Implementation and outcomes of an active defaulter tracing system for HIV, prevention of mother to child transmission of HIV (PMTCT), and TB patients in Kibera, Nairobi, Kenya

Kerry A. Thomson [a,*,1], Erastus O. Cheti [a], Tony Reid [b,2]

[a] Médecins Sans Frontières (MSF) Operational Centre Brussels, PO BOX 38897 Postal Code 00623, Parklands, Nairobi, Kenya
[b] Médecins Sans Frontières (MSF) Operational Centre Brussels, rue Dupre 94, Brussels 1090, Belgium

ARTICLE INFO

ABSTRACT

Retention of patients in long term care and adherence to treatment regimens are a constant challenge for HIV, prevention of mother to child transmission of HIV (PMTCT), and TB programmes in sub-Saharan Africa. This study describes the implementation and outcomes of an active defaulter tracing system used to reduce loss to follow-up (LTFU) among HIV, PMTCT, TB, and HIV/TB co-infected patients receiving treatment at three Médecins Sans Frontières clinics in the informal settlement of Kibera, Nairobi, Kenya. Patients are routinely contacted by a social worker via telephone, in-person visit, or both very soon after they miss an appointment. Patient outcomes identified through 1066 tracing activities conducted between 1 April 2008 and 31 March 2009 included: 59.4% returned to the clinic, 9.0% unable to return to clinic, 6.3% died, 4.7% refused to return to clinic, 4.5% went to a different clinic, and 0.8% were hospitalized. Fifteen percent of patients identified for tracing could not be contacted. LTFU among all HIV patients decreased from 21.2% in 2006 to 11.5% in 2009. An active defaulter tracing system is feasible in a resource poor setting, solicits feedback from patients, retains a mobile population of patients in care, and reduces LTFU among HIV, PMTCT, and TB patients.

© 2011 Royal Society of Tropical Medicine and Hygiene. Published by Elsevier Ltd. All rights reserved.

1. Introduction

Patient adherence to antiretroviral therapy (ART) and/or tuberculosis (TB) treatment is paramount to achieving positive clinical outcomes and preventing drug resistance.[1–4] Both retention of patients in long term care and adherence to treatment regimens are challenges that many countries in sub-Saharan Africa face as they scale up ART programmes to effectively manage the human immunodeficiency virus (HIV) as a chronic disease.

Attrition from ART programmes includes loss to follow-up (LTFU), death, and transfer out to other treatment facilities. A 2007 systematic review concluded that ART programmes in sub-Saharan Africa were retaining an average of 62% of patients after two years on treatment, and most attrition (56%) was due to LTFU.[5] An updated systematic review in 2010 showed that average retention at two years had increased to 70%, but the proportion of LTFU also slightly increased to 59%.[6] A 2009 study in Kibera, an urban slum in Nairobi, found that 29% of patients started on ART dropped out of the programme at least once for 90 days or more, and the probability of remaining in the programme at two years was only 65%.[7] Patient retention has also been difficult for prevention of mother to child transmission of

HIV (PMTCT) programmes.[8–11] There is even less literature on the true outcomes of TB defaulters.[12] Documented completion of TB treatment in Africa ranges from 22% to 94%.[5]

Patient tracing is one tool for retaining patients in HIV treatment programmes, and understanding the true outcomes of alleged defaulters.[4,5,13–21] Modes of patient tracing briefly described in other studies include telephone calls, letters, outreach teams and home visits.[4,7,14,16,17,22] Classifying all patients whose vital status (e.g. death, transfer out) is unknown as LTFU contributes to inaccurate conclusions about the effectiveness of a given programme.[23,24] A 2009 systematic review and meta-analysis of 17 point-in-time ART LTFU studies concluded that only 63% of patients could be found to ascertain their vital status, and 46% of patients in African studies had died by the time they were traced.[19]

Existing LTFU studies have been limited to retrospectively examining the true outcomes of an entire ART cohort at one point-in-time months or years after patients actually defaulted.[4–6,16,17,23,25,26] Simple patient monitoring systems and reliably ascertaining true treatment outcomes are two key interventions that Harries et al. recently recommended to reduce LTFU in ART programmes.[27] There is limited literature[28] describing how such systems are routinely operationalised close to the time of a missed appointment, and their impact on the rate of defaulting and determining true outcomes.

The purpose of this operational research study is to describe how a defaulter tracing system is implemented to actively trace HIV, PMTCT, TB, and HIV/TB co-infected patients in the informal settlement of Kibera, Kenya. We describe in detail how patients who missed appointments are traced, and what the outcomes of tracing activities are. Results of tracing activities from one year of implementation are reported.

2. Methods

2.1. Study design

This study was a retrospective, descriptive analysis of routinely-collected programme data.

2.2. Study setting and treatment schedule

Kibera is an informal settlement on the outskirts of Nairobi, Kenya. The exact population of Kibera is unknown, but it is believed to be one of the largest slums in Africa. It is characterized by a large population, impoverished living conditions, and limited infrastructure and services. Kibera residents are a highly transient population. Most move to the slum from rural areas in search of employment, but are forced to return 'up country' when economic opportunities are scarce or when they have family responsibilities.

Since 2003, Médecins Sans Frontières (MSF) Operational Centre Brussels has operated three healthcare clinics within Kibera, two of which are operated in collaboration with the Kenyan Ministry of Public Health and Sanitation. The clinics target previously underserved areas of the slum and offer a free-of-charge and complete HIV, PMTCT, TB, and primary health care package as a 'one stop service' for adults and children.

Patients on ART are most commonly given medication for a 30 day period. Based on adherence, stability, and other logistical considerations, some patients are provided with a 60–90 day supply of ART at the clinician's discretion. Appointments for non-ART patients are scheduled every two to six months, depending on CD4 count and WHO stage. At the time of the current study the PMTCT programme followed the 2006 WHO Guidelines,[29] and provided HAART or dual therapy based on the mother's clinical eligibility. The programme regards a patient who misses one or more scheduled appointment(s) as a potential defaulter. If an HIV patient does not return to the clinic within six months, or if a PMTCT patient does not return within two months they are declared LTFU. Cumulative LTFU among HIV, PMTCT, and HIV/TB co-infected patients from all three clinics was 40% at the end of 2006.

The self administered therapy (SAT) approach is used for initial treatment of TB: a patient reports to the clinic at specified intervals and is given a supply of medication to take at home independently and unobserved. In 2006, 19% of TB patients were categorized as LTFU.

The unique characteristics of our patient population, combined with the high LTFU rates observed in the programmes, led MSF to develop and implement an active defaulter tracing system (Figure 1). The system was piloted from May to December 2007, and officially implemented in January 2008. The current study presents data collected on tracing activities conducted between April 2008 and March 2009.
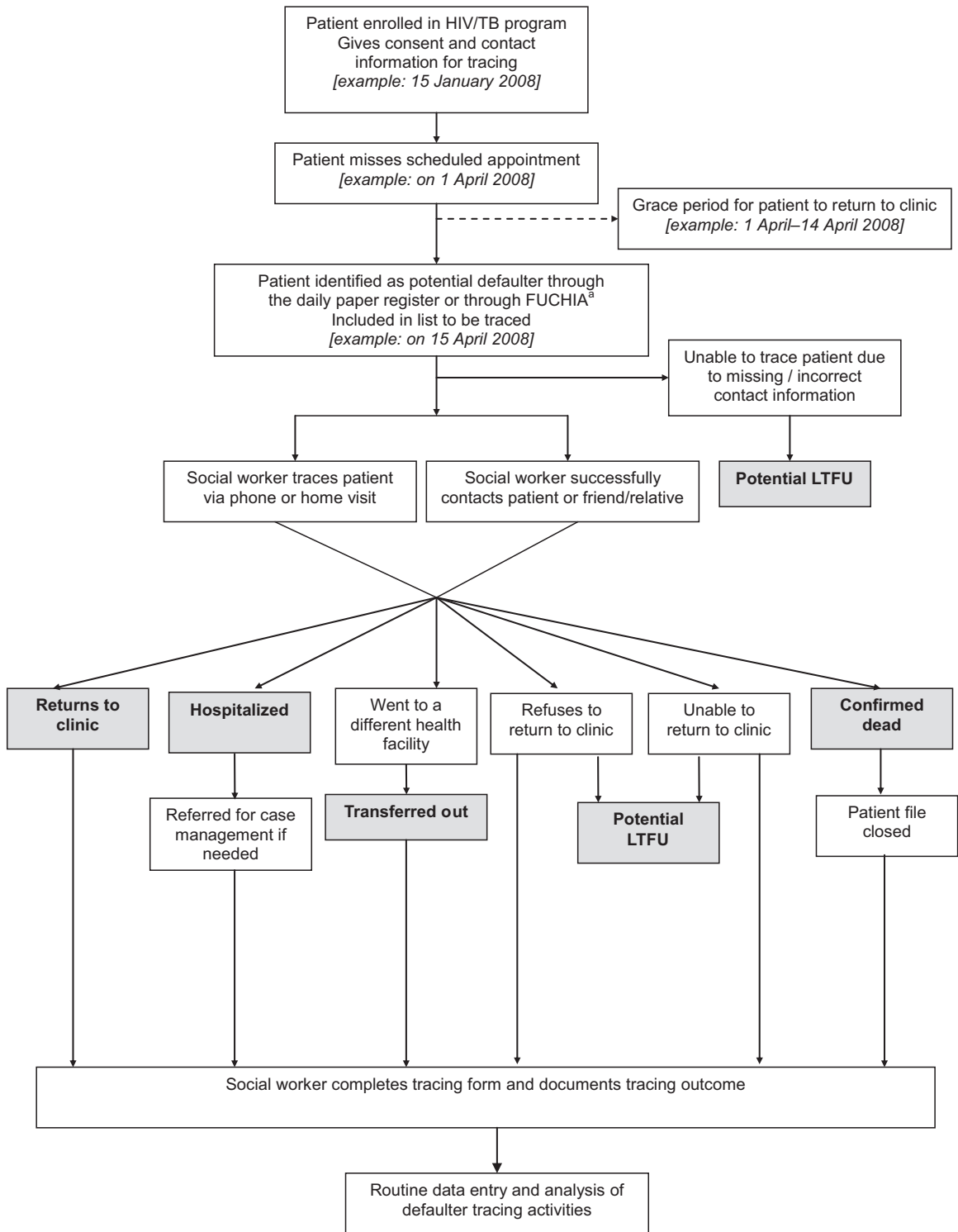
2.3. Defaulter tracing system

2.3.1. Consent for tracing

At the time of enrolment, patients are asked if they are willing to be traced by MSF staff if they miss a scheduled appointment. Patients who consent to be traced are asked to provide personal contact information (e.g., phone number, physical address). They are also asked to identify and provide contact information of a trusted person (e.g., friend or relative) who can be contacted if the patient cannot be reached. If patients do not consent to tracing, they can decline to be traced, decline to give the necessary contact information, or provide erroneous contact information that would make tracing impossible. For patients less than 15 years of age a parent or guardian gives consent for tracing and provides the necessary details. Patients are able to receive care and treatment at all three MSF clinics regardless of whether or not they consent to tracing. If a patient does not consent for tracing the intake worker notes this on the intake form that remains in the patient file. Aggregate data on refusals are not collected; staff continuously report that very few patients refuse to provide contact information for tracing.

2.3.2. Identification of patients to be traced

A multi-pronged approach is used to identify patients who have missed their scheduled appointment. All clinics have a paper-based booking and attendance diary system.

^a Follow-Up and Care of HIV Infection and AIDS database

Figure 1. Illustration of Defaulter Tracing System, Médecins Sans Frontières HIV, TB and PMTCT Program, Kibera, Nairobi, Kenya.

The clinician indicates if a patient has attended the appointment by placing a check mark by their name. The social workers review the diaries daily to identify patients who did not attend their scheduled appointment. Nutritionists maintain a separate attendance diary. Patients who miss a scheduled nutrition appointment (e.g. PMTCT patients receiving formula) are referred to the social workers for tracing. Patients are given a three day grace period to return to the clinic before tracing commences, unless their case is medically urgent.

For monitoring, the clinics use FUCHIA (Follow-Up and Care of HIV Infection and AIDS), an electronic database developed by Epicentre (Paris, France). Data on all HIV, PMTCT and HIV/TB co-infected patients are entered into FUCHIA following each consultation, including their date of next visit. On a weekly basis, the Data Manager generates a list from FUCHIA of patients who have missed their scheduled appointments. It includes patients who missed their appointments two to three weeks prior to the day the list is generated and have not yet returned to the clinic. As a result, in this system, patients are given a grace period ranging from 5 to 14 days depending on where their date of missed appointment falls within the time period for producing the list. The FUCHIA-derived list is forwarded to the social worker at each clinic. Thus, there are two parallel systems for identifying patients who miss appointments. The FUCHIA list serves as a back-up to the paper attendance diaries, to ensure that all patients who miss an appointment are flagged for tracing.

However, the FUCHIA list is not used for patients with TB only because FUCHIA only captures HIV and PMTCT data. Each of the clinics has one or more days dedicated to seeing TB patients. The files for the patients who have a scheduled appointment are pulled and set aside in a designated place at the beginning of the day. Files that remain at the end of the day belong to patients who missed their appointments. The TB nurse then refers these patients to the social workers for immediate tracing. The unique features of TB defaulter tracing have been described previously.[30]

2.3.3. Tracing

Patient tracing is primarily done by the social workers. The project employs one social worker at each clinic and one social work supervisor. The social workers devote the majority of their workday to patient tracing. Case managers (a nurse counselor who closely follows and coordinates care for cases identified as high risk for death or defaulting, e.g., second line ART, malnourished, HIV/TB co-infected patients), and post test club (PTC) members (a group of people who are infected with or affected by HIV and support one another) also trace patients as needed. Active PTC members also assist with various clinic activities such as health education. The first tracing attempt is made via a phone call. Each clinic has a dedicated (mobile) phone for patient tracing. If the patient cannot be reached by mobile phone (e.g., number no longer active or no answer) the social worker will visit the address provided at enrolment. They are de-identified of any MSF uniform or logo and conduct home visits in a discrete fashion. After three unsuccessful attempts to trace the patient the social worker will attempt to contact the trusted individual whom the patient identified at enrolment, first by phone and then in-person.

2.3.4. Data collection

A one page tracing form is completed for each tracing activity by the person doing the tracing. The form includes patient demographic data (e.g. name, age, gender, contact information, type of patient) and tracing information (e.g. date, outcome). Patients are categorized according to the primary type of treatment appointment they missed: (1) HIV Positive and on ART or non-ART, (2) PMTCT mothers and babies, including replacement feeding, (3) HIV/TB co-infected and (4) TB-only infected patients.

Patients can have one of seven final outcomes: (1) confirmed dead, (2) came back to clinic, (3) admitted to hospital, (4) went to another health structure, (5) refused to come back to clinic, (6) unable to come back to clinic and (7) not possible to trace. Patients are only categorized as 'came back to clinic' if they returned to the clinic for care within the timeframe that the patient specified would be feasible. The patients are categorized based on a combination of the reasons they report for missing their appointment, and the professional judgement of the social worker doing the tracing. An individual patient can be traced more than once, and have more than one tracing outcome, in a given time period if they miss more than one scheduled appointment.

Staff attempt to capture relevant details such as the location and reason for a transfer, hospitalization or death. Location and cause of death are collected from a friend/relative if the death occurred at home or from clinic staff at the health facility where the patient died. If the final outcome for a patient is 'refused to come back' or 'unable to come back', staff ask for a reason why. These qualitative responses are recorded on the tracing form.

2.3.5. Data analysis and reporting

Once a tracing activity has a final outcome, the tracing form is sent to the Data Manager for data entry. Data is entered into Epi Info software v 3.2 (Centers for Disease Control and Prevention, Atlanta, GA). Data analysis is performed using a combination of Epi Info v 3.5 and Microsoft Excel® (Microsoft Corp., Redmond, WA, USA). Data from the tracing forms are merged with data exported from the FUCHIA database to explore clinical characteristics of HIV positive and HIV/TB co-infected patients. For the purposes of the current study, two of the study authors independently reviewed the qualitative reasons captured for patients who had the final outcome 'refused to come back' or 'unable to come back' and identified recurring themes.

A report of the defaulter tracing system, and results of tracing activities, is routinely produced for MSF on a quarterly, mid-year and annual basis. The findings are used to inform clinic operations and improve efforts to retain patients in care.

3. Results

A total of 1066 tracing activities were conducted across all three MSF Kibera clinics between 1 April 2008 and 31 March 2009. The majority of tracing (93.2%) was conducted

Table 1

Médecins Sans Frontières HIV, TB and PMTCT Program, Kibera, Nairobi, Kenya: tracing outcomes by type of patient who missed an appointment, April 2008 – March 2009 ($n = 1066$)

Tracing outcome	Total 1066[b] (100.0)	Frequency (%)[a]			
		HIV[c] 633 (59.7)	PMTCT 269 (25.4)	TB 85 (8.0)	HIV/TB Co-infected 74 (7.0)
Returned to clinic	633 (59.4)	379 (59.9)	162 (60.2)	45 (52.9)	44 (59.5)
Refused to return to clinic	50 (4.7)	28 (4.4)	9 (3.3)	8 (9.4)	5 (6.8)
Unable to return to clinic	96 (9.0)	53 (8.4)	31 (11.5)	5 (5.9)	7 (9.5)
Went to a different health facility	48 (4.5)	32 (5.1)	6 (2.2)	6 (7.1)	4 (5.4)
Hospitalized	9 (0.8)	5 (0.8)	2 (0.7)	0 (−)	2 (2.7)
Confirmed dead	67 (6.3)	41 (6.5)	14 (5.2)	5 (5.9)	7 (9.5)
Not possible to trace	163 (15.3)	95 (15.0)	45 (16.7)	16 (18.8)	5 (6.8)

[a] Proportions may not add to 100% exactly due to rounding.
[b] 'Type of patient traced' was not specified for 5 activities.
[c] Includes ART and non-ART patients.

Table 2

Médecins Sans Frontières HIV, TB and PMTCT Program, Kibera, Nairobi, Kenya: all patient outcomes, 2006–2009

	Frequency (%)[a]			
	2006	2007	2008	2009
Total HIV Patients[b]	2971	3369	4389	5398
Active	2108 (71.0)	2544 (75.5)	3492 (79.6)	4399 (81.5)
Loss to follow-up	629 (21.2)	559 (16.6)	539 (12.3)	620 (11.5)
Transferred out	141 (4.7)	169 (5.0)	237 (5.4)	231 (4.3)
Dead	93 (3.1)	97 (2.9)	121 (2.8)	148 (2.7)
Total TB cases[c]	135	359	414	461
Cured / treatment completed	81 (60.0)	221 (61.6)	282 (68.1)	316 (68.5)
Dead	10 (7.4)	21 (5.8)	17 (4.1)	28 (6.1)
Failure	0 (−)	2 (0.6)	2 (0.5)	7 (1.5)
Treatment interrupted/ Loss to follow-up	26 (19.3)	54 (15.0)	66 (15.9)	56 (12.1)
Transferred out	18 (13.3)	61 (17.0)	47 (11.4)	54 (11.7)

[a] Proportions may not add to100% exactly due to rounding.
[b] Includes all HIV, PMTCT, and co-infected patients, and PMTCT infants (HIV negative or HIV not known).
[c] Includes TB only and co-infected patients.

by social workers. In 48.8% of tracing activities the patient could not be reached via phone and staff made an in-person visit, while in 47.7% of cases a phone call was sufficient. In only 4.1% of cases were both phone and in-person visits required to trace a patient. Table 1 presents the tracing outcomes by type of patient who missed an appointment. Of the 1066 tracing activities, 633 (59.7%) were for HIV patients (on ART or not on ART), 269 (25.4%) were for PMTCT or replacement feeding patients, 74 (6.9%) were for HIV/TB co-infected patients, 85 (8.0%) were for TB patients, and for five tracing activities the type of patient was not specified.

Nearly 60% of tracing activities resulted in the patient returning to the clinic. Sixty-seven tracing activities (6.3%) identified patients who had died, 48 (4.5%) who had gone to a different health facility for treatment, and nine (0.8%) who had been hospitalized. Ninety-six patients (9.0%) were unable to come back to the clinic. The two most common barriers these patients reported were increased distance from the clinic as a result of moving or travelling 'up country' or difficulty coming to the clinic due to the schedule and location of their work. Fifty patients (4.7%) refused to come back to the clinic. Qualitative comments made by these patients to the social workers suggest that the patients were in denial of their diagnosis and/or refusing HIV or TB treatment. Fifteen percent of tracing activities did not result in a final outcome; the patient was not possible to trace due

to incomplete, outdated, or erroneous contact information.

Tracing outcomes were similar across the four types of patients. A slightly higher proportion of HIV/TB co-infected patients were confirmed dead (9.5%). A slightly higher proportion of TB patients refused to return (9.4%) or went to a different health facility for treatment (7.1%). Hence, a smaller proportion of TB patients returned to the MSF clinic (52.9%).

Table 2 presents outcome data on all HIV and TB patients who were attending one of the three MSF clinics in Kibera between 2006 and 2009. The proportion of LTFU among all types of HIV and TB patients decreased since the defaulter tracing system was first piloted in May 2007. LTFU among HIV patients steadily decreased from 21.2% in 2006 to 11.5% in 2009, with the largest decrease seen between the end of 2006 and the end of 2007. LTFU among TB patients decreased from 19.3% in 2006 to 12.1% in 2009.

4. Discussion

In response to high LTFU rates for HIV and TB patients in the informal settlement of Kibera, MSF developed an active defaulter tracing system that resulted in a high resumption of appointments by patients, information on the reasons for missed appointments, and accurate and current information on patients' vital status. This was unique because the tracing activities began very soon after the missed

appointments and the majority of patients were successfully contacted.

A tracing outcome was ascertained for almost 85% of patients who missed an appointment. Fifty nine percent of all patients who missed an appointment, and 77% of all patients who were traced and still living returned to the clinic for treatment. Since implementation of this system, LTFU among all patients has decreased, with the most substantial decrease observed among HIV, PMTCT, and HIV/TB co-infected patients. LTFU among these patients is now within the WHO recommendation of <20%.[31] Active tracing provides an opportunity for patients who refuse to return to the clinic, have sought treatment at other facilities, or are unable to return to the clinic to share barriers to seeking care and feedback on care received at MSF facilities. Only 4.7% of patients refused to come back and 4.5% of patients chose to be treated at a health facility other than MSF.

Fifteen percent of patients who missed an appointment could not be traced due to incorrect contact information. Although this is a low proportion compared to point-in-time studies,[4,16,19,25,26] there is still a need to continuously update the current physical addresses, phone numbers, and other contact information of MSF patients, particularly given how mobile the Kibera population is.

Active tracing serves several functions. It is a primary prevention tool, intervening soon after a patient misses an appointment but before they may default entirely. It also contributes to improved care and treatment of HIV and TB patients. Because the system is patient-centred, information gathered during tracing activities enables clinic staff to modify an individual patient's treatment or social support plan immediately based on their unique circumstances and mitigate barriers to clinic attendance. Tracing patients who have been hospitalized facilitates timely follow-up with appropriate clinical and social services. Only 6% of traced patients were reported to have died, a very low proportion compared to previously published literature.[4–6,16,19,22] Routine tracing is especially critical for higher risk patients (e.g., second line ART, multi-drug resistant TB). Kibera was a site of conflict during the post-election violence that followed the disputed Kenyan presidential election in December 2007; the tracing system greatly facilitated the identification of patients and continuation of treatment as soon as possible.[32]

An important feature of the MSF defaulter tracing system is how the data suggest improvements to protocols and project implementation. The system has created an ongoing feedback loop between patients, social workers, clinicians and project staff that fosters discussion of and solutions to the challenges of adherence and retention. The involvement of multiple staff roles (e.g., receptionists, clinicians, social workers, case managers, PTC) has promoted participation in the system at many levels. Detailed categorization of attrition from the program allows MSF to have a more accurate picture of LTFU from HIV, PMTCT and TB cohorts. Without the defaulter tracing system patients who have died or been transferred to other health facilities would be erroneously classified as LTFU.

This study's strengths are that it documented a tracing outcome for 85% of patients, and there was a very low refusal rate to accept tracing as a feature of care or to return to the clinic after tracing. The study was based in a programmatic setting, giving a realistic appraisal of challenges in the field. However, there are some limitations. The data for tracing outcomes is reported by the patient or the trusted contact identified at enrolment. A patient, or their contact, may not feel comfortable disclosing the true reason for a missed appointment. As a result, patients may be misclassified with regard to tracing outcomes. Many factors at the individual, clinic, and community levels can influence attrition and retention of patients in HIV, PMTCT and TB treatment programmes. Although it is reasonable to believe that the implementation of the defaulter tracing system has contributed to the decrease in LTFU from the MSF Kibera Programme, we cannot conclude that it the sole reason. Not all of the 633 patients who returned to the clinic during the study period would have been classified as LTFU without the defaulter tracing system; some would have returned to clinic on their own accord without intervention.

The defaulter tracing system uses financial resources and infrastructure (e.g., staff salaries, mobile phones, computer systems) that may not be available in all public-sector programmes. Electronic medical records (EMR) can expedite patient tracing.[3,14] Although efforts to scale-up EMR are increasing, these systems are not yet widely available. Modifications, such as an entirely paper-based system, could make a similar intervention more feasible in programmes with fewer resources. The system we describe has been institutionalized to prevent defaulting from clinics that operate under a public–private partnership between MSF and the Kenyan Ministry of Public Health and Sanitation. A similar intervention was found to be successful in the public sector in rural Malawi.[28] Rosen and Ketlhapile concluded that piloting patient tracing in public–private clinics in South Africa was costly, but acknowledged that if done routinely the intervention would only increase the cost of ART per patient by <1%.[26]

Despite a challenging urban slum setting and highly mobile population this operational research demonstrated that a defaulter tracing system was feasible for early and vigorous tracing of HIV and TB patients who missed their appointments. Active tracing contributed to a reduction in LTFU, and more accurately attributed reasons for programme attrition.

Cooperation (NORAD) and The Directorate-General for Development Cooperation (DGDC).

Conflicts of Interest: None declared.

Ethical Approval: Ethical approval for this study was obtained from the Ethics Review Board of Médecins Sans Frontières.

References

1. Myer L, El-Sadr W. Expanding access to antiretroviral therapy through the public sector – the challenge of retaining patients in long-term primary care. *S Afr Med J* 2004;**94**:273–4.
2. Mills EJ, Nachega JB, Buchan I, Orbinski J, Attaran A, Singh S, et al. Adherence to antiretroviral therapy in sub-Saharan Africa and North America. *JAMA* 2006;**296**:679–90.
3. Fraser HSF, Allen C, Bailey C, Douglas G, Shin S, Blaya J. Information systems for patient follow-up and chronic management of HIV and tuberculosis: a life-saving technology in resource poor areas. *J Med Internet Res* 2007;**9**:e29.
4. Dalal RP, MacPhail C, Mqhayi M, Wing J, Feldman C, Chersich M, et al. Characteristics and outcomes of adult patients lost to follow-up at an antiretroviral treatment clinic in Johannesburg, South Africa. *J Acquir Immune Defic Syndr* 2008;**47**:101–7.
5. Rosen S, Fox M, Gill C. Patient retention in antiretroviral therapy programs in sub-Saharan Africa: a systematic review. *PLoS Med* 2007;**4**:1691–701, doi:10.1371/journal.pmed.0040298, e298.
6. Fox M, Rosen S. Patient retention in antiretroviral therapy programmes up to three years on treatment in sub-Saharan Africa, 2007-2009: Systematic review. *Trop Med Int Health* 2010;**15**:1–15.
7. Unge C, Södergård B, Ekström AM, Carter J, Marjory W, Ilako F, et al. Challenges for scaling up ART in a resource-limited setting: a retrospective study in Kibera, Kenya. *J Acquir Immune Defic Syndr* 2009;**50**:397–402.
8. Manzi M, Zachariah R, Teck R, Buhendwa L, Kazima J, Bakali E, et al. High acceptability of voluntary counselling and HIV-testing but unacceptable loss to follow up in a prevention of mother-to-child HIV transmission programme in rural Malawi: scaling up requires a different way of acting. *Trop Med Int Health* 2005;**10**:1242–50.
9. Jones SA, Sherman GG, Varga CA. Exploring socio-economic conditions and poor follow up rates of HIV-exposed infants in Johannesburg, South Africa. *AIDS Care* 2005;**17**:466–70.
10. Painter TM, Diaby KL, Matia DM, Lin LS, Sibailly TS, Kouassi MK, et al. Women's reasons for not participating in follow up visits before starting short course antiretroviral prophylaxis for prevention of mother to child transmission of HIV: qualitative interview study. *BMJ* 2004;**329**:543.
11. Ginsburg AS, Hoblitzelle CW, Sripipatana TL, Wilfert CM. Provision of care following prevention of mother-to-child HIV transmission services in resource-limited settings. *AIDS* 2007;**21**:2529–32.
12. Kruyt MI, Kruyt ND, Boeree MJ, Harries AD, Salaniponi FM, Van Noord PA. True status of smear-positive pulmonary tuberculosis defaulters in Malawi. *Bull World Health Organ* 1999;**77**:386–91.
13. Assefa Y, Jerene D, Lulseged S, Ooms G, Van Damme W. Rapid scale-up of antiretroviral treatment in Ethiopia: successes and system-wide effects. *PLoS Med* 2009;**6**:1–4, doi:10.1371/journal.pmed.1000056, e1000056.
14. Forster M, Bailey C, Brinkhof MWG, Graber C, Boulle A, Sphor M, et al. Electronic medical record systems, data quality and loss to follow-up: survey of antiretroviral therapy programmes in resource-limited settings. *Bull World Health Organ* 2008;**86**:939–47.
15. Hedt BL, Wadonda-Kabonda N, Makombe S, Harries AD, Schouten EJ, Limbambala E, et al. Early warning indicators for HIV drug resistance in Malawi. *Antivir Ther* 2008;**13**:69–75.
16. Yu JKL, Chen SCC, Wang KY, Chang CS, Makombe SD, Schouten EJ, et al. True outcomes for patients on antiretroviral therapy who are "lost to follow-up" in Malawi. *Bull World Health Organ* 2007;**85**:550–4.
17. MacPherson P. Mortality and loss to follow-up among HAART initiators in rural South Africa. *Trans R Soc Trop Med Hyg* 2009;**103**:588–93.
18. Zacariah R, Teck R, Buhendwa L, Fitzgerald M, Labana S, Chinji C, et al. Community support is associated with better antiretroviral treatment outcomes in a resource-limited rural district in Malawi. *Trans R Soc Trop Med Hyg* 2005;**101**:79–84.
19. Brinkhof MWG, Pujades-Rodriguez M, Egger M. Mortality of patients lost to follow-up in antiretroviral treatment programmes in resource-limited settings: systematic review and meta-analysis. *PLoS ONE* 2009;**4**:e5790, doi:10.1371/journal.pone.0005790.
20. Van Deventer C, Radebe M. The role of the multidisciplinary team meeting in an antiretroviral treatment programme. *South Afr J HIV Med* 2009;**10**:50–2.
21. Ekouevi DK, Balestre E, Ba-Gomis F-O, Eholie SP, Maiga M, Amani-Bosse C, et al. Low retention of HIV-infected patients on antiretroviral therapy in 11 clinical centres in West Africa. *Trop Med Int Health* 2010;**15**:34–42.
22. Brinkhof MWG, Dabis F, Myer L, Bangsberg DR, Boulle A, Nash D, et al. Early loss of HIV-infected patients on potent antiretroviral therapy programmes in lower-income countries. *Bull World Health Organ* 2008;**86**:559–67.
23. Geng EH, Glidden DV, Emenyonu N, Musinguzi N, Bosco Bwana M, Neilands TB, et al. Tracking a sample of patients lost to follow-up has a major impact on understanding determinants of survival in HIV-infected patients on antiretroviral therapy in Africa. *Trop Med Int Health* 2010;**15**:63–9.
24. Yiannoutsos CT, An M-W, Frangakis CE, Musick BS, Braitstein P, Wools-Kaloustian K, et al. Sampling-based approaches to improve estimation of mortality among patient dropouts: experience from a large PEPFAR-funded programme in western Kenya. *PLoS ONE* 2008;**3**:e3843, doi:10.1371/journal.pone.0003843.
25. McGuire M, Munyenyembe T, Szumillin E, Heinzelman A, Le Paih M, Bouithy N, et al. Vital status of pre-ART and ART patients defaulting from care in rural Malawi. *Trop Med Int Health* 2010;**15**:55–62.
26. Rosen S, Ketlhapile M. Cost of using a patient tracer to reduce loss to follow-up and ascertain patient status in a large antiretroviral therapy programme in Johannesburg, South Africa. *Trop Med Int Health* 2010;**15**:98–104.
27. Harries AD, Zachariah R, Lawn SD, Rosen S. Strategies to improve patient retention on antiretroviral therapy in Sub-Saharan Africa. *Trop Med Int Health* 2010;**15**:70–5.
28. Tweya H, Gareta D, Chagwera F, Ben-Smith A, Mwenyemasi J, Chiputula F, et al. Early active follow-up of patients on antiretroviral therapy (ART) who are lost to follow-up: the "Back-to-Care" project in Lilongwe, Malawi. *Trop Med Int Health* 2010;**15**:82–9.
29. WHO. *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: towards universal access. Recommendations for a public health approach*. Rev ed. Geneva: World Health Organization; 2006.
30. Kizito KW, Dunkley S, Kingori M, Reid T. Lost to follow up from tuberculosis treatment in an urban informal settlement (Kibera), Nairobi, Kenya: what are the rates and determinants? *Trans R Soc Trop Med Hyg* 2011;**105**:52–7.
31. Bennet DE, Bertagnolio S, Sutherland D, Gilks CF. The World Health Organization's Global Strategy for Prevention and Assessment of HIV Drug Resistance. *Antivir Ther* 2008;**13**:1–13.
32. Reid T, van Engelgem I, Telfer B, Manzi M. Providing HIV care in the aftermath of Kenya's post-election violence Medecins Sans Frontieres' lessons learned January-March 2008. *Confl Health* 2008;**2**:15.