Mobility and Treatment Outcomes among People Living with HIV and/or Tuberculosis in East African Cross-Border Regions

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Cover

Fishing boats at Sio Port, Kenya. Photo: Khou Xiong, MEASURE Evaluation.

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ABBREVIATIONS

ART	antiretroviral therapy
ARV	antiretroviral
CI	confidence interval
CPT	co-trimoxazole preventative therapy
DR TB	drug resistant tuberculosis
KM	kilometer
MDR	multidrug resistant
SE	standard error
TB	tuberculosis
UIC	unique identifier code
USAID	United States Agency for International Development

EXECUTIVE SUMMARY

Regional economic integration and trade are high on the political and development agendas of East African leaders. Greater regional integration and increased trade are expected to enhance opportunities for income generation and employment, resulting in increased movement of people as they look for new and expanded opportunities in the region. However, the increased movement of humans, animals, and goods across nations leads to intensified transmission of infectious diseases, including HIV/AIDS and tuberculosis (TB), which do not respect political boundaries. Health affects peoples' ability to work, the type of work they can perform, and how long they can work. Unless specifically addressed in health programming, infectious diseases have the potential to dampen trade and even reverse economic growth.

This report presents the results of a study—funded by the United States Agency for International Development and the United States President's Emergency Plan for AIDS Relief—to understand mobility patterns, treatment outcomes, and the feasibility of regional tracing strategies among patients in care for HIV and/or TB in the Lake Victoria region. This study was undertaken by MEASURE Evaluation and local partners from the Lake Victoria Consortium for Health Research: Uganda Virus Research Institute and the International AIDS Vaccine Initiative; Kenya Medical Research Institute; Medical Research Council/Uganda Virus Research Institute and the London School of Hygiene and Tropical Medicine; and the Mwanza Intervention Trials Unit. Results of this study will improve treatment strategies for mobile populations, identify facilities serving mobile populations, and inform planning for cross-border coordination of health services, including medical record linkages, patient referrals, and defaulter tracing.

Figure ES1. Health facilities included in the study

Methods

The study included 12 health facilities on the shores of Lake Victoria (including one island-based facility) where the number of TB cases were relatively high, and four island-based facilities, where the number of HIV cases were high.

Cohorts of patients on TB treatment and in HIV care were created from medical records at the facilities.

At the 12 shore-based facilities, a TB cohort was constructed from all people (including those coinfected with HIV and TB) who had started TB treatment in the six months before the study and were ages 18 and over on the date of data collection. For each TB case, an additional patient in HIV care was selected for an HIV cohort at shore-based facilities. Patients were eligible for the HIV cohort if they were age 18 at the time of data collection and entered HIV care during or after 2016, with a target distribution of one-third of patients entering HIV care in each of the years 2016, 2017, and 2018 to 2019. An additional HIV cohort was constructed with up to 180 eligible patients with HIV per facility from island-based facilities, with the same age eligibility and target distribution of entry to care dates.

Participants at all stages of TB treatment and those in HIV care were recruited for quantitative interviews during their routine health facility visits. The questions focused on mobility before and after HIV or TB diagnosis, experiences receiving HIV and/or TB care and treatment, and potential unique identifier components. Similar topics were asked about during qualitative interviews with patients, healthcare workers, and community leaders.

At the end of the study period, TB treatment outcomes were determined from TB registers and a tracing study.

Key Findings and Recommendations

1. The characteristics of people enrolling in care for HIV and TB at selected facilities were similar to those among patients seeking care for these conditions at other sites in East Africa. Facility data illustrated that people seeking care for HIV at study sites were predominantly female, whereas people seeking care for TB were predominantly male. People enrolling in TB care tended to be older, on average, than people enrolling in HIV care (Table ES1).

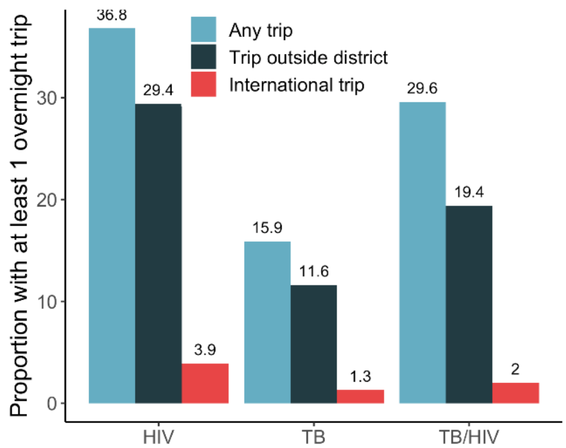
Table ES1. Characteristics of the study population

Characteristic	HIV N = 1603		TB N = 473		TB/HIV N = 300	
	n	%	n	%	n	%
Sex						
Female	928	57.9	172	36.4	144	48.0
Male	675	42.1	301	63.6	156	52.0
Country where recruited						
Kenya	486	30.3	61	12.9	43	14.3
Tanzania	354	22.1	257	54.3	83	27.7
Uganda	763	47.6	155	32.8	174	58.0
Age at TB treatment initiation						
Missing			329		31	
18–24			22	15.3	1	0.4
25–34			36	25.0	24	8.9
35–44			32	22.2	71	26.4
45+			54	37.5	94	34.9
Age at enrollment in HIV care						
Missing	530				157	
< 18	20	1.9			4	2.8
18–24	208	19.4			10	7.0
25–34	472	44.0			43	30.1
35–44	255	23.8			53	37.1
45+	118	11.0			33	23.1

2. Health facilities and health systems in the area surrounding Lake Victoria were often in a position of providing care to migrants and mobile populations. Among those in HIV care, 7.5 percent were enrolled in care in a country other than their birth country. The proportion of people enrolled in HIV care at a site outside the country where they were born was much higher in Kenya (14.7%) compared with Tanzania (4.9%) or Uganda (3.4%) (data not shown). The reasons may include differences in policies, accessibility of the selected facilities to migrants, and perceptions of the facilities among migrant populations. Among people receiving TB treatment, 4.5 percent reported being born in a country other than the country where they were receiving TB treatment. **Migration-aware policies**

and planning that accounts for migrant patients in the health system and supply chain may benefit the health of mobile populations and the general public.

Figure ES2. Overnight trips after TB and/or HIV diagnosis



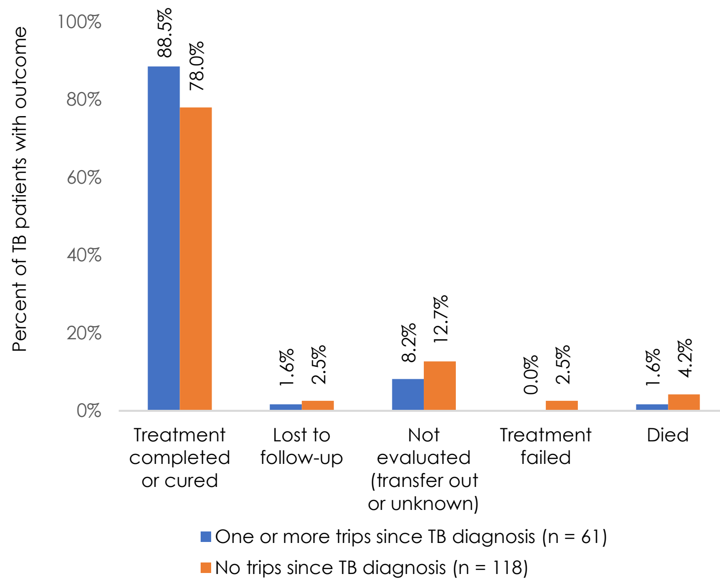
3. More than one-third of all participants in the quantitative survey took at least one trip outside their district (in Kenya, sub-counties) of residence in the six months before study recruitment, and patients continued to take long trips after TB and/or HIV diagnoses. The overall proportion traveling outside their home districts fell to under 30 percent after HIV diagnosis, TB diagnosis, or TB/HIV diagnosis, although the proportion varied dramatically by country, sex, and disease type. People living with HIV were more likely to travel outside their home districts compared with people living with TB or TB/HIV. People in care for TB took fewer trips, spent fewer nights away from home, and traveled shorter distances compared with both people living with HIV in this study and people in the general population in East Africa in other studies. Nevertheless, more than 11 percent of patients with TB, but not with HIV, reported spending at least one night away from their districts of residence, as did more than 19 percent of TB/HIV patients (Figure ES2). The trips were long, averaging more than eight days (data not shown). **The length of these trips indicated that health facilities serving patients with TB should be prepared to both provide patients with appropriate quantities of medications for longer trips and educate patients on the importance of notifying their health providers before extended travel.**

4. Qualitative interviews with healthcare workers, patients, and community members revealed that healthcare workers often viewed mobile populations as troublesome. In providing care to mobile people, facilities may miss their treatment targets, have an inflated number of patients lost to follow-up, and experience shortages in treatment supply when supply quantities were based on resident populations. Because of these risks, some healthcare workers refused care in the absence of a transfer letter, and facilities were generally not welcoming to mobile groups. **Improving care for mobile populations requires addressing negative perceptions of these groups among healthcare workers.**

5. Among people receiving TB and HIV care around Lake Victoria, the most common reason for travel was work. This finding contrasted sharply with reports from other settings in East Africa, where only a small fraction reported labor-related travel and nearly one-half of the population reported nonlabor related travel. Although healthcare workers stated that they frequently counseled patients with TB not to travel, the high proportion of trips in this study that were labor-related implied that interventions to reduce mobility among people in treatment for HIV and/or TB may be ineffective.

6. Mobility was not strongly associated with access to care or treatment outcomes. Time to TB care, the probabilities of biological specimen testing, experiences of medication stockouts, and interruptions in TB treatment did not differ substantially between people who did and did not travel overnight outside their home districts since TB diagnosis. This finding was consistent with previous reports from South Africa in which spending at least one night away from home was not associated with time from symptom onset to seeking TB care. Some participants reported travel-related barriers to treatment adherence and access to care. In the quantitative survey, the top two barriers to HIV and TB treatment adherence were work and travel away from home. Among the 20 patients who reported during the qualitative interviews of defaulting on their HIV or TB medications, nearly one-half defaulted for reasons related to travel or being away from home unexpectedly. A report of trips outside the home district after TB diagnosis was associated with a slightly increased probability of treatment completion or cure (Figure ES3). One possible explanation was that people likely to do well on treatment (i.e., those with greater resources, better access to care, and a better prognosis) may be more likely than other people to be mobile. This finding also aligned with recent findings from an international cohort of TB/HIV patients that found that greater contact with the health facility and more intensive TB care was not always associated with better treatment outcomes.

Figure ES3. TB treatment outcomes among TB (including TB/HIV) patients according to whether trips were taken outside the district of residence since TB diagnosis



7. Participants expressed enthusiasm for a regional unique identifier, with almost all reporting a willingness to provide fingerprints as a unique identifier. The study examined the uniqueness and reliability of user-generated unique identifier codes (UICs) that could permit the linkage of records across multiple health facilities; reduce the phenomenon of mobile people retesting for TB or HIV to receive care at a new facility when away from home; and reduce the need to disclose privately identifiable information. UICs that use at least five of the prompts examined in this study would be expected to have a high proportion of unique values, meaning that there would be a low chance of two people generating the same code. However, the study data indicated that such codes would have low reliability, meaning that patients would not be certain to answer the prompts in such a way as to generate the same code on more than one occasion. In the qualitative interviews, respondents noted concerns about the user-generated prompts, specifically for those who were not literate and given different cultural conventions in defining some elements of the prompts. Nevertheless, the patients saw the benefits of the unique identifier system, and were hopeful that it might allow them to travel without their treatment cards, which they viewed as stigmatizing to carry. Nearly all participants reported a willingness to provide fingerprints as a unique identifier**. When developing UICs to be used at any level, it will be critical to consult with a wide range of representatives from civil society to ensure**

that any concerns are addressed. Moreover, when multijurisdictional linkages are planned, it will be essential to work with experts in data security to protect against breaches in confidentiality.

Conclusion

A substantial proportion of people living with TB and/or HIV in shore and island communities around Lake Victoria were mobile, with mobility driven largely by work-related factors. Because of economic pressure to travel, efforts to reduce mobility during treatment for TB or HIV may be unsuccessful. Alternative strategies that remove structural barriers to accessing care and medication adherence when away from a patient's home area may prove more effective. A strategy to implement a regional unique identifier system that would allow access to health records across facilities is one approach that would reduce some barriers to obtaining appropriate care and treatment when away from home. However, the optimal unique identifier system should weigh concerns about confidentiality, security, portability, and stigma. User-generated UICs address some, but not all these factors. In this study, we found that longer user-generated UICs were likely to be unique but were unreliable, meaning that they were unlikely to be generated the same way on more than one occasion, limiting their utility.

Regional connectivity stimulates mobility and economic opportunity across East Africa. As connectivity grows, ongoing TB and HIV prevention and treatment efforts can benefit from structural changes to health systems, including regional, cross-facility linkage of patient records; new strategies for the provision of HIV and TB medications during extended or unexpected travel; and addressing other barriers to accessing health services when away from home. These strategies can improve the continuity of care for people living with HIV and/or TB in East African cross-border regions.

INTRODUCTION

The overall goal of this study was to improve services and outcomes for people living with HIV and/or tuberculosis (TB) in East African cross-border regions by providing information about the relationship between mobility and health outcomes in this population.

Regional economic integration and trade are high on the political and development agendas of East African leaders, who consider the development of transport corridors to be paramount to the success of regional trade and economic growth. Greater regional integration and increased trade are expected to enhance opportunities for income generation and employment, resulting in increased movement of people as they look for new and expanded opportunities in the region (Heshmati, 2016).

However, as history has shown, the increased movement of humans, animals, and goods across nations leads to intensified transmission of infectious diseases, including HIV/AIDS and TB. Infectious diseases do not respect political boundaries, and unless specifically addressed in health programming, more HIV and TB infections throughout the region, especially in cross-border communities, may be an unintended consequence of increased integration and trade. Infectious diseases have the potential to dampen trade and even reverse economic growth. Health affects peoples' ability to work, the type of work they can perform, and how long they can work. When a population experiences poor health outcomes, productivity can decline, leading to decreased trade and stunted economic development.

Mobile people comprise a key population with heightened risk for HIV and TB. Although Africa's transport corridors serve as its economic lifelines, they are also significant routes of HIV transmission (Nzyuko, Lurie, McFarland, Leyden,, Nyamwaya, & Mandel, 1997). Studies have documented high rates of HIV infection among truck drivers in East, Central, and Southern Africa, ranging from a low of 10 percent to a high of 56 percent (Atilola, Akpa, & Komolafe, 2010; Mbugua, et al., 1995; Ramjee & Gouws, 2002; Delany-Moretlwe, et al., 2014; Bwayo, et al., 1994). High-risk sexual behavior, including frequent unprotected sex with sex workers, alcohol abuse, gender-based violence, and anal intercourse with both women and men make these groups highly vulnerable to HIV infection.

The East African Cross-Border Integrated Health Study (2017) found that more than 14 percent of people living with HIV reported symptoms consistent with TB infection. Among specific vulnerable groups, this proportion was even higher; for example, nearly 25 percent of female sex workers with HIV reported TB-related symptoms. Although health facility data were not available for people coinfected with HIV and TB, the rate of discontinuation of TB treatment overall was more than 10 percent.

Recent published articles from the region indicate that between 0.4 percent (Tanzania) and 4.4 percent (Uganda) of newly diagnosed TB infections were multidrug resistant (MDR). Among recurrent TB cases, the prevalence of MDR ranged from 3.9 percent in Tanzania to 17.7 percent in Uganda (Kidenya, et al., 2014). Understanding mobility patterns, treatment outcomes, and the feasibility of regional tracing strategies among people coinfected with HIV and TB will inform treatment programs for this population in cross-border areas.

Technology has the power to improve care for people living with TB and/or HIV by providing complete, up to the minute medical records to healthcare providers no matter where they are located. Technological innovations can also be used to monitor the potential spread of infectious diseases by providing insight on mobility and migration patterns among people living with these diseases. With finite resources to develop and deploy such innovations, a critical first step is to understand the scale and scope of mobility and migration among people living with TB and/or HIV. For such technologies to be implemented effectively, key health facilities serving mobile and migrant populations should be identified and prioritized for intervention. It is also important to determine the feasibility and acceptability of proposed innovations, such as a regional unique identifier system, to facilitate medical record linkages, patient referrals, and defaulter tracing.

A key finding of the East Africa Cross-Border Integrated Health Study (MEASURE Evaluation, 2017) was the need to develop a regional system for patient referral and defaulter tracing among facilities located near land and lake borders that served clients from different countries. The study found that loss to follow-up plagued care and treatment programs at cross-border health facilities. Moreover, across all programs examined in the study—HIV, antenatal care, immunization, prevention of mother-to-child transmission, and TB treatment—the health facilities could not easily distinguish loss to follow-up from silent transfers to a new health facility, especially if the health facility was on the other side of an international border. Healthcare workers at the facilities included in the study reported that the main barrier to communication with facilities in neighboring countries was the absence of a mechanism or platform to support such a system, which they believed could improve both retention in care and continuity of care.

The results of this study will provide important information to improve treatment programs for people living with HIV and/or TB in cross-border areas. As efforts to link patient records between health facilities expand, this study's findings will be critical to assessing the feasibility of such linkages, the health facilities where such systems would be most useful, and the acceptability of such linkages to patients. The study will also provide data on the extent and scope of mobility among people infected with HIV and/or TB, and how mobility affects treatment and overall health outcomes.

This study provides critical information to design optimal technological solutions to link important health and treatment history information between health facilities and to perform real-time disease monitoring.

Objectives

The objectives of this activity were to:

- Describe mobility and migration among people living with HIV and/or TB in East African cross-border areas.
- Estimate the prevalence of MDR TB among people living with TB in cross-border areas.
- Assess the relationship between mobility and access to HIV- and TB-related services among people living with HIV, TB, and HIV/TB.
- Quantify the association between mobility and HIV and TB treatment outcomes among people living with HIV, TB, and HIV/TB.
- Assess the feasibility and potential public health impact of a regional unique identifier system for people living with HIV, TB, and HIV/TB.
- Identify priority health facilities that serve mobile and migrant populations for interventions to improve care and treatment for mobile people living with HIV, TB, and HIV/TB.
- Present results to regional stakeholders, including the United States Agency for International Development (USAID), the East African Community, implementing partners, and other donors to inform policy development in this area.

METHODS

Study Team

This study was led by MEASURE Evaluation in collaboration with local partners from the Lake Victoria Consortium for Health Research: Uganda Virus Research Institute and the International AIDS Vaccine Initiative; Kenya Medical Research Institute; Medical Research Council/Uganda Virus Research Institute and the London School of Hygiene and Tropical Medicine; and the Mwanza Intervention Trials Unit.

Study Sites

The study team selected health facilities in Kenya, Tanzania, and Uganda using the following criteria:

- Evidence that the facility had a high number of TB and/or HIV patients.
- For shore facilities, the facility had or was linked to a Gene Xpert machine for the diagnosis of MDR TB.
- For shore facilities, the facility had the capacity to provide treatment for TB and MDR TB.
- The facility agreed to participate.
- The facility maintained and allowed access to patient-level data on HIV and, at shore facilities, TB treatment.

The health facilities selected fell into two groups: twelve health facilities on the shores of Lake Victoria (including one island-based facility), where the number of TB cases were relatively high, and four island-based facilities where the number of HIV cases were high (Figure 1). The study populations for each group of facilities are described in the next section.

Shore-Based Health Facilities (including Kalangala Health Centre)

- Karungu Sub-County Hospital, Migori, Kenya
- Macalder Sub-County Hospital, Migori, Kenya
- Mbita Sub-County Hospital, Homa Bay, Kenya
- Suba Sub-County Hospital Homa Bay, Kenya
- Bukoba Regional Hospital, Kagera, Tanzania
- Mgana Hospital, Kagera, Tanzania
- Shirati Hospital, Mara, Tanzania
- Tarime Hospital, Mara, Tanzania
- Entebbe Hospital, Wakiso, Uganda
- Kalangala Health Centre, Kalangala, Uganda
- Kakuuto Health Centre, Kyotera, Uganda

- Mild May Hospital, Wakiso, Uganda

Island-Based Health Facilities

- Remba Health Centre, Homa Bay, Kenya
- Sena Health Centre, Homa Bay, Kenya
- Mazinga Health Centre, Kalangala, Uganda
- Lujjabwa Health Centre, Kalangala, Uganda

Figure 1. Study sites

Study Population and Data Collection Components

The study was conducted in six stages:

- In Stage 1, cohorts were created from clinical records to represent each target population of interest: people in care for TB at shore-based facilities, people in care for HIV at shore-based facilities, and people in care for HIV at island-based facilities.

- In Stage 2, a subset of patients eligible to be included in Stage 1 were recruited for quantitative interviews to better understand mobility and access to services.
- In Stage 3, a subset of participants who participated in the quantitative interviews were selected for qualitative interviews.
- In Stage 4, in-depth interviews with healthcare workers were conducted.
- In Stage 5, small focus group discussions with community leaders were conducted.
- In Stage 6, the study team collected data on TB treatment outcomes.

Stage 1: Creation of Cohorts

In Stage 1, three cohorts of patients were constructed from records provided by health facility staff at shore- and island-based facilities:

1. TB cohort: a census of all patients enrolled in TB treatment in the six months before the study at shore-based facilities.
2. HIV cohort A: patients with HIV from the same health facilities as the TB cohort.
3. HIV cohort B: patients with HIV from the island-based health facilities.

The TB cohort included all people living with TB (including those coinfected with HIV and TB) who had started treatment for TB in the six months before the study and were ages 18 or over on the date of data collection.

For each TB case, an eligible patient with HIV was selected for HIV cohort A according to the following criteria: the patient should have entered care for HIV at age 15 or later during or after 2016 and not already have been selected for the TB cohort. The target number of patients in HIV cohort A was distributed as follows: one-third entered care in 2016, one-third entered care in 2017, and one-third entered care in 2018 to 2019.

HIV cohort B included up to 180 eligible patients with HIV per facility from island-based facilities selected according to the following criteria: the patient should have entered care for HIV at age 15 or later during or after 2016. The target number of patients in HIV cohort B was distributed as follows: one-third entered care in 2016, one-third entered care in 2017, and one-third entered care in 2018 to 2019.

Stage 2: Quantitative Survey with a Sample of TB and/or HIV-Positive People

To be eligible for inclusion in the quantitative survey, patients with TB or TB/HIV should have started TB treatment in the six months before data collection and be age 18 or over. Patients with HIV only should have entered HIV care during or after 2016 and have been age 18 or over.

Participants at all stages of treatment were recruited for the quantitative interviews. The study team recruited eligible participants at the health facility following or before a routine HIV or TB visit. During the interviews, participants responded to questions about mobility patterns before and after HIV or TB diagnosis, experiences receiving HIV and/or TB care and treatment, and other health outcomes. The interviews lasted approximately

30 to 45 minutes. At the end of the interview, participants were asked for contact information to facilitate outcome determination among patients no longer in care at the health facility.

Stage 3: In-Depth Interviews with a Subsample of Patients with HIV and/or TB

Patients who reported mobility during their HIV and/or TB treatment were purposively sampled to gather more detailed information about their mobility and the facilities accessed, and barriers and facilitators to HIV and/or TB care and treatment. Participants were also asked about various regional unique identifier options and their willingness to use them.

Stage 4: In-Depth Interviews with Health Facility Staff

At each health facility, a staff member was selected to undergo a qualitative interview focused on how treatment and health outcomes were impacted by the mobility of patients with HIV and/or TB, and the feasibility of implementing a regional unique identifier system across international borders.

Stage 5: Small Focus Group Discussions with Community Leaders

Ten small focus group discussions (five with men and five with women) were conducted with community leaders in communities located near the participating health facilities. The discussions focused on understanding the mobility patterns of men and women in the community, the health issues affecting men and women in the community, and challenges men and women face accessing healthcare services when traveling.

For all qualitative interviews (Stages 3 through 5), discussions were recorded and transcribed in English.

Stage 6: Abstraction of TB Treatment Outcomes at the End of Follow-Up

Between three and six months after the initial data collection, the study team returned to the shore-based facilities and gathered data on TB treatment outcomes among people in the study with TB. Because the target population was mobile, some patients were expected to be missing outcome data at the end of follow-up. To make inference about treatment outcomes in these patients, a tracing study was performed among people selected for (and consenting to) the quantitative interviews who had provided their contact details. The study team used the contact information provided to determine the TB treatment outcomes for those quantitative interview participants who began TB treatment at least six months before follow-up data collection but whose facility records at the time of follow-up indicated a missing TB treatment outcome or an outcome of lost to follow-up, not evaluated (including transfer out and unknown), or other.

Table 1 summarizes the study objectives, methods, and outcomes/themes.

Table 1. Study objectives, methods/data sources, and outcomes/themes

Objective	Method/data source	Outcomes/themes
Estimate the prevalence of MDR TB among people living with TB in cross-border areas	• TB cohort abstracted from facility records	• Percentage of those diagnosed with TB with multidrug resistance • Percentage of recurrent infections with multidrug resistance
Describe the mobility of people living with HIV, TB, and HIV and TB	• Quantitative survey • In-depth interviews with patients and facility staff • Small focus group discussions with community members	• For the past six months, describe: o Districts/counties visited in the home country o Other countries visited o Reasons for travel • Gather information on country of origin and place of HIV and TB diagnosis
Assess the relationship between mobility and access to HIV- and TB-related services	• Quantitative survey • In-depth interviews with patients and facility staff • Small focus group discussions with community members	• Compare indicators above with self-reported facility access • Identify barriers and/or incentives to accessing HIV- and TB-related services when away from home
Quantify the association between mobility and HIV and TB treatment outcomes among people living with HIV, TB, and HIV/TB	• Quantitative survey • In-depth interviews with patients and facility staff • Small focus group discussions with community members	• Compare mobility indicators above with self- and facility-reported TB treatment outcomes • Determine self-reported health status, including comorbid conditions, related symptoms, and quality of life
Assess the feasibility and utility of a regional unique identifier system for people living with HIV and/or TB	• Quantitative survey • In-depth interviews with patients and facility staff • Small focus group discussions with community members	• Determine the acceptability of various unique identifier solutions (based on patient interviews) • Determine the feasibility of various unique identifier systems (based on facility staff interviews) • Determine the scale and scope of mobility among people living with HIV and coinfected with TB and HIV
Identify priority health facilities that serve mobile and migrant populations	• Quantitative survey	• Determine the common focal points where migrants and mobile populations access care for TB and HIV

Fieldwork and Training

Training of the core study team members and field testing of tools took place in February 2019. MEASURE Evaluation met with principal investigators and other staff from each local partner to review the specific registers and treatment cards to be used in the study, confirm in-country protocols for TB treatment and testing, revise study tools to improve suitability for the local context, and confirm processes for protecting patient confidentiality and data security. The core study team visited a health facility in Entebbe, Uganda with MEASURE Evaluation team members to field test the data collection materials.

Each local partner recruited a team of data collectors who were subsequently trained by the core study team members in research ethics and confidentiality, study procedures, and quantitative and qualitative interviewing techniques. Data collectors were also trained to use Android tablets and, specifically, Open Data Kit (ODK) software.

The data collectors conducted the six stages of data collection between May 2019 and December 2019. The data collectors used multiple ODK forms to capture specific fields of interest from the country-specific HIV and TB registers and cards, responses to the quantitative interviews, TB treatment outcomes, and results from the tracing study. These forms were completed on password-protected, encrypted tablets, and the completed forms were encrypted and regularly uploaded to a secure server at MEASURE Evaluation. MEASURE Evaluation staff performed quality checks as the forms were communicated with core study team members about progress toward targets. The data collectors used standardized qualitative interview guides to conduct the in-depth interviews with patients and health facility staff and the small focus group discussions with community leaders.

Sample

Quantitative Sample

A total of 615 participants in care for HIV, TB, or both TB and HIV were recruited from the health facilities selected that were offering TB or HIV services. Participants were recruited using an unselected consecutive sample of patients as they arrived at the health facility for HIV- or TB-related services. Among the participants, the average age was 38, with a range from 18 to 82, and 49 percent were women. Among those recruited for the quantitative survey, 51.5 percent were in the HIV cohort, 23.7 percent were in the TB cohort, and 24.7 percent were in the TB/HIV cohort.

Qualitative Sample

Healthcare Workers

Sixteen healthcare workers participated in the qualitative interviews, one from each health facility. They were selected based on their positions (working with HIV and/or TB patients) and included two nurses, five antiretroviral therapy (ART) clinic in-charges, three TB coordinators, one facility in-charge, two clinical officers and one assistant medical officer, a patient support center coordinator, and a community linkage coordinator. The average age of respondents was 34, with a range of 23 to 57.

Community Leaders

A total of 41 community members (21 women and 20 men) participated in the small focus group discussions. The average age of the women was 40, with a range of 21 to 62; the average age of the men was 43, with a range of 26 to 62. Of the five female focus groups, one was held in Kenya, one in Tanzania, and three in Uganda. The same was true for the five male focus groups. The locations were selected near participating health centers. The participants held a wide variety of roles in their respective communities, including village health team and Beach Management Unit members, peer educators, and members of other community groups, such as motorbike associations and self-help groups.

Patients

Sixty-two patients participated in the qualitative interviews (22 women and 40 men). The average age of the women was 37, with a range of 22 to 69. The average age of the men was 40, with a range of 22 to 67. Twenty-six patients were in the HIV cohort, 14 were in the TB cohort, and 22 were in the TB/HIV cohort. Twenty-three were recruited from Kenya, 16 from Tanzania, and 23 from Uganda.

Analysis

Quantitative Data

Frequencies and percentages were used to describe the characteristics of patients in each cohort. Because the cohorts were constructed to be a census or a random sample of patients meeting eligibility criteria, each cohort was expected to be representative of the target population without the need for weighting or complex analyses. For all analyses, the cohorts were reorganized into an HIV cohort (consisting of HIV cohort A and HIV cohort B), a TB cohort (consisting of people entering TB care during the specified study period at a shore-based facility), and a TB/HIV cohort (consisting of people entering TB care during the specified study period at a shore-based facility who had previously or concurrently been diagnosed with HIV).

Data management and quantitative analysis was performed in SAS 9.4 (SAS Institute, Cary, NC) and R 3.6.0.

Mobility

To examine mobility, the analyses were limited to the 615 participants in the quantitative survey with enough data to be matched to records in the cohort database. Information on self-reported country of birth was used to estimate the proportion of participants recruited at a country outside the country of their birth. The average number of trips per month, the average total distance traveled outside the patient's home district per month, the average number of nights spent away from home per month, and the average number of international trips per month were also estimated. A "trip" was defined as a period during which the respondent reported spending at least one night away from home. The number of kilometers (kms) traveled was computed as the difference between the centroid of the reported district of residence on the trip departure date and the centroid of the reported destination district. Land distances (i.e., those not involving travel to or departure from an island) were computed as driving highway distance using Google's Distance Matrix API. Distances involving island departures or destinations were computed as the sum of the straight-line distance from the island to the most logical port, and the highway distance from the port to the destination. All distances were reported as "one-way" distances to the reported destination.

Mobility metrics were averaged by month to account for variable lengths of the reporting period because of recruiting participants at different points in the HIV or TB treatment trajectory. To compute the monthly averages, the metrics for all trips taken when in care for TB or HIV were summed and then divided by the total number of months the participant reported being in care for HIV, TB, or both TB and HIV. Summary metrics were computed for both the overall population and for the subset of "mobile" people, defined as those taking at least one trip outside their districts of residence during the study period.

The proportion of participants traveling at least various numbers of kms per month and spending various numbers of nights away from home per month were reported using nonparametric Kaplan-Meier survival functions. This function provides information about the proportion of participants traveling at least 25, 50, 100, 200, and 300 kms away from their home districts per month, on average.

Last, the characteristics of individual trips taken among participants with HIV, TB, or both HIV and TB, including the total number of trips taken, the average duration, and the average distances traveled, were described. The primary reported reason for travel and mode of transportation using frequencies and percentages were also reported.

Where feasible, all results on mobility were stratified by country of recruitment and sex.

Regional Unique Identifier

One aim of the study was to determine the acceptability and feasibility of a nonbiometric unique regional identification code that patients could use to access health services throughout East Africa. Each person's code would be comprised of a series of components that could easily be remembered through prompting questions. For example, a unique code could be comprised of the first two letters of the mother's first name, the first two letters of the father's first name, either a 1 for male or a 2 for female, and the last two digits of the year of birth. So, a women whose mother's name was Eleanor and whose father's name was Walter and who was born in 1966 would have the code El + Wa + 2 + 66 or ElWa266. If the woman forgot the code, she could be prompted by a healthcare worker to remember it by asking about each component.

The quantitative survey instrument tested seventeen prompts that could be potential components of a unique identifier code (UIC). Participants were asked the full series of questions twice, once immediately before and once immediately after the quantitative survey:

- What are the first two letters of your first name?
- What are the last two letters of your first name?
- What are the first two letters of your last name?
- What are the last two letters of your last name?
- In what month were you born?
- In what year were you born?
- Where do you fall in the birth order in your family?
- What are the first two letters of your mother's first name?
- What are the last two letters of your mother's first name?
- What are the first two letters of your mother's last name?
- What are the last two letters of your mother's last name?
- What are the first two letters of your father's first name?
- What are the last two letters of your father's first name?
- What are the first two letters of your father's last name?

- What are the last two letters of your father's last name?
- Are you right- or left-handed?
- What are the first two letters of the district you were born in?

These prompts were chosen based on their use in projects in Central America, Papua New Guinea, Central Asia, Ghana, and Kenya (FHI 360, 2016).

For each question, the number and proportion of participants who responded, "do not know," the number and proportion of participants who refused to respond, and the number and proportion of responses that were unique (i.e., given by one, and only one, participant) were computed. The percentage agreement between pre- and post-survey responses to each question was also computed.

Five potential UICs were generated by combining the responses to three, four, five, six, and seven questions. First, the three questions with the highest percentage agreement between pre- and post-survey responses were selected. A fourth, fifth, sixth, and seventh question sequentially in descending order of percentage agreement were then added. Using the survey data, each potential code was evaluated in terms of: (1) the percentage agreement between identifiers generated from pre- versus post-survey responses; and (2) the percentage of identifiers that were unique (i.e., generated by only one participant). The percentage of identifiers that were unique using the pre-survey responses and post-survey responses separately were calculated and the average of the two was reported.

To assess whether the performance of codes varied by participant characteristics or by country, differences in the reliability of potential codes by participant sex and country were examined. A logistic regression model for agreement between pre- and post-survey responses was fitted to estimate the parameters using generalized estimating equations. Predictors included the five potential codes, participant sex, country, and all two-way interactions of sex or country with code. Clustering within participants was accounted for in the calculation of standard errors (SEs) and confidence intervals (CIs).

Qualitative Data

All interviews were recorded and transcribed in English. The transcripts were reviewed and responses were entered in matrices for each type of respondent (community leader, healthcare worker, and patient). The matrices were then analyzed to identify relevant themes and patterns of responses to help explain and supplement the quantitative findings. Differences in responses by type of respondent and country were noted.

TB Outcome Classification

Outcome codes were harmonized across the three sets of national TB treatment records. The harmonized outcome categories used were: "cured," "treatment failed," "deceased," "lost to follow-up," "not evaluated (including transfer out and unknown)," "other," and "missing/no outcome." Given that for some cohort members, six months had not elapsed between the time of TB treatment initiation and outcome data collection, the "missing/no outcome" group was further subdivided according to time of TB treatment initiation into the groups: "outcome missing, presumed still on treatment" and "outcome missing 6 or more months since treatment started."

For the purposes of analysis, the outcome recorded in the health facility records was considered to be the true outcome for patients with a recorded outcome of cured, treatment completed, treatment failed, or deceased. The outcome in the facility records was also used for patients who did not participate in or provide contact information during the quantitative interview, because no further outcome determination was possible for these patients.

The study team attempted to clarify the outcome data for patients who provided contact details during the quantitative survey, who were approximately six or more months from their TB treatment initiation date, and whose facility records reflected losses to follow-up, nonevaluation of outcome (including transfer out and unknown), or missing/no outcome. When attempting to contact patients, the study team made note of patients who were identified as deceased. Patients who were reached were asked about their recent TB care experiences and treatment outcome. Findings from the tracing study were used to update treatment outcomes for these patients.

RESULTS

1. Who was included in the study?

This section describes the characteristics of the people included in the HIV, TB, and TB/HIV cohorts, and the characteristics of the subsample of people in the three cohorts who participated in a quantitative interview.

Characteristics of the HIV, TB, and TB/HIV Cohorts

Table 2. Characteristics of the study population

Characteristic	HIV N = 1603		TB N = 473		TB/HIV N = 300	
	n	%	n	%	n	%
Sex						
Female	928	57.9	172	36.4	144	48.0
Male	675	42.1	301	63.6	156	52.0
Country where recruited						
Kenya	486	30.3	61	12.9	43	14.3
Tanzania	354	22.1	257	54.3	83	27.7
Uganda	763	47.6	155	32.8	174	58.0

A total of 2,376 people were included in the three study cohorts created through the abstraction of clinical records: people living with HIV, people living with TB, and people coinfected with TB and HIV. The HIV cohort (1,603 people) was 57.9 percent female; 47.6 percent of the cohort was recruited from Uganda, 30.3 percent from Kenya, and 22.1 percent from Tanzania. The TB cohort (473 people) was 36.4 percent female; 54.3 percent of the cohort was recruited from Tanzania, 32.8 percent from Uganda, and 12.9 percent from Kenya. The TB/HIV cohort (300 people) was 48.0 percent female; 58.0 percent of the cohort was recruited from Uganda, 27.7 percent from Tanzania, and 14.3 percent from Kenya (Table 2).

Among the people in the HIV cohort, 44.0 percent were enrolled in HIV care between the ages of 25 and 34, 23.8 percent were enrolled between the ages of 35 and 44, and 19.4 percent were enrolled between the ages of 18 and 24. Among people in the TB/HIV cohort, enrollment in HIV care tended to occur at a somewhat older age, with 37.1 percent enrolled between the ages of 35 and 44, 30.1 percent between the ages of 25 and 34, and 23.1 percent at age 45+ (Table 3).

Most people in the HIV cohort were recently enrolled in care, with 78.7 percent enrolled in 2016 or later. By contrast, most people in the TB/HIV cohort (53.0%) were enrolled in care before 2010, although 25.3 percent were enrolled in care in 2019 (Table 3).

Table 3. Characteristics of the study population related to HIV care

Characteristic	HIV N = 1603		TB N = 473		TB/HIV N = 300	
	n	%	n	%	n	%
Age at enrollment in HIV care						
Missing	530				157	
< 18	20	1.9			4	2.8
18–24	208	19.4			10	7.0
25–34	472	44.0			43	30.1
35–44	255	23.8			53	37.1
45+	118	11.0			33	23.1
Calendar year at enrollment in HIV care						
Before 2010	305	19.0			159	53.0
2010–2015	37	2.3			33	11.0
2016	415	25.9			9	3.0
2017	343	21.4			11	3.7
2018	275	17.2			12	4.0
2019	228	14.2			76	25.3
Type of site						
Shore	861	53.7			300	100.0
Island	742	46.3			0	0.0

Among people in the TB cohort, 37.5 percent initiated TB treatment at age 45+, 22.2 percent initiated treatment between the ages of 35 and 44, and 25.0 percent initiated treatment between the ages of 25 and 34. Among people in the TB/HIV cohort, 34.9 percent initiated TB treatment at age 45+, 26.4 percent initiated treatment between the ages of 35 and 44, and 8.9 percent initiated treatment between the ages of 25 and 34 (Table 4).

Approximately one-half of the people in TB cohort initiated TB treatment between April and June 2019, and approximately one-half of the people in the TB/HIV cohort initiated care between July and September 2019 (Table 4).

Age at enrollment in HIV care varied by country. In Kenya, 72.4 percent of those in the HIV cohort enrolled in HIV care between the ages of 18 and 34, and 75.6 percent of those in the TB/HIV cohort enrolled in HIV care between the ages of 25 and 44. In Tanzania, enrollment in HIV care tended to be at a later age. Of those in the HIV cohort, 65.3 percent enrolled in HIV care between the ages of 25 and 44, and 70.3 percent of those in the TB/HIV cohort enrolled in care at age 35+. In Uganda, similar percentages of those in the HIV cohort

(76.9%) and those in the TB/HIV cohort (73.7%) enrolled in HIV care between the ages of 25 and 44 (Table 5).

In Kenya and Tanzania, more than 97 percent of respondents in the HIV cohort enrolled in HIV care in 2016 or later. In Uganda, only 57.7 percent of those in the HIV cohort enrolled in care in 2016 or later. Among those in the TB/HIV cohort in Kenya and Tanzania, approximately 40 percent enrolled in HIV care in 2019, whereas in Uganda, most (70.7%) enrolled in HIV care before 2010 (Table 5).

Table 4. Characteristics of the study population related to TB care

Characteristic	HIV N = 1603		TB N = 473		TB/HIV N = 300	
	n	%	n	%	n	%
Age at TB treatment initiation						
Missing			329		31	
18–24			22	15.3	1	0.4
25–34			36	25.0	24	8.9
35–44			32	22.2	71	26.4
45+			54	37.5	94	34.9
Month and year of TB treatment initiation						
10/2018–12/2018			9	1.9	79	29.4
1/2019–3/2019			173	36.6	3	1.0
4/2019–6/2019			232	49.0	88	29.3
7/2019–9/2019			58	12.3	151	50.3
10/2019–12/2019			1	0.2	58	19.3

Table 5. Characteristics of the study population related to HIV care, by country

Characteristic	Kenya				Tanzania				Uganda			
	HIV N = 486		TB/HIV N = 43		HIV N = 354		TB/HIV N = 83		HIV N = 763		TB/HIV N = 174	
	n	%	n	%	n	%	n	%	n	%	n	%
Age at enrollment in HIV care												
Missing	21		2		14		19		495		136	
< 18	9	1.9	1	2.4	5	1.5	3	4.7	6	2.2		
18–24	129	27.7	3	7.3	41	12.1	2	3.1	38	14.2	5	13.2
25–34	208	44.7	13	31.7	119	35.0	14	21.9	145	54.1	16	42.1
35–44	91	19.6	18	43.9	103	30.3	23	35.9	61	22.8	12	31.6
45+	28	6.0	6	14.6	72	21.2	22	34.4	18	6.7	5	13.2
Calendar year at enrollment in HIV care												

Characteristic	Kenya				Tanzania				Uganda			
	HIV N = 486		TB/HIV N = 43		HIV N = 354		TB/HIV N = 83		HIV N = 763		TB/HIV N = 174	
	n	%	n	%	n	%	n	%	n	%	n	%
Before 2010	9	1.9	10	23.3	8	2.3	26	31.3	288	37.7	123	70.7
2010–2015	3	0.6	7	16.3	0	0.0	10	12	34	4.5	16	9.2
2016	150	30.9	3	7.0	106	29.9	4	4.8	159	20.8	2	1.1
2017	116	23.9	4	9.3	105	29.7	5	6.0	122	16.0	2	1.1
2018	113	23.3	2	4.7	64	18.1	5	6.0	98	12.8	5	2.9
2019	95	19.5	17	39.5	71	20.1	33	39.8	62	8.1	26	14.9
Type of site												
Shore	120	24.7	43	100.0	354	100.0	83	100.0	387	50.7	174	100.0
Island	366	75.3	0	0.0					376	49.3		

Age at initiation of TB treatment also varied by country. Of those in the TB cohort, 48.1 percent in Uganda, 56.7 percent in Kenya, and 78.0 percent in Tanzania initiated treatment at age 35+. Among those in the TB/HIV cohort, 57.9 percent in Uganda, 66.7 percent in Kenya, and 72.0 percent in Tanzania initiated treatment at age 35+ (Table 6).

Of those in the TB cohort, 90.8 percent in Kenya, 74.3 percent in Tanzania, and 79.6 percent in Uganda initiated TB treatment between January and June 2019. Approximately three-quarters of those in the TB/HIV cohort initiated TB treatment in the same period in all three countries (Table 6).

Table 6. Characteristics of the study population related to TB care, by country

Characteristic	Kenya				Tanzania				Uganda			
	TB N = 65		TB/HIV N = 42		TB N = 264		TB/HIV N = 78		TB N = 175		TB/HIV N = 157	
	n	%	n	%	n	%	n	%	n	%	n	%
Age at TB treatment initiation												
Missing	35				196		3		98		32	
18–24	7	23.3	3	7.1	3	4.4	5	6.7	16	20.8	12	9.5
25–34	6	20.0	11	26.2	12	17.6	16	21.3	24	31.2	40	31.7
35–44	9	30.0	17	40.5	22	32.4	23	30.7	16	20.8	42	33.3
45+	8	26.7	11	26.2	31	45.6	31	41.3	21	27.3	31	24.6
Month and year of TB treatment initiation												
10/2018–12/2018	2	3.1	3	7.1	5	1.9	1	1.3	1	0.6	4	2.5
1/2019–3/2019	29	44.6	8	19.0	80	30.3	27	34.6	71	40.6	49	31.2
4/2019–6/2019	30	46.2	23	54.8	142	53.8	31	39.7	82	46.9	76	48.4
7/2019–9/2019	4	6.2	8	19.0	36	13.6	19	24.4	21	12.0	28	17.8

Characteristic	Kenya				Tanzania				Uganda			
	TB N = 65		TB/HIV N = 42		TB N = 264		TB/HIV N = 78		TB N = 175		TB/HIV N = 157	
	n	%	n	%	n	%	n	%	n	%	n	%
10/2019–12/2019	0	0.0	0	0.0	1	0.4	0	0.0	0	0.0	4	2.5

Characteristics of Quantitative Survey Participants

A total of 615 people participated in the quantitative survey: 317 people in the HIV cohort, 146 in the TB cohort, and 152 people in the TB/HIV cohort. Among those in the HIV cohort, 53.9 percent were female; 46.7 percent of the cohort was recruited from Uganda, 33.1 percent from Kenya, and 20.2 percent from Tanzania. Among those in the TB cohort, 39.0 percent were female; 43.8 percent were recruited from Tanzania, 38.4 percent from Uganda, and 17.8 percent from Kenya. Among those in the TB/HIV cohort, 48.0 percent were female; 46.7 percent were recruited from Uganda, 38.8 percent from Tanzania, and 14.5 percent from Kenya (Table 7).

Among those in the HIV cohort, 44.5 percent were ages 25 to 34 at the time of interview, 28.4 percent were ages 35 to 44, and 16.4 percent were age 45+. Among people in the TB cohort, 37.0 were ages 35 to 44 at the time of interview, 26.0 percent were ages 25 to 34, and 21.9 percent were ages 35 to 44. Among people in the TB/HIV cohort, 38.2 percent were ages 35 to 44 at the time of interview, 30.3 percent were ages 45+, and 22.4 percent were ages 25 to 34 (Table 7).

Most people in the HIV cohort were recently enrolled in care, with 74.7 percent enrolled in the last two years. Similarly, among those in the TB/HIV cohort, 62.5 percent had enrolled in HIV care in the past two years. Among those in the TB cohort, all had initiated TB treatment in the past five or more months; the same was true among those in the TB/HIV cohort (Table 7).

Table 7. Characteristics of participants in the quantitative survey

Characteristic	HIV N = 317		TB N = 146		TB/HIV N = 152	
	n	%	n	%	n	%
Sex						
Missing						
Female	171	53.9	57	39.0	73	48.0
Male	146	46.1	89	61.0	79	52.0
Country where recruited						
Kenya	105	33.1	26	17.8	22	14.5
Tanzania	64	20.2	64	43.8	59	38.8
Uganda	148	46.7	56	38.4	71	46.7
Age at interview						
Missing	--	--			--	--
18–24	34	10.7	22	15.1	14	9.2

Characteristic	HIV N = 317		TB N = 146		TB/HIV N = 152	
	n	%	n	%	n	%
25–34	141	44.5	38	26.0	34	22.4
35–44	90	28.4	32	21.9	58	38.2
45+	52	16.4	54	37.0	46	30.3
Time since enrollment in HIV care						
Missing	48	.	--			.
< 1 year	100	37.2	--	--	78	51.3
1–2 years	101	37.5	--	--	17	11.2
3–4 years	62	23.0	--	--	8	5.3
5+ years	6	2.2	--	--	49	32.2
Time since TB treatment initiation						
Missing	--					
< 1 month	--	--	9	6.2	14	9.2
1–2 months	--	--	38	26.0	34	22.4
3–4 months	--	--	43	29.5	63	41.4
5+ months	--	--	56	38.4	41	27.0

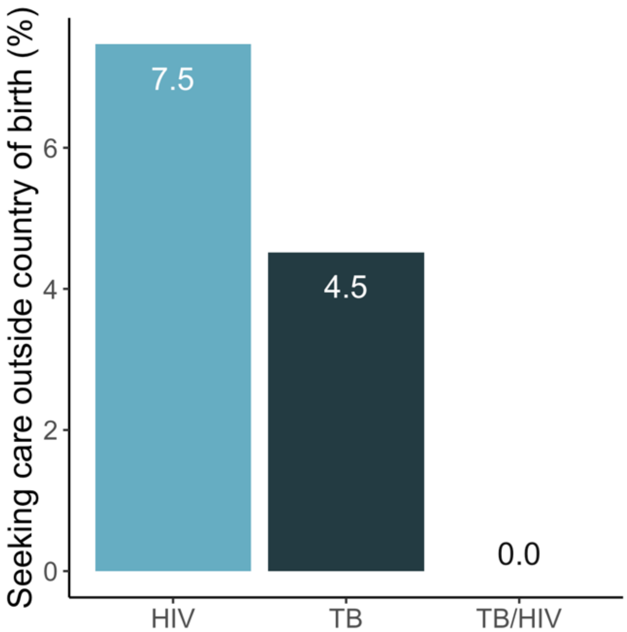
2. How mobile are people living with HIV and/or TB in East Africa?

This section presents the findings of the quantitative survey on the mobility of people living with HIV and/or TB.

Proportion of Respondents Born Outside the Country of Recruitment

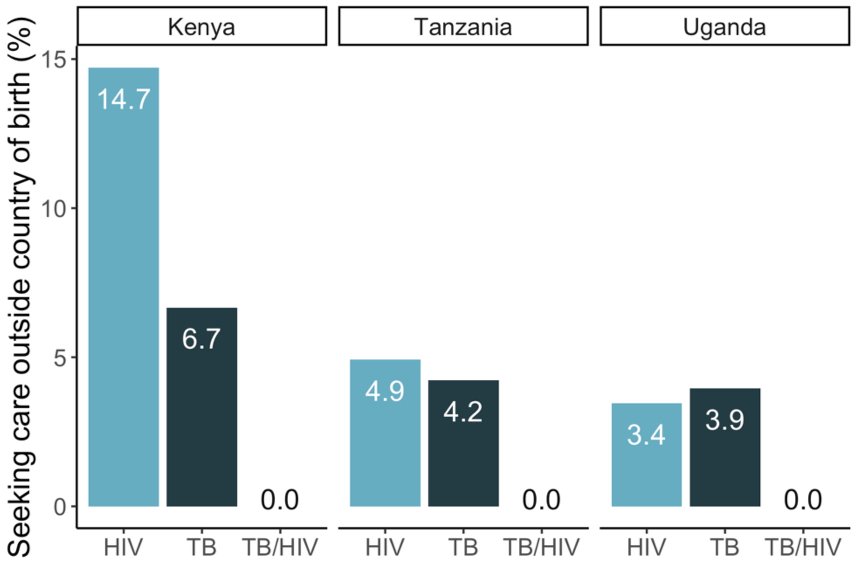
Of the 615 quantitative survey respondents in the HIV cohort, 7.5 percent reported that they were born outside the country where they were recruited for the survey, as did 4.5 percent of those in the TB cohort. None of the respondents in the TB/HIV cohort reported that they were born outside the country where they were recruited (Figure 2).

Figure 2. Proportion of each cohort (HIV, TB/HIV, and TB) born outside the country of the health facility where they were recruited, among 615 respondents to the quantitative survey



Respondents recruited in Kenya were more likely than those recruited in Tanzania and Uganda to report that they were born outside the country where they were recruited for the survey. Among those recruited in Kenya, 14.7 percent of those in the HIV cohort reported that they were born outside Kenya, as did 6.7 percent of those in the TB cohort. Among respondents recruited in Tanzania, 4.9 percent of those in the HIV cohort and 4.2 percent of those in the TB cohort reported being born outside Tanzania. Among respondents recruited in Uganda, only 3.4 percent of those in the HIV cohort and 3.9 percent of those in the TB cohort, reported being born outside Uganda (Figure 3).

Figure 3. Proportion of each cohort (HIV, TB/HIV, and TB) born outside the country of the health facility where they were recruited, among 615 respondents to the quantitative survey, by country of recruitment



Mobility of People in Care for HIV and/or TB

In the quantitative survey, a trip was defined as an overnight stay of at least one night away from the patient's home after diagnosis with HIV and/or TB in the six months before the survey. Distance traveled outside the patient's home district on a trip was calculated as the farthest distance traveled outside the home district on that trip. The distance for trips taken within the patient's home district was calculated as 0 kms.

A higher proportion of people in the HIV cohort reported travel compared with those in the TB and TB/HIV cohort. Of those in the HIV cohort, 36.8 percent reported any trip, 29.4 percent reported at least one trip outside the districts where they lived, and 3.9 percent reported at least one international trip. Of those in the TB cohort, 15.9 percent reported any trip, 11.6 percent reported at least one trip outside the districts where they lived, and 1.3 percent reported at least one international trip. Of those in the TB/HIV cohort, 29.6 percent reported any trip, 19.4 percent reported at least one trip outside the districts where they lived, and 2.0 percent reported at least one international trip (Figure 4).

Among respondents in the HIV cohort, 37.7 percent in Kenya, 22.7 percent in Tanzania, and 48.1 percent in Uganda reported taking any trip when in care for HIV, whereas 27.9 percent, 16.4 percent, and 41.9 percent in each country, respectively, reported taking at least one overnight trip outside their home districts. Among respondents in the TB cohort, 25.5 percent in Kenya, 12.1 percent in Tanzania, and 15.9 percent in Uganda reported taking any trip when on TB treatment, whereas 15.7 percent, 9.7 percent, and 11.9 percent in each country, respectively, reported taking at least one overnight trip outside their home districts. Among respondents in the TB/HIV cohort, 28.6 percent in Kenya, 22.4 percent in Tanzania, and 42.9 percent in Uganda reported taking any trip when on HIV or TB treatment, whereas 14.3 percent, 14.3 percent, and 32.1 percent in each country, respectively, reported taking at least one overnight trip outside their home districts. International overnight trips were rare for all cohorts in all study countries (Figure 5).

Figure 4. Proportion of respondents reporting any overnight trip, at least one overnight trip outside the districts where they live, and at least one overnight international trip after enrollment in care for HIV, TB, or HIV and TB

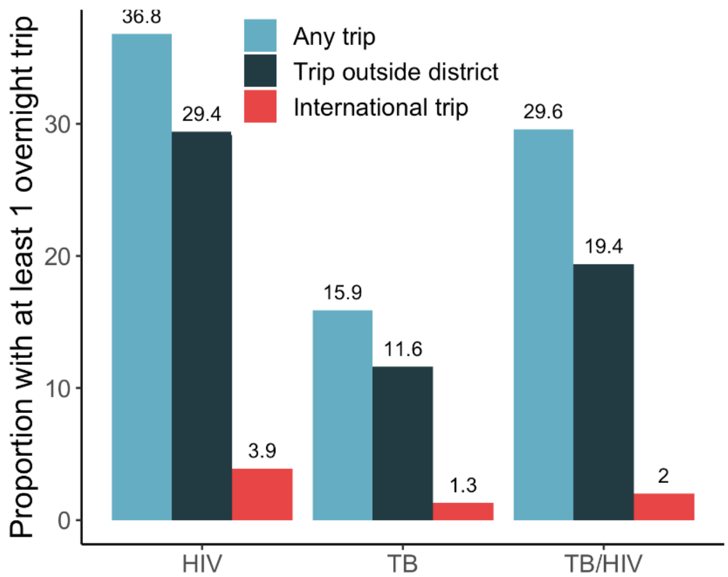
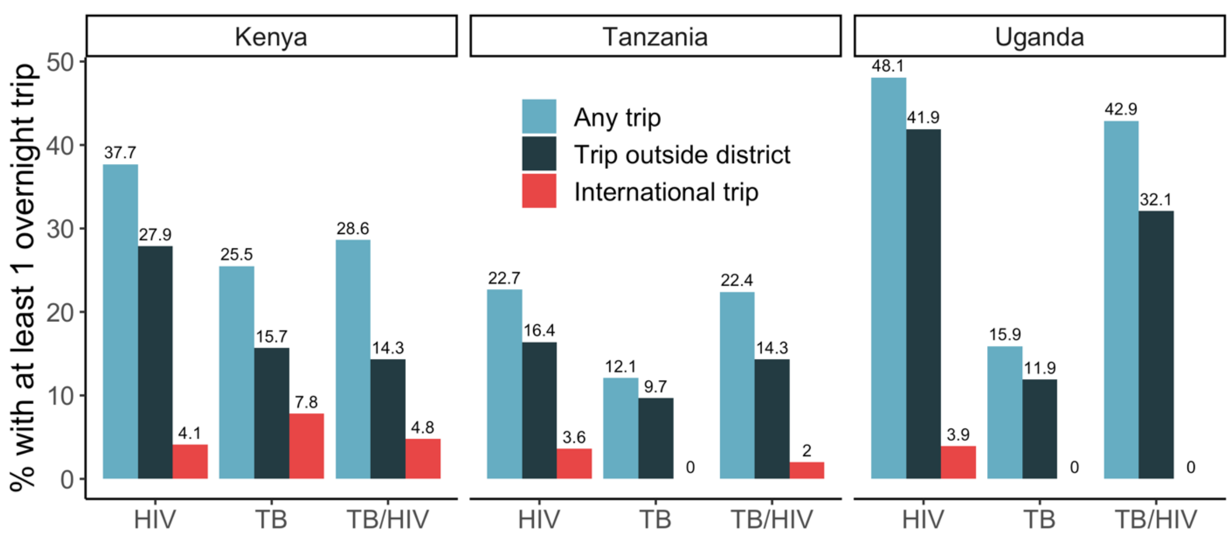


Figure 5. Proportion of respondents reporting any overnight trip, at least one overnight trip outside the districts where they live, and at least one overnight international trip after enrollment in care for HIV, TB, or HIV and TB, by country of recruitment



Women in the HIV cohort were slightly more likely to report any trip compared with men in the same cohort. Whereas 34.1 percent of women reported taking any trip, only 31.1 percent of men reported the same (data not shown). Approximately one-quarter of both men and women in the HIV cohort reported taking at least one overnight trip outside their home districts. Men in the TB and HIV/TB cohorts were more likely to report travel compared with women in these cohorts. Whereas 19.3 percent of men in the TB cohort reported any trips, only 11.5 percent of women reported the same. In addition, 14.6 percent of men and 7.7 percent of women in the TB cohort reported at least one overnight trip outside their home districts. Among those in the TB/HIV cohort, 30.1 percent of men and 25.0 percent of women reported any trip, and 22.6 percent of men and 18.4 percent of women reported at least one overnight trip outside their home districts. International overnight travel was rare for both men and women in all three cohorts (Figure 6).

Figure 6. Proportion of respondents reporting any overnight trip, at least one overnight trip outside the districts where they live, and at least one overnight international trip after enrollment in care for HIV, TB, or HIV and TB, by sex

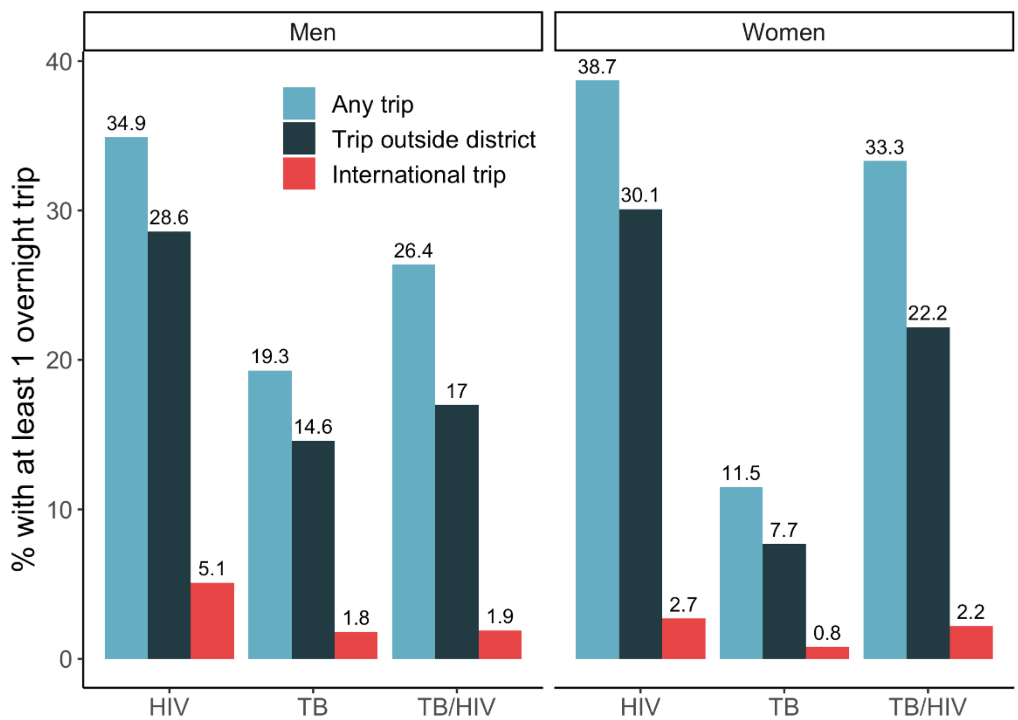


Table 8 compares mobile people (defined for the purposes of the study as those who took at least one trip outside their home districts during the study period) with nonmobile people. Of the quantitative respondents, 222 (36.1%) met the criteria for mobile. Mobile people were most prominent in the HIV cohort (56.3%) and 48.6 percent of mobile people were female. Most (55.4%) were recruited in Uganda. Approximately one-half were 35+ in age and the majority (57.7%) reported informal employment. As to housing, 47.3 percent lived in a freestanding house and 44.6 percent lived in a room in a shared residential building.

A higher proportion of nonmobile respondents were present in the TB and TB/HIV cohorts, compared with mobile respondents, and a similar percentage were female. A higher percentage of nonmobile respondents were recruited in Kenya and Tanzania, compared with mobile respondents. Non-mobile respondents also tended to be slightly older than mobile respondents, and slightly less likely to be employed in the formal sector. Non-mobile respondents were more likely than mobile respondents to live in a freestanding house (Table 8).

Table 8. Comparison of characteristics between mobile and nonmobile respondents*

Characteristic	Mobile N = 222		Non-Mobile N = 393	
	n	%	n	%
Cohort				
HIV cohort	125	56.3	183	46.7
TB cohort	55	24.8	122	31.1
TB/HIV cohort	42	18.9	87	22.2
Sex				
Female	108	48.6	193	49.1
Male	114	51.4	200	50.9
Country where recruited				
Kenya	54	24.3	99	25.2
Tanzania	45	20.3	142	36.1
Uganda	123	55.4	152	38.7
Age at interview				
Missing				
18–24	27	12.2	43	10.9
25–34	83	37.4	130	33.1
35–44	66	29.7	114	29.0
45+	46	20.7	106	27.0
Employed				
No, but looking for work	24	10.8	52	13.2
No, and not looking for work	15	6.8	66	16.8
Informally employed	128	57.7	218	55.5
Yes, occasional or part-time work	27	12.2	24	6.1
Yes, full time work	28	12.6	33	8.4
Housing type				
Free-standing house	105	47.3	219	55.7
Apartment	12	5.4	23	5.9
Rooms in shared residential building	99	44.6	132	33.6
Bar/pub/club	1	0.5	2	0.5
Hotel/lodge/guesthouse	2	0.9	--	--
Other	3	1.4	17	4.3

*Respondents were classified as "mobile" if they took at least one trip outside their home districts during the study period, regardless of whether they had TB or HIV at the time of the trip.

Respondents in the HIV cohort tended to travel more frequently than those in the TB or TB/HIV cohorts. Among those in the HIV cohort, the mean number of trips taken per month was 0.7, compared with only 0.3 among those in the TB cohort and 0.2 among those in the TB/HIV cohort. Those in the HIV cohort traveled a mean total distance of 47.9 kms outside their home districts per month, whereas those in the TB and TB/HIV cohorts only traveled a mean total distance of approximately 10 kms outside their home districts. Those in the HIV cohort also tended to spend a higher total number of days away from home each month (1.3 days) compared with those in the TB cohort (0.8 days) and those in the TB/HIV cohort (0.7 days) (Table 9).

Among mobile respondents (those who reported at least one trip outside their home districts), the mean number of trips reported per month was nearly double what was reported overall. Depending on the cohort for which the comparison is made, total kms traveled per month outside the home districts for mobile respondents was also two to five times what was reported overall, and the mean number of days spent away from home was two to four times what was reported overall. However, the mean number of international trips per month was only greater among mobile respondents in the TB cohort (Table 9).

Table 9. Mobility among people in care for HIV and/or TB in selected cross-border areas

Activity	HIV		TB		TB/HIV	
	Mean	SE	Mean	SE	Mean	SE
Overall						
Number of trips per month	0.7	8.9	0.3	2.5	0.2	1.2
Total distance (kms) traveled outside the home district per month	47.9	549.6	9.8	45.3	10.7	59.3
Number of days away from home per month	1.3	4.2	0.8	3.9	0.7	3.1
Number of international trips per month	0.1	1.0	0.1	1.7	0.0	0.0
Among those reporting at least one trip outside the home district						
Number of trips per month	1.9	15.3	0.7	3.3	0.6	2.2
Total distance (kms) traveled outside the home district per month	137.1	923.8	46.3	166.9	42.8	105
Number of days away from home per month	2.6	5.3	2.1	6.4	2.9	6.4
Number of international trips per month	0.1	0.9	0.5	3.2	0.0	0.0

Respondents recruited in Kenya tended to be more mobile than those recruited in Tanzania and Uganda. The mean number of trips per month among respondents recruited in Kenya was 1.8 among those in the HIV cohort, 1.2 among those in the TB cohort, and 0.1 among those in the TB/HIV cohort. Respondents recruited in Tanzania reported a mean of 0.1 trips per month or less for each cohort, and those recruited in Uganda reported a mean of 0.3 trips or less for each cohort. Among those in the HIV cohort, the mean total distance traveled per month was 132.6 kms among respondents recruited in Kenya, but only 10.6 kms among those recruited in Tanzania and 14.3 kms among those recruited in Uganda. There was less variation by country in the mean total distance traveled per month among those in the TB or TB/HIV cohorts. The mean total days spent away from home per month varied from 0.2 to 2.0 per month across countries and cohorts (Table 10).

Table 10. Mobility among people in care for HIV and/or TB in selected cross-border areas, by country of recruitment

Activity	HIV		TB		TB/HIV	
	Mean	SE	Mean	SE	Mean	SE
Kenya						
Number of trips per month	1.8	16.4	1.2	5.3	0.1	0.2
Total distance (kms) traveled outside the home district per month	132.6	1010.8	8.4	33.1	7.2	19.1
Number of days away from home per month	1.5	5.0	2.0	7.1	0.2	0.4
Number of international trips per month	0.1	1.1	0.7	4.2	0.0	0.0
Tanzania						
Number of trips per month	0.1	0.2	0.1	0.8	0.0	0.1
Total distance (kms) traveled outside the home district per month	10.6	40	10.6	50	4.4	15.7
Number of days away from home per month	0.6	2.1	0.4	2.9	0.3	1.4
Number of international trips per month	0.0	0.0	0.0	0.0	0.0	0.0
Uganda						
Number of trips per month	0.3	1.6	0.2	1.5	0.3	1.8
Total distance (kms) traveled outside the home district per month	14.3	34.9	9.5	44.8	17.0	84.5
Number of days away from home per month	1.6	4.6	0.7	2.8	1.1	4.2
Number of international trips per month	0.1	1.3	0.0	0.0	0.0	0.0

Table 11 presents mobility results among mobile people (those who took at least one trip outside their home districts) who were in care for HIV and/or TB, by country of recruitment. Mobile respondents recruited in Kenya tended to take more trips than those recruited in Tanzania and Uganda. The mean number of trips per month among mobile respondents recruited in Kenya was 4.8 among those in the HIV cohort, 2.3 among those in the TB cohort, and 0.2 among those in the TB/HIV cohort. Mobile respondents recruited in Tanzania reported a mean of 0.5 trips per month or less for each cohort, and those recruited in Uganda reported a mean of 0.9 trips per month among those in HIV and TB/HIV cohorts, but only 0.1 trips per month for those in the TB cohort (Table 11).

Among those in the HIV cohort, the mean total distance traveled per month was 340.1 kms among mobile respondents recruited in Kenya, but only 46.1 kms among those recruited in Tanzania and 57.4 kms among those recruited in Uganda. Among those in the TB cohort, the mean total distance traveled per month was

101.6 kms among mobile respondents recruited in Kenya, but only 47.1 among those recruited in Tanzania and 24.9 among those recruited in Uganda. Among those in the TB/HIV cohort, the mean total number of kms traveled per month was highest in Uganda (60.4), followed by Tanzania (24.5) and Kenya (16.5). The mean total days spent away from home per month varied from 2.4 to 2.7 for those in the HIV cohort. Among mobile respondents in the TB cohort, the mean number of days spent away from home was 4.6 among those recruited in Kenya, but only 1.5 days among those recruited in Tanzania and Uganda. Among mobile respondents in the TB/HIV cohort, the mean number of days spent away from home was 4.4 among those recruited in Uganda, but only 1.7 days among those recruited in Tanzania and 0.3 days among those recruited in Kenya. (Table 11).

Table 11. Mobility among people in care for HIV and/or TB in selected cross-border areas, among mobile populations, by country of recruitment*

Activity	HIV		TB		TB/HIV	
	Mean	SE	Mean	SE	Mean	SE
Kenya						
Number of trips per month	4.8	27.5	2.3	6.9	0.2	0.2
Number of kms traveled per month	340.1	1678.4	101.6	342.6	16.5	26.6
Number of days away from home per month	2.4	6.3	4.6	10.8	0.3	0.5
Number of international trips per month	0.3	1.6	2.3	6.9	0.0	0.1
Tanzania						
Number of trips per month	0.2	0.3	0.5	1.7	0.2	0.2
Number of kms traveled per month	46.1	73.4	47.1	96.4	24.5	28.4
Number of days away from home per month	2.4	3.2	1.6	5.6	1.7	2.7
Number of international trips per month	0.0	0.1	0.0	0.0	0.0	0.1
Uganda						
Number of trips per month	0.9	5.6	0.1	0.2	0.9	2.9
Number of kms traveled per month	57.4	253.8	24.9	71	60.4	137.3
Number of days away from home per month	2.7	5.4	1.4	3.8	4.4	8.2
Number of international trips per month	0.0	0.0	0.0	0.0	0.0	0.0

*Mobile people were those who took at least one trip outside their home districts during the study period.

Figure 7A and Table 12 present the proportion of respondents traveling outside their home districts for various distances after enrolling in care for HIV, TB, or HIV and TB. Among those in the HIV cohort, 26.3 percent reported any travel outside their home districts, compared with only 10.9 percent of those in the TB cohort and 20.8 percent of those in the TB/HIV cohort. Travel just outside the home district was more common than travel farther away for all three cohorts.

Figure 7A) Proportion of respondents traveling various distances per month when in care for HIV, HIV/TB, and TB; B) Proportion of respondents spending various numbers of nights away from home after enrollment in care for HIV, TB, or both HIV and TB

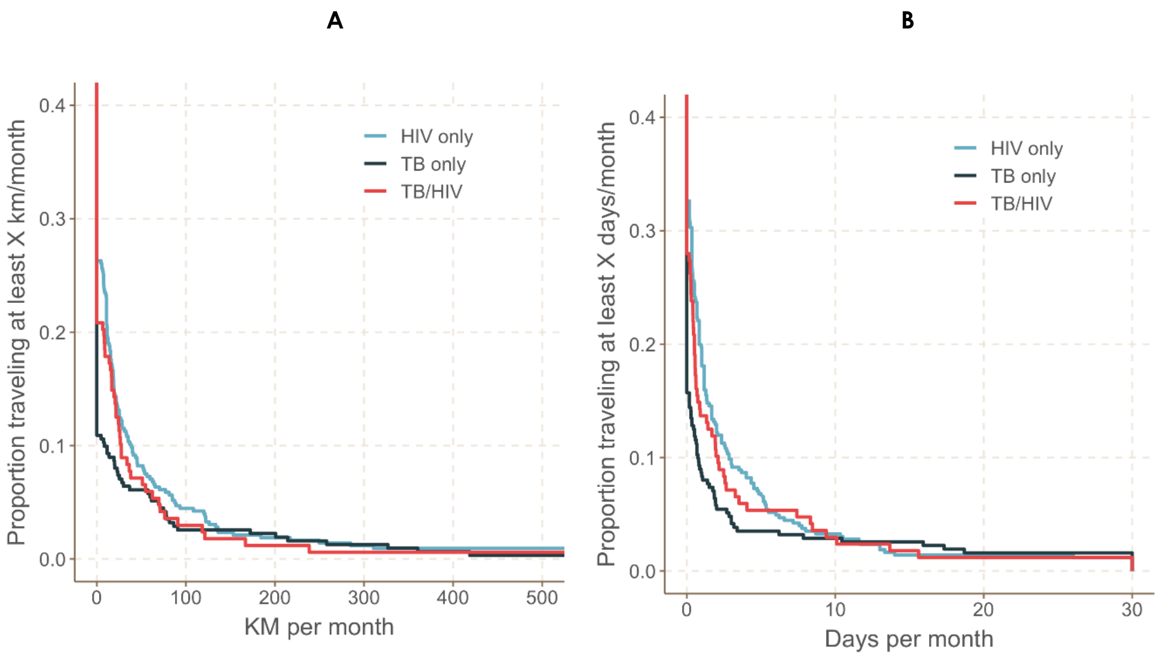


Table 12. Proportion of respondents traveling outside their home districts at least 25, 50, 100, 200, and 300 kms after enrolling in care for HIV, TB, or both TB and HIV

Activity	HIV		TB		TB/HIV	
	Proportion	95% CI	Proportion	95% CI	Proportion	95% CI
Reporting any travel outside the home district	26.3	22.4, 30.8	10.9	7.9, 15	20.8	15.5, 28
Traveling outside the home district at least 25 kms/month	12.4	9.7, 16	7.1	4.7, 10.5	10.7	6.9, 16.6
Traveling outside the home district at least 50 kms/month	8	5.8, 11	5.8	3.7, 9	6.5	3.7, 11.6
Traveling outside the home district at least 100 kms/month	4.2	2.7, 6.6	2.2	1.1, 4.7	2.4	0.9, 6.3
Traveling outside the home district at least 200 kms/month	1.6	0.8, 3.4	1.9	0.9, 4.2	0.6	0.1, 4.2
Traveling outside the home district at least 300 kms/month	0.9	0.4, 2.5	1	0.3, 3	0.0	0, 0

The proportion of respondents reporting any travel outside their home districts after enrolling in care for HIV, TB, or TB/HIV was highest for those in the HIV cohort, followed by those in the TB/HIV cohort, and lowest for those in the TB cohort in all three countries. Among respondents recruited in Kenya, 28.0 percent of those in the HIV cohort reported traveling outside their home districts after enrolling in care, compared with 16.0 percent in the TB/HIV cohort, and 9.4 percent in the TB cohort. Among those recruited in Tanzania, these proportions were 14.4 percent, 10.9 percent, and 8.8 percent, respectively, and among those recruited in Uganda, they were 30.7 percent, 20.3 percent, and 12.7 percent, respectively (Table 13).

Table 13. Proportion of participants traveling outside their home districts at least 25, 50, 100, 200, and 300 kms after enrolling in care for HIV, TB, or both TB and HIV

Activity	HIV		TB		TB/HIV	
	Proportion	95% CI	Proportion	95% CI	Proportion	95% CI
Kenya						
Reporting any travel outside the home district	28.0	21.1, 37.1	9.4	4.1, 21.7	16.0	6.5, 39.3
Traveling outside the home district at least 25 kms/month	15.2	10.0, 23.0	7.5	2.9, 19.4	8.0	2.1, 30.2
Traveling outside the home district at least 50 kms/month	8.8	5.0, 15.5	5.7	1.9, 17	4.0	0.6, 27.3
Traveling outside the home district at least 100 kms/month	5.6	2.7, 11.5	0.0	0, 0	0.0	0.0, 0.0
Tanzania						
Reporting any travel outside the home district	14.4	9.4, 22.1	8.8	5, 15.5	10.9	5.4, 22.0
Traveling outside the home district at least 25 kms/month	7.2	3.8, 13.5	4.8	2.2, 10.5	6.2	2.4, 16.1
Traveling outside the home district at least 50 kms/month	5.6	2.7, 11.5	4.0	1.7, 9.4	1.6	0.2, 10.9
Traveling outside the home district at least 100 kms/month	4.0	1.7, 9.4	2.4	0.8, 7.3	0.0	0.0, 0.0
Uganda						
Reporting any travel outside the home district	30.7	24.6, 38.3	12.7	8.1, 19.8	20.3	13.1, 31.4
Traveling outside the home district at least 25 kms/month	13.1	8.9, 19.1	6.7	3.6, 12.6	7.6	3.5, 16.4
Traveling outside the home district at least 50 kms/month	9.7	6.1, 15.2	5.2	2.5, 10.7	5.1	1.9, 13.2
Traveling outside the home district at least 100 kms/month	3.4	1.6, 7.5	0.7	0.1, 5.3	2.5	0.6, 9.9

The proportion of respondents reporting that they spent any nights away from home after enrolling in care for HIV, TB, or HIV and TB was highest for those in the HIV cohort (32.6%) followed by those in the TB/HIV cohort (28.0%) and those in the TB cohort (15.7%). Travel for fewer nights was more common for all three cohorts (Table 14 and Figure 7B).

Table 14. Proportion of participants spending any nights, and 2, 3, 5, and 10 nights away from home after enrolling in care for HIV, TB, or both TB and HIV

Activity	HIV only		TB only		TB/HIV	
	Percentage	95% CI	Percentage	95% CI	Percentage	95% CI
Reporting any nights away from home	32.6	28.5, 37.4	15.7	12.1, 20.3	28	21.9, 35.7
Reporting at least 2 nights away from home per month	12.0	9.3, 15.5	5.1	3.2, 8.3	9.5	6, 15.2
Reporting at least 3 nights away from home per month	9.2	6.8, 12.3	4.2	2.4, 7.1	6.5	3.7, 11.6
Reporting at least 5 nights away from home per month	6.3	4.4, 9.1	3.2	1.7, 5.9	4.8	2.4, 9.4
Reporting at least 10 nights away from home per month	3.1	1.8, 5.2	2.6	1.3, 5.1	2.4	0.9, 6.3

The proportion of respondents reporting that they spent any nights away from home after enrolling in care for HIV, TB, or TB/HIV was highest for those in the HIV cohort, followed by those in the HIV/TB cohort, and lowest for those in the TB cohort in all three countries. Among respondents recruited in Kenya, 37.6 percent of those in the HIV cohort reported spending any nights away from home after enrolling in care, compared with 28.0 percent in the TB/HIV cohort, and 22.6 percent in the TB cohort. Among those recruited in Tanzania, the proportions were 20.0 percent, 14.1 percent, and 12.0 percent, respectively, and among those recruited in Uganda, they were 34.7 percent, 24.1 percent, and 17.2 percent, respectively (Table 15).

Table 15. Proportion of participants spending any nights, and at least 2, 3, and 5 nights away from home per month after enrolling in care for HIV, TB, or both TB and HIV, by country of recruitment

Activity	HIV only		TB only		TB/HIV	
	Proportion	95% CI	Proportion	95% CI	Proportion	95% CI
Kenya						
Reporting any nights away from home	37.6	30, 47.1	22.6	13.8, 37.2	28.0	14.9, 52.5
Reporting at least 2 nights away from home	12.0	7.5, 19.3	5.7	1.9, 17	0.0	0.0, 0.0
Reporting at least 3 nights away from home	8.8	5.0, 15.5	5.7	1.9, 17	0.0	0.0, 0.0
Reporting at least 5 nights away from home	4.8	2.2, 10.5	5.7	1.9, 17	0.0	0.0, 0.0
Tanzania						
Reporting any nights away from home	20.0	14.1, 28.4	12.0	7.5, 19.3	14.1	7.7, 25.8
Reporting at least 2 nights away from home	7.2	3.8, 13.5	2.4	0.8, 7.3	4.7	1.6, 14.1
Reporting at least 3 nights away from home	4.8	2.2, 10.5	1.6	0.4, 6.3	3.1	0.8, 12.2
Reporting at least 5 nights away from home	3.2	1.2, 8.4	0.8	0.1, 5.6	0.0	0.0, 0.0
Uganda						
Reporting any nights away from home	34.7	28.3, 42.5	17.2	11.8, 24.9	24.1	16.3, 35.6
Reporting at least 2 nights away from home	13.6	9.4, 19.8	6.0	3, 11.7	7.6	3.5, 16.4
Reporting at least 3 nights away from home	11.4	7.5, 17.2	3.7	1.6, 8.8	5.1	1.9, 13.2
Reporting at least 5 nights away from home	8.5	5.3, 13.8	3.0	1.1, 7.8	5.1	1.9, 13.2

Characteristics of Trips Taken After Enrollment in Care for HIV, TB, or TB/HIV

Respondents in the HIV cohort reported a total of 678 trips after enrollment in care for HIV. Those in the TB cohort reported 410 total trips since enrollment in TB treatment, and those in the TB/HIV cohort reported a total of 183 trips since enrollment in care for either TB or HIV. For all three cohorts, the average duration of trips was approximately eight days. The average distance traveled outside the home district was highest for trips taken by those in the TB cohort (179.6 kms), followed by trips taken by those in the HIV cohort (122.7 kms), and lowest for trips taken by those in the TB/HIV cohort (84.2 kms).

Fewer trips were taken by women than by men; this was especially notable for trips taken by people in the TB cohort (18 by women and 392 by men) and trips taken by people in the TB/HIV cohort (24 by women and

159 by men). Trips taken by women in the HIV and TB/HIV cohorts had an average duration of 9.1 and 10.3 days, respectively, whereas those taken by women in the TB cohort had an average duration of just 5.4 days. Trips taken by men in the HIV and TB/HIV cohorts had an average duration of 6.9 and 6.7 days, respectively, whereas those taken by men in the TB cohort had an average duration of 9.4 days. The average distance traveled was approximately 135 kms for trips taken by women in the HIV and TB cohorts, but only 120 kms for trips taken by women in the TB/HIV cohort. The average distance traveled was approximately 200 kms for trips taken by men in the TB cohort, but only 112 kms for trips taken by men in the HIV cohort and 65 kms for trips taken by men in the TB/HIV cohort (Table 16).

Table 16. Characteristics of the 1,271 trips taken after enrollment in HIV care, TB treatment, or TB/HIV, overall and by sex

Activity	HIV (n= 678 trips)		TB (n= 410 trips)		TB/HIV (n= 183 trips)	
Overall	Count/mean	SD	Count/mean	SD	Count/mean	SD
Number of trips taken	678		410		183	
Average duration of trips (days)	8.0	13.3	8.1	14.1	8.0	11.5
Average distance traveled outside the home district (kms)	122.7	168.9	179.6	203.4	84.2	130.3
Women						
Number of trips taken	284		18		24	
Average duration of trips (days)	9.1	15.0	5.4	9.5	10.3	13.7
Average distance traveled outside the home district (kms)	133.7	199.0	135.8	203.6	119.7	190.7
Men						
Number of trips taken	394		392		159	
Average duration of trips (days)	6.9	11.6	9.4	15.7	6.7	10.0
Average distance traveled outside the home district (kms)	112.9	137.1	199.8	202.7	65.2	77.0

Table 17 presents the primary reasons for travel. Of the 678 trips taken by people in the HIV cohort, 43.4 percent were for work or to conduct business, 15.0 percent were to visit family or friends, and 36.0 percent were for other reasons. Of the 410 trips taken by people in the TB cohort, 51.2 percent were for work or to conduct business, 25.0 percent were to visit family or friends, and 22.4 percent were for other reasons. Of the 183 trips taken by people in the TB/HIV cohort, 57.4 percent were taken to look for a new job, 9.3 percent were taken to visit family or friends, and 28.0 percent were taken for other reasons. Very few trips were taken for health-related reasons.

Table 18 presents the mode of travel used. For each trip, more than one mode could be used. Among the 678 trips taken by people in the HIV cohort, the most common means of transport were motorbike (29.8%), taxi (28.0%) and minibus (22.0%). Of the 410 trips taken by people in the TB cohort, the most common form of transport was "other" (47.8%), followed by motorbike (26.8%), and approximately 15 to 18 percent of trips involving transport by minibus, taxi, bus, ferry (sitting inside), and ferry (sitting outside). Of the 182 trips taken by people in the TB/HIV cohort, the most common form or transport was taxi (75.6%), followed by personal vehicle (58.5%), and motorbike (26.2%).

Table 17. Primary reason for travel for the 1,271 trips taken by participants with HIV, HIV/TB, and TB in selected cross-border areas

Characteristic	HIV (n = 678 trips)		TB (n = 410 trips)		TB/HIV (n = 183 trips)	
	No. trips	% of trips	No. trips	% of trips	No. trips	% of trips
To look for a new job	1	0.1	26	6.3	105	57.4
To work/conduct business	294	43.4	210	51.2	14	7.7
To escape stigma due to HIV	0	0.0	0	0.0	1	0.5
To get HIV care	9	1.3	0	0.0	12	6.6
To get TB care	1	0.1	0	0.0	1	0.5
To get other types of healthcare	3	0.4	1	0.2	0	0.0
To get support from family/friends for HIV care	2	0.3	0	0.0	1	0.5
To get support from family/friends for reasons not related to TB/HIV	2	0.3	0	0.0	1	0.5
To visit family/friends	102	15.0	25	6.1	17	9.3
To attend to a sick family member	9	1.3	2	0.5	3	1.6
To attend to land/field/animals	1	0.1	0	0.0	0	0.0
To shop/buy things	7	1.0	0	0.0	13	7.7
Holiday/vacation	3	0.4	31	6.0	0	0.0
Other reasons	244	36.0	115	22.4	14	7.7

Table 18. Mode of travel for the 1,271 trips taken by respondents with HIV, TB, or both TB and HIV

Characteristic	HIV (n = 678 trips)		TB (n = 410 trips)		TB/HIV (n = 183 trips)	
	No. trips	% of trips	No. trips	% of trips	No. trips	% of trips
Minibus	149	22.0	69	16.8	22	12.0
Motorbike	202	29.8	110	26.8	48	26.2
Taxi	190	28.0	64	15.6	140	76.5
Bus	59	8.7	73	17.8	7	3.8
Truck	2	0.3	0	0.0	3	1.6
Ferry (sitting inside)	48	7.1	69	16.8	4	2.2
Ferry (sitting outside)	28	4.1	70	17.1	6	3.3
Personal vehicle	10	1.5	38	9.3	107	58.5
Other form of transport	56	8.3	196	47.8	21	11.5

Qualitative Findings

Healthcare Workers

Healthcare workers estimated the percentage of their patients who travelled when on ART. Twelve healthcare workers provided an estimate of the percentage of patients on ART who travelled. The remaining four did not feel able to provide an accurate estimate but noted that a portion of their patients did travel. Estimates ranged from 20 percent to 90 percent., with seven reporting less than 50 percent and five reporting 50 percent or more. The most common reason for travel was employment in fishing or other work-related travel. Other reasons for travel included funerals, visiting relatives, or attending to sick relatives.

Fourteen healthcare workers provided an estimate of the percentage of patients on TB treatment who travelled; the remaining two did not feel able to provide an accurate estimate. Estimates ranged from less than one percent to 60 percent. Nine estimated that 10 percent or fewer of the TB patients travelled, and five reported that more than 10 percent travelled. The primary reasons for travel were to attend to family obligations, such as funerals, or taking children to boarding school. Some also travelled for fishing.

Most healthcare workers reported that they inquired indirectly about travel when a patient was first enrolled on ART and/or diagnosed with TB by asking where a new patient had come from or for how long he or she had been in the area. They also asked about the patient's occupation to gauge travel because some occupations (e.g., fishing, truck driving) are associated with travel. For TB patients, this information can be used for contact tracing and to help determine where the person was infected.

Community Leaders

Female and male community leaders reported that people come from other countries in East Africa to their area, primarily for work in the fishing industry. Female community leaders also reported that women come for sex work, to work in bars, or to work as housemaids.

Community leaders stated that local people who are engaged in the fishing industry and in sex work travel frequently among the islands of Lake Victoria and mainland fish landing sites. As one male community leader explained:

> *They [men] don't have specific islands they go to but as long as they get communication that there is fish on a certain island, then they just move there…Scarcity of fish is the main reason that fishermen leave their residence to go somewhere else in order to catch fish.* — Male focus group participant, Uganda

Similarly, female community members explained:

> *Many women, especially sex workers, usually get communication from their peers about particular islands and fish landing sites that are booming as far as the fishing business is concerned. They frequently travel to these areas to make ends meet.* — Female focus group participant, Uganda

> *[Women] may come… spend a week, when they realize they have earned good money, they spend even another second week. And they see that two weeks have passed and they may decide to go to another island…for like one week per island rotating around just like that for a period of two to three months, then they may decide to go home.* — Female focus group participant, Uganda

Community leaders also reported that local people travel for holidays in December, to bring their children to boarding school, to visit relatives, and to engage in other family obligations, such as funerals.

3. What proportion of people in treatment for TB or TB/HIV have resistance to one or more TB drugs?

Of the 473 patients in the TB cohort created from clinical records, only 11 (2.3%) had a positive diagnosis of drug resistant TB (DR TB), with three of the 11 testing positive for MDR TB. Similarly, among the 300 patients in the TB/HIV cohort, only seven (2.3%) had a positive diagnosis for DR TB, with two of the seven diagnosed with MDR TB (Table 19).

Table 19. Number of patients in the TB and TB/HIV cohorts diagnosed with DR TB and MDR TB in clinical records

	TB N = 473		TB/HIV N = 300	
	n	%	n	%
Tested positive for DR TB	11	2.3	7	2.3
Tested positive for MDR TB	3	0.6	2	0.7

Table 20 presents the characteristics of people living with resistant TB in all cohorts. Fifty-five percent were male and the majority (55.0%) were recruited in Tanzania, followed by Uganda (30.0%), and Kenya (15.0%). Most (43.8%) initiated TB treatment between the ages of 35 and 44, followed by ages 25 to 34 (31.3%), and age 45+ (25.0%). Just under one-half (45.0%) were also diagnosed with HIV.

Table 20. Characteristics of patients with resistant TB infection

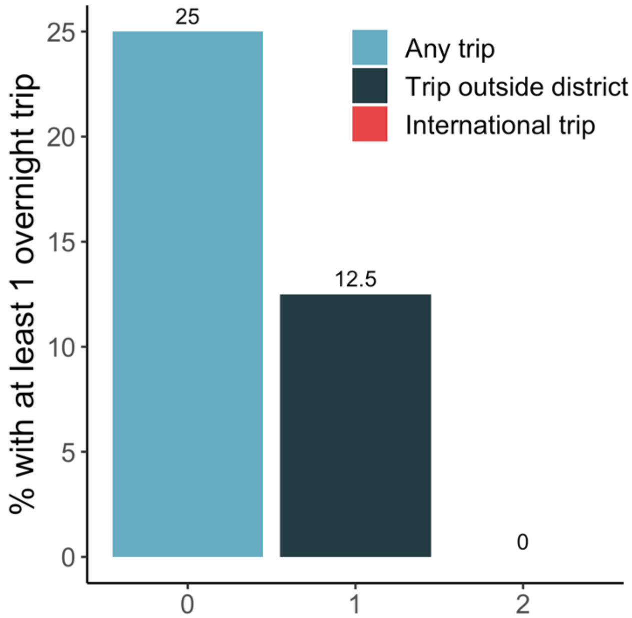
Characteristics	People living with resistant TB infection in all cohorts* N = 20	
	n	%
Male	11	55.0
Country where recruited		
Kenya	3	15.0
Tanzania	11	55.0
Uganda	6	30.0
Age at TB treatment initiation		
Missing	4	
18–24	0	0.0
25–34	5	31.3
35–44	7	43.8
45+	4	25.0
Month and year of TB treatment initiation		
10/2018–12/2018	1	5.0
1/2019–3/2019	4	20.0
4/2019–6/2019	14	70.0
7/2019–9/2019	1	5.0
10/2019–2/2019	0	0.0
Also diagnosed with HIV	9	45.0

*Includes two people testing positive for resistant TB infection recruited for the HIV cohort island-based facilities.

Sixteen respondents with DR TB completed the quantitative survey. Of these, 25.0 percent (n = 4) reported any trip after TB diagnosis, and 12.5 percent (n = 2) reported at least one overnight trip outside the district in which they lived (Figure 8).

Of those who traveled, one person was away from home for six days, two people were away for four days, and one was away for one day. Of the two people who traveled outside their home districts, one traveled 995 kms during three trips and the other traveled 38 kms during one trip. The reasons for travel included to get healthcare (for care other than TB or HIV), to visit family/friends, and to attend to a sick family member (data not shown). No respondents with DR TB reported travel outside their country of residence during the study period.

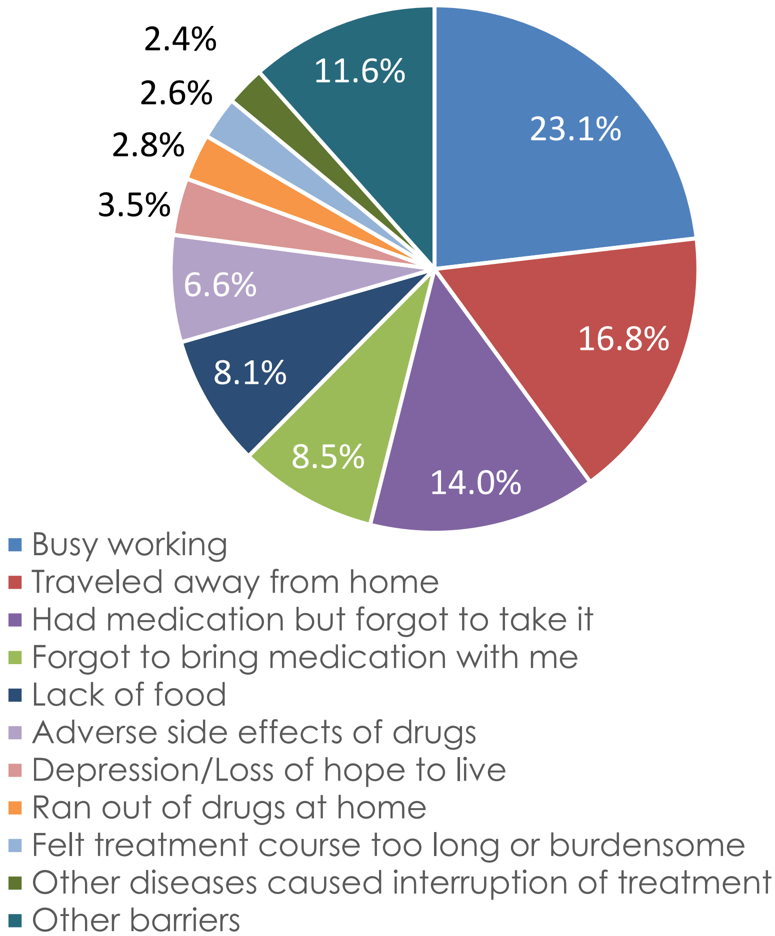
Figure 8. Proportion of 16 patients with DR TB who also answered the quantitative questionnaire reporting at least one overnight trip after TB diagnosis



4. What is the relationship between mobility and access to HIV- and TB-related services?

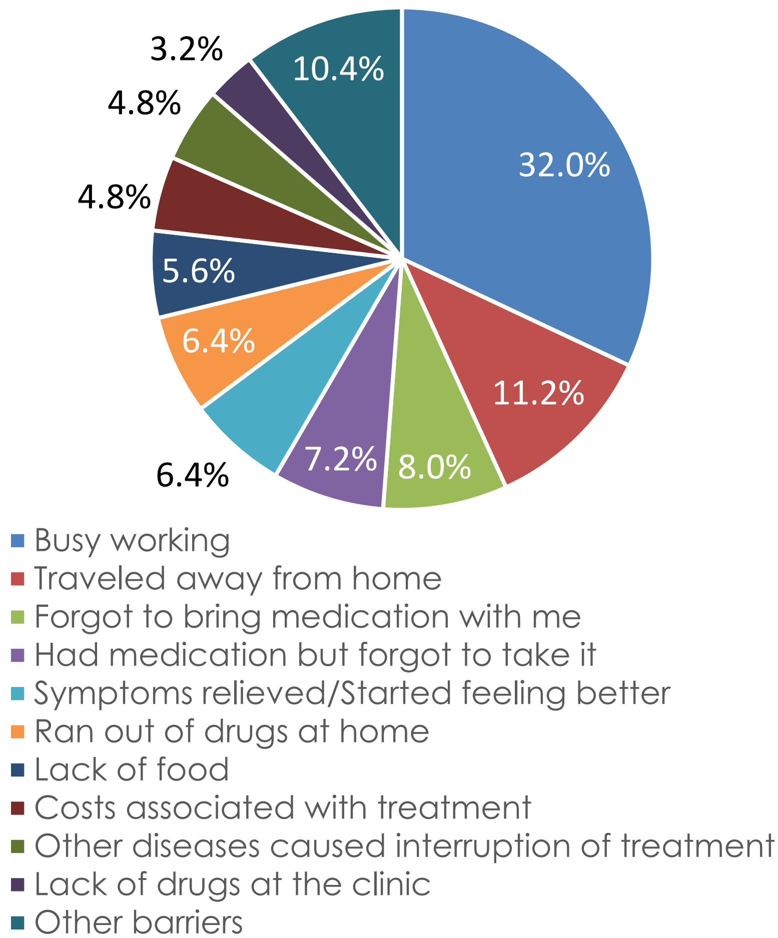
Patients on ART were asked to describe barriers to treatment adherence for each of the last 12 months during which they were prescribed ART. A total of 458 barriers were reported to ART treatment adherence. Of these, the most frequently reported barriers were busy working (23.1%), traveled away from home (16.8%), had medication but forgot to take it (14.0%), forgot to carry medication with them (8.5%), and lack of food (8.1%) (Figure 9).

Figure 9. Reported barriers to HIV treatment adherence among patients reporting suboptimal adherence (n = 458 barrier reports)



Patients on TB treatment were asked to describe barriers to treatment adherence for each month in which they were on TB treatment. A total of 125 barriers were reported to TB treatment adherence. Of these, the most frequently reported barriers were busy working (32.0%), traveled away from home (11.2%), forgot to carry medication with them (8.0%), and had medication but forgot to take it (7.2%) (Figure 10).

Figure 10. Reported barriers to TB treatment adherence among patients reporting suboptimal adherence (n = 125 barrier reports)

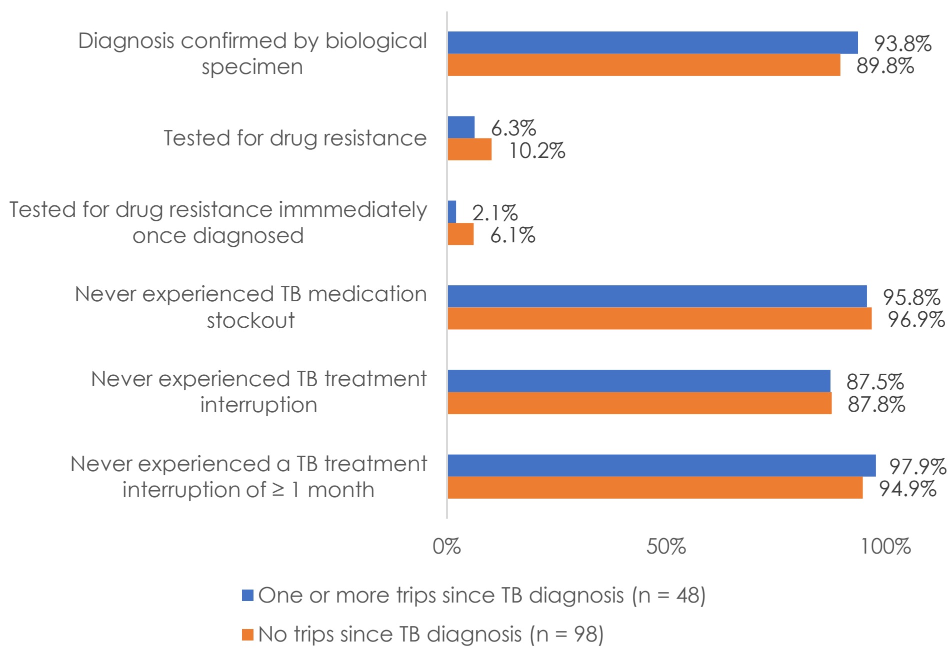


Among patients with TB but not HIV, a higher percentage of those who did not have an overnight trip outside their home districts since TB diagnosis (42.9%) sought care within the six weeks of onset of TB symptoms compared with those who reported an overnight trip outside the district after receiving their TB diagnosis (35.4%). Among patients with TB and HIV, a lower percentage of those who did not have an overnight trip outside their home districts since TB diagnosis (46.8%) sought care within the six weeks of onset of TB symptoms compared with those who reported an overnight trip outside the district after receiving their TB diagnosis (56.1%) (data not shown).

Figures 11 and 12 show TB care services and gaps experienced by patients in the TB and TB/HIV cohorts by the time of recruitment to the quantitative survey, by level of mobility. It is important to note that patients reported receipt of services up to the time of participation in the quantitative interview. Some services not yet received by the time of the interview may have subsequently been rendered during the course of treatment.

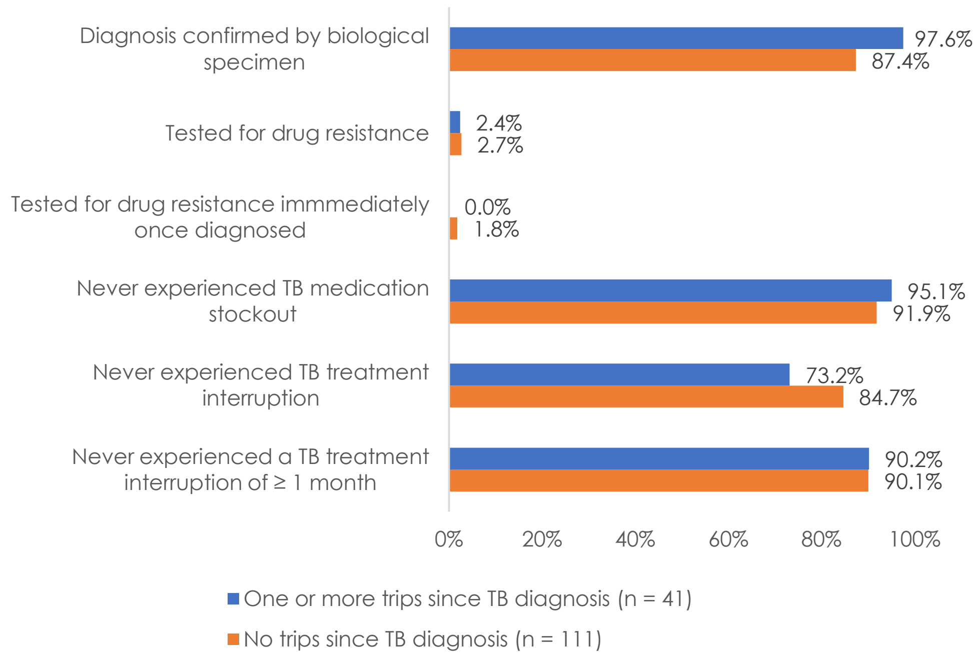
Among patients with TB but not HIV who took an overnight trip outside their home districts, 93.8 percent reported that their TB diagnosis was confirmed by a biological specimen, compared with 89.8 percent of patients who did not take such a trip since TB diagnosis. Of those who traveled outside their home districts overnight since TB diagnosis, 6.3 percent reported that they had been tested for drug resistance by the time of the interview, with 2.1 percent of these more mobile patients reporting that they were tested for drug resistance immediately upon TB diagnosis. Among the TB patients who did not take such trips, 10.2 percent reported drug resistance testing, with 6.1 percent reporting that this testing took place immediately. Among both groups, reports of TB medication stockouts were uncommon, at less than 5 percent. TB treatment interruptions by the time of the interview were uncommon and were reported at similar levels, approximately 12 percent, among TB patients who did and did not spend any nights outside the district of residence. Few patients reported interruptions of one month or longer (Figure 11).

Figure 11. TB care experiences up to the time of interview among patients with TB (but not HIV), among those who did and did not take overnight trips outside their home districts since TB diagnosis



Most patients with TB and HIV had their diagnosis confirmed by biological specimen (97.6% of those who traveled outside their home districts after diagnosis and 87.4% of those who did not travel). Less than 3 percent of TB/HIV patients reported that they had been tested for drug resistance by the time of the interview. TB medication stockouts were reported by 4.9 percent of those who traveled overnight out of their home districts and by 8.1 percent of those who did not. TB treatment interruptions were more common among those who traveled overnight outside their home districts; 84.7 percent of those who had not traveled overnight outside their home districts had never experienced a treatment interruption, and only 73.2 percent of those who had traveled reported that they had never experienced an interruption in their TB treatment. Among TB/HIV patients who did and did not take overnight trips outside their home districts, approximately 10 percent reported a TB treatment interruption of one month or longer (Figure 12). Although 56.1 percent of those who traveled overnight outside their home districts since TB diagnosis were taking co-trimoxazole preventative therapy (CPT), only 43.2 percent of those who did not travel outside their home districts were on CPT (data not shown).

Figure 12. TB care experiences up to the time of interview among patients with TB and HIV, among those who did and did not take overnight trips outside their home districts since TB diagnosis



Qualitative Findings

Healthcare Workers

Healthcare workers reported that when they were aware that a patient on ART intended to travel, they counseled them on adherence, provided them with extra medication, encouraged them to carry their treatment card with their regimen on it, and/or provided a transfer letter. In Kenya and Tanzania, healthcare workers advised patients to visit a nearby facility when traveling if they ran out of medication.

Most healthcare workers reported that they encouraged patients on TB treatment not to travel, especially during the first two months of treatment, but provided additional medication to those who chose to travel. If a patient informed them that they planned to be away for an extended period, the healthcare worker would provide a referral letter and, when possible, coordinated with the facility they were transferring to.

Community Leaders

Community leaders discussed access to healthcare when traveling but also noted issues with health services in their communities. Community leaders highlighted three main barriers to access to services in their communities: transport (lack of transport and/or cost of transport to heath facilities, especially if traveling from an island to the mainland), shortage of healthcare workers, and stockouts of medications, coupled with the high cost of buying medication from a private clinic or pharmacy.

Patients

The majority of patients interviewed about traveling when on ART and/or TB medication reported that they traveled for short periods and took a sufficient supply of medication with them.

5. How strong is the association between mobility and HIV and TB treatment outcomes?

Adherence

Using a visual analog scale, quantitative survey respondents self-reported their medication adherence on a scale of 0 (took none of the prescribed medication that month) to 10 (took all prescribed medication that month). Respondents were asked about adherence to HIV and/or TB medications, as relevant, given their diagnosis.

Respondents who were taking antiretrovirals (ARVs) were asked to self-report their ARV adherence for each of 12 months, from August 2018 to July 2019. Patients were only asked about adherence during months in which they had been prescribed ARVs; therefore, some patients (e.g., those recently diagnosed with HIV) rated adherence for fewer than 12 months. The mean monthly ARV adherence scores were similar across countries, ranging from 9.6 to 9.8 for respondents in the HIV cohort and from 9.6 to 10.0 for respondents in the TB/HIV cohort (Table 21).

Table 21. Mean monthly adherence* to ARVs among patients with HIV and with TB/HIV

Location of facility	HIV			TB/HIV		
	Mean	SE	Person-months	Mean	SE	Person-months
Kenya	9.8	1.0	894	10.0	0.2	163
Tanzania	9.8	0.9	483	9.6	1.4	351
Uganda	9.6	1.3	1455	9.6	1.7	440

*Statistics summarize the mean monthly adherence rating, the SE of the mean, and the total number of person-months over which the mean monthly adherence was calculated.

Respondents who were on TB treatment were asked to self-report their monthly adherence to TB medication for each month of treatment. They were asked to rate their adherence starting with their first month of TB treatment (month 1), up to the month of the interview; therefore, most patients (e.g., those who recently initiated TB treatment) rated adherence for fewer than six months. Overall, the mean monthly TB treatment adherence scores were similar across countries, ranging from 9.4 to 9.9 for respondents in the TB cohort and from 9.3 to 9.7 for respondents in the TB/HIV cohort (Table 22).

Table 22. Mean monthly adherence* to TB medication among patients with TB and with TB/HIV, across all months of treatment

Location of facility	TB			TB/HIV		
	Mean	SE	Person-months	Mean	SE	Person-months
Kenya	9.4	2.3	97	9.3	2.4	86
Tanzania	9.9	0.9	247	9.5	1.6	225
Uganda	9.5	1.7	315	9.7	1.0	342

*Statistics summarize the mean monthly adherence rating, the SE of the mean, and the total number of person-months over which the mean monthly adherence was calculated.

There was little variation in adherence to TB treatment by month of treatment in either cohort. However, there was a slight decline in adherence as treatment progressed in the TB cohort (Table 23).

Table 23. Mean adherence* to TB medication by treatment month among patients with TB and with TB/HIV

Treatment month	TB			TB/HIV		
	Mean	SE	N	Mean	SE	N
Month 1	9.8	1.1	146	9.5	1.9	152
Month 2	9.8	1.3	137	9.7	1.2	136
Month 3	9.7	1.1	115	9.7	1.1	120
Month 4	9.4	2.0	95	9.5	1.7	104
Month 5	9.3	2.1	74	9.8	0.8	70
Month 6	9.4	2.0	57	9.6	1.4	43

*Statistics summarize the mean adherence rating for that month, the SE of the mean, and the number of patients who reported on their adherence during that month of treatment.

TB Treatment Outcomes

Table 24 presents results on TB treatment outcomes. Among the 462 respondents in the TB cohort with no recorded drug resistance, 29.7 percent completed treatment, 10.4 percent were cured, 7.4 percent died, and 0.9 percent failed treatment. More than 31 percent were not evaluated, 4.3 percent were lost to follow-up, and 15.2 percent were still on treatment. Among the 293 respondents in the TB/HIV cohort with no recorded drug resistance, 28.7 percent completed treatment, 12.6 percent were cured, 10.2 percent died, and none failed treatment. Only 6.5 percent were not evaluated, 5.1 percent were lost to follow-up, and 36.2 percent were still on treatment.

Among the eight respondents in the TB cohort with single drug resistance, four completed treatment, two were cured, one was presumed to be still on treatment, and one had an "other" outcome. Among the five respondents in the TB/HIV cohort with single drug resistance, one completed treatment, two were not evaluated, and two were still on treatment. (Table 24).

Among the three respondents in the TB cohort with multidrug resistance, one completed treatment and two were not evaluated. Among the two respondents in the TB/HIV cohort with multidrug resistance, both were presumed to be still on treatment (Table 24).

Drug susceptibility	Treatment outcome	TB (n = 473)		TB/HIV (n = 300)	
		Percentage	N	Percentage	N
Respondents with no recorded drug resistance	Cured	10.4	48	12.6	37
	Treatment completed	29.7	137	28.7	84
	Treatment failed	0.9	4	0.0	0
	Died	7.4	34	10.2	30
	Lost to follow-up	4.3	20	5.1	15
	Not evaluated (includes transfer out and unknown)	31.2	144	6.5	19
	Outcome missing, presumed still on treatment	15.2	70	36.2	106
	Outcome missing, 6 or more months since treatment started	1.1	5	0.7	2
Respondents with single drug resistance (DR TB)	Cured	25.0	2	0.0	0
	Treatment completed	50.0	4	20.0	1
	Not evaluated (includes transfer out and unknown)	0.0	0	40.0	2
	Other	12.5	1		
	Outcome missing, presumed still on treatment	12.5	1	40	2
Respondents with MDR TB	Treatment completed	33.3	1	0.0	0
	Not evaluated (includes transfer out and unknown)	66.7	2	0.0	0
	Outcome missing, presumed still on treatment	0.0	0	100	2

Tracing Survey Results

The study team attempted to trace 91 patients who participated in the quantitative survey, who did not have their TB treatment outcome data recorded in the TB register, and who were approaching or beyond six months since the start of TB treatment. Of the 91, 19 were not reached; among these, two participants were reported to be deceased.

The mean number of facilities visited for TB care during TB treatment was 1.3 among those in the TB cohort and 1.2 among those in the TB/HIV cohort. Ten respondents in the TB cohort reported that they had transferred facilities. Six reported that the reason for the transfer was distance to the facility, three reported that the reason was cost of transport to the facility, and one returned to the facility where he or she had been diagnosed. Ten participants in the TB/HIV cohort also reported transferring facilities. Four reported that the reason for the transfer was distance to the facility, three reported that the reason was cost of transport to the facility, one reported that transport was unavailable or difficult to find, one stated that needed services were not offered, and one stated that drugs were not available at the facility (Table 25).

Table 24. TB treatment outcomes (stratified by TB and HIV/TB)

Respondents who completed the tracing survey also reported on the frequency of travel outside their home districts during TB treatment. Approximately two-thirds of those in the TB cohort reported that they never traveled, 14.7 percent traveled once a month or less, 11.8 traveled two to four times a month, and 3.0 percent traveled two to three times a week. Nearly 60 percent of those in the TB/HIV cohort reported that they never traveled, 18.4 percent traveled once a month or less, 7.9 traveled two to four times a month, 5.3 percent traveled two to three times a week, and 5.3 percent traveled four or more times a week (Table 25).

Respondents who completed the tracing survey also reported their TB treatment outcome. Among those in the TB cohort, 71.9 percent reported that they were still on treatment, 18.8 percent reported that they had completed treatment, and 9.4 percent reported that they were cured. Among those in the TB/HIV cohort, 71.1 percent reported that they were still on treatment, 15.8 percent reported that they had completed treatment, and 10.5 percent reported that they were cured (Table 25).

Table 25. Summary of tracing data for 72 quantitative survey respondents with missing TB treatment outcome data who were successfully traced

	TB (n = 34)		TB/HIV (n = 38)	
	Mean	**SE**	**Mean**	**SE**
Number of facilities visited for TB care during TB treatment	1.3	0.5	1.2	0.5
Among those who transferred facilities at any time, reported reasons for transfer	**Percentage**	**Number**	**Percentage**	**Number**
Cost of transport to the facility	33.3	3	60.0	3
Distance to the facility	66.7	6	80.0	4
Transport unavailable or difficult to use/find	0.0	0	20.0	1
Needed services that were not offered	0.0	0	20.0	1
Drugs not available at facility	0.0	0	20.0	1
Returning to facility of diagnosis	11.1	1	0.0	0
	Mean	**SE**	**Mean**	**SE**
Number of times patient changed residence (to a different district or, in Kenya, sub-county) during TB treatment	0.0	0.2	0.5	1.4
Frequency of travel outside the home district/sub-county during TB treatment	**Percentage**	**Number**	**Percentage**	**Number**
Never	64.7	22	57.9	22
Once a month or less	14.7	5	18.4	7
2 to 4 times per month	11.8	4	7.9	3
2 to 3 times per week	3.0	1	5.3	2
4 or more times per week	0.0	0	5.3	2
Refused	5.9	2	5.3	2
Experienced a TB treatment interruption of 2 or more consecutive months	3.0	1	5.3	2
TB treatment outcome	**Percentage**	**Number**	**Percentage**	**Number**
Cured	9.4	3	10.5	4
Treatment completed	18.8	6	15.8	6
Treatment ongoing	71.9	23	71.1	27
Unsure	0.0	0	2.6	1

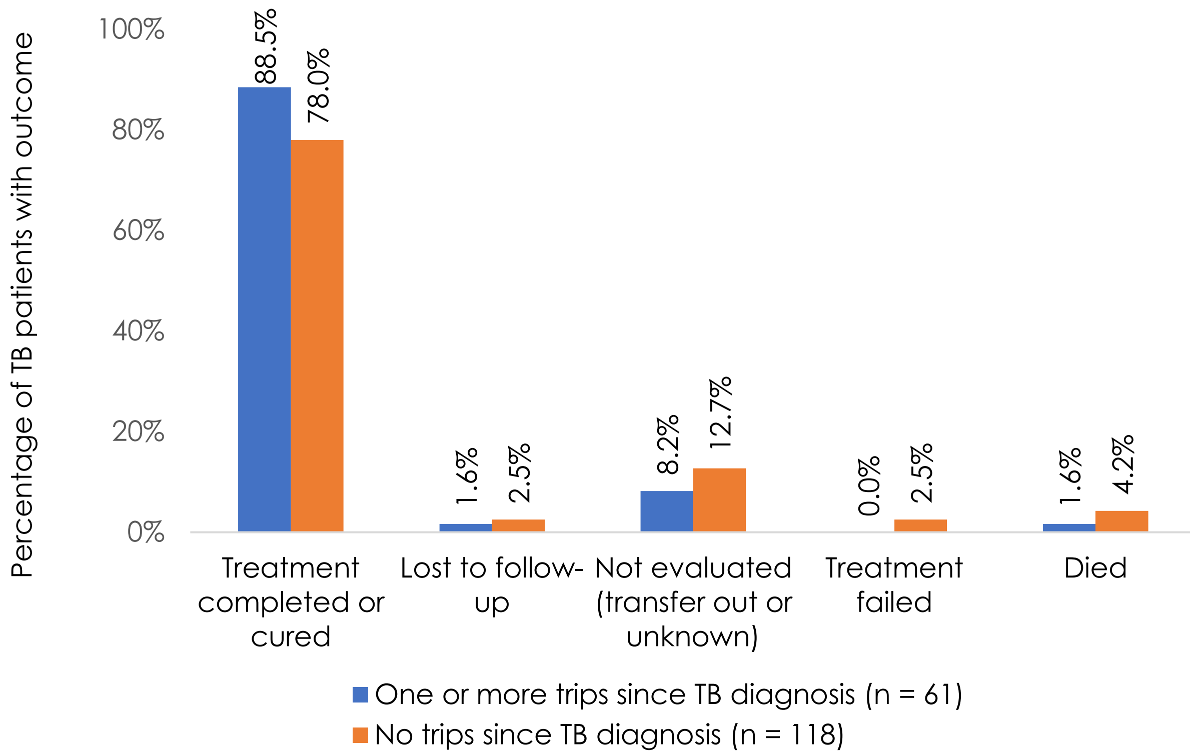
Table 26 presents TB treatment outcomes among TB and TB/HIV patients by level of mobility. Patients in the TB cohort who took overnight trips outside their districts of residence during the time following their TB diagnosis were more likely to have completed their TB treatment or be cured (85.7%) compared with those who did not take such a trip (69.4%). The results were similar among those in the TB/HIV cohort. Patients in the TB/HIV cohort who took overnight trips outside their districts of residence during the time following their TB diagnosis were slightly more likely to have completed their TB treatment or be cured (92.3%) compared with those who did not make such a trip (87.5%) (Table 26).

Table 26. TB treatment outcomes among 97 TB patients and 82 TB/HIV patients participating in the quantitative survey, by mobility level

	Any overnight trips outside the home district since TB diagnosis?			
	Yes (n = 35)		No (n = 62)	
Patients with TB (but not HIV)	**Percentage**	**N**	**Percentage**	**N**
Treatment completed or cured	85.7	30	69.4	43
Lost to follow-up	0.0	0	3.2	2
Not evaluated (transfer out or unknown)	11.4	4	19.4	12
Treatment failed	0.0	0	4.8	3
Died	2.9	1	3.2	2
	Any overnight trips outside the home district since TB diagnosis?			
	Yes (n = 26)		**No (n = 56)**	
Patients with TB/HIV	**Percentage**	**N**	**Percentage**	**N**
Treatment completed or cured	92.3	24	87.5	49
Lost to follow-up	3.8	1	1.8	1
Not evaluated (transfer out or unknown)	3.8	1	5.4	3
Died	0.0	0	5.4	3

Figure 13 summarizes TB treatment outcomes by mobility level across all patients in TB treatment who reported mobility data and had outcomes available at the time of follow-up (n = 179). Treatment completion and cure were more common among patients who reported one or more overnight trips outside their home districts since TB diagnosis (88.5% of those who took a trip were cured or completed treatment, compared with 78.0% of those who did not take such a trip).

Figure 13. TB treatment outcomes among quantitative survey participants on TB treatment (including TB and TB/HIV patients) who did and did not take overnight trips outside their districts of residence since TB diagnosis



The most common reasons patients reported taking trips outside their home districts during the time since their TB diagnosis were to visit family or friends, to work, or to attend a funeral (Table 27).

Table 27. Reasons for overnight trips outside the home districts during TB treatment

Reason for trip	Number of unique trips made for this purpose
To visit family/friends	33
To work/conduct business	24
Burial/funeral	21
To get HIV care	11
To get TB care	10
Other reason(s)	9
Prayers/religious activities	8
To attend to a sick family member	6
Holiday/vacation	5
To look for a new job/work	3

Qualitative Findings

Healthcare Workers

When asked about the implications of travel for HIV and TB patients, healthcare workers reported that travel was linked to poor adherence and loss to follow-up. In turn, they linked poor adherence to both drug resistance and the spread of new infections in the community. As one Uganda healthcare worker explained:

> *If a person moves from other health facilities without a transfer letter and comes here for medication, the first question we will ask them is for their transfer letter. And if you don't have it then we will tell you that we shall help you with medicine for only one month so after that, you can either go back to your health facility and get treatment there or get a transfer letter. And it's so hard for these people to go back to their health facilities...They will always tell you I come from very far please assist me with medicine for one more month yet accounting for such medicine is difficult so we just tell them to go back and get transfer letter. Some will decide to stay without taking any medication...therefore we can see high viral load and drug resistance because these people miss their medication.*— Healthcare worker, Uganda

Community Leaders

When traveling, community leaders in all countries reported that if people living with HIV or TB inform their heath facility, they will generally be given a sufficient supply of medication to take with them. In Kenya and Tanzania, they also noted that people can take their treatment card with them and obtain a refill from a nearby facility. However, in Uganda, the community leaders noted challenges with obtaining refills when traveling, explaining that ART refills can only be accessed at the facility where the patient was registered.

> *With those women on ART care… one may be receiving care from Masaka or Kampala, then when they come here to do work their drugs may not be enough to sustain them for the duration of their stay…but they can't access treatment from here….They refused to give [ART] to me because they budget for the people whom they give drugs to…that means I am suffocating them and one person will be affected because I may be taking his or her drugs.*— Female focus groups participant, Uganda

Another Ugandan community leader noted that the inability to get refills of ARVs at a facility other than where the patient was registered results in some people resorting to retesting and restarting on care as a new client to get ART.

> *[People] take medication with them when traveling but sometimes they take longer than planned and run out. They have to find money to come back to Lujjabwa because you can't get a refill elsewhere. Other option is to retest and restart.* — Female focus groups participant, Uganda

Still others may resort to sharing ART medication, trying to ensure that they were taking the proper regimen by comparing the shape and color of pills and the time they were supposed to be taken.

> *I have traveled and found myself without drugs. I didn't bother going to a nearby facility because I knew they couldn't give me a refill. So I looked for a person who takes the same regimen as mine to assist me with some tablets to last the duration.* — Female focus groups participant, Uganda

Community leaders also commented that stigma causes people to default on their ART or TB medications when traveling. They noted that ARVs were packaged in a tin that was noisy and explained that the sound of the pills in the container when traveling was believed to give away people's HIV status. As a result, people took the pills out of the tin and wrapped them in paper or something similar, and they could be damaged by heat or water.

> *When I have traveled I do not even want someone to hear the drugs making noise. I remove the drugs from the bottle and I put [them] in paper.* — Male focus group participant, Kenya

> *People do not like moving with the drugs due to their packaging… because these drugs shake…[and] they don't want people to know their status and that they are on drugs…especially for TB drugs. Those drugs are put in a big pack and if one moves from here [health facility] holding it, people will start discriminating against him, knowing he has TB…I emphasize this packaging is a big problem.* — Male focus group participant, Uganda

Community leaders also commented that people may travel abruptly for work, for example, if their employer tells them to move to another fishing location. Because most people have not disclosed their status, they do not tell their employer that they need to obtain a refill, and travel without a sufficient supply of medication. The community leaders also noted that it was not uncommon for fisherman to be detained for illegal fishing, sometimes for months, and they lack medication as a result.

Community leaders raised issues that affect adherence to ART and TB medications that were unrelated to travel. They included side effects, not wanting to take medication when one lacked food because it was hard on an empty stomach, and not wanting to disclose one's status to one's spouse and hiding ARVs or keeping them with a friend (and thus not taking them at the proper time or skipping doses).

Patients

Twenty of 62 patients reported defaulting on their ARV or TB medication; all but one defaulted for three days or less. Of the 20 who defaulted, nine were due to travel-related reasons, or being away from home unexpectedly.

Eight (five men and three women) of the 26 patients with HIV (only) reported that they had defaulted. A fisherman reported that he defaulted when he did not take his full tin of ARVs with him on a fishing trip, and the few pills he had brought got wet and were spoiled. Two other fishermen reported that they defaulted for a day when engine problems kept them on the water a day longer than planned. One man reported that he was detained in prison for a week and was told that they had no ARVs to provide him. One woman reported that she had traveled to take care of her sick child and did not have a sufficient supply ARVs with her. Another woman reported defaulting because of lack of food, and one man and one woman reported that they had forgotten to take their ARVs on occasion.

Four of the 14 patients with TB (only) reported defaulting. One man reported that he was stranded away from home for a night. Another man reported that he traveled to an island to fish and defaulted for a full month. Two other men reported that they forgot to take their TB medication for a single day.

Of the 26 patients coinfected with TB and HIV, five reported defaulting on their ART and three reported defaulting on their TB medication. Three women reported defaulting on their ART; one forgot to take her medication, one experienced bad side effects, and one reported that flooding in her community spoiled her medication. Two men defaulted on their HIV medication. One had an unplanned overnight from home and the other was sent to work away from home by his employer and was not comfortable disclosing his HIV status to his employer so he could be given permission to visit a health a facility to obtain a sufficient supply of medication before traveling. Three women reported defaulting on their TB medication because of side effects, lack of food, and failure to refill medication on time, respectively.

6. What is the feasibility and potential public health impact of a regional unique identifier system for people living with HIV, TB, and HIV/TB?

Implementing a system of user-generated UICs is one approach to maintain patient confidentiality while ensuring linkage of health records across study sites. Seventeen questions (or "prompts") that could be used to construct a user-generated UIC were evaluated, as shown in Table 32. Of the 17 prompts, the number of unique values (values reported by one, and only one, respondent) ranged from 0 ("In what month were you born?" and "Are you right- or left-handed?") to 61 ("What are the first two letters of your father's last name?"). Overall, few participants refused to provide answers to prompts; the maximum number of 615 quantitative survey respondents who refused to respond to a given question was four (0.7%). The percentage of respondents who answered, "do not know" to a prompt ranged from 0 ("Are you right- or left-handed?") to more than 23 percent ("In what month were you born?"). Agreement between pre- and post-survey responses to the same prompts was calculated as the percentage of respondents who gave the same answer twice and did not answer "do not know." Agreement ranged from 73.8 percent ("What are the last two letters of your mother's last name?") to 99.4 percent ("Are you right- or left-handed?").

Table 28 presents the results by country. Agreement between pre- and post-survey responses ranged from 68.0 to 99.3 percent in Kenya, from 51.9 percent to 98.9 percent in Tanzania, and from 69.8 percent to 100.0 percent in Uganda.

Table 28. Selected diagnostics and comparison of responses pre- and post-survey for potential prompts used to generate unique identifiers

Prompt	Pre-survey						Post-survey						Agreement
	Unique values*		Do not know		Refusals		Unique values*		Do not know		Refusals		
	n	%	n	%	n	%	n	%	n	%	n	%	%
What are the first two letters of your first name?													
	40	6.5	74	12.0	1	0.2	38	6.2	80	13.0	1	0.2	83.9
What are the last two letters of your first name?													
	53	8.6	81	13.2	2	0.3	50	8.1	84	13.7	1	0.2	79.8
What are the first two letters of your last name?													
	54	8.8	77	12.5	1	0.2	48	7.8	81	13.2	1	0.2	81.0
What are the last two letters of your last name?													
	33	5.4	80	13.0	1	0.2	35	5.7	82	13.3	1	0.2	78.9
In what month were you born?													
	0	0.0	150	24.4	2	0.3	0	0.0	144	23.4	4	0.7	69.1
In what year were you born?													
	7	1.1	1	0.2	2	0.3	6	1.0	0	0.0	2	0.3	95.3
Where do you fall in the birth order in your family?													
	4	0.7	3	0.5	2	0.3	4	0.7	3	0.5	2	0.3	97.6
What are the first two letters of your mother's first name?													
	45	7.3	108	17.6	1	0.2	37	6.0	108	17.6	1	0.2	77.2
What are the last two letters of your mother's first name?													
	46	7.5	112	18.2	1	0.2	43	7.0	114	18.5	1	0.2	74.1
What are the first two letters of your mother's last name?													
	50	8.1	113	18.4	2	0.3	54	8.8	112	18.2	2	0.3	75.8
What are the last two letters of your mother's last name?													
	42	6.8	113	18.4	2	0.3	41	6.7	113	18.4	2	0.3	73.8

Prompt	Pre-survey						Post-survey						Agreement
	Unique values*		Do not know		Refusals		Unique values*		Do not know		Refusals		Agreement
	n	%	n	%	n	%	n	%	n	%	n	%	%
What are the first two letters of your father's first name?													
	53	8.6	101	16.4	3	0.5	47	7.6	101	16.4	3	0.5	76.6
What are the last two letters of your father's first name?													
	52	8.5	103	16.8	3	0.5	51	8.3	102	16.6	2	0.3	74.3
What are the first two letters of your father's last name?													
	57	9.3	104	16.9	3	0.5	61	9.9	105	17.1	2	0.3	75.3
What are the last two letters of your father's last name?													
	34	5.5	108	17.6	3	0.5	33	5.4	105	17.1	2	0.3	74.3
Are you right- or left-handed?													
	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	99.4
What are the first two letters of the district you were born in?													
	29	4.7	83	13.5	2	0.3	24	3.9	76	12.4	2	0.3	81.0

*Unique values are values reported by one, and only one, respondent.

To assess whether the performance of codes varied by participant characteristics or by country, differences in the reliability of potential codes by participant sex and country were examined. As expected, the odds of agreement were significantly lower for UICs 2, 3, 4 and 5 compared with UIC 1. There were no differences in the odds of agreement among males and females. There were significantly lower odds of agreement among participants in Tanzania compared with those in Uganda and Kenya. The percentage agreement between pre- and post-survey responses was lower on most questions among participants in Tanzania compared with those in Uganda and Kenya, and the proportion of participants who responded "do not know" was also much higher in Tanzania (Table 29).

Table 29. Select diagnostics and comparison of responses pre- and post-survey for potential prompts used to generate unique identifiers, by country

Prompt		Pre-survey						Post-survey						Agreement
		Unique values*		Do not know		Refusals		Unique values*		Do not know		Refusals		
	N	n	%	n	%	n	%	n	%	n	%	n	%	%
What are the first two letters of your first name?														
Kenya	153	30	19.6	5	3.3	0	0.0	30	19.6	7	4.6	0	0.0	92.2
Tanzania	187	40	21.4	51	27.3	1	0.5	38	20.3	55	29.4	1	0.5	66.3
Uganda	275	35	12.7	18	6.6	0	0.0	35	12.7	18	6.6	0	0.0	91.3
What are the last two letters of your first name?														
Kenya	153	37	24.2	9	5.9	0	0.0	37	24.2	10	6.5	0	0.0	87.6
Tanzania	187	40	21.4	53	28.3	2	1.1	37	19.8	56	30.0	1	0.5	63.1
Uganda	275	37	13.5	19	6.9	0	0.0	32	11.6	18	6.6	0	0.0	86.9
What are the first two letters of your last name?														
Kenya	153	22	14.4	7	4.6	0	0.0	25	16.3	9	5.9	0	0.0	88.9
Tanzania	187	47	25.1	56	30.0	1	0.5	41	21.9	57	30.5	1	0.5	58.3
Uganda	275	32	11.6	14	5.1	0	0.0	31	11.3	15	5.5	0	0.0	92.0
What are the last two letters of your last name?														
Kenya	153	36	23.5	9	5.9	0	0.0	32	20.9	10	6.5	0	0.0	86.3
Tanzania	187	35	18.7	57	30.5	1	0.5	34	18.2	58	31.0	1	0.5	56.2
Uganda	275	17	6.2	14	5.1	0	0.0	21	7.6	14	5.1	0	0.0	90.2
In what month were you born?														
Kenya	153	1	0.7	35	22.9	1	0.7	0	0.0	30	19.6	2	1.3	68.0
Tanzania	187	1	0.5	39	20.9	1	0.5	1	0.5	43	23.0	1	0.5	69.0
Uganda	275	0	0.0	76	27.6	0	0.0	1	0.3	71	25.8	1	0.4	69.8
In what year were you born?														

Prompt		Pre-survey						Post-survey						Agreement
		Unique values*		Do not know		Refusals		Unique values*		Do not know		Refusals		
	N	n	%	n	%	n	%	n	%	n	%	n	%	%
Kenya	153	13	8.5	0	0.0	0	0.0	12	7.8	0	0.0	0	0.0	95.4
Tanzania	187	13	7.0	0	0.0	1	0.5	12	6.4	0	0.0	0	0.0	96.3
Uganda	275	12	4.4	1	0.4	1	0.4	10	3.6	0	0.0	2	0.7	94.5
Where do you fall in the birth order in your family?														
Kenya	153	2	1.3	1	0.7	0	0.0	2	1.3	1	0.7	0	0.0	99.3
Tanzania	187	5	2.7	1	0.5	1	0.5	5	2.7	1	0.5	1	0.5	95.7
Uganda	275	7	2.5	1	0.4	1	0.4	8	2.9	1	0.4	1	0.4	97.8
What are the first two letters of your mother's first name?														
Kenya	153	23	15.0	10	6.5	0	0.0	25	16.3	10	6.5	0	0.0	91.5
Tanzania	187	33	17.6	58	31.0	1	0.5	33	17.6	58	31.0	1	0.5	62.0
Uganda	275	40	14.5	40	14.6	0	0.0	38	13.8	40	14.6	0	0.0	79.6
What are the last two letters of your mother's first name?														
Kenya	153	22	14.4	13	8.5	0	0.0	24	15.7	13	8.5	0	0.0	87.6
Tanzania	187	25	13.4	59	31.6	1	0.5	22	11.8	59	31.6	1	0.5	58.8
Uganda	275	30	10.9	40	14.6	0	0.0	28	10.2	42	15.3	0	0.0	77.1
What are the first two letters of your mother's last name?														
Kenya	153	28	18.3	14	9.2	0	0.0	28	18.3	13	8.5	0	0.0	85.6
Tanzania	187	42	22.5	69	36.9	2	1.1	49	26.2	68	36.4	2	1.1	53.5
Uganda	275	30	10.9	30	10.9	0	0.0	32	10.9	31	11.3	0	0.0	85.5
What are the last two letters of your mother's last name?														
Kenya	153	26	17.0	13	8.5	0	0.0	29	19.0	13	8.5	0	0.0	86.9
Tanzania	187	37	19.8	68	36.4	2	1.1	33	17.6	67	35.8	2	1.1	51.9
Uganda	275	30	10.9	32	11.6	0	0.0	26	9.5	33	12.0	0	0.0	81.5

Prompt		Pre-survey						Post-survey						Agreement
		Unique values*		Do not know		Refusals		Unique values*		Do not know		Refusals		Agreement
	N	n	%	n	%	n	%	n	%	n	%	n	%	%
What are the first two letters of your father's first name?														
Kenya	153	35	22.9	9	5.9	0	0.0	32	20.9	9	5.9	0	0.0	90.0
Tanzania	187	37	19.8	59	31.6	2	1.1	37	19.8	59	31.6	2	1.1	59.4
Uganda	275	48	17.5	33	12.0	1	0.4	45	16.4	33	12.0	1	0.4	80.4
What are the last two letters of your father's first name?														
Kenya	153	37	24.2	11	7.2	0	0.0	38	24.2	11	7.2	0	0.0	88.9
Tanzania	187	45	24.1	60	32.1	2	1.1	38	24.1	59	31.6	1	0.5	55.6
Uganda	275	32	11.6	32	11.6	1	0.4	35	11.6	32	11.6	1	0.4	78.9
What are the first two letters of your father's last name?														
Kenya	153	29	19.0	12	7.8	0	0.0	30	19.6	12	7.8	0	0.0	88.2
Tanzania	187	50	26.7	62	33.2	3	1.6	43	23.0	63	33.7	2	1.1	55.6
Uganda	275	29	10.5	30	10.9	0	0.0	32	11.6	30	10.9	0	0.0	81.5
What are the last two letters of your father's last name?														
Kenya	153	33	21.6	13	8.5	0	0.0	35	22.9	12	7.8	0	0.0	88.9
Tanzania	187	25	13.4	64	34.2	3	1.6	28	15.0	63	33.7	2	1.1	51.9
Uganda	275	25	9.1	31	11.3	0	0.0	30	10.9	30	10.9	0	0.0	81.5
Are you right- or left-handed?														
Kenya	153	1	0.7	0	0.0	0	0.0	1	0.7	0	0.0	0	0.0	98.7
Tanzania	187	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	98.9
Uganda	275	1	0.4	0	0.0	0	0.0	1	0.4	0	0.0	0	0.0	100.0
What are the first two letters of the district you were born in?														

Prompt		Pre-survey						Post-survey						Agreement
		Unique values*		Do not know		Refusals		Unique values*		Do not know		Refusals		
	N	n	%	n	%	n	%	n	%	n	%	n	%	%
Kenya	153	15	9.8	6	3.9	0	0.0	13	8.5	5	3.3	0	0.0	89.5
Tanzania	187	13	7.0	56	30.0	1	1.1	12	6.4	53	28.3	2	1.1	63.1
Uganda	275	15	5.5	21	7.6	1	0.0	19	6.9	18	6.6	0	0.0	88.4

*Unique values are values reported by one, and only one, respondent.

The five potential UICs generated from the data ranged from six to 14 characters in length (Table 30). The shortest code had the highest agreement between pre- and post-survey responses (92.8%), but only 47.6 percent of the codes generated were truly unique. The longest code had the lowest agreement between pre- and post-survey responses (65.4%), but generated the highest proportion of unique IDs (99.1%). Table 31 presents the five potential codes, by country.

Table 30. Five potential UICs, with examples

UIC	Elements	Example	Length	Unique IDs %*	Agreement %
1	• Are you right- or left-handed? • Where do you fall in the birth order in your family? • In what year were you born?	141981	6	47.6	92.8
2	• Are you right- or left-handed? • Where do you fall in the birth order in your family? • In what year were you born? • What are the first two letters of your first name?	141981ME	8	97.0	78.2
3	• Are you right- or left-handed? • Where do you fall in the birth order in your family? • In what year were you born? • What are the first two letters of your first name? • What are the first two letters of your last name?	141981MECL	10	98.6	73.7
4	• Are you right- or left-handed? • Where do you fall in the birth order in your family? • In what year were you born? • What are the first two letters of your first name? • What are the first two letters of your last name? • What are the first two letters of the district you were born in?	141981MECLKE	12	98.9	68.8
5	• Are you right- or left-handed? • Where do you fall in the birth order in your family? • In what year were you born? • What are the first two letters of your first name? • What are the first two letters of your last name?	141981MECLKEMU	14	99.1	65.4

UIC	Elements	Example	Length	Unique IDs %*	Agreement %
	• What are the first two letters of the district you were born in? • What are the last two letters of your first name?				

*Average of (1) the percentage of identifiers generated from pre-survey responses that were unique; and (2) the percentage of identifiers generated from post-survey responses that were unique.

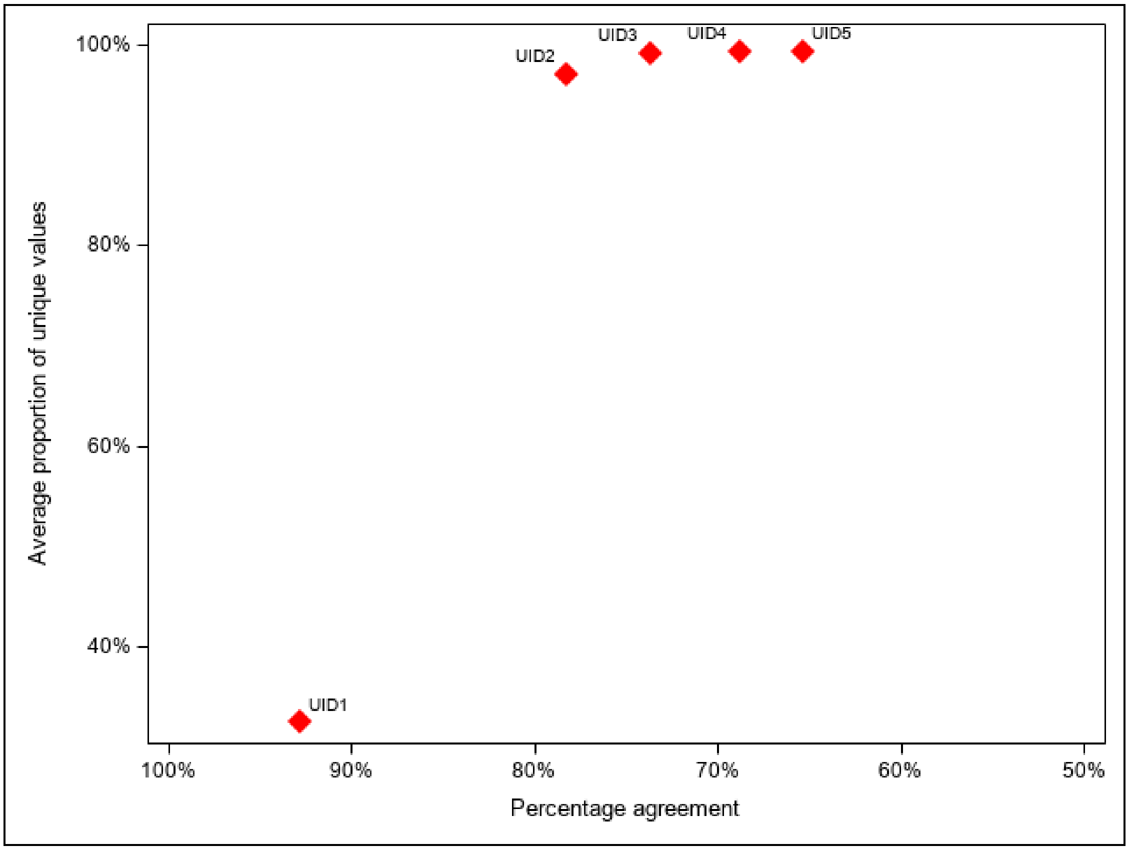
Table 31. Five potential UICs, diagnostics by country

UIC	Unique IDs, %*			Agreement, %		
	Kenya	Tanzania	Uganda	Kenya	Tanzania	Uganda
1	79.9	56.2	65.5	94.1	91.4	93.1
2	100.0	98.1	98.5	86.3	61.0	85.5
3	100.0	99.2	99.3	83.0	50.2	84.4
4	100.0	99.2	100.0	77.8	45.5	79.6
5	100.0	99.2	100.0	75.8	42.2	75.3

*Average of (1) the percentage of identifiers generated from pre-survey responses that were unique; and (2) the percentage of identifiers generated from post-survey responses that were unique.

Figure 14 demonstrates the trade-off between the reliability of a UIC and the proportion of unique values it generates. Codes with fewer elements had higher reliability, but were less likely to generate a high proportion of unique IDs. As additional elements were added, more unique values were generated, but reliability decreased. Even questions with high reliability (>80%), when combined, can yield codes with somewhat lower reliability (<70%), as in the case of UIC 5. The code that performed the best in the sample was UIC 2. Of all the identifiers generated using UIC 2, 97.0 percent were unique. Moreover, the identifiers generated from pre-survey responses agreed with the identifiers generated from post-survey responses for 78.2 percent of participants.

Figure 14. Plot of the percentage of truly unique identifiers versus the percentage agreement between pre- and post-survey responses for five potential unique identifiers



Qualitative Findings

Healthcare Workers

Healthcare workers were asked about the availability of electricity and Internet at their facilities, which would be needed to support an interoperable electronic medical records system and a regional unique identifier. In Kenya, three of six healthcare workers reported that their facility had irregular electricity and no backup generator, including both island-based facilities. A fourth reported that they had a backup generator but fuel for the generator was not always available. Two had electricity and a generator. Three had no Internet services (including both island-based facilities), one had unreliable Internet, and two had reliable Internet. In Tanzania, all four healthcare workers reported that their facility had electricity, a backup generator, and Internet. In Uganda, similar to Kenya, three of six healthcare workers reported that their facility had irregular electricity and no backup generator, including both island-based facilities. The remaining three had electricity and a back-up generator. Three facilities, including both island-based facilities, were reported to have no or weak Internet, and the remaining three had Internet.

Healthcare workers were also asked about their thoughts on a nonbiometric regional unique identifier comprised of prompts. With regard to specific prompts, most healthcare workers felt the easiest for patients to answer would be letters of their own names, year of birth, and birth order. Many concerns were noted about the use of the name prompts with people who were not literate, or were very old with memory/dementia issues. Some also worried that people would not feel comfortable using letters of their parent's name as components, or that they might not know their parents' names if they were not raised by them.

Overall, healthcare workers were enthusiastic about the idea of a regional unique identifier (as part of a regional system of interoperable electronic medical records) because it would allow patients to be tracked from one health facility to another and would also allow healthcare workers access to patient records.

> *If one has a unique identifier it will be easy to learn more about that person and to give her or her treatment without beginning from scratch.* — Healthcare worker, Kalangala Health Centre IV, Uganda

Healthcare workers in Uganda, where it was difficult for existing patients to access HIV services at a facility other than the one where the patient was registered without a transfer letter, felt that a unique identifier system would reduce retesting and double counting of HIV patients.

> *[A unique identifier system] will help avoid duplication in the number of HIV positive clients because you can count one person more than once. That person will leave this place without a referral letter ...and will be tested and started as a new client yet we are also counting that person...but if we have a unique identifier... he will not be considered a new client since all his records will be available in the system.* — Healthcare worker, Kalangala Health Centre IV, Uganda

Patients

Patients with TB and/or HIV were enthusiastic about the concept of a regional unique identifier as part of a system that would enable health facilities across East Africa to access their medical records and provide them with care when they traveled.

> *It can help me if I leave home and go to another shore. I know with that [unique identifier] I can still get treatment…they [other health facility] can recognize it and won't ask me for referral letters.* — Female HIV patient, Kenya

I live at the border of Tanzania and Kenya, therefore this service [unique identifier] will help me improve access to medicine regardless of where I am. For example, if my medicine runs out while I am in Kenya, I can use the code to access medicine while I am in Kenya. — Male HIV patient, Tanzania

If you are getting ART from Kalangala and you go to Mpigi…they will refer you to where you registered from unless you have a transfer letter…The [unique identifier] system will help a lot whereby in case one travels and they become short of medicine they can go to a nearby facility and get ART. — Female TB/HIV patient, Uganda

Patients also felt a regional unique identifier could enhance confidentiality because some patients were uncomfortable traveling with their treatment cards due to stigma.

Not everyone is comfortable carrying [treatment] cards…it [unique identifier] will give much more privacy than having oneself carry documents related to the disease. — Male HIV patient, Kenya

I like the idea [of unique identifier] because it will simplify access to health services and reduce if not eliminate the issue of carrying the treatment card around. — Male HIV patient, Tanzania

Although patients were supportive of the concept of a regional unique identifier, many expressed concerns about the prompts tested in the quantitative survey, noting that letters of names would be challenging for people who were not literate, and that parent's names were not known to some.

Patients were also asked about their willingness to provide their fingerprint as an unique identifier; all but one of the 62 patients readily agreed that they would be willing to do so. Some found the idea of a fingerprint preferable to memorizing a unique code. A concern expressed by a few was whether someone could still collect medication for a patient if a fingerprint was required for identification.

7. Which health facilities serve mobile and migrant populations living with HIV, TB, and HIV/TB?

Respondents in the quantitative survey reported whether they sought healthcare when traveling. Trips with the same origin and destination were counted only once. A total of 239 unique trips were reported by respondents in the HIV cohort. During 8.0 percent of these trips, care was sought at 26 different health facilities. Of the 26 facilities, 30.8 percent were hospitals, 30.8 percent were health centers, and 7.7 percent were dispensaries.

A total of 80 unique trips were reported by respondents in the TB cohort. During 8.8 percent of these trips, care was sought at nine different health facilities. Of the nine facilities, 77.8 percent were hospitals and 22.2 percent were health centers.

A total of 91 unique trips were reported by respondents in the TB/HIV cohort. During 24.2 percent of these trips, care was sought at 22 different health facilities. Of the 22 facilities, 53.1 percent were hospitals, 18.2 percent were health centers, and 4.6 percent were dispensaries (Table 32).

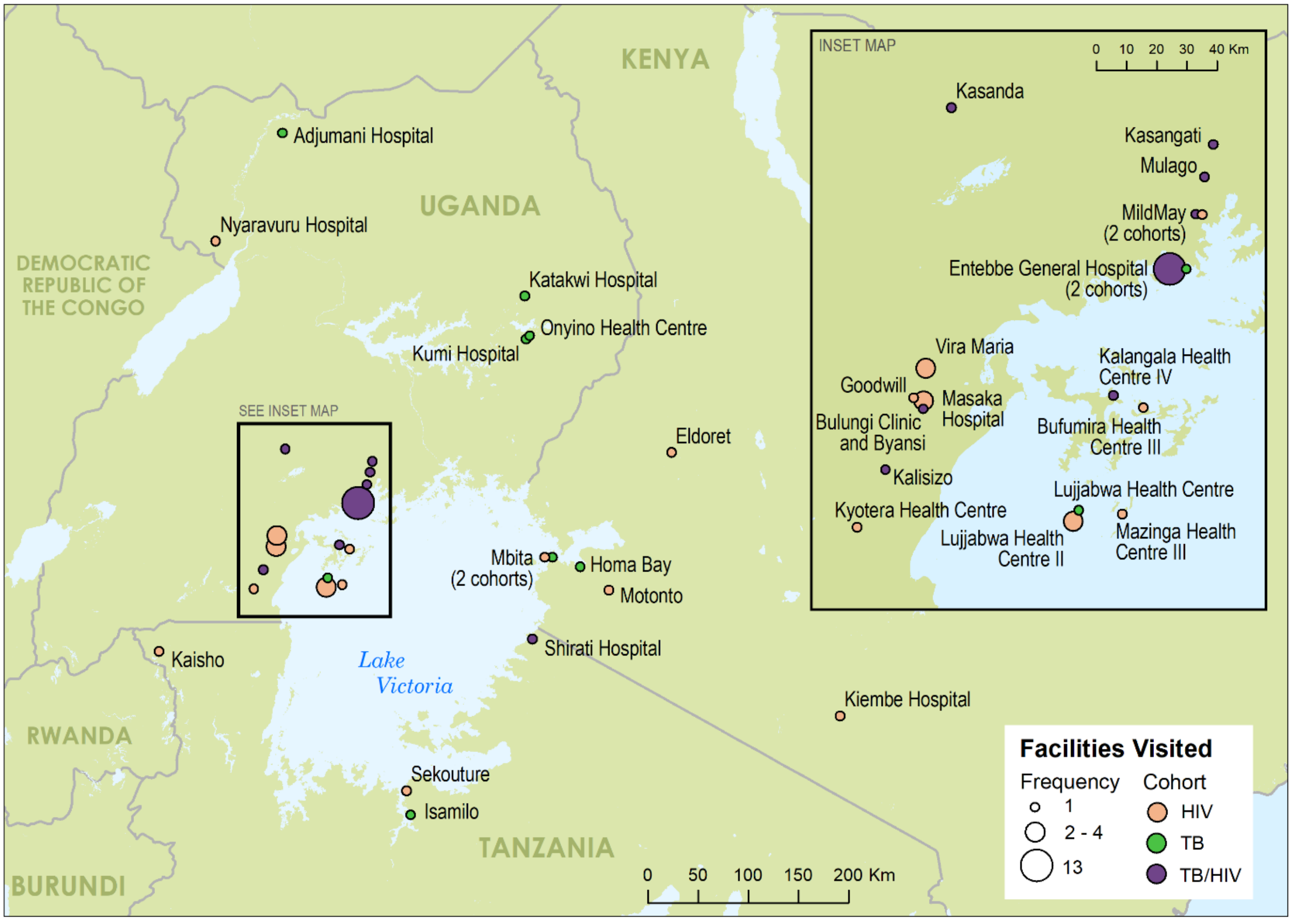
Table 32. Characteristics of care sought at health facilities during trips away from home

	HIV		TB		TB/HIV	
	Number	%	Number	%	Number	%
Total number of unique trips*	239		80		91	
Trips during which respondents sought care from at least one health facility	19	8.0	7	8.8	22	24.2
Total number of facilities at which participants sought care	26		9		22	
Type of facility at which care was sought						
Dispensary	2	7.7	0	0.0	1	4.6
Health center	6	23.1	2	22.2	4	18.2
Hospital	8	30.8	7	77.8	17	53.1
Not sure	8	30.8	0	0.0	0.0	0.0
Other	2	7.8	0	0.0	0.0	0.0

*Trips with the same origin and destination were not counted more than once per person in this metric.

Figure 15 depicts the health facilities at which respondents sought care when traveling and were able to provide the name of the health facility. Respondents in the HIV cohort named 15 facilities at which they sought care. Those in the TB cohort named nine facilities, and those in the TB/HIV cohort also named nine facilities. Entebbe General Hospital was mentioned by the greatest number of respondents (13). Although the facilities were spread throughout Tanzania, Kenya, and Uganda, many were clustered on the northwestern shore and islands of Lake Victoria in Uganda.

Figure 15. Map of health facilities at which respondents sought care when traveling, by cohort and frequency



DISCUSSION

This study describes a set of vulnerable populations living with HIV, TB, or TB and HIV in key areas around Lake Victoria. The selected study sites are areas where people are likely to be mobile due to geography (e.g., need to travel to access services) and occupation (e.g., need to travel for one's job). The study uses an innovative combination of routinely collected clinical data on TB and HIV services, quantitative survey data, and qualitative interview data to paint a comprehensive picture of the challenges and opportunities involved with improving care and treatment for these populations.

In recent years, there have been calls to develop "migration-aware" and "mobility-competent" responses to health (Vearey, 2018). In HIV, current "universal test and treat" strategies may not adequately account for population dynamics associated with the movement of people living with HIV across international and subnational borders. Moreover, the traditional TB treatment model, which requires frequent visits to health facilities, may not optimally serve people who must travel for more than a few days at a time. Although health systems attempt to adapt to such challenges, resource constraints, stigma, and xenophobia hinder HIV and TB programs and interventions in settings with substantial population movement. The findings in this report are intended to inform policies to improve HIV and TB prevention, care, and treatment in the Lake Victoria region and beyond by addressing systemic barriers to positive treatment outcomes.

Summary of Findings in Context

Many Participants Sought Care Outside Their Country of Birth

The characteristics of people enrolling in care for HIV and TB at selected facilities are similar to those among patients seeking care for these conditions at other sites in East Africa. Facility data illustrate that people seeking care for HIV at study sites are predominantly female, and people seeking care for TB are predominantly male. These patterns are similar to those seen among people linking to HIV care in other East African sites (Brown, et al., 2016; Ssemmondo et al., 2016). Moreover, in this study, people enrolling in care for TB tend to be older, on average, than people enrolling in care for HIV, a trend also suggested in other recent studies in East Africa (Ssemmondo et al., 2016).

Recent studies conducted among the general population in East Africa suggest that less than one percent of people are migrants from another country (Camlin, et al., 2018). However, in this study, we find that a not-insignificant proportion of people in care for HIV are enrolled in care in a country other than their birth country (7.5%). The high proportion of people seeking HIV care outside their birth country could reflect a larger than usual population of migrants in the communities of the selected facilities or could be a sign that these communities play host to mobile populations or migrant workers seeking care away from their home countries. Moreover, 4.5 percent of people in care for TB reported being born in a country other than the country where they were recruited for the study. At the very least, these findings indicate that health facilities and health systems are often in a position of providing care to migrants and mobile populations, who may not be counted in estimates used for health system and supply chain planning. Indeed, previous studies have found that, in high incidence settings, in- and out-migration of HIV-infected people slow efforts at population-level ART coverage and viral suppression (Larmerange, et al., 2018).

The proportion of people enrolled in HIV care at a site outside the country where they were born is much higher in Kenya (14.7%) compared with Tanzania (4.9%) or Uganda (3.4%). This discrepancy could be a function of site selection. That is, the communities in the selected Kenyan sites may be more accessible for mobile populations or may have characteristics that make them appealing to migrant workers. Alternatively, this finding could reflect care seeking behavior where mobile populations are more likely to seek care in Kenya than in other countries because of policies or perceived quality of care.

People in Care for TB and HIV Travel

More than one-third of all participants in the quantitative survey took at least one trip outside their home districts (or sub-counties) of residence in the six months before study recruitment, meaning that they are classified as "mobile." The overall proportion traveling outside their home districts falls to under 25 percent after HIV diagnosis, TB diagnosis, or TB/HIV diagnosis; however, this proportion varies dramatically by country, sex, and disease type. Across all categories, people living with HIV are more likely to travel outside their home districts than people living with TB or TB/HIV. Although a substantial number of people in the study travel, the overall proportion is lower than that among participants without TB or HIV in other studies in East Africa (Camlin, et al., 2018). These differences could be due to differences in definitions of mobility (e.g., our definition of "trip" requires that the participant spend at least one night away from home) or barriers to mobility, such as living on an island, that are present in our study but absent from other studies on this topic.

People in care for TB take fewer trips, spend fewer nights away from home, and travel shorter distances than both people living with HIV in this study and people in the general population in East Africa in other studies (Camlin, et al., 2017). This reduced mobility among people in care for TB is not surprising given the demands of TB treatment and the need for frequent visits to the health facility. However, although mobility is reduced among participants with TB, these participants did travel; more than 11 percent of those with TB (but not HIV) report spending at least one night away from their home districts (or sub-counties, in Kenya). People coinfected with TB and HIV are even more mobile, with more than 19 percent reporting at least one night away from their home districts during the study period. Moreover, trips taken by participants enrolled in TB treatment are long, averaging more than eight days. The length of these trips indicates that health facilities serving patients with TB should be prepared to both supply patients with appropriate quantities of medications for longer trips and to educate patients on the importance of notifying their health providers before extended travel.

The qualitative interviews with healthcare workers, patients, and community members, and discussions with key stakeholders, indicate that healthcare workers often view mobile populations as troublesome. There is a tendency for healthcare workers to consider mobile groups as "defaulters" or "lost to follow-up," resulting in refusals to provide care without a transfer letter and an environment that is not welcome to mobile groups. Moreover, providing care to mobile populations without a transfer letter may cause health facilities to miss treatment targets, inflate numbers of "lost to follow-up," and cause treatment shortages (because treatment supply is based on resident populations). Improving care for mobile populations requires addressing such challenges.

The Most Frequent Reason for Travel Was Related to Work

By far the most common reason for travel is to work, conduct business, or look for a new job. This finding contrasts sharply with reports from other settings in East Africa, where only a small fraction reported labor-related travel and nearly one-half of the population reported nonlabor related travel (Camlin, et al., 2019). Although healthcare workers reported that they frequently counsel patients with TB not to travel, the high proportion of trips that are labor-related in this study implies that interventions to reduce mobility among people in treatment for HIV and/or TB may be ineffective.

Mobility Was Not Strongly Associated with Access to Care or Treatment Outcomes

People reporting overnight trips after TB diagnosis do not have substantially different time to TB care, probabilities of biological specimen testing, experiences of medication stockouts, or interruptions in TB treatment compared with people reporting no overnight trips. This finding concurs with previous reports from South Africa in which spending at least one night away from home was not associated with time from symptom onset to seeking TB care (Peterson, 2019). In this study, among both TB and TB/HIV cohorts, reporting any trips outside the patient's home district after TB diagnosis is associated with a slightly increased probability of successful treatment. Recent studies have found that more contact with the health facility and more intensive TB care are not always associated with better outcomes. For example, Pettit, et al. (2019) illustrate that the provision of directly observed treatment is not associated with improved TB treatment outcomes in a large international cohort of people living with HIV in Africa, Asia, and the Americas. Moreover, people likely to do well on treatment (i.e., those with more resources, better access to care, and better prognosis) may be more likely than other people to be mobile. Based on these earlier studies, the absence of an association between mobility and TB treatment outcomes is not surprising.

Although the assessed mobility metric is not strongly associated with access to care or treatment outcomes, participants in both the quantitative and qualitative surveys report barriers to treatment adherence and access to care when traveling. In fact, of the 20 patients who report defaulting on their HIV or TB medications during the qualitative interviews, nearly one-half defaulted for travel-related reasons or being away from home unexpectedly. In the quantitative survey, the top two barriers to HIV and TB treatment adherence are work and travel away from home.

Participants Expressed Enthusiasm for a Regional Unique Identifier

The purpose of creating and applying a UIC system is to allow record linkage across multiple health facilities and to reduce the need to disclose privately identifiable information. The study examines the uniqueness and reliability of user-generated UICs. UICs that use at least five of the prompts examined in this study would be expected to have a high proportion of unique values, meaning that there would be a low chance of two people generating the same code; however, study data indicate that such codes would have low reliability, meaning that patients would not be certain to answer the prompts in such a way as to generate the same code on more than one occasion. The qualitative interviews reveal that participants see the benefits of the unique identifier system, especially if it would allow them to travel without their treatment cards, because they find it stigmatizing to carry the cards. UICs, along with a corresponding system to link health records using the unique identifier, would also reduce the phenomenon of mobile people retesting for TB or HIV to receive care at a new facility when away from home. However, participants are skeptical about the user-generated prompts, noting challenges for those who are not literate, and different cultural conventions about how to define some elements of the prompts. Nearly all participants report willingness to provide fingerprints as a unique identifier. However, when developing UICs to be used at any level, consulting with a wide range of representatives from civil society is critical to ensure that concerns are addressed before implementation (Rice, et al., 2018). Moreover, when multijurisdictional linkages are planned, working with experts in data security is essential to protect against breaches of confidentiality.

Limitations

This study is subject to several limitations. Findings based on quantitative and qualitative interviews are limited to people who returned for care at a selected health facility. This selection presents two issues: (1) people seeking care at the selected health facilities may not be representative of all people living with TB and HIV in the Lake Victoria region; and (2) people who return to care may be systematically different from those who enroll in care and never return. However, based on collaborative discussions with key stakeholders from around the region, we have reason to believe that the selected facilities provide an adequate snapshot of the conditions of health facilities on the shores and islands of Lake Victoria. Moreover, the study recruited people in care for TB and HIV at various times after TB and HIV diagnosis, limiting the potential for selection bias by ensuring that at least some patients early and late in their courses of treatment are included.

Strengths

The TB/HIV mobility study leverages routinely collected longitudinal HIV care and treatment data to develop cohorts of people in care for HIV, TB, and TB/HIV. This broad longitudinal dataset is augmented by rich, cross-sectional survey data on a subset of participants, which provides detailed information about mobility, barriers to seeking care, and behaviors. Moreover, a follow-up tracing study was conducted to complete outcome ascertainment among participants in the quantitative survey. This three-pronged approach to data collection improves data quality, allows triangulation of findings between data sources, and provides a level of detailed information on treatments, follow-up, and individual-level characteristics not found in any one data source alone.

CONCLUSION

A substantial proportion of people living with TB and/or HIV in shore and island communities around Lake Victoria are mobile, with mobility driven largely by work-related factors. Because of economic pressure to travel, efforts to reduce mobility during treatment for TB or HIV may be unsuccessful. Alternative strategies that remove structural barriers to accessing care and medication adherence when away from one's home area may prove more effective. A strategy to implement a regional unique identifier system that would allow access to health records across facilities is one approach that would reduce some barriers to accessing appropriate care and treatment when away from home. However, the optimal unique identifier system should weigh concerns about confidentiality, security, portability, and stigma. User-generated UICs address some, but not all these factors. In this study, we find that longer user-generated UICs are likely to be unique but are unreliable, meaning that they are unlikely to be generated the same way on more than one occasion, limiting their utility.

Regional connectivity stimulates mobility and economic opportunity across East Africa. As connectivity grows, ongoing TB and HIV prevention and treatment efforts can benefit from structural changes to health systems, including a regional, cross-facility linkage of patient records; new strategies for the provision of HIV and TB medications during extended or unexpected travel; and addressing other barriers to accessing health services when away from home. These strategies can improve the continuity of care for people living with HIV and/or TB in East African cross-border regions.

RECOMMENDATIONS

Migrants and mobile populations should be accounted for in health system and supply chain planning to ensure adequate resources to serve these and resident populations.

Health facilities serving patients with TB should be prepared both to supply patients with appropriate quantities of medications for longer trips and to educate patients on the importance of notifying their health providers before extended travel.

Health facilities and health systems should address stigmatization of mobile populations in the health system and improve delivery of services to these populations.

Because most travel among people on TB and/or HIV treatment is economically motivated, interventions should focus on improving services for mobile population rather than reducing mobility among people in treatment.

Given high acceptability of fingerprint-based identifiers among study participants, future studies should explore broad-based acceptability and data security matters surrounding the use of fingerprints in a regional unique identifier system.

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