived facilitators & barriers to enrollment & retention in HIV care

<table>
<thead>
<tr>
<th>Enrollment in HIV care</th>
<th>Retention in HIV care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presence of symptoms</td>
<td>Proximity to health facility</td>
</tr>
<tr>
<td>Early enrollers, community leaders</td>
<td>Early enrollers</td>
</tr>
<tr>
<td>Lack of symptoms</td>
<td>Disrespect by health workers, poor quality of healthcare, Lack of money for food and transport</td>
</tr>
<tr>
<td>Late enrollers, never enrolled, drop-outs, patient support group, and health workers</td>
<td>Early enrollers, late enrollers, drop-outs, patient support group, health workers, and outreach workers</td>
</tr>
<tr>
<td>Early enrollers</td>
<td>Early enrollers, late enrollers, and drop-outs</td>
</tr>
</tbody>
</table>

CONCLUSION AND RECOMMENDATIONS

We noted substantial LTFU at all steps of the HIV cascade, with large variation between health facilities. Our estimates of overall enrollment and retention in HIV care are substantially lower than routine health data suggest, likely because we measured enrollment among all people estimated to have been identified HIV-positive and measured retention among all patients initially registered in HIV care.

We also found that routinely reported data on HIV testing grossly underestimates the likely number of those who truly tested HIV-positive and thus may be an unreliable denominator to measure linkages to HIV care. Moreover, registration at ART clinics does not necessarily measure effective enrollment or linkage to care because a very large proportion of registered “ART” patients either do not have evidence of having had charts created or do not initiate ART.

These findings, and the high variability in measures of enrollment and retention among the health facilities, suggest that more accurate monitoring and interventions at the facility level may have a substantial impact to improve enrollment and retention in HIV care. Modifiable barriers to enrollment and retention include common health facility practices such as modification of patient flow and pharmacy hours. Stigma remains a strong perceived barrier to retention in HIV care, both at health facilities and in the community.

The validity of this study was limited by one of the major findings—the absence, incompleteness, and inconsistency of HIV testing data and individual patient charts, and the incomplete recording of events and follow up both in patient charts and pharmacy refill forms. The imputation of estimated values to replace missing and implausible data is by no means certain to provide accurate estimates. The likelihood of patients moving from one ART site to another, and the infrequent recording of transfers in patient charts or registries, suggest that our study may have modestly overestimated LTFU.

The study team and its MOH partners recommended the following:

1. Data collection for testing, enrollment, and retention (including patient charts) should be simplified and monitored routinely at health facilities to identify early loss to follow up.

2. Patient transfers to other HIV care facilities should be routinely recorded.
3. Guidelines should be established to standardize patient and information flow.

4. Health workers should be coached to improve their respect for and management of HIV-positive patients, to provide a friendlier environment for them.

5. Pharmacies should establish longer hours for distribution of ARV medicines.

6. Archiving of patient charts should be organized better to facilitate their location and utilization.

7. Best practices should be shared across health facilities that provide HIV care.

8. Key interventions to improve linkages of HIV-positive clients to enrollment and retention in HIV care should be developed, implemented, and tested (suggested by MOH and USAID).

Recommendations that are relevant at a global level include the following:

1. Simplify data requirements and data collection methods.

2. Conduct routine chart review for early identification of and action to prevent LTFU.

3. Track base enrollment and retention on clear and valid denominators of HIV patients in the system.

4. Share best practices among health facilities.
INTRODUCTION

In late 2014, UNAIDS announced its 90-90-90 targets to drive progress toward ending the AIDS epidemic by 2030 (UNAIDS 2014). The targets included 90 percent of those diagnosed with HIV infection to be receiving sustained antiretroviral therapy (ART) and 90 percent of those having viral suppression. These targets thus call for high enrollment and retention in HIV care. Shortly thereafter, PEPFAR 3.0 embraced UNAID’s 90-90-90 targets and called for a strengthened data-driven approach that strategically targets geographic areas and populations to achieve high impact results (PEPFAR 3.0 2014). Both of these initiatives underscore the importance of accurate data to assess linkages from diagnosis of HIV infection to enrollment and retention in HIV care. Nevertheless, there is ample evidence that current national and sub-national data for sub-Saharan Africa may substantially underestimate the true levels of enrollment and retention in ART (Rosen and Fox 2011, Brennan et al. 2014).

In 2005, the Mozambique Ministry of Health (MOH) initiated the process of integrating HIV testing, care, and treatment into the primary health care system. Testing and treatment programs that were scaled up had previously relied on free-standing voluntary counseling and testing (VCT) sites with referrals to “day hospital” HIV clinics that initially focused on palliative care. Universal antiretroviral therapy (ART) was initiated in Mozambique in 2004, and by 2008, HIV testing and counseling (HTC) was integrated into HIV care in many sites throughout the country (Lambdin et al. 2013; Pfeiffer et al. 2010). Since then, provider initiated testing and counseling (PITC) has been conducted in inpatient wards, outpatient clinics, antenatal clinics, maternity, postpartum, child at-risk services, health centers, health posts, free-standing patient-initiated community sites (NGO, private, and government), home-based sites, mobile testing, and special sites for adults (e.g., workplace testing) and adolescents (Ministério da Saúde 2013). This expansion of testing access should have led to substantial increases in testing coverage. There has also been an expansion of health facilities that prescribe and manage ART.

Few recent systematic analyses have been published in Mozambique on the magnitude and characteristics of HIV testing, or regarding the gaps in linkages between testing HIV-positive and enrollment and retention in HIV care. A few Mozambique studies have been published showing inconsistent proportions of HIV-positive people enrolled and retained in HIV care. Auld et al. (2011) reported less than 20 percent loss to follow up (LTFU) among ART-eligible (enrolled) patients in most of the seven African countries assessed (including Mozambique), whereas Micek et al. (2009) reported over 40 percent non-enrollment but similar (< 20 percent) LTFU among enrollees. Delay in enrollment into HIV care is associated with lower CD4 cell counts (The ART-LINC Collaboration 2008), contributing to higher mortality in the first year after initiating treatment (Lawn et al. 2008). Little is known regarding the pathways of HIV-positive persons to care and why some PLHIV enroll shortly after diagnosis while others delay or never enroll in treatment clinics. Better understanding of these linkages to enrollment and retention in care, including the patient and facility characteristics that are associated with linkage performance, could provide important information for effective interventions to improve linkages and retention, and to reduce HIV mortality.
**STUDY AIMS AND SPECIFIC OBJECTIVES**

This evaluation was conducted to better understand and address patient linkages from HIV testing to enrollment and retention in HIV care in central Mozambique, where USAID supports HIV program activities of the MOH and its NGO partners. The linkages between people testing HIV-positive and enrollment and retention are defined as 1) the proportion of those who tested positive for HIV who are registered in HIV care, 2) the proportion of those registered in HIV care who have evidence of initiating HIV care (ART and pre-ART), and 3) (for retention only) the proportion of those with evidence of initiating ART who remain in active treatment at stipulated time periods.

The overall goals of this evaluation were to: (a) understand the quantitative and qualitative dynamics of linkages from HIV testing to enrollment and retention in HIV care; (b) provide a set of detailed recommendations, informed by locally relevant evidence, for the MOH and USAID/Mozambique to consider when they develop interventions to improve HIV care, and (c) develop tools that can be used by providers and program managers in health facilities and elsewhere to rapidly collect information to inform the development of effective linkages from care to retention interventions.

The original specific study objectives are listed below. The first objective was modified to reflect the feasibility of achieving this objective.

1. Identify and describe the universe of HIV testing and linkages from HIV testing services to HIV care (ART) in the target districts, including variability of linkages within or between different types of HTC sites (community-based and/or facility-based) and different geographic areas.

   Note: Measurement of the variability regarding types of HTC sites was not possible since the data regarding HIV testing from different types of HTC was grossly incomplete. Furthermore, different codes were used for testing and enrollment and testing codes were not registered in treatment sites. Thus, data for analysis of individual linkages from HIV testing to HIV care sites was not available and consequently the variability of linkages within and between different HTC sites was not possible to measure.

2. Identify the major community, household, individual, and health-system factors perceived to affect linkages to enrollment in HIV care and treatment.

3. Examine how HIV-positive clients describe their experiences and perceptions of their sero-status and their health-seeking trajectory in the context of HIV, including how social and structural factors may affect utilization of health care services.

4. Assess how client perceptions of HIV testing and HIV care might affect behaviors regarding enrollment and utilization of HIV care, including delayed enrollment (>1 month after testing) and LTFU within HIV care.

5. Use a participatory approach with health workers and clients to identify possible points of intervention, including tools for providers to improve outreach, services, and care for HIV-positive adults and adolescents.
METHODOLOGY

We conducted the study in six districts in Sofala and Manica Provinces, central Mozambique, using quantitative and qualitative methods. The districts were the city districts of Beira and Chimoio and the rural districts of Dondo, Buzi, Manica, and Barue. We selected these districts because of their high HIV prevalence, their mix of rural and urban conditions, their mix of health facilities and their accessibility, and their acceptable security during a period of political strife in the region. We selected eight key referral facilities within these districts that offered ART care to provide an in-depth quantitative and qualitative analysis of linkages and retention in HIV care. (See the Figure 1 map and Table A in the Appendix showing the districts and health facilities included in the study.)

To accomplish the assessment goals, the study team engaged health workers, patients, and community leaders to better understand 1) the landscape of testing and linkages to and retention in HIV care, 2) the extent to which these linkages to and retention in HIV care are occurring, 3) the perceived risk factors, barriers, and facilitators affecting initial enrollment in HIV care and/or treatment of people living with HIV (PLHIV), and 4) concerns and perceptions of health workers, clients, and community members regarding testing access and referrals to care in target sites. After presenting preliminary findings, we solicited community and health-worker participation to inform the design of potential pilot interventions that could be implemented at the community or site level (HTC or care & treatment) to improve these linkages and retention.

TESTING AND ENROLLMENT ASSESSMENT IN SIX DISTRICTS

To get an overview of the treatment cascade in the six districts, we examined HIV program data from all 87 health facilities that provided HIV testing or treatment in the six selected districts. We first abstracted data on HIV testing and HIV care enrollment from reports archived at provincial and district levels, both paper reports and from the electronic health information system data (locally known as Módulo Básico). Standard MOH HIV testing report forms are tabular with 12 columns, one for each site or type of testing (voluntary counseling/testing sites, triage, general medicine consultations, prenatal care, well-child care, hospital wards, maternities, TB care, blood bank, laboratory, adolescent clinics, and community testing) and 47 demographic (age groups, sex) and testing categories (types of tests and results). We also collected district and facility-level pharmacy reports (when available) that identified numbers of tests distributed and positives by each type of test they distributed to each health facility. Enrollment in care was measured by the numbers of newly identified HIV-positive individuals who had been registered in general HIV care (pre-ART registry books) and individuals enrolled in ART (ART registry books). These data were collected for the period of April 2012 through March 2013. We chose to start with April 2012 because new HIV data collection and monitoring tools were introduced and implemented throughout Mozambique during the previous several months.

Missing data were common, especially for HIV testing. A missing data point was defined as a non-submitted report from a facility for a given month (typically a completely empty monthly data cell) that did not appear in paper or electronic form at the district or provincial level. Missing data were reported
separately for HIV tests, HIV-positives, registry in pre-ART, and registry in ART. Because of the large amounts of missing and inconsistent data, especially for HIV testing and HIV test results (nearly always missing together), we made visits to 19 of the larger health facilities to abstract primary source data from HIV testing registries, pre-ART and ART books, and pharmacy records of tests distributed and reported to review any primary data that were available. We then re-visited district-level health offices to assess the plausibility of each data point. When data were still missing (or inconsistent) after these extra visits for a given month at any facility, HIV testing values and ART registry values were adjusted (estimated) using standard imputation methods. We examined missing value patterns over time and by health facility, and tested three imputation methods to substitute missing values: (1) single imputation using mean, trimmed means (replacing values above 50 percent of the mean for facilities that had less than five months of data) and median, (2) Poisson generalized linear modelling, and (3) iterative singular value decomposition (SVD) method (specifically rank-1 SVD approximation). None of these methods yielded consistently higher or lower imputed values than the other methods. We finally used the single imputation method because it gave the most conservative values. The single imputation method was performed as follows:

For each missing month, we substituted the median or mean value (whichever was smaller) of HIV-positives or new pre-ART registrants reported for the other months in the same year at that facility. When a facility had five or fewer months with reported values, we eliminated outlier months (HIV-positive values 50 percent greater than the mean number of HIV-positive results per month) prior to imputation. Where no reliable testing data were available for any months, we used pharmacy reports that included reports of HIV-positives from that facility for the missing month. We used R (version 3.2) to perform imputations.

We defined initial enrollment as being registered in a pre-ART registry book at any one of the 34 ART facilities in the six districts, since Mozambique Ministry of Health (MOH) policy stipulates that all newly diagnosed HIV-positive patients be first registered in pre-ART registries, even those who are already eligible for ART. Once initiated on ART, these ART patients are also registered in the ART registries. Typically, registration in the pre-ART registry occurs on the same day as the initial HIV test when patients are tested HIV-positive at one of the 34 ART sites, and some days afterward for those tested HIV-positive at non-ART sites. We assumed that the adjusted number of newly registered patients in pre-ART divided by the adjusted number of newly identified HIV-positive patients in the same reporting period would provide a reasonable estimate of the proportion of PLHIV enrolled in HIV care for that time period.

During the district-level assessment, interviews and discussions with key community stakeholders were conducted to revise and refine the study objectives, establish strong community relationships for the study process, and prepare for study analysis, intervention selection, and implementation. Stakeholders were identified by local representatives of the National AIDS Commission. This process provided an ethnographic background to contextualize healthcare-seeking patterns among PLHIV to help frame the approach to the study.
Figure 1  Districts and health facilities included in the study, Manica and Sofala Provinces

**RETENTION AND PERCEPTIONS OF HIV CARE AT EIGHT ART HEALTH FACILITIES**

The eight selected facilities for in-depth assessment included the main ART referral sites in four rural districts and four high-to-moderate volume referral facilities from the two provincial capitals (Beira and Chimoio). Denominator data of PLHIV enrolled in HIV care were abstracted from the pre-ART and ART registry books at each of the facilities. These registry books included dates of HIV-positive and CD4 tests, and, in the ART registry, the date of ART initiation. MOH policy stipulates that patient charts be created (opened) for all pre-ART and ART patients registered at the facility. The study team randomly selected enough registrants from the pre-ART and ART registries to obtain 100 patient charts (up to 50 ART charts and 50 pre-ART charts) at each ART facility. Women in prevention of mother-to-child transmission (PMTCT) programs¹ and children under 15 years old² were excluded. The study team then searched for the selected patient charts in archives, consultation rooms, and other locations in the health facilities to attempt to find all of the selected patient charts. Data abstracted from the patient charts that were located included demographic characteristics, type of testing site, dates for ordering a CD4 test,....

¹As in many countries, PMTCT patients in Mozambique receive their ART-related services in antenatal care clinics.
²Within the Mozambique National Health System, 0-14 year olds are categorized as pediatric patients while those 15 years and older are categorized as adults. Charts and registries are organized by the adult and pediatric categorization.
Assessing linkages between HIV testing and HIV care enrollment and retention in central Mozambique

receipt of the CD4 test results, enrollment into care, ART initiation, consultations, and ART pick-ups until the time of the study team visit. As previously stated, the data did not allow for analysis of individual linkages to HIV care once diagnosed with HIV, since different codes were used for testing and ART registries, and because testing codes were not linked to registries in the ART sites.

Enrollment rates were measured in two steps: initial enrollment (at the district level) and effective enrollment (at the facility level). Initial enrollment was measured by the total number of pre-ART registrants in a given district divided by the number of new HIV-positive patients in that same district during the study period, as indicated above. Secondary enrollment was measured in each of the eight health facilities by the proportion of HIV charts found among the randomly selected group of pre-ART or ART registrants at that facility. Retention rates were measured by the proportion of those ART patient charts with any evidence of an ART clinic visit or antiretroviral (ARV) pickup (verified by examination of the ARV refill form from the facility's pharmacy) within the 30, 60, or 90-day time period prior to the study team visit to the facility. Retention was examined separately for pre-ART and ART subpopulations. We used Stata 13.1 for data cleaning and analysis.

At each of the eight facilities and surrounding areas, we conducted in-depth individual interviews (IDIs) with health facility directors and with PLHIV who were: (1) early enrollers—those who enrolled in HIV care within 30 days of their HIV-positive test, (2) late enrollers—those who enrolled after 30 days from their positive test result, (3) drop outs—those who enrolled but eventually dropped out of HIV care, and (4) never enrolled—those who never appeared in HIV care after their HIV-positive test. Participants were at least 18 years old and provided written consent. Outreach workers and/or healthcare providers helped recruit PLHIV. We conducted focus group discussions (FGDs) with HIV care providers and facility-based community outreach workers, members of patient-support groups, and community leaders.

During the interviews and FGDs, study teams explored factors that inhibit or facilitate ability to enroll and be retained in HIV care. The teams attempted to identify what respondents perceived to be core elements of what constitutes accessible and acceptable HIV and AIDS treatment services. Respondents were asked about their perceptions of the steps (individual, family, community, health system) to initial enrollment in care and to retention in care. We reconstructed an HIV patient flow map, based on the national ART guidelines (see Figure 10, page 23).

We audio-recorded the IDIs and FGDs, and two interviewers took notes to improve accuracy. We used audio recording to expand notes and improve reliability. Data were coded and analyzed using ATLAS.ti 7TM (http://atlasti.com/).

Collection of both quantitative and qualitative data was conducted from June 2013 to January 2015. The study team spent several working days in the MOH health offices of each of the six districts gathering in-depth quantitative and qualitative information. An additional 10–15 working days were required in each of the eight ART facilities. One of the most time consuming activities was identification of the categories and numbers of PLHIV registered in pre-ART and ART, locating the patient charts of pre-ART and ART registrants, and abstracting data from their charts. Additional data collection time was required to revisit health facilities with persistent incomplete, inconsistent, or implausible data to compare all potential sources of primary data to make the best possible estimates.

Preliminary results were presented to health facility, district, and provincial health providers to clarify and refine the study team's observations and interpretations.
KEY FINDINGS

DISTRICT-LEVEL ESTIMATES OF HIV-POSITIVE CLIENTS AND ENROLLMENT IN HIV CARE

Routine monthly reports from health facilities to district offices regarding HIV testing were frequently missing. Overall, 46 percent of the 1,944 monthly HIV testing reports expected from the 87 health facilities were missing. The range was 26 to 65 percent missing among districts. Of the reports that were successfully submitted to the district level, few included data from all 13 services where HIV testing might have occurred. When examining these findings from district-level reports and primary sources against the data from the electronic HIS, the latter generated even lower numbers of HIV-positive people, including three districts without any reports for any HIV testing data during the study period. By contrast, only 7 percent (range: 1 to 15 percent among districts) of monthly reports from health facilities regarding numbers of registrants in pre-ART or ART care were missing. The percentage missing for pre-ART and ART reports was identical.

Figure 2 shows the proportion of missing monthly reports from the health facilities for HIV testing and for enrollment in HIV care (from the pre-ART registries) from each of the districts.

Figure 2  Proportion of annual missing monthly reports from health facilities of HIV testing and pre-ART registration (from provincial reports of pre-ART registry data)

Example: 50% annual missing reports means that in District X with 20 facilities, 20x12m=240 reports were due and 120 were submitted.
As a result of low reporting for HIV-positives and higher reporting for pre-ART and ART, the reported proportion of newly registered pre-ART patients divided by diagnosed HIV-positive people was 97 percent (23,820/24,667), with three districts reporting more new pre-ART registrants than new HIV-positive patients. Figure 3 shows the unadjusted (raw) reported numbers of HIV-positive patients compared to enrollees.

**Figure 3** HIV testing and enrollment in HIV care—raw unadjusted reported data per district (from national health information system)

After the study team visited the facilities to obtain primary data and made imputations for months with missing data, our adjusted aggregate estimate for HIV-positive patients (33,228) in the six districts was 35 percent, over one-third greater than the officially reported numbers (24,677) based on monthly reports for the 12-month study period. Similar adjustments made to estimate the number of individuals registered in pre-ART increased the totals by only 4.2 percent. One ART facility reported data so implausible and inconsistent on both HIV testing and pre-ART registries—and without alternative data—that it was eliminated from the analysis. Table 1 demonstrates the large differences between the monthly officially reported and adjusted numbers of HIV-positive patients compared to the pre-ART registrants at each of the six districts. After adjustment, the overall proportion of HIV-positive clients who enrolled in any kind of HIV care was 75 percent (range: 46 to 92 percent) in the six districts. These numbers do not account for HIV-positive clients who might have registered at an HIV care facility outside of their district, or who registered in more than one HIV care site inside or outside of their district.
Table 1  Monthly reported and adjusted number and proportion of HIV-positive patients enrolled in pre-ART

<table>
<thead>
<tr>
<th>Districts</th>
<th>Number of HIV-positive patients</th>
<th>Number of pre-ART enrollees</th>
<th>Proportion of HIV-positive patients enrolled in pre-ART</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Reported</td>
<td>Adjusted</td>
<td>Reported</td>
</tr>
<tr>
<td>Búzi</td>
<td>2,104</td>
<td>3,363</td>
<td>1,549</td>
</tr>
<tr>
<td>Dondo</td>
<td>2,898</td>
<td>2,757</td>
<td>1,681</td>
</tr>
<tr>
<td>Beira</td>
<td>8,143</td>
<td>12,040</td>
<td>11,061</td>
</tr>
<tr>
<td>Manica</td>
<td>2,404</td>
<td>3,498</td>
<td>2,660</td>
</tr>
<tr>
<td>Bárue</td>
<td>2,096</td>
<td>2,164</td>
<td>1,194</td>
</tr>
<tr>
<td>Chimoio</td>
<td>7,032</td>
<td>7,406</td>
<td>5,675</td>
</tr>
<tr>
<td>Total</td>
<td>24,677</td>
<td>33,228</td>
<td>23,820</td>
</tr>
</tbody>
</table>

RETENTION IN HIV CARE AT EIGHT HEALTH FACILITIES

Missing charts
In each of the eight health facilities, 100 patient charts were located and analyzed. In four of the sites, half (50) of those charts were from patients registered in the ART registry and the other half from the pre-ART registry. In the remaining four sites, more pre-ART charts were abstracted; 51 pre-ART vs. 49 ART charts in Eduardo Mondlane, 53 vs. 47 in Catandica, 60 vs. 40 in Manica, and 73 vs. 27 in Manga Nhaconjo in Beira City. These differences in chart abstraction numbers were due to study team communication lapses regarding the methods.

After the substantial effort of our study team to locate the charts of the randomly selected HIV-positive registrants, we found an overall mean proportion of 60 percent (range: 7 to 83 percent) of pre-ART patient charts and 66 percent (range: 25 to 85 percent) of ART patient charts at the eight ART facilities. Figure 4 shows the proportion of pre-ART and ART patient charts found and the high variability in patient charts between the eight facilities.
**Time to first ART consultation and ART initiation among charts found**

Our team abstracted data from the patient charts that were found, and analyzed the time to first consultation, CD4 count, initiation of ART, and evidence of the patient having had a clinic or pharmacy visit within 60 or 90 days prior to the time of the study team visit. Figure 5 shows the mean days elapsed from the reported HIV-positive test until the first consultation per ART facility (overall mean 7 days; range 0–11 days). The reported time elapsed between the reported HIV-positive test and the first CD4 test result (not shown) was shorter (mean 4 days; range 1–11 days). Figure 6 shows the months elapsed from the reported HIV-positive test until the initiation of ART per ART facility (overall mean 1.6 months; range 0.8–2.2 months). The vertical red lines indicate the first, second, and third interquartile ranges.
Figure 5  Days from HIV-positive test to first consultation, by HIV care facility

Figure 6  Months from HIV-positive test to initiation of ART in eight ART health facilities
Evidence of retention in ART (among charts found and pharmacy records)

Figure 7 shows the proportion of ART patient charts in the eight ART facilities who had evidence of having received ARVs within 60 or 90 days prior to the study team visit. Only 33 percent and 25 percent of all the ART patients whose charts were found had evidence of a clinic visit or ARV pickup within 90 or 60 days, respectively, prior to the study team visit. Number of days for which ARVs were dispensed was frequently missing in the charts. However, providers consistently told the study team that ARVs were usually dispensed for 60 days when patients were stable, and sometimes prescribed for 90 days. Again, there was wide variation among the ART facilities in their measures of retention. In our selection of patient charts, the mean time interval followed up from ART initiation until the study visit was 1.5 years, with a range of 12 to 24 months.

Figure 7  Proportion of patient charts with evidence of clinical visit or ARV pick-up
60 and 90 days before study visit

Overall HIV care cascade

To construct an overall HIV care cascade, we combined data from several sources: district-level proportion of estimated HIV-positive patients registered in pre-ART, proportion of patients registered in ART in the eight ART facilities whose charts were found, and proportion of those patient charts with any evidence of clinic visit or ARV pick up within 90 days of our study team visit. Figure 8 shows the aggregate constructed HIV care cascade, starting from the estimated total number of HIV-positive adults in the six districts (excluding PMTCT patients)—arbitrarily set at 100 percent to compare the percentage drop-offs at each cascade step. The LTFU at each step was substantial: 25 percent lost prior to registry in pre-ART, 44 percent of charts lost among ART registrants (using ART charts as the best-case for retention), and non-active charts (i.e., no evidence of a visit within 90 days) comprised 63 percent of the charts found. The calculations suggest that, in the aggregate, approximately 18 percent of the HIV-positive patients identified in the district health facilities during the study period had evidence that they were retained in treatment 1–2 years later. Figure 9 below shows the same HIV care cascade for each of the eight health
facilities, demonstrating a high variability of LTFU in different steps of the cascade in different facilities. Note that the registry in HIV care column is based on district data, whereas the proportion of charts found and proportion with evidence of treatment is based on data from each of the eight health facilities.

**Figure 8** Overall HIV treatment cascade—from HIV testing to enrollment to charts located to retention—Aggregate data from all eight ART facilities

Note: Retention was defined by evidence of retention 90 days prior to study team visit.

**Figure 9** Proportion of patient charts with evidence of clinical visit or ARV pick-up, 30, 60, and 90 days before study visit

![Graph showing percentages of HIV-positive patients, charts found, and retention](image)
PERCEIVED FACILITATORS AND BARRIERS TO ENROLLMENT AND RETENTION IN HIV CARE

Table 2 below summarizes numbers, categories, and locations of the individual interviews and focus group discussions. Nearly half (23) of the 50 interviews were conducted with HIV-positive patients who enrolled within 30 days of HIV test (early enrollment patients). Despite our best efforts, only two people were located who had an HIV-positive test result and never enrolled in HIV care. The seven late HIV care enrollees had enrolled over 30 days after the positive HIV test.

<table>
<thead>
<tr>
<th>Type of interview</th>
<th>Sofala Province</th>
<th>Manica Province</th>
<th>Total</th>
<th>%</th>
<th>Facilities where present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual interview</td>
<td>31</td>
<td>19</td>
<td>50</td>
<td>100</td>
<td>8</td>
</tr>
<tr>
<td>Health facility directors</td>
<td>5</td>
<td>3</td>
<td>8</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>Early enrollment patients</td>
<td>14</td>
<td>9</td>
<td>23</td>
<td>46</td>
<td>8</td>
</tr>
<tr>
<td>Late enrollment patients</td>
<td>7</td>
<td>0</td>
<td>7</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>Drop outs</td>
<td>5</td>
<td>5</td>
<td>10</td>
<td>20</td>
<td>6</td>
</tr>
<tr>
<td>Patients never enrolled</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Focus group discussions</td>
<td>15</td>
<td>10</td>
<td>25</td>
<td>100</td>
<td>8</td>
</tr>
<tr>
<td>Community leaders</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>24</td>
<td>6</td>
</tr>
<tr>
<td>Health workers</td>
<td>5</td>
<td>3</td>
<td>8</td>
<td>32</td>
<td>8</td>
</tr>
<tr>
<td>Outreach workers</td>
<td>4</td>
<td>2</td>
<td>6</td>
<td>24</td>
<td>6</td>
</tr>
<tr>
<td>Patient support groups</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>20</td>
<td>5</td>
</tr>
</tbody>
</table>

PLHIV interviewed were largely sexually active adults (aged 20–49 years), mostly women (62 percent), married or widowed, who had children. Slightly over half of people living with HIV interviewed had attended primary school, while nearly a third had attended secondary school or higher. They were mostly domestic workers, small business owners, or workers in agriculture/fishing. A full description of socio-demographic characteristics of the IDI participants are described in the Appendix, Table B. We only report main facilitators and barriers for HIV testing and linkages to enrollment and retention in HIV care, i.e., those mentioned by at least three out of the four types of the PLHIV, and in at least four out of the eight study sites.

During IDIs and FGDs, most respondents said that they preferred to be tested at sites that provided ART and were near their place of residence. Health facilities that provided antiretroviral therapy (ART) were the preferred sites for HIV counseling and testing. This was stated among interviewees who enrolled early at all health facilities. A 39-year-old, single man from Manica Province, father of three children, stated the following: “I prefer to do the HIV test in the hospital. Because here […] here they are able to tell you go to this or to that door where you will receive care.” Far less preferred (and mentioned) were community-based HIV testing sites and health facilities that do not provide ART. The most preferred sites for HIV testing were near one’s place of residence for all participants.
The most widely mentioned facilitator for obtaining an HIV test and enrolling in HIV care was the presence of signs or symptoms of illness. However, this was mentioned only by early enrollers and by community leaders. Women (all non-PMTCT patients) who enrolled early mentioned that their primary reason for enrolling in HIV care was their desire to protect their children from vertical transmission and wishing to live longer to be able to raise their children. The main perceived barrier for enrollment was lack of signs or symptoms of illness. This was mentioned by healthcare providers and by all types of patients except early enrollers.

Regarding retention, only early enrollers mentioned a facilitator of retention, namely living near the health facility where one receives HIV care. The main perceived barriers for retention included the perception of poor and disrespectful service at the health facility and lack of money for food and for transportation. Many respondents complained about providers’ harsh treatment of people on ART who show up late for their ARV medicine pickup appointments. One female drop-out said:

I missed a consultation appointment because I had been to a burial. I…came back the following day…. I gave them my card…. They [healthcare providers] looked at my card very late, and said that at this time we do not attend to people who have cards…. ‘No, go back and see your promotor [case manager].’ I went to see with that man. He said, ‘No, this is not my business anymore, because I am tired of people who do not come to refill their prescriptions.’ I said ‘no, I did not miss my appointment; I was just late.’ ….He said, ‘No, come back tomorrow.’ The following day was worse, because it was no longer my appointment date…. I got there at six a.m.. He [the case manager] even used to swear at me. I always used to go there and return home late, for three days. Then I decided to stay home. I did not go [back to the health facility] for three months....

—Female, 36 years old, Manica Province

Lack of money for food and for transportation was mentioned by men and women in all but one health facility, by all categories of participants except PLHIV who never enrolled in HIV care. A married mother of four children who enrolled late in HIV care described how distance from her residence to the health facility where she received HIV care, coupled with the lack of money for transportation was a barrier to her continuing in ART. She explained that transportation from her house to the health facility cost 100 Mozambican Metical (Mt; approximately USD 2) per round trip, and that before she got that transportation she needed to walk 8–9 kilometers to get the boat to cross the river. To cross the river, she payed 20 Mt (USD .40) per round trip. According to her, since it was difficult for her to get all that money, she decided to skip consultation visits and ARV refill appointments. She said:

I stayed almost a year without coming to the health facility. I only came today. When I arrived at the health facility I went to the reception and I showed my patient card, and they asked me where I had been all this time I did not come to my consultations. That’s when I started explaining why. I live 36 kilometers away from the district town, at the other margin of the Búzi River.

—Female, 36 years old, Sofala Province

Secondary barriers to retention in HIV care included lack of symptoms of illness and improvement in health after starting ART, and work-related travel and other work commitments that precluded getting to appointments or ARV pickups.
Table 3 summarizes the main barriers and facilitators of enrollment and retention in HIV care, mentioned by different types of research participants during IDIs and FGDs in the eight facilities and surrounding areas.

During FGDs, healthcare providers at all health facilities confirmed the quantitative findings of many HIV-positive patients being lost at different steps along the HIV continuum of care. They reported this happening especially between receiving their HIV-positive result and creating the chart, or between having their blood drawn for laboratory tests and receiving those results. At all eight health facilities, charts were not created in the same room where HIV tests were done and where the results were disclosed. In some health facilities, patients were sent to queue at the health facility reception to have their charts created. Frequently charts were not created at all. At some facilities, providers said they took the patient test results and went to create the chart themselves at the reception. Blood samples for CD4 counts were frequently sent to referral health facilities for testing, and results took up to two weeks to be returned to patients.

**Table 3 Perceived facilitators and barriers to enrollment and retention in HIV care**

<table>
<thead>
<tr>
<th>Facilitators</th>
<th>Mentioned by</th>
<th>Barriers</th>
<th>Mentioned by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enrollment in HIV care</td>
<td>Presence of symptoms</td>
<td>Lack of symptoms</td>
<td>Late enrollers, never enrolled, drop-outs, patient support group, healthcare providers</td>
</tr>
<tr>
<td></td>
<td>Early enrollers, community leaders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retention in HIV care</td>
<td>Proximity to health facility</td>
<td>Disrespect by health workers, poor quality of healthcare</td>
<td>Early enrollers, late enrollers, drop-outs</td>
</tr>
<tr>
<td></td>
<td>Early enrollers</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of money for food and transport</td>
<td>Early enrollers, late enrollers, drop-outs patient support group, healthcare providers, outreach workers</td>
</tr>
</tbody>
</table>

Figure 10 shows a model of an HIV-positive patient flow map, based on the Mozambique 2014 national ART guidelines. Black LTFU pointers indicate where patients are lost in the HIV continuum of care in the study health facilities. The gray box denotes people whose HIV status is unknown. Red boxes are newly diagnosed HIV-positive patients. The boxes become blue when HIV-positive patients are eligible to start ART. Arrows (unbroken) indicate clear national guidelines regarding steps, including how long it should take between each step. Dashed arrows indicate when the national guidelines are not clear about how long it takes from one step to the other. Based on our FGDs with healthcare providers at the eight study health facilities, we indicate, with the vertical black LTFU arrows, where in the flow map patients are typically lost to follow-up. Our interviews and FGDs confirmed highly variable patient flow patterns and loss to follow-up (LTFU) across the facilities.
Figure 10  Patient flow map showing loss-to-follow up at along the HIV care continuum
CONCLUSIONS AND RECOMMENDATIONS

This study demonstrated substantial losses to follow up of HIV-positive persons at all points along the HIV care and treatment cascade. Our enrollment and retention estimates are substantially lower than nationally reported estimates for the similar time period (Auld et al. 2011, UNAIDS 2014), though not substantially different from other studies in sub-Saharan Africa (Rosen et al. 2011, Brennan et al. 2014). HIV-positive patients and health care providers identified major facilitators and barriers for enrollment and retention in HIV care, including individual, health systems, and structural factors.

Our findings suggest that routine reported health system data in Mozambique may grossly overestimate the true linkages to enrollment and retention in HIV care, including ART. We found that a large proportion of those who register in pre-ART (and are thus considered to be linked to HIV care) have no evidence of subsequent encounters with the health system. When reported retention estimates are based on charts or pharmacy pick up records of HIV-positive patients, these patients likely represent a subsample with substantially better retention than the overall sample of people tested positive for HIV in the health system—many of whom never get charts or start ART.

We know that routine health system information, including data from health facility registers and patient charts, can provide a high-resolution measure of linkages to care and also provide information to understand the processes associated with linkage to care. However, the large underestimate of people who are tested HIV-positive grossly overestimates linkages to enrollment in HIV care. Moreover, the large proportion of HIV-positive patients who register in care but who are lost to follow-up prior to the creation of patient charts (thus effectively enrolling in care) skews our estimates of retention in care if we only follow up those HIV-positive patients with charts. Finally, the poor evidence of retention in the patient charts that are found raises further concerns regarding effective retention in ART. Follow-up of pharmacy records may provide better data on patient retention, especially when they are better filled out than patient charts. However, overall retention estimates will be truly valid only when they are based on the denominator of the total numbers of HIV-positive patients registered in care at the health facility.

Other lower resolution proxy measures (e.g., viral load) may provide broader generalizability for the measurement of trends in linkage to care over time (Das et al. 2013). Additional studies have also raised related concerns and have called for the use of multiple measures of linkages to enrollment and retention in HIV care and treatment based on the desired outcome (Firth et al. 2014, Keller et al. 2013, Mugavero et al. 2012). Given the global focus on achieving the UNAIDS 90-90-90 goal (UNAIDS 2014, WHO 2015), this research can help to deepen the understanding of how to use proxy measures of linkage to care and treatment to match the desired programmatic or clinical outcome.

Our estimate of the proportion of people diagnosed with HIV who are registered in pre-ART care was slightly higher than other estimates in sub-Saharan Africa (Rosen 2015). However, our overall retention estimates are much lower than nationally reported retention estimates in Mozambique for 2014 (67
percent at 12 months after ART initiation, and 56 percent at 24 months) (Ministério da Saúde 2014, PEPFAR 3.0 2014). Our low retention estimates are, however, not substantially different than other studies in sub-Saharan Africa (Brennan et al. 2014, UNAIDS 2014). Our facilitators for enrollment in pre-ART and ART care (e.g., proximity to ART services and severity of illness) were similar to studies elsewhere (Govindasamy et al. 2012, Tomori et al. 2014). Yet, in contrast to those studies, facilitators for enrollment and retention in our study seemed to only help those who enrolled early in care (within 30 days of their HIV diagnosis). Our barriers for retention (e.g., lack of symptoms, perceived poor quality of healthcare) were also consistent with other studies in sub-Saharan Africa (Roura et al. 2009, Tomori et al. 2014).

The large variations in patient flow patterns and in LTFU found among the eight ART facilities suggest that targeted health systems change, including simplification of patient flow, improved patient information, and improving health worker behavior, might substantially improve performance. The data also suggest that there is an urgent need for strategies to re-link patients into HIV care in Mozambique, using lessons learned from the country and other low-resource settings (Raper et al. 2014). Strategies might include having healthcare workers, with whom many patients have developed close relationships, contact patients who have dropped out and understand reasons why they dropped out. Judgmental attitudes or threatening patients is not helpful, as has been reported in other sub-Saharan African contexts (Ware et al. 2013). However, in Mozambique, many of these healthcare workers battle with work overload (McKay et al. 2012, Pfeiffer and Chapman 2015) or lack of motivation because they feel “exploited and ultimately abandoned” by the nature of global HIV interventions (Kalofonos 2014). Working conditions need to be addressed to complement training. Improving workforce morale, understanding individual patient circumstances (including reasons beyond their control), and bearing in mind that missing visits are inevitable over the lifelong course of HIV care can help in the process of re-linking patients into care (Ware et al. 2013). Another strategy, based on our results, would be to simplify algorithms of patient care and confusing patient flow patterns, and to address challenges with patient chart management.

LIMITATIONS
The poor quality of reported data was both a principal finding of the study and a limitation. The validity of our estimates was limited by the absence, incompleteness, and inconsistency of HIV testing data, individual patient charts, and the incomplete recording of events and follow up both in patient charts and pharmacy refill forms. Our imputation methods were designed to obtain more accurate estimates of HIV testing and pre-ART and ART registry data; however, we cannot be completely certain that the adjusted estimates reflect the true picture of registration and enrollment in care. Patients may have received effective ART without adequate evidence of their treatment in patient charts or mix-up of patient names between HIV registries and pharmacy registries. Transfers of patients in or out of the eight ART facilities to obtain care in other ART facilities were infrequently noted in the charts or registries. Since transfers of patients certainly do occur, especially in urban settings, our estimates of retention were likely to modestly underestimate the true retention of our sample of HIV-positive registrants. However, transfers into or out of the six district study area would have been rare, since nearly all of the ART facilities serving these districts were included in the study. Referrals to (or from) the only larger hospital in Mozambique (in Maputo) were also likely to be rare, given the distance and presence of the second largest ART facility in Beira, which was included in the study.
The qualitative assessment was limited by the small numbers of HIV-positive people we were able to interview who had enrolled late, dropped out, or never enrolled in care. However, we interviewed diverse enough a sample that includes patients, health providers, and community leaders. The findings related to health systems barriers were limited by the numbers and only represent the practices at these eight facilities. Other facilities might have presented substantially different qualitative (and quantitative) findings. Nevertheless, our diverse sample that included perspectives of people living with HIV, health providers, and community outreach workers and members provided wide-ranging perceptions.

CONCLUSIONS
This study found low proportions of PLHIV linked to and retained in HIV care. The poor quality of data reported by the national HIS, especially regarding HIV testing, is a major barrier to identifying bottlenecks in the HIV care cascade. More attention needs to be given to improving the quality and analysis of routine data regarding all steps of the cascade at each health facility in Mozambique. Study results also suggest that individual, health system, and structural factors were important perceived barriers to enrollment and retention in care. The large variations in patient flow patterns, observance of national norms, and LTFU found among the eight HIV care facilities suggests that targeted health systems changes, including simplification of patient flow, improved patient information, and addressing health worker behavior might substantially improve performance. Modifying these health system factors with attention to individual, community, and structural factors should substantially improve linkages and retention in HIV care as documented in other parts of the world (Kranzer et al. 2015, Roura et al. 2009, Rowan et al. 2014), combining effective interventions to enhance linkages and retention will enhance global efforts to achieve the UNAIDS 90-90-90 goals.

RECOMMENDATIONS
The study team presented preliminary findings to the provincial authorities in both provinces, a meeting including representatives from all districts, and at special meetings in five of the six districts. We solicited comments to clarify our findings and recommendations. Findings were subsequently presented and discussed with the national HIV control and medical care division of the Ministry of Health, as well as to USAID/Maputo and USAID/Washington officials. The principal recommendations from these meetings, mostly Mozambique specific, were the following:

1. Data collection for testing, enrollment, and retention (including patient charts) should be simplified and monitored routinely at health facilities to identify early LTFU.
2. Recording patient transfers to other HIV care facilities should be strengthened.
3. Guidelines should be established to standardize patient and information flow.
4. Health workers should be coached to improve their respect and management of HIV-positive patients, to provide a friendlier environment for them.
5. Pharmacies should establish more flexible hours for distribution of ART.
6. Archiving of patient charts should be organized better to facilitate their location and utilization.
7. Best practices should be shared across health facilities that provide HIV care.

8. A package of key interventions to improve linkages of HIV-positive clients to enrollment and retention in HIV care should be developed, implemented, and assessed (suggested by MOH and USAID).

Recommendations that are relevant at a global level include the following:

1. Simplify data requirements and data collection methods.
2. Carry out routine chart review for early identification and action to prevent LTFU.
3. Base enrollment and retention on valid denominators of HIV patients in the system.
4. Share best practices among health facilities.
REFERENCES


Assessing linkages between HIV testing and HIV care enrollment and retention in central Mozambique


## APPENDIX

### Table A  Study sites

<table>
<thead>
<tr>
<th>Province</th>
<th>Situational analysis</th>
<th>In-depth investigation</th>
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<tr>
<td><strong>Sofala</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Beira</td>
<td>CS da Ponta-Gêa, CS Manga Mascarenhas, CS Manga Nhaconjo</td>
</tr>
<tr>
<td></td>
<td>Dondo</td>
<td>CS Dondo-sede</td>
</tr>
<tr>
<td></td>
<td>Búzi</td>
<td>HR de Búzi</td>
</tr>
<tr>
<td><strong>Manica</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chimoí</td>
<td>CS Eduardo Mondlane</td>
</tr>
<tr>
<td></td>
<td>Cidade Manica</td>
<td>CS Vila Manica</td>
</tr>
<tr>
<td></td>
<td>Bárué</td>
<td>CS Catandica</td>
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Table B Facility and patient characteristics in eight study sites

<table>
<thead>
<tr>
<th>Sites</th>
<th>HR Buzi</th>
<th>HR Catandica</th>
<th>HD Dondo</th>
<th>CS Eduardo</th>
<th>CS Mango Mascarenhas</th>
<th>CS Manga Nhaconjo</th>
<th>CS Ponta Gea</th>
<th>HD Manica</th>
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<td>Facility characteristics</td>
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<tr>
<td>Facility type</td>
<td>Rural Hospital</td>
<td>District Hospital</td>
<td>Urban Center A</td>
<td>Urban Center B</td>
<td>Urban Center A</td>
<td>Urban Center C</td>
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<td>Rural Hospital</td>
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<td>Bed capacity</td>
<td>59</td>
<td>87</td>
<td>75</td>
<td>0</td>
<td>0</td>
<td>20</td>
<td>24*</td>
<td>4*</td>
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<td>Health workers</td>
<td>64</td>
<td>92</td>
<td>122</td>
<td>66</td>
<td>0*</td>
<td>56</td>
<td>76</td>
<td>0*</td>
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<tr>
<td>Patient charts reviewed (Total/ART)</td>
<td>100/50</td>
<td>98/48</td>
<td>100/50</td>
<td>100/49</td>
<td>100/50</td>
<td>100/27</td>
<td>100/50</td>
<td>100/40</td>
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<td>Age (years)</td>
<td>33.7</td>
<td>33.3</td>
<td>33.2</td>
<td>32.4</td>
<td>33.3</td>
<td>34.1</td>
<td>34.8</td>
<td>33.3</td>
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<tr>
<td>Female</td>
<td>46%</td>
<td>56%</td>
<td>59%</td>
<td>71%</td>
<td>61%</td>
<td>64%</td>
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<td>Voluntary testing</td>
<td>17 (17.0%)</td>
<td>85 (86.7%)</td>
<td>77 (77.0%)</td>
<td>86 (86.0%)</td>
<td>8 (8.0%)</td>
<td>94 (94.0%)</td>
<td>17 (17.2%)</td>
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<tr>
<td>Clinical services</td>
<td>83 (83.0%)</td>
<td>13 (13.3%)</td>
<td>23 (23.0%)</td>
<td>14 (14.0%)</td>
<td>92 (92.0%)</td>
<td>6 (6.0%)</td>
<td>82 (82.8%)</td>
<td>7 (%)</td>
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<tr>
<td>(excluding PMTCT)</td>
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<td></td>
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<td></td>
<td></td>
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<td>26 (32.5%)</td>
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<td>27 (28.1%)</td>
<td>26 (32.1%)</td>
<td>45 (46.9%)</td>
<td>28 (28.3%)</td>
<td>34 (37.0%)</td>
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<td>HIV Stage III &amp; IV</td>
<td>42 (42.0%)</td>
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*Unlikely figures that need verification
### Table C  Socio-demographic characteristics of people living with HIV

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<th>Sociodemographic characteristics</th>
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<th>Early enrollment</th>
<th>Late enrollment</th>
<th>Never enrolled</th>
<th>TOTAL n %</th>
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<td><strong>Sex</strong></td>
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<tr>
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<td>Male</td>
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<tr>
<td>20–49 years old</td>
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<td>2</td>
<td>40 95.2</td>
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<td>50+ years old</td>
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<td>Yes</td>
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<td>1</td>
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<td>Artisan, driver, security</td>
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<td>7 15.2</td>
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<td>1</td>
<td>2 2.2</td>
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