

Effectiveness of the treatment advocate strategy in tracking lost to follow up clients on antiretroviral therapy in sauti yetu project within Temeke municipality

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**EFFECTIVENESS OF THE TREATMENT ADVOCATE STRATEGY IN
TRACKING LOST TO FOLLOW UP CLIENTS ON ANTIRETROVIRAL
THERAPY IN SAUTI YETU PROJECT WITHIN TEMEKE
MUNICIPALITY**

By

Joel Elia Mwanga

**A Dissertation Submitted in (Partial) Fulfillment of the Requirements for the Degree
of Master of Science in Project Management, Monitoring and Evaluation in Health of**

**Muhimbili University of Health and Allied Sciences
October, 2019**

CERTIFICATION

The undersigned certify that, they have read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences for a dissertation entitled: *“Effectiveness of the Treatment Advocate Strategy in Tracking Lost to follow up clients on Antiretroviral Therapy in Sauti Yetu Project within Temeke Municipality”*, in (partial) fulfillment of the requirements for the Master of Science in Project Management, Monitoring and Evaluation in Health of Muhimbili University of Health and Allied Sciences.

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Date

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Date

DECLARATION AND COPYRIGHT

I, **Joel Elia Mwanga**, declare that this **dissertation** is my own original work and that it has not been submitted for a similar degree in any other University.

Signature:

Date:

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DEDICATION

This dissertation is dedicated to my parents, the late Mr. Elia Mwanga Sungita and my loving mother Grace Dedu Amasi, who instilled in me the value of education.

ABSTRACT

Background: Despite the efforts in expansion of Antiretroviral Therapy (ART) programs in Tanzania, studies have shown that a large numbers of patients are lost to follow up after ART initiation. Therefore, the National Council of People Living with HIV and AIDS has been implementing Sauti Yetu Project in Temeke Municipality since 2016 to address the lost to follow up challenge through Treatment Advocate strategy.

Objective: To assess the effectiveness of the Treatment Advocate strategy in tracking lost to follow up of clients on ART within Sauti Yetu Project in Temeke Municipality.

Materials and Methods: This was a pre and post intervention comparison research design that used both quantitative and qualitative methods of data collection. An interview guide was used to collect data from Treatment Advocates, Care and Treatment Clinic Staff, and Project staff. The questions in the interview guide focused on facilitating factors and barriers in tracking lost to follow up clients on Antiretroviral Therapy. Quantitative data on the number of ART clients lost to follow up pre and post Treatment Advocate intervention was collected from the DHIS2 database, ART registers and project reports. Data were analyzed descriptively to determine the proportion of lost to follow up before and at the end of the Project. The Standard Normal Deviate test was used to compare proportions. For the qualitative data, content analysis was used to explore facilitating factors and barriers in tracking lost to follow ups.

Results: There was significant decrease in proportion of lost to follow up ART clients from 45.1% before the project to 29.6% after the project. The decrease was statistically significant ($p < 0.001$). The facilitating factors found to influence tracking of lost to follow up clients included provision of follow up transport; support of community leadership; provision of technical support; availability of reporting tools; and adequate knowledge among Treatment Advocates in using reporting tools. However, incorrect client's information recorded; large

area coverage; and inadequate number of staff in the Care and Treatment Clinics were mentioned as barriers in tracking lost to follow up.

Conclusion and Recommendations: Treatment Advocate Strategy has been found to be effective in reducing and tracking lost to follow up clients on Antiretroviral Therapy. Considering the effectiveness of the strategy, it is recommended that relevant authorities should scale up this intervention in other areas.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immuno Deficiency Syndrome
ART	Antiretroviral Therapy
CHWs	Community Health Workers
CTC	Care and Treatment Clinic
GIPA	Great Involvement of People living with HIV
HIV	Human Immunodeficiency Virus
HSA	Health Surveillance Assistants
IMAI	Integrated Management of Adolescent and Adult Illness
IRB	Institutional Review Board
LTFU	Lost to Follow Up
MoHCDGEC	Ministry of Health, Community Development, Gender, Elderly and Children
MUHAS	Muhimbili University of Health and Allied Sciences
NACOPHA	National Council of People Living with HIV and AIDS
PEPFAR	Presidents Emergency Plan for AIDS Relief
PLHAs	People Living with HIV and AIDS
SND	Standard Normal Deviate
TA	Treatment Advocates
TACAIDS	Tanzania Commission for AIDS
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV and AIDS
URT	United Republic of Tanzania
USAID	United States Agency for International Development
WCSA	Women Creative Solutions Association
WHO	World Health Organization

OPERATIONAL DEFINITIONS OF TERMS

Effectiveness is an ability of the Treatment Advocate Strategy to track the lost to follow up clients on ART.

Unknown treatment outcomes include unreported deaths, transfer of care to a different facility without documentation, and disengagement from care (Mcmahon *et al.*, 2013).

Lost To Follow Up: Patients who had failed to attend the ART clinic for more than 12 weeks and who are not known to have died, been transferred to another ART clinic or disengaged from care (WHO, 2010; Kamkuemah *et al.*, 2015).

Patient tracking: Combination of interventions embarked on by treatment advocates to reach patients who dropped from care (NACOPHA, 2016).

Treatment Advocates: PLHAs who were recruited by NACOPHA in the year 2016 through Sauti Yetu Project to track Lost to Follow up Clients on ART (NACOPHA, 2016).

Linked back clients: PLHAs who defaulted from using ART and resumed back following TAs interventions (NACOPHA, 2016).

Tracked clients: Clients with known LTFU outcomes (i.e dead, transferred to other site or defaulted from treatment) (Mcmahon *et al.*, 2013).

A confirmed lost to follow Up: A patient who could not be tracked by Treatment Advocates up to 3 attempts (Kamkuemah *et al.*, 2015).

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Globally, over 36.7 million people were living with HIV and AIDS in 2015 (UNAIDS, 2016). It led to the global move to expand the efforts across the HIV and AIDS treatment cascade, from testing through to Antiretroviral Therapy (ART) adherence and viral load suppression (UNAIDS, 2016). Investing in increased provision of Antiretroviral Treatment has had significant outcomes among patients who are HIV positive (Bartlett and Shao, 2009). However, many ART programs and cohort studies have shown large numbers of patients lost to follow up (LTFU) following ART initiation (Mata *et al.*, 2017). Studies in sub-Saharan Africa have reported high rates of LTFU within 6 months following ART initiation (Brennan *et al.*, 2010; Brinkhof *et al.*, 2008). Therefore, LTFU of HIV-infected patients is an increasing problem in sub-Saharan Africa (Brinkhof *et al.*, 2008). In a systematic review of ART in sub-Saharan Africa, the authors found that up to 40% of patients were LTFU, with large variation in retention rates between programs (Rosen, Fox and Gill, 2007). Furthermore, mortality among patients lost to follow up in sub-Saharan settings has been reported to range from 20% to 87% (Brinkhof, Pujades-rodriguez and Egger, 2009).

Tanzania Mainland has made a significant progress in the fight against HIV epidemic, decreased HIV prevalence rates among adults ages 15 - 49 years from 7.0 percent in 2004 to 4.8 percent in 2017 (URT, 2017). An estimated 1.4 million people are living with HIV and AIDS, with approximately 8.6 percent being under the age of 15 years (URT, 2018). Over two thirds (68.9%) of the estimated 1.4 million PLHA are currently on ART (URT, 2018). However, it was reported that more than half of the patients who received ART in the care and treatment centers in the country were Lost To Follow Up (LTFU) within 3 months of ART initiation (Makunde *et al.*, 2012).

LTFU represents a serious threat to the integrity of scientific evidence guiding the global delivery of ART (Geng *et al.*, 2010). Previous studies indicate issues pertaining to tracking lost to follow up clients on ART including contextual issues such as limited resources and poor information collection practices (Kerry, Erastus and Tony, 2011); inadequate staff and transportation challenges, the vast geographical coverage, inconsistent and sometime unreliable patient locator information, shortage of health workers, organizational challenges, high costs, distance from the hospital and patients migration to other areas (Deribe *et al.*, 2008; Brinkhof, Pujades-rodriguez and Egger, 2009; Rachlis *et al.*, 2015).

In responding to the LTFU challenge in Tanzania, the National Council of People living with HIV and AIDS (NACOPHA) and its partners, Women Creative Solutions Association (WCSA) under Presidents Emergency Plan for AIDS Relief (PEPFAR) has been implementing Sauti Yetu (Literally our voice) Project in Temeke Municipality. It is a four-years Project started in 2016 through 2019 that aims at ensuring greater involvement of People living with HIV (GIPA) in the HIV and AIDS response. This follows the World Health Organization's (WHO) Integrated Approach to HIV Prevention, Care, and Treatment (IMAI) that recommends adoption of PLHA as treatment advocates (TAs) to track patients who have not appeared at the clinic for at least three months (LTFU) through phone calls and home visits (Kwizeera *et al.*, 2017). Among other objectives of the Project is to reduce LTFU by 50% in Temeke Municipality by 2019 through the use of TAs who are PLHAs. However, there has been no study conducted to assess the effectiveness of a Treatment Advocate Strategy in tracking LTFUs since the inception of the Project. Therefore, this study is imperative for the generation of evidence-based recommendation for increasing access and utilization of HIV services through linkages and retention of person on ART for the epidemic control in the Country.

1.2 Problem Statement

The government of Tanzania has made a lot of efforts to improve access and utilization of HIV services through establishment of CTCs with provision of free ART in most of areas in the country. This could be manifested through the significant gain made in the scale-up of ART programs in Tanzania (NACOPHA, 2016). Despite the remarkable investment made by the government in ART programs, yet there has been a problem of LTFU in Care and Treatment Clinics. It has been reported that in facilities with more than 5,000 patients on ART, LTFU is between 25- 40% of the enrolled patients (Beney *et al.*, 2016; NACOPHA, 2016). Additionally, LTFU among PLHAs enrolled in ART in Tanzania, is estimated to be 49% and it varies with duration in ART care (Siril *et al.*, 2017). About 18 and 36% of PLHAs in Tanzania were reported to be LTFU at the end of their first and third year respectively after ART initiation (Siril *et al.*, 2017). It is known that patients lost to follow up are at high risk of mortality and morbidity. So, addressing LTFU challenge contributes to the UNAIDS fast track strategy of reaching the 2nd and 3rd 90 by increasing access and utilization of HIV services through linkages and retention of person on ART for the epidemic control in the Country.

In addressing the challenge of LTFU, NACOPHA embarked into an implementation of Sauti Yetu Project that seeks to reduce LTFU by 50% in Temeke Municipality by December 2019. The project strives to ensure that LTFU clients are tracked and linked back into care through use of Treatment advocates who are PLHAs. However, it is the last year of project implementation and knowledge on the effectiveness of Treatment Advocate Strategy is missing and therefore called for an assessment. Hence, this study assessed the effectiveness of a Treatment Advocate Strategy in Sauti Yetu Project within Temeke Municipality.

1.3 Rationale

It is envisaged that the findings of this study will help in drawing evidence-based lessons emerging over the course of project implementation on the effect of Treatment Advocates in tracking patients on ART. Findings will feed other stakeholders implementing HIV and AIDS programs to plan interventions to roll out similar interventions in Tanzania and also add to the body of knowledge. Furthermore, the study will inform HIV and AIDS response programs that work towards UNAIDS' fast track strategy of reaching the 2nd and 3rd 90 by increasing access and utilization of HIV services through linkages and retention of person on ART for HIV epidemic control in the Country.

1.4 Conceptual Framework

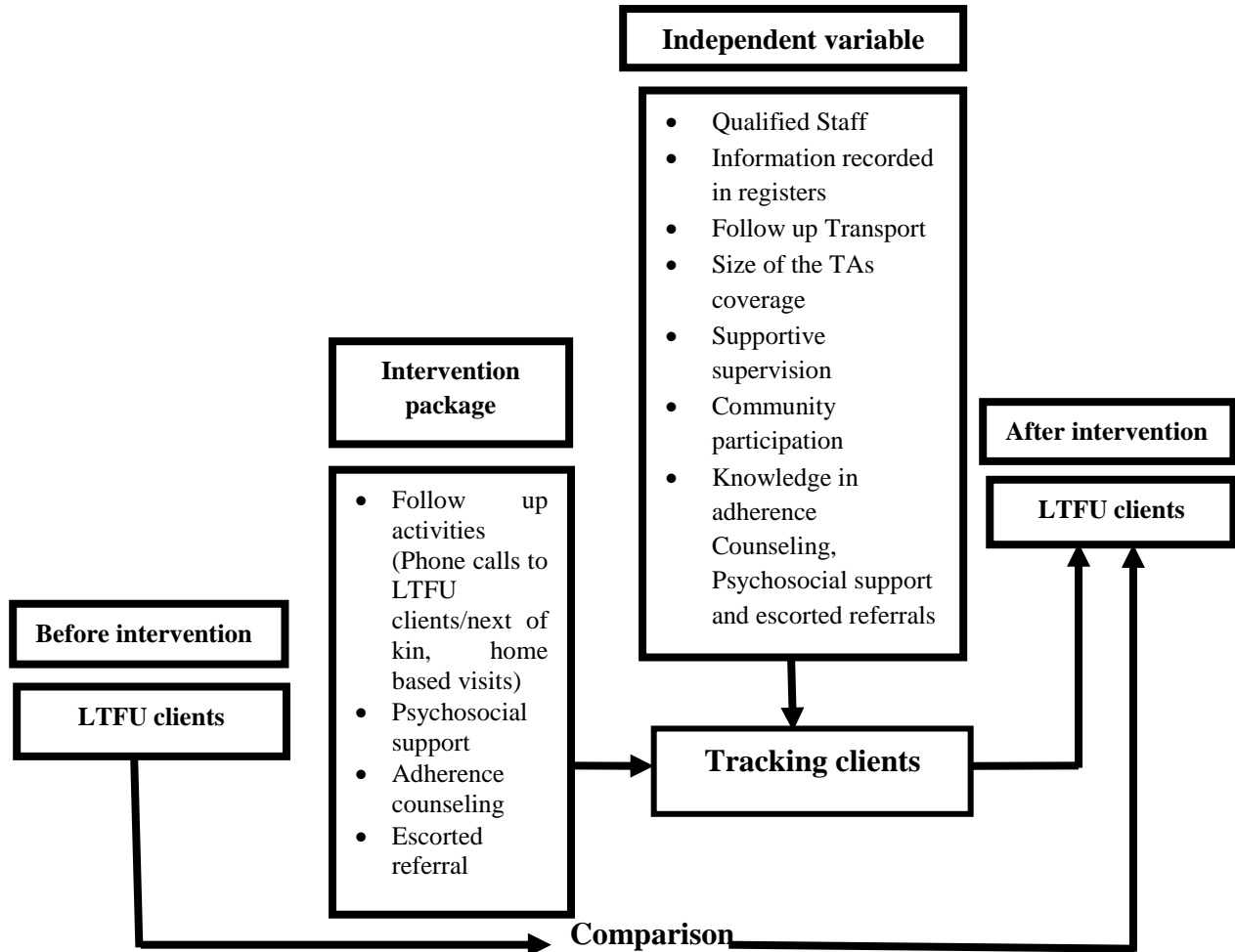


Figure 1: The conceptual framework for assessing the Treatment Advocate Strategy

The conceptual framework guiding this study was adopted and modified from the World Health Organization (WHO). The WHO developed an Integrated Approach to HIV Prevention, Care and Treatment using PLHAs which aims to comprehensively scale up HIV care, treatment and prevention as structured in current health systems. The approach provides a robust blueprint of realizing ambitious scale-up targets of the 2nd and 3rd 90 through integrating simplified clinical management of HIV and AIDS into the routine work of existing

health services with strong community support. PLHA as community health workers, can track patients who have been lost to follow-up; do contact tracing; provide directly observed therapy for ART; do social mobilization and community education on HIV testing and treatment (WHO, 2007). This study modified the approach to relate to the evaluation of the TA Strategy in addressing lost to follow up clients on ART. The modified framework is as presented in Figure 1.

It is shown in figure 1 that proportion of LTFU before Sauti Yetu Project was conceived to be higher compared to after the project. The presented framework shows interventions for tracking LTFU clients on ART including identification of LTFU clients from ART register, making phone calls to LTFU clients or next of kin and ultimately home visit for outcome recording as well as provision of psychosocial support; adherence counseling and referral escort for LTFU clients who are alive to link them back into care and treatment. However, a framework accommodates a set of independent variables that are thought of influencing lost to follow up clients on ART after the project. The independent variables incorporated in this framework include qualified staff, information recorded in registers, follow up transport, size of Treatment Advocate coverage area, supportive supervision, community participation and knowledge in adherence counseling, Psychosocial support and escorted referral. All these independent variables were conceived of having direct effect on Lost to follow up clients after the implementation of Sauti Yetu Project.

1.5 Research questions

1.5.1 Main Research question

What is the effectiveness of a treatment advocate strategy in tracking the lost to follow up clients on Antiretroviral Therapy in Sauti Yetu Project within Temeke Municipality?

1.5.2 Specific Research questions

1. What is the proportion of lost to follow up clients in Sauti Yetu Project Clinics before and after the introduction of the Treatment Advocate Initiative?
2. What is the proportional change in lost to follow up clients following deployment of Treatment Advocates in Sauti Yetu Project within Temeke Municipality?
3. What are the factors affecting the tracking lost to follow up clients in Sauti Yetu Project within Temeke Municipality?
4. What are the barriers in tracking lost to follow up clients in Sauti Project within Temeke Municipality?

1.6 Objectives

1.6.1 Broad Objective

To assess the effectiveness of a treatment advocate strategy in tracking lost to follow up clients on Antiretroviral Therapy in Sauti Yetu Project within Temeke Municipality.

1.6.2 Specific Objectives

1. To determine proportion of lost to follow up clients in Sauti Yetu Project Clinics before and after the introduction of the Treatment Advocate Initiative
2. To compare the proportion of lost to follow up clients before and after the introduction of the treatment advocate initiative
3. To explore factors affecting the tracking of lost to follow up clients in Sauti Yetu Project within Temeke Municipality
4. To explore barriers in tracking lost to follow up clients in Sauti Yetu Project within Temeke Municipality

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Concept of Tracking Lost To Follow Ups

Patient tracking activities have been emphasized in ART programs and the term ‘lost to follow up’ is commonly used for the activities. Lost to follow up is defined as patients who had failed to attend the clinic for more than 12 weeks and who were not known to have died or been transferred to another ART clinic (Nglazi *et al.*, 2010). LTFU is a generic term referring to “patients who initiate ART but who have unknown treatment outcomes. These unknown treatment outcomes may be divided into 3 general categories: unreported deaths, unknown transfer of care to a different facility without documentation, and disengagement from care” (Brinkhof, Pujades-rodriguez and Egger, 2009).

Patient tracking is basically an interplay of various intervention factors that are combined through treatment advocates in reaching patients who have dropped or abandoned care. The aim is to encourage them to return and continue on care and support for their own benefits and/or the benefit of the larger population. A good example of a system that undertakes patient tracking can be observed in HIV/TB program which has an outline of the following procedural steps: First, enrolment of patients into a particular program; second, identification of enrolled patients who have missed scheduled appointment; third, identification of potential LTFU patient based on records kept in daily register; fourth, social worker tracks patient (via phone, home visit); Fifthly, tracking lost to follow up clients (Kerry, Erastus and Tony, 2011).

2.2 Great Involvement of People living with HIV Principle

In the recent past, patient-centered initiatives have begun involving HIV patients in routine care services for the purpose of carrying out tasks that are specific in HIV care and treatment continuum, while at the same time providing awareness and assistance to facilities and home-based HIV services. This principle is known as the Great Involvement of People living with HIV (GIPA) Principle. This principle was adopted and supported by 192 countries, including

Tanzania, who members of the United Nations in 2006 and stood as the Political Declaration of Commitment on HIV and AIDS.

The aim of this principle had been to ensure realization of rights and responsibilities of people living with HIV, such as the right to self-determination and participation in decision-making processes affecting their lives. It is also aiming at advancing quality and effective AIDS response including tracking lost to follow up clients on ART through Treatment roll-out and preparedness. This is to say, People living with HIV support treatment roll-out through educating others on treatment options, side effects, adherence and are also involved as home-based and community health-care workers (UNAIDS, 2007). It has been reported that being People Living with HIV and AIDS (PLHAs), enabled to understand and resolve psychosocial barriers to ART adherence of their peers in the community to an extent that was not obtained during consultations at the health facility (Tenthani *et al.*, 2012). People living with HIV have direct experience of factors that render communities and individuals more vulnerable to HIV infection and have useful knowledge on HIV-related illnesses and strategies relevant for managing them. Therefore, their inclusion in developing and implementing care and treatment programs enhances the relevancy, legitimacy and effectiveness of particular programs (UNAIDS, 2007). Experience has shown that when communities are proactively involved in ensuring their own well-being, success is more likely to happen (NACOPHA, 2016).

The engagement of people living with HIV contributes into scale up of countries' national AIDS responses to achieve the goal of universal access to prevention, treatment, care and support services. This engagement has significant impact at individual level as involvement of people living with HIV improves self-esteem and one's morale (NACOPHA, 2016). Also, that, it decreases possibilities of being isolated and getting depression, as well as improving health by improving accessibility to information on prevention and care. Likewise, in organizations, the involvement of people living with HIV has the potential of changing perceptions and providing valuable knowledge and experiences. It should also be noted that by publically involving people living with HIV at community and social levels may significantly

defeat fear and prejudice through showing their faces and demonstrating that they are people whom can produce and contribute to achieving societal goals despite their conditions. Based on the principle, Sauti Yetu Project contributes to the 3rd 90 by tracking lost to follow up through PLHA peers. These peers are well positioned to address the special needs and issues of fellow PLHAs, their partners, and children through sharing of experiences, best practices for HIV disclosure, medication adherence, sexual risk reduction, and positive living (NACOPHA, 2016).

2.3 Proportion of Lost to Follow up Clients

Retention of patients in long term treatment programs has not given due attention since most large-scale treatment providers have limited resources to trace missing patients. It has been reported that Lost to follow up patients cannot easily be reached out in most of the cases, because patients involved in such situation have decided to be out of care, either voluntarily or involuntarily (Seifu, Ali and Meresa, 2018). However, a number of interventions have been conducted to address the problem of lost to follow up clients on ART in different countries.

A patient tracing program implemented in Trinidad and Tobago to address the problem of Lost to follow up clients on ART has reported that using patient tracing contact methods, trained personnel attempted to contact 1,058 patients lost to follow up (LTFU) within a year (Jeffrey *et al.*, 2019). Of the 1,058 LTFU, 192 were ineligible: 27 (2.5%) were transferred to another clinic, 64 (6%) deceased, 35 (3.3%) hospitalized, 50 (4.7%) migrated and 16 (1.5%) incarcerated. Of the 866 eligible patients for patient tracing, 277 (32%) remained permanently LTFU and 589 (68%) were successfully contacted, re-engaged in care and received adherence counseling. The reported overall incidence rate of loss to follow up in Ethiopia was 14.8% (Seifu, Ali and Meresa, 2018). The finding was found to be lower than studies conducted in other Sub Saharan countries which ranged between 20 - 40% but similar to analogous studies done in Northwest Ethiopia, Bahrdar Feleg Hiwot Hospital and Gonder Referral Hospital which showed that the lost to follow up rate were 8.4, 18 and 19% respectively (Karcher *et al.*, 2007; Ahmed *et al.*, 2013). However, it is reported that there was a progressive decrease in the

incidence of LTFU patients with each year after initiation of ART (Karcher *et al.*, 2007). The incidence of loss to follow up in a study was found to be 85.3, and 50.2% by the end of the 2nd and 5th year respectively. However, this is contrast with other studies finding whereby there is progressive increase in LTFU overtime (Cornelet *et al.*, 2011).

Since Sauti Yetu Project strives to ensure that LTFU clients are tracked and linked back into care through use of Treatment advocates who are PLHAs, the knowledge on the effectiveness of Treatment Advocate strategy was missing and called for an evaluation.

2.4 Factors facilitating the tracking lost to follow up clients

In developing countries, scaling up of ART treatment needs a long-term relationship with patients, accessibility of accurate records of each patient's history, as well as methods relevant for tracking the patient's progress. In fact, those highly influenced by the intervention include lost patients who are alive, can personally be contacted, and not enrolled for care anywhere else. The effect of tracing has been even larger contributing to a rise in probability of return by 22% (Bershetyn *et al.*, 2017). It has been observed that a high percentage of traced patients eventually returned to care thus accounting for positive outcome as an effective intervention to retention toolbox (Armstrong and Rio, 2017).

Better patient tracing procedures, better understanding of Lost to Follow Up and earlier initiation of ART to reduce mortality are needed if retention is to be improved (Rosen and Ketlhapile, 2010). In Brazil, the tracers were provided with lists of lost to follow-up patients. These tracers travelled in public transports or used motorcycles or went on foot depending on the means available to them. After managing to secure contact with patients, tracers would seek from patients' information related to updated care status and reasons causing their non-return. Observation made indicated the use of semi-structured interaction with three to five questions designed for 10-15 minutes duration in soliciting information on current care status and reasons let them to stop or transfer their care. Also, in each of their programs tracers provided routine counseling and encouragement based on standard practices relevant as per

routine tracing which aimed at encouraging patients to return. No financial incentives nor any other kind of inducement was offered (Bershetyn *et al.*, 2017).

2.5 Barriers in tracking lost to follow up clients

Several studies have revealed some issues that impede the implementation of tracking lost to follow up activities. Some have reported contextual issues such as limited resources and poor information collection practices were likely to hamper the patient follow up activities (Kerry, Erastus and Tony, 2011). Additionally, staff and transportation constraints, the vast geographical coverage, inconsistent and sometime unreliable patient locator information, contributes to the failure of tracking patients (Ojwang' *et al.*, 2016). In a study conducted to evaluate TAs role in the health system in the context of HIV and AIDS related services, it was reported that inadequate materials or supplies, absence of necessary equipment for coping with special or harsh weather conditions, unreliable transportation for accessing areas that are troublesome to reach, inconsistency in remuneration, absence of performance-driven rewards, limited mentoring, supervision and support, lack of recognition and inadequate community Participation were some of the factors that affected performance of Treatment Advocates in accomplishing their roles (Jerome and Ivers, 2010).

It was also reported that about 43 percent of TAs in South Africa considered the large number of assigned households a barrier to their work (Suri, Gan and Carpenter, 2007). In spite of increasing numbers of individuals in HIV care and on ART, health worker shortages, organizational challenges and high costs continue to limit the ability of HIV programs to track all patients who are missing or LTFU (Rachlis *et al.*, 2015). In the study conducted in Ethiopia to determine rates and factors associated with defaulting among ART users, several reasons for unsuccessful tracing of 65 (37.6%) cases were identified and reported. These included an incorrect address in the register (61.5%); LTFU clients who lived relatively farer away from the hospital had no telephone access (21.5%). Due to financial limitations, it was challenging to trace such patients; patients had relocated elsewhere (9.2%); those who had their addresses not kept in records (4.6%); or not found during repeated visits (3.1%) (Deribe

et al., 2008). The findings concurred with a study conducted in India which revealed that among the patients who were not found, the reported challenges involved incorrect or missing telephone numbers and addresses (Brinkhof, Pujades-rodriguez and Egger, 2009).

Likewise, in Malawi it was reported that health surveillance assistants (HSAs) and data clerks had several challenging issues in the process of tracing. The challenges included incorrect phones numbers or incorrectly recorded data in tracing forms, or missing phone numbers or addresses (Mchacha, 2017). Confidentiality was also continually mentioned as the challenge among partners that sometimes women were not in one way or the other that their male partners were on ART. Thus, if an HSA would attempt reaching the patient through his number and someone else answered the phone, or if the HAS would directly go to a particular patient's home, then that would present a challenge of disclosing the reason behind the need to speak to the intended patient (Mchacha, 2017).

However, as far as TAs play key role in providing health services in various parts of developing countries, it is important to acknowledge the increasing need for ensuring that these TAs possess necessary knowledge and are competent enough to effectively execute their roles. However, inadequate training leads to poor service quality while knowledge and competency among TAs is acknowledged as central to the success of programs (USAID, 2015).

CHAPTER THREE

3.0 MATERIALS AND METHODS

3.1 Study Design

The study followed a pre and post intervention evaluation research design which adopted quantitative and qualitative data collection methods. The reasons behind this choice were one, to find the change that might be attributed to the intervention. Secondly, the study explored facilitating factors and barriers in tracking lost to follow up clients. Therefore, the nature of the problem required data from both quantitative and qualitative perspective.

3.2 Study Area

Temeke Municipality in Dar es Salaam was chosen as the study area due to the fact that, it is the geographical coverage of Sauti Yetu Project. The District was among the Presidents' Emergency Plan for AIDS Relief (PEPFAR) Tanzania Priority Districts with high prevalence of HIV. It was the area where Sauti Yetu Project was being implemented in accordance with the new PEPFAR principle of doing the right thing, at the right time to the right target population and geographical area. Therefore, choice of the study area was convenient for the evaluation of Treatment Advocate Strategy.

3.3 Study Population

This study targeted personnel involved in the treatment advocacy strategy including Treatment Advocates, Project staff and Care and Treatment Clinic staff in Sauti Yetu Project within Temeke Municipality. The sampling unit was Care and Treatment Clinics where Treatment Advocates reported, and records reviewed.

3.4 Sample Size and Sampling

The qualitative part of the study was guided by the saturation theory which required sample size determined after data collection continued until in analysis nothing new came out of the data. Based on this criterion, 12 participants were obtained following sufficient and depth

information which met the purposes of the research. Therefore, the study interviewed 12 Key Informants

(i.e 7 Treatment Advocates, 4 Care and Treatment Clinics' staff and a Project staff) for Sauti Yetu Project. Sampling of these participants was purposively done based on their role in the project.

All thirty (30) Care and Treatment Clinics in Temeke Municipality were considered for collection of quantitative data on reported PLHIVs in ART Program. These were all Care and Treatment Clinics where the Treatment Advocate Strategy was employed.

3.5 Inclusion and Exclusion criteria

3.5.1 Inclusion Criteria

People living with HIV and AIDS deployed as Treatment advocates and worked on the project for not less than three years within Temeke Municipality under Sauti Yetu Project. Project staff who worked on the project for more than three years from when the Project started were taken on board.

3.5.2 Exclusion Criteria

People living with HIV and AIDS deployed as Treatment advocates but worked on the project for less than three years. Project staff who worked on the Project for less than three years were not considered for the collection of qualitative data. The two populations were not considered in the study due to the fact that they were thought to have less information about the project.

3.6 Data Collection Methods

A combination of quantitative and qualitative data collection methods was used to collect data to inform the specific objectives of this study. The descriptions of the methods were as follows:

3.6.1 Quantitative data collection method

This involved review DHIS2 database, ART registers and quarterly and annual project reports, baseline report and monitoring reports. A checklist was used to guide systematic data collection on the number of ART clients and lost to follow ups.

3.6.2 Qualitative data collection method

A total number of 12 in-depth interviews were conducted. Data were collected by using in-depth interview guide. The questions on the interview guide focused on the facilitating factors and barriers in tracking lost to follow up clients on ART. The interview guide was prepared in English and translated into Kiswahili. The in-depth interviews were conducted in Kiswahili. Participants of the in-depth interview included 7 Treatment Advocates, 1 project staff, and 4 Care and Treatment Clinic staff. One in-depth interview took a maximum of 30 minutes. The Principle Investigator (P.I) and research assistants conducted in-depth interviews. Conducive rooms in Care and Treatment Clinics facilities were secured to provide privacy and free conversations. In-depth interviews were recorded, and notes were also taken.

3.7 Pre- test

In ensuring validity and reliability of data, the investigation tools were pre-tested prior to data collection. The pre-testing tools ensured that collected data were true (valid) and that data were consistent (reliable) (Kothari, 2004). The pre-test exercise was conducted at Vingunguti and Buguruni Care and Treatment Clinics within Ilala Municipality. In-depth interview guides and a checklist were pre-tested to 2 Treatment Advocates, 2 Care and Treatment Clinics' staff and NACOPHA Project staff apart from the Monitoring and Evaluation officer for Sauti Yetu Project. The pre-testing exercise helped to improve on the data collection tools by ensuring the questions are well understood by the respondents and they lead to appropriate responses.

3.8 Data Analysis

i. Quantitative Data

Descriptive analysis was used to determine the proportion of LTFU before and after Sauti Yetu Project. Standard Normal Deviate (SND) statistical test was used to compare proportions of LTFU before and after introduction of the Treatment Initiative. Line graph was used to show the trend in proportion of the LTFU before and after the Project.

ii. Qualitative Data

Content analysis was used to explore facilitating factors and barriers in tracking lost to follow up clients in Sauti Yetu Project. Qualitative data were analysed manually using content analysis. Interviews were transcribed in kiswahili and then translated in English. The transcripts were read and re-read in full to interpret any thoughts in the margin. This involved examining the text closely, line by line, to facilitate a micro analysis of the data. In preparing a codebook in excel, parent nodes were identified from research objectives; child nodes were developed from parent nodes as reflected in already collected data; and description of parent nodes and child nodes were made to give their operational meaning.

3.9 Ethical issues

The ethical clearance was obtained from Muhimbili University of Health and Allied Sciences - Institutional Review Board (IRB). Permission to access DHIS2 database and ART registers for selected facilities at Temeke was given by the Temeke Municipal Director.

A written consent was also sought from the Treatment Advocates, CTC staff and Project staff before they participated in the study. Participants were informed that their participation to the study was voluntary. They were also informed that interviews would be tape recorded and asked to consent being recorded and informed that the recorded information would not be disclosed to anyone else except the researcher. Participants were further informed that no name or other identifying information would be on the record. Participants were further informed that they were free to refuse to answer any question and stop the interview at any time. It was explained that refusal to participate or withdrawal from the study would not involve any penalty. However, the benefit of the study was explained to the participants that the information provided would help to improve access and utilization of HIV services through reduced LTFUs for the epidemic control in the Country. Additionally, the collected information from the DHIS2 database and ART registers were strictly anonymous and confidentiality was assured by not revealing it to any other person.

CHAPTER FOUR

4.0 RESULTS

4.1 Socio-Demographic Characteristics of study populations

The studied population included facility records of 63,105 People Living with HIV and AIDS (PLHIVs) for quantitative part; 7 Treatment Advocates, 4 CTC staff and 1 Project staff for qualitative part. There were a total of 15,517 and 47,588 PLHIVs recorded in DHIS2 database, ART registers and Project reports for the periods of 2015 and 2018, respectively. About 9,714 (62.6%) and 32,110 (67.5%) of the total PLHIVs recorded for the periods of 2015 and 2018 respectively were females. As figure 2 depicts groups included percentages of persons who were on the 1st and 2nd line regimen during the end of respective year.

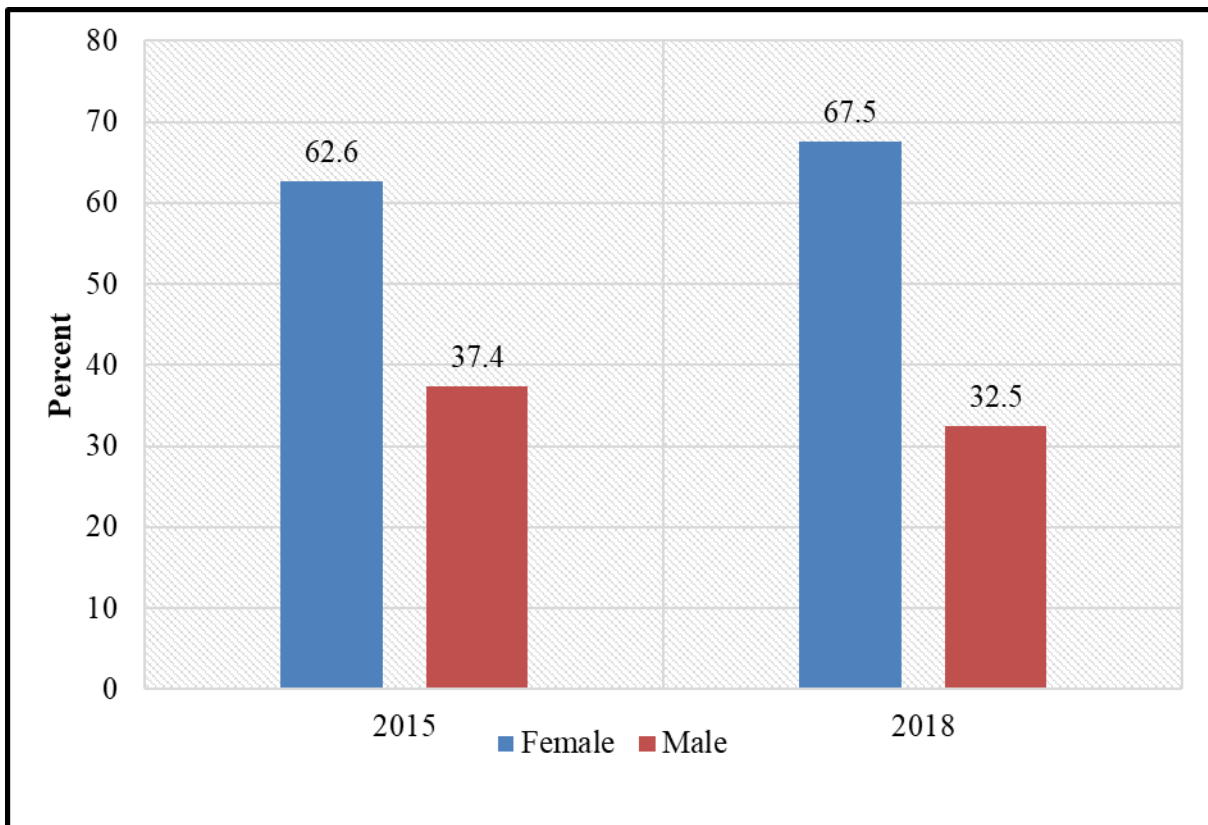


Figure 2: Sex distribution of ART clients for the period of 2015 and 2018 years

4.2 Population of Treatment Advocates

Among seven (7) Treatment Advocates (TAs) who were obtained through the saturation theory for qualitative part, about 4 (57.1%) were females. The age of the TAs ranged from 29 to 48 years. However, about 57.7% among 7TAs were at the age between 43 years and above. The mean age for all 7TAs was 39.6 ± 5.18 years. In terms of education, the study findings revealed that about 42.8% had attained Primary education. However, in terms of occupations, about 57.1% were not employed while 28.6% were self-employed. The socio-demographic characteristics of the TAs are shown in Table 1.

Table 1: Socio-Demographic Characteristics of Treatment Advocates

Variable	Frequency	Percent
	N	%
Sex		
Male	3	42.9
Female	4	57.1
Age category		
Between 29 - 35 years	1	14.3
Between 36 - 42 years	2	28.6
Between 43 - 48 years	4	57.1
Education		
Illiterate	2	28.6
Primary School	3	42.8
Secondary School	2	28.6
Occupation		
Not employed	4	57.1
Employed	1	14.3
Self employed	2	28.6

4.3 Proportion of Lost to follow up clients

The findings indicated that there were 15,517; and 47,588 clients recorded in DHIS2 database, ART registers and Project reports in 2015 and 2018 respectively. This emanated from the summation of number of persons who were on 1st line regimen during the reporting period (Include Transfer In (TI) on ART) and number of persons who were on 2nd line regimen during the reporting period (Include TI on ART) taken in the months of October to December for periods under assessment. The findings revealed that the number of LTFU clients on ART before the project kept on increasing in quarterly basis i.e 5,943, 6,222, 7,852 and 7,945 while those after the project were decreasing i.e. 21,462, 19,368, 16,989 and 14,086. In summary, the proportions of LTFU obtained from respective quarters are shown in Figure 3.

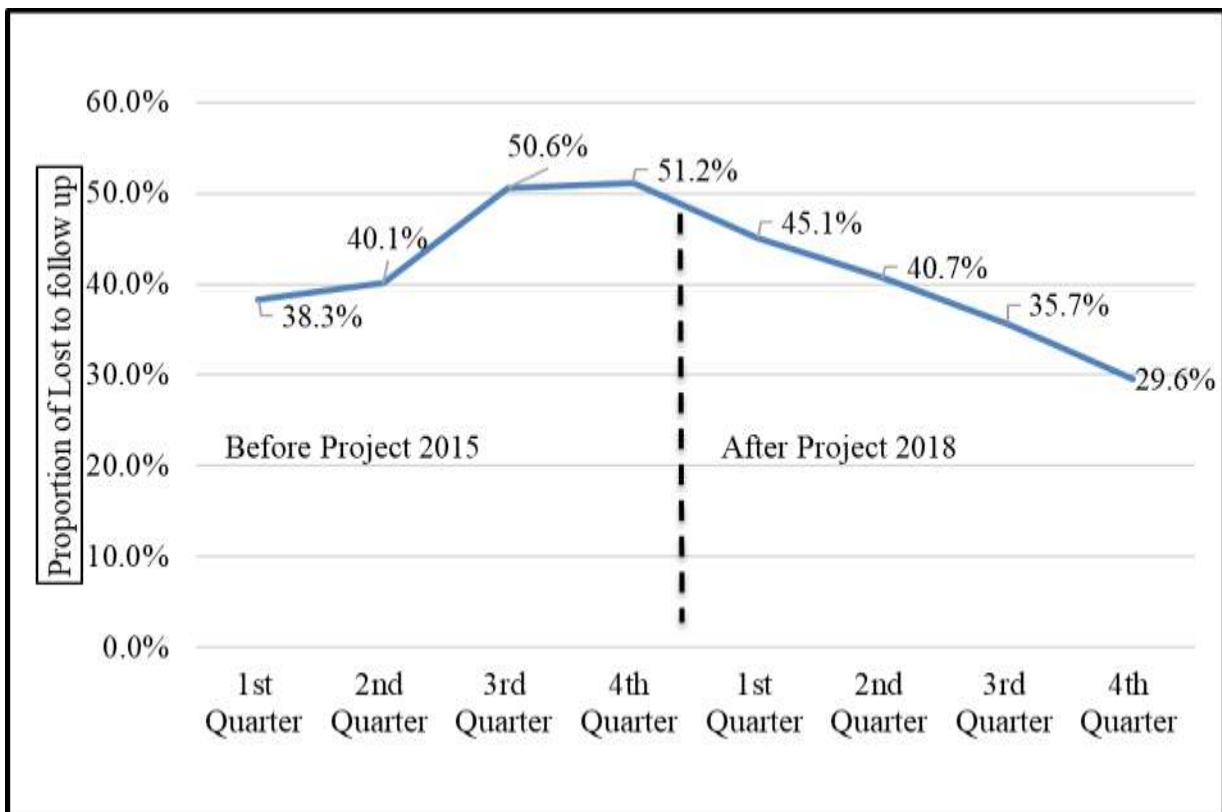


Figure 3: Proportion of lost to follow up for the period of 2015 and 2018 years

4.4 Comparison of Proportion of lost to follow up clients before and after the Project

The findings revealed about 51.2% among 15,517 clients on ART were confirmed to be lost to follow up before the Project. However, about 29.6% among 47,588 clients were confirmed to be lost to follow up after the Project. Therefore, the difference between the two proportions was statistically significant ($p < 0.001$).

4.5 Factors affecting the tracking of lost to follow up clients

A total of 12 respondents were interviewed using in-depth interview guide. This includes 7 Treatment Advocates working in tracking lost to follow up clients on ART, 4 CTC staff working in the clinics where Treatment Advocates report and 1 Project staff who was the Monitoring and Evaluation Officer. This study noted down the factors affecting the tracking of lost to follow up clients on ART. Most factors that were commonly mentioned by Treatment Advocates included the provision of follow up transport; provision of technical support on how to track lost to follow ups; support of community leadership; availability of reporting tools; and adequate knowledge in using reporting tools.

It was reported that provision of follow up transport to Treatment Advocates enabled them to track lost to follow up clients on ART. This response was mentioned by almost all Treatment Advocates. This was observed during in-depth interview with one of the Treatment Advocates who said:

“Sauti Yetu Project provides transport in monthly basis to facilitate tracking exercise. Tracking would have been very difficult if there was no transport support. This could limit movement from one place to another in following my clients” (Female, 37 years).

During an in-depth interview with a CTC staff, it was attested that transport which is one of the incentives for Treatment Advocates has helped a lot to improve tracking of lost to follow up clients in the facility. It has facilitated Treatment Advocates to move from one place to the other in such for lost to follow up clients.

“Tracking has been so much improved in my facility as compared to before Sauti Yetu project. This is attributed to incentives such as monthly allowances that the project provides to the Treatment Advocates. The situation used to be worse before the project. No one bothered to track lost to follow up clients because trackers were not supported financially. It was not easy to use own funds to track clients” (Male, 31 years).

Technical support in tracking lost to follow up clients was noted as another important facilitating factor in tracking lost to follow up. This has been acknowledged by most Treatment Advocates as one of the factors that improved their skills in tracking clients. The technical support embarked into capacity building activities whereby Treatment Advocates were trained on how best to provide counseling sessions among tracked lost to follow up clients in order to reduce the problem of self-stigma.

“We are very much privileged when it comes to assistance for technical support in tracking lost to follow up clients. The organization has been providing us with very useful and beneficial trainings, the most recent one was the one that was carried out in Masasi Mtwara where we were provided training on how to accept our HIV status as this is among the crucial element as a Treatment Advocate. We were also taught how we can systematically track clients who were lost to follow up, for sure it was an awesome training experience” (Male, 43 years).

Informants from this study revealed the contribution of Treatment Advocates in facilitating data quality assessment (DQA) exercise. It was reported that Treatments Advocates were very supportive in ensuring availability of source documents; data completeness; timely reporting and data verification exercise. This attributed in strengthening the monitoring and evaluation aspect of ART Program.

“Apart from tracking lost to follow up clients, Treatment Advocates have been very supportive in data quality assessment that we normally do in quarterly basis. Sauti

Yetu Project has empowered them with adequate knowledge especially on ART Program” (Female, 35 years).

Community participation fosters higher levels of motivation and enhances effectiveness of interventions. The study noted support of community leadership as an important factor that helped in tracking lost to follow up clients. This was reported from the in-depth interview with KI at different occasions and places. It was been documented that community leaders in those places where Treatment Advocates visited for performing their roles, were very supportive in the program. One of the key informants during the in-depth interviews said:

“We have been working hand in hand with the community leaders from all levels, they have been extremely supportive. Working with issues related to HIV highly requires collaborations from different stakeholders. You cannot just simply work alone if you want to successfully meet your targets” (Female, 30 years).

Adequate availability of tools is one of the important factors that enable reporting of interventions. Reporting tools helps in documentation of the project deliverables. It has been noted from the study that Treatment advocates were provided with adequate tools that facilitated them to report what they performed. In an interview with Treatment Advocates, he stated:

“The project has provided us with adequate tools for reporting purposes. Without these tools we would have nowhere to write our reports which could limit our performance in tracking lost to follow up clients. With these tools we can report what we do in the field including provided services, referral status of tracked clients, whether a tracked client has agreed to be linked back into care and treatment” (Male, 48 years).

Training is a cornerstone to capacity development. This study has revealed that apart from provision of reporting tools to Treatment Advocates, they have been trained adequately on the indicators for reporting. Skills development in completing reports helps a lot in effective

performance in tracking lost to follow up clients on ART. This echoed in one of the in-depth interviews with KI who claimed:

“We have been equipped with essential training regularly especially on how to use the tool used for data collection, at first we faced some difficulties understanding the proper filling of the tool because it was something new to us, but practice makes perfect, and for sure experience is a good teacher. Through continuous assistance from the organization, we came to adequately master the tool. As for me I have memorized and mastered the tool perfectly” (Female, 29 years).

4.6 Barriers in tracking lost to follow up clients

Despite the efforts to track lost to follow up clients on ART, this study has noted down that there exist barriers that in one way or the other hinder effective performance of Treatment Advocates from tracking lost to follow up clients. The following were some of the barriers; incorrect client’s information; too large coverage; and staff inadequacy at CTCs.

Incorrect client information was the problem that existed in most of CTCs and it has led into a difficult situation in tracking our clients. The mentioned information included incorrect phone number and address. This barrier was noted from in-depth interview with one KI who said:

“There are clients, who are very problematic, imagine some of the clients if they feel that they do not want to be traced when they default, they simply give you wrong information of phone numbers and their residential addresses. This is a big challenge in tracking lost to follow up clients on ART” (Female, 44 years).

A lot of work in tracking lost to follow up clients to bring them to care and treatment was appreciated during the in-depth interviews with Key informants. However, the study revealed that it has been very hectic in tracking individuals whose contact information were not correct.

“I once had a teenage client who was a very beautiful and an innocent young girl. She was 17 years old. At first her trend of visiting the CTC clinic was excellent but after

almost a year or so, she was nowhere to be found. I tirelessly tried to trace her but was not successful, that's when I later discovered that she had given me wrong personal details. I was so disappointed, I just pray wherever she might have gone she is still on medication because some of clients keep changing CTC centres once they find out there is something they hate about the clinic they were previously attending” (Male, 35 years).

Another barrier which was frequently mentioned by most Treatment Advocates included large coverage. It was noted that despite the provision of follow up transport to Treatment Advocates, there is a problem of large area to reach all lost to follow up clients. It was echoed from one of the in-depth interviews with KI who said:

“Working in large coverage is very hectic as it needs a lot of money. For example, there are some places where there are poor roads that can only be reached with a motorbike. Sometimes it costs almost four thousand shillings. This becomes very expensive as it needs a lot of efforts to reach a client” (Male, 42 years).

Staff inadequacy at CTCs was noted as a contributing factor in increasing the number of unrecorded ART clients. They fail to serve and record when overwhelmed with clients. Unavailability of client's information in facilities makes it difficult to track when a need to do so arises. In one of the in-depth interviews with KI, it was said:

“Sometimes client's information in the facility is not recorded. This can be attributed to staff inadequacy. A good example is in our facility that sometimes it happens more than 300 clients are newly initiated on ART and making it difficult to record their respective information in a very huge staff to client's ratio. So once clients whose information is missing in the facility are lost to follow up, it becomes difficult to track them” (Female, 33 years).

CHAPTER FIVE

5.0 DISCUSSION

The study finding revealed that there was an increase of lost to follow up proportion from 38.3% to 51.2% throughout the year before initiation of Sauti Yetu Project. This implies that the efforts which were in place in tracking lost to follow up clients before the project were probably not effective. It was expected that the proportion of lost to follow up clients to decrease instead of increasing. The results on the proportion of lost to follow up clients before the project was found to be higher than studies conducted in other Sub Saharan countries which ranged between 20 - 40% (Karcher *et al.*, 2007; Ahmed *et al.*, 2013). Reasons for higher proportions could be attributed to the presence of ineffective or non- existent strategy in tracking lost to follow up clients on ART. Similar findings were reported in other studies whereby there was a progressive increase in proportion of lost to follow up clients overtime (Cornelet *al.*, 2011).

However, the results of proportion of lost to follow up clients on ART after Sauti Yetu Project indicate that there was a decreased proportion from 45.1 to 29.6 percent. This result implies that majority of clients who were lost to follow up were effectively tracked and that Treatment Advocate Strategy in Sauti Yetu Project was effective in tracking lost to follow up clients. This finding is almost in line to what has been reported in Trinidad and Tobago that there was a progressive decrease in the incidence of LTFU patients after implementation of a patient tracking program in the Country (Jeffrey *et al.*, 2019). Reasons for this similarity might be attributed to the effectiveness of the tracking strategy.

In comparing proportion of lost to follow up clients before and after the Project, the study revealed the significant difference between the two proportions at the value of $p < 0.001$. This is equally important to say, Sauti Yetu Project has contributed a significant change in tracking lost to follow up clients on ART within the visited facilities at Temeke Municipality. The change was likely contributed by the effectiveness of the Project. The proportion of 29.6% is

almost similar to what has been reported in Trinidad and Tobago that about 32% of ART clients remained permanently lost to follow up clients after implementation of a patient tracking program (Jeffrey et al., 2019). The patient tracing program could be the one contributing to this. Similar proportions were reported in studies conducted in other Sub Saharan countries which ranged between 20 - 40% (Karcher et al., 2007; Ahmed et al., 2013).

Responding to the question to identify the factors affecting tracking of lost to follow up clients; the key informants mostly mentioned provision of follow up transport; support of community leadership; provision of technical support; availability of reporting tools; and adequate knowledge in using reporting tools. The facilitating factors were identified by majority as the ones which enabled Treatment Advocates to perform their exercise of tracking lost to follow up clients successfully. In order to improve the effectiveness of the treatment advocates, the project provided them with follow up transport to hasten the tracking role. The finding is also comparable to a study conducted in rural Haiti to evaluate TAs role in the health system in the context of HIV and AIDS related services whereby it was reported that lack of adequate transportation for hard to access areas, inadequate supervision and support and inadequate community participation were some of the factors that affected performance of Treatment Advocates in accomplishing their roles (Jerome and Ivers, 2010). The identified facilitating factors in tracking lost to follow up clients on ART emanated from assessment of Sauti Yetu Project were similar to those reported in rural Haiti (Jerome and Ivers, 2010).

In responding to identification of barriers affecting performance of treatment advocates in tracking lost to follow up clients on ART, the most mentioned barriers included incorrect client's information; too large coverage area making it difficult to reach all lost to follow up clients; and inadequate number of staff at CTCs. These findings are in line to what has been reported in Kenya that staff constraints and the vast geographical coverage contribute to the failure of tracking patients who were lost to follow ups (Ojwang' *et al.*, 2016). These results are also in line to what was reported in a study conducted in South Africa that the large number of assigned households was a barrier to the performance of Treatment Advocates (Suri, Gan and Carpenter, 2007).

Furthermore, the problem of shortage of health workers was among the factors which brought similarity between Sauti Yetu Project and another study conducted in western Kenya that evaluated outcomes related to patients who were lost to follow-up in a large comprehensive care treatment program (Rachlis *et al.*, 2015). It is also in line with the study conducted in Ethiopia to determine rates and factors associated with defaulting among ART users that an incorrect address in the register; no telephone access; and patient's address not on record were among the barriers in tracking lost to follow up clients on ART (Deribe *et al.*, 2008). Similar findings were also reported in a study conducted in India which revealed that among patients not found, telephone numbers and addresses were frequently incorrect or missing (Brinkhof, Pujades-rodriguez and Egger, 2009). Similarly, in Malawi it was reported that data clerks and health surveillance assistants faced a number of challenges during the tracing process, including incorrect phone numbers or addresses been recorded on tracing forms, or missing phone numbers or addresses (Mchacha, 2017). Wrong client's addresses and difficulty in accessing lost to follow up clients through phone calls were the similar factors reported in Sauti Yetu Project and other aforementioned studies conducted in Kenya, Ethiopia, India, Malawi and Kenya (Ojwang' *et al.*, 2016; Suri, Gan and Carpenter, 2007; Rachlis *et al.*, 2015; Deribe *et al.*, 2008; Brinkhof, Pujades-rodriguez and Egger, 2009 & Mchacha, 2017).

5.1 Limitation of the Study

Besides the reported findings, the study faced some limitations including recall bias from interviewing TAs, CTC staff and Project staff as well as missing information in DHIS2 database and ART registers. Respondents were somehow not able to remember the previous data on the number of tracked clients due to the fact that, the time interval been asked about was longer. This clearly predisposed them to recall bias. In addressing this limitation, respondents were asked to refer to their quarterly reports submitted to NACOPHA for the periods under study. However, a limitation of missing information was also mitigated by visiting all implementation reports considered for the study under evaluation. Additionally, despite the fact that respondents consented to participate in the study, they were hesitant to provide some information. They requested to be paid transport and meals allowance during interview session. In addressing this limitation, Research assistants and the Principle Investigator explained to respondents the importance of the study and advised them to talk about real situation so that existing challenges (if any) would be addressed. Furthermore, good understanding of the study helped respondents especially Treatment Advocates to avoid giving a favorable image of themselves.

CHAPTER SIX

6.0 CONCLUSION

There was a significant difference between the proportions of lost to follow up clients on ART before and after the project. The implementation of the Treatment Advocate Strategy is likely to influence significant change in reducing proportions of lost to follow up clients on ART.

Facilitating factors for the tracking of lost to follow up clients in Sauti Yetu Project within Temeke Municipality were the provision of follow up transport; provision of technical support; community leadership support; availability of reporting tools; and adequate knowledge in using reporting tools.

Barriers that hindered tracking of lost to follow up clients on ART included incorrect client's information; too large coverage to reach all lost to follow up clients; and staff inadequacy at CTCs. The aforementioned factors hinder tracking exercise of lost to follow up clients on ART.

6.1 Recommendations

Based on the study findings, the following recommendations are given to facilitate improvement of access to ART services. The recommendations are divided into policy and facility level.

6.1.1 Policy level

- i. Government to adopt Treatment Advocate Strategy in CTCs to reduce the problem of lost to follow up.
- ii. Government should address barriers for tracking lost to follow up clients as reported from the findings of this study. This can be addressed through deployment of adequate number of staff at CTCs. Additionally, there should be an increased number of CTCs to serve area with vast coverage.

6.1.2 Facility level

- i. CTC facilities should collaborate with implementing partners in tracking lost to follow up clients on ART.
- ii. Facilities in collaboration with implementing partners should address the barriers reported in the finding to address the problem of lost to follow up effectively. There should be an adequate number of Treatment Advocates at CTCs to reduce the workload in too large coverage areas. Furthermore, a thorough counseling of HIV clients during the first visit to CTCs is crucial in obtaining correct and reliable information.

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APPENDICES

Appendix I: Informed Consent - English Version

Greetings. My name is, a researcher from Muhimbili University of Health and Allied Sciences (MUHAS). I am conducting a study about tracking Lost to Follow Up (LTFU) clients on ART. The information you provide will help to increase access and utilization of HIV services through reduced LTFUs for the epidemic control in Tanzania.

Purpose of the study: The study will assess the Treatment Advocate Strategy in addressing Lost to follow up (LTFU) clients on ART within Sauti Yetu project in Temeke Municipality.

Required Participation: If you agree to participate in this study, you was required to answer series of questions that have been prepared for the study through interviewing in order to obtain the intended information regarding tracking of LTFU clients on ART. The information was recorded and was considered confidential and no one else except the researcher will have access to them.

Confidentiality: I assure you that all the information collected from you was kept confidential. Only people working in this research will have access to the information. However, we will compile a report which will contain responses from Treatment Advocates, CTC and Project Staff without any reference to any individual. We will not put your name or other identifying information on the records of the information you provide.

Risks: You may refuse to answer any particular question and stop the interview at any time. We do not expect any harm to happen to you because of your participation.

Right to withdraw: Taking part in this study is completely your choice. If you choose not to participate in the study or if you decide to stop participating in the study, you will not get any harm. You can stop participating in this study at any time, even if you have already given your consent. Refusal to participate or withdrawal from the study will not involve any penalty.

Benefits: The information you provide will help to improve access and utilization of HIV services through reduced LTFUs for the epidemic control in the Country.

In case of injury: We do not anticipate that any harm will occur to you as a result of your participation.

Whom to contact: If you have questions about this study, please don't hesitate to contact Joel Elia Mwangi, Principal Investigator, MUHAS (Tel. no. +255 783 505 897). Also Dr. Rose Mpendeni (+255 784 394 636) and Dr. Idda Masha (+255 787 122 568) who are my supervisors. Either, if you have any question about your rights as a participant, you may contact Dr. Bruno Sunguya, a Chairperson of the Senate Research and Publications Committee, MUHAS, P.O Box 65001, Dar Es Salaam, Tanzania, (Tel: +255 2150252 - 6).

I, have read the content in this form and understood it, my questions have been adequately answered. I agree to participate in this study.

Signature of a Participant.....Date.....

Signature of a Researcher.....Date.....

Appendix II: Informed Consent – Swahili Version

Habari yako. Jina langu naitwa, ni mtafiti kutoka Chuo Kikuu cha Sayansi na Tiba Muhimbili. Nipo hapa kwa ajili ya kupata taarifa muhimu kutoka kwako zitakazosaidia katika utafiti ninaoufanya.

Lengo la utafiti: Kutathimini mchango wa Mradi wa SautiYetu katika kuboresha utumiaji wahuduma za Ukimwi na Tiba kwa kupunguza changamoto ya kupotea kwa wateja wanaotumia dawa za kupunguza makali ya virusi vya UKIMWI.

Ushiriki: Ushiriki wako ni wakujitolea na iwapo utakubali kushiriki basi nitapenda kukuuliza maswali machache kwa ajili ya kupata taarifa sahihi. Pia ningependa kukujulisha kwamba mahojiano kati yetu yatarekodiwa kwa lengo la kuepuka kupotea kwa taarifa utakazonipatia.

Usiriwataarifa: Napenda kukuhakikishia kwamba taarifa zote nitakazokusanya kutoka kwako zitakuwa ni siri kati ya muhojaji na muhojiwa. Hapatakuwepo na jina ama utambulisho wako wa namna yeyote ile utakaojumuishwa katika taarifa nitakayoandika.

Madhara: Utafiti huu haulengi kukuletea madhara yeyote yale kwa kushiriki kwako. Iwapo utahisi kuwepo madhara basi unauhuru wa kutokujibu swali lolote unalohisi lina madhara kwako. Pia unaruhusiwa kukatisha mahojiano wakati wowote ule utakapohisi panakuletea shida.

Haki ya Kujitoa: Napenda ufahamu kwamba ushiriki wako katika utafiti huu ni kwa ridhaa yako mwenyewe. Kwahiyo hapatakuwa na madhara yeyote yale iwapo utachagua kutokushiriki ama kukatisha mahojiano. Aidha, hapatakuwa na adhabu yeyote ile kwa uamuzi wako wakutokushiriki.

Faida ya Utafiti: Taarifa nitakazozipata kutoka kwako zitasaidia katika kuhakikisha kwamba huduma za Ukimwi na Tiba nchini zinaboreshwa kwa kupunguza tatizo la utoro wa wateja wa dawa za kupunguza ushamiri wa virusi vya Ukimwi.

Mawasiliano: Tafadhali iwapo utakuwa na swali lolote lile usisite kuwasiliana name kwa namba +255 783 505 897. Unaweza pia kuwasiliana na wasimamizi wangu wa utafiti, Dr. Rose Mpembeni kwa namba +255 784 394 636 ama Dr. Idda Mosha kwa namba +255 787 122 568 kama utahisi pana haja ya kufanya vile. Dr. Mpembeni na Dr. Mosha wao ni wahadhiri katika Chuo Kikuu cha Afya na Tiba Muhimbili. Pia, iwapo ungependa kufahamu haki zako za ushiriki katika utafiti huu, naomba uwasiliane na Dr. Bruno Sunguya, kwa namba +2552150252-6. Dr. Sunguya ni Mwenyekiti Kamati ya Tafiti na Machapisho katika Chuo Kikuu cha Afya na Tiba Muhimbili, S.L.P 65001.

Mimi....., nimesoma na kuelewa kilichopo katika fomu hii ya ridhaa. Aidha nimekubali kushiriki katika utafiti huu baada ya maswali yangu kupata majibu.

Saini ya Mshiriki..... Tarehe.....

Saini ya Mtafiti..... Tarehe.....

Appendix III: Interview guide for Treatment Advocates

Identification number of a participant.....

Date of interview.....

Ward name.....

Facility name.....

Questions

A. SOCIAL - DEMOGRAPHIC CHARACTERISTICS

1. Sex Male Female
2. Age
3. Education No formal education Secondary School College/University
4. Occupation Not employed Employed Self employed

B. PROPORTION OF LOST TO FOLLOW UP

5. What is a LTFU in the context of ART?
6. Did you attend any training on LTFU and how to capture LTFU clients?
7. How do you track back LTFU clients?
8. How was the trend of LTFU clients in quarterly basis for the year 2018?

C. COMPARISON OF THE PROPORTION OF LOST TO FOLLOW UP

9. What change in terms of LTFU have you brought following your deployment?
10. How do you compare proportion of LTFU before and after the Project?

D. FACILITATING FACTORS IN TRACKING LOST TO FOLLOW UP CLIENTS

11. How was the situation of adequacy/inadequacy of qualified Staff during the implementation of the project?
12. How correct was the clients' information recorded in ART registers during the implementation of the project?
13. How was the situation of transport to physically visit LTFU client?

- 14. Does the size of the coverage where you work impede your tracking role? Explain
- 15. Does the project team conduct regular supportive supervision?
- 16. If yes, how is it done? How does it help you?
- 17. How do community leaders support you in accomplishing your role? How is their participation?
- 18. What are the procedures do you follow after tracking lost to follow up clients?
- 19. Are there tools in place that you use to capture LTFU clients?
- 20. If yes, how were you oriented on its use?

E. BARRIERS IN TRACKING LOST TO FOLLOW UP

What are the barriers in tracking lost to follow up clients? Mention and explain

.....

.....

.....

F. VIEWS TO IMPROVE TRACKING OF LOST TO FOLLOW UP

.....

.....

.....

.....

.....

Thank you very much for your time

Appendix IV: Mwongozo wa mahojiano na Wakiri Tiba

Namba ya utambulisho wa Mshiriki.....

Tarehe ya Mahojiano.....

Jina la Kata.....

Jina la Kliniki.....

Maswali

A. TAARIFA ZA MUHOJIWA

1. Jinsi [] Me [] Ke
2. Umri
3. Elimu [] Hajasoma [] Msingi [] Sekondari [] Chuo
4. Kazi [] Hajaajiriwa [] Amejiriwa [] Amejiajiri

B. UWIANO WA KUPOTEA KWA WATEJA WA DAWA

5. Nini maana ya watejawaliopotea katika dhana ya dawa za kupunguza makali ya Virusi vya UKIMWI?
6. Uliwahi kuhudhuria mafunzo yoyote yanayohusiana na wateja waliopotea na namna ya kuwatafuta?
7. Ni kwa namna gani unawatafuta wateja waliopotea katika dawa?
8. Kuna mwelekeo gani (kupungua ama kuongezeka) kwa uwiano wa waliopotea kwenye tiba yakufubaza makali ya Virusi vya UKIMWI kwa kila robo kwa mwaka 2018?

C. KULINGANISHA UWIANO KABLA NA BAADA YA MRADI

9. Nini mwenendo wa uwiano wa wateja uliowapata toka uanze kutekeleza majukumu yako hadi sasa?
10. Unawezaje kulinganisha mwenendo wa uwiano wa wateja waliopotea kabla na baada ya kuanza utekelezaji wa mradi wa Sauti Yetu?

D. MAMBO YANAYOFANIKISHA UTAFUTAJI WA WALIOPOTEA KATIKA DAWA

11. Hali ikoje katika uwepo/ukosefu wa wataalam wenye sifa katika kituo cha kutolea huduma unachotoa taarifa?
12. Ni kwa kiasi gani taarifa za mgonjwa katika kituo cha kutolea huduma zipo sahihi wakati wa utekelezaji wa mradi wa Sauti Yetu?
13. Hali ikoje ya upatikanaji wa nauli wakati wa kufuatilia wateja waliopotea?
14. Ni kwa kiasi gani ukubwa wa eneo unalofanyia kazi linaathiri utendaji kazi wako?
15. Je umekuwa ukipata msaada wowote wa kitaalamu kutoka kwa maafisa wa mradi wakati wa ufuatiliaji?
16. Kama ni ndiyo, huo msaada umekusaidiaje katika kutekeleza shughuli zako?
17. Ni kwa kiasi gani uongozi katika jamii unayofanyia kazi inakusaidia katika kutekeleza majukumu yako? Je, ushiriki w aukoje?
18. Ni kipi unachokifanya baada ya kuwapata wateja walioacha dawa?
19. Ni hatua zipi utakazozichukua baada ya kuwapata?
20. Je kuna zana za kutolea taarifa?
21. Uelewa wako ukoje katika kutumia zana hizo?

E. MAMBO YANAYOATHIRI UTAFUTAJI WA WALIOPOTEA KATIKA DAWA

Ni mambo yapi yanayoathiri utafutaji wa waliopotea katika dawa?

.....

F. TOA MAONI YAKO KATIKA KUBORESHA UTAFUTAJI WA WATEJA WALIOPOTEA KATIKA DAWA

.....

.....

Nakushukuru sana kwa muda wako

Appendix V: Interview guide for care and treatment clinic staff

Date of interview_____

Ward name_____

Name of a Facility_____

Identification number of a participant_____

Age:_____

Sex: Female Male

Questions

1. What is LTFU in the context of ART?
2. What is the difference of LTFU trend before and after deployment of TAs?
3. Did TAs attend any training before starting to work? If yes explain
4. What are the tools that are required by Treatment Advocates to perform their role?
5. Are the Treatment Advocates knowledgeable on the tools? Explain
6. How accurate are the reports submitted by Treatment Advocates to the facility?
7. What support do the Project provide to the Treatment Advocates to enable them to perform their role?
8. What are the challenges that Treatment Advocates encounter in performing their roles?
9. What do you suggest addressing those challenges?
10. Do you recommend roll out of Sauti Yetu Project in other areas? If yes/no, explain why

Thank you very much for your time

Appendix VI: Mwongozo wa mahojiano na wafanyakazi wa Klinik

Namba ya utambulisho wa Mshiriki_____

Tarehe ya Mahojiano_____

Jina la Kata_____

Jina la Klinik_____

Miaka _____

Jinsi [] KE [] ME

Maswali:

1. Nini maana ya wateja waliopotea katika dhana ya dawa za kupunguza makali ya Virusi vya UKIMWI?
2. Unaongeleaje uwiano wa wateja wa dawa waliopotea kabla na baada ya utekelezaji wa Mradi?
3. Je kuna mafunzo yeyote ambayo Wakiri Tiba walipatiwa kabla ya kuanza kutekeleza shughuli zao? Eleza
4. Taja zana wanazotumia Wakiri Tiba katika utekelezaji wa majukumu yao katika mradi.
5. Je unadhani Wakiri Tiba wanauelewa wa kutosha kuhusu kutumia zana hizo? Eleza
6. Je, taarifa mnazopokea kutoka kwa Wakiri Tiba zinakuwa sahihi? Eleza
7. Ni msaada upi wanaopokea Wakiri Tiba kutoka Mradini ambao unawawezesha kutekeleza majukumu yao?
8. Taja changamoto wanazokumbana nazo Wakiri Tiba katika utekelezaji wa shughuli za Mradi.
9. Unashauri nini katika kutatua changamoto hizo?
10. Nini maoni yako katika upanuzi wa Mradi katika vituo vingine vya kutolea huduma za Tiba na Matibabu?

Nakushukuru sana kwa muda wako

Appendix VII: Interview guide with project staff

Identification number of a participant.....

Date of interview.....

Questions

1. What is LTFU in the context of ART?
2. How were Treatment Advocates recruited?
3. Did they attend any training before start working?
4. What do you do after the recruitment to enable them to perform their roles?
5. What are the tools that are required by Treatment Advocates to perform their role?
6. How knowledgeable on the tools Treatment Advocates are?
7. How accurate are the reports submitted by Treatment Advocates?
8. How often do you monitor/supervise them? Explain
9. What are the challenges in monitoring the TAs?
10. What do you suggest solving those challenges?
11. Explain if there is any difference in LTF trend after their deployment
12. What are the weaknesses of the Project in supporting the TAs?
13. What are the strengths of the Project in supporting the TAs?
14. What are your suggestions in improving the performance of the TAs?

Thank you very much for your time

Appendix VIII: Mwongozo wa mahojiano na mfanyakazi wa mradi

Namba ya utambulisho wa Mshiriki.....

Tarehe ya Mahojiano.....

Maswali

1. Nini maana ya wateja waliopotea katika dhana ya dawa za kupunguza makali ya Virusi vya UKIMWI?
2. Ni namna gani mradi uliwapata Wakiri Tiba?
3. Je kuna mafunzo yeyote ambayo Wakiri Tiba walipatiwa kabla ya kuanza kutekeleza shughuli zao? Eleza
4. Mradi unawasaidiaje Wakiri Tiba katika kutekeleza majukumu yao?
5. Ni zana zipi wanazotumia Wakiri Tiba katika kutolea taarifa zao?
6. Je wanauelewa kiasi gani wa kutumia zana hizo?
7. Je taarifa mnazozipokea kutoka kwa Wakiri Tiba zinakuwa sahihi? Eleza
8. Je ni kwa kiasi gani na ni mara ngapi mnawasimamia katika utekelezaji wa shughuli zao?
9. Ni changamoto zipi unazozipata katika kuwasimamia?
10. Nini maoni yako katika utatuzi wa changamoto zilizopo?
11. Eleza mwenendo wa uwiano wa wateja waliopotea baada ya kuanza utekelezaji wa mradi wa Sauti Yetu
12. Nini mapungufu ya Mradi katika kuwawezesha Wakiri Tiba
13. Mradi unakuwezesha je katika kutekeleza majukumu yao?
14. Nini maoni yako katika kuboresha utendaji kazi wa Wakiri Tiba?

Nakushukuru sana kwa muda wako

Appendix X: Approval to share project documents


**THE NATIONAL COUNCIL OF PEOPLE
LIVING WITH HIV IN TANZANIA
(NACOPHA)**
BARAZA LA TAIFA LA WATU WANAOSHISHI NA VIRUSI VYA UKIMWI TANZANIA

18th July, 2019

Ref: NACOPHA/ED/PT/2019/028

Director of Postgraduate Studies,
MUHAS,
P.O Box 65001,
DAR ES SALAAM.

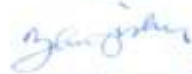
Dear Sir,

RE: APPROVAL TO SHARE PROJECT DOCUMENTS FOR RESEARCH PURPOSES

Please refer to the above heading.

The management of the National Council of People Living with HIV and AIDS in Tanzania (NACOPHA), with its headquarter in Dar Es Salaam, has approved a request of your Postgraduate Student, named Joel Elia Mwangi (MSc. Project Management, Monitoring and Evaluation in Health) to use Sauti Yetu project documents for research review purposes. In addition, he will be provided with all appropriate support needed to accomplish his study goals. However, he will be required to share the study findings with NACOPHA to help in improving and replication of similar interventions in the country.

Kind regards,



Gregory Kamugisha
For Chief Executive Officer

Appendix XI: Ethical Clearance

**MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR OF POSTGRADUATE STUDIES**

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Ref. No. DA.287/298/01A/

02nd August, 2019

Mr. Joel E. Mwangi,
MSc. PMMEH,
School of Public Health and Social Sciences
MUHAS.

RE: APPROVAL OF ETHICAL CLEARANCE FOR A STUDY TITLED: " ASSESSING THE EFFECTIVENESS OF A TREATMENT ADVOCATE STRATEGY IN TRACKING LOST OF FOLLOW UP CLIENTS ON ANTIRETROVIRAL THERAPY IN SAUTI YETU PROJECT WITHIN TEMEKE MUNICIPAL "

Reference is made to the above heading.

I am pleased to inform you that, the Chairman has, on behalf of the Senate, approved ethical clearance for the above-mentioned study. Hence you may proceed with the planned study.

The ethical clearance is valid for one year only, from **02nd August, 2019 to 01st August 2020**. In case you do not complete data analysis and dissertation report writing by **01st August, 2020**, you will have to apply for renewal of ethical clearance prior to the expiry date.


Dr. Emmanuel Balandya
ACTING: DIRECTOR OF POSTGRADUATE STUDIES

cc: Director of Research and Publications
cc: Dean, School of Public Health and Social Sciences, MUHAS

Appendix XII: Introductory Letter

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR OF POSTGRADUATE STUDIES

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Ref. No. HD/MUH/T.605/2017 05th August, 2019

Municipal Director,
 Temeke Municipal Council,
 P.O. Box 46343,
 DAR ES SALAAM

Re: INTRODUCTION LETTER


The bearer of this letter Mr. Joel E. Mwangi is a student at Muhimbili University of Health and Allied Sciences (MUHAS) pursuing MSc. Project Management Monitoring and Evaluation in Health.

As part of his studies he intends to do a study titled: "*Assessing the Effectiveness of a Treatment Advocate Strategy in Tracking lost to follow up Clients on Antiretroviral Therapy in Sauti Yetu Project within Temeke Municipal.*"


The research has been approved by the Chairman of University Senate.

Kindly provide him the necessary assistance to facilitate the conduct of his research.

We thank you for your cooperation.



Ms. Sharifa Kamby
For: DIRECTOR, POSTGRADUATE STUDIES



cc: Dean, School of Public Health and Social Sciences, MUHAS
 c.c. Mr. Joel E. Mwangi

*Imepokelewa
 5/8/2019
 Rm (13)*

Appendix XIII: Permission Letter to Conduct Research

TEMEKE MUNICIPAL COUNCIL

[ALL CORRESPONDENCE SHOULD ADDRESS TO MUNICIPAL DIRECTOR]

Tel: +255 22-2928132/2928138/2928139
 Fax: +255 22-2928137
 Email: temekemc@temeke.go.tz
 Website: www.temeke.go.tz



Director Office
 92 Mandela/Taifa Road
 P.O. Box 46343,
15883 - DAR ES SALAAM,
 TANZANIA.
 Date: 05th August 2019

REF: **TMC/MD/ N.14/19/94**

Joel Elia Mwangi,
 MUHAS
 P.O Box 65001,
 Dar Es Salaam.


RE: PERMISSION TO CONDUCT RESEARCH AT TEMEKE MUNICIPALITY

Reference is made to the heading above.

Temeke Municipal council received the letter dated 05th August 2019 with Ref. No. HD/MUH/T.605/2017 from the Director of Postgraduate Studies, Muhimbili University of Health and Allied Sciences (MUHAS) requesting permission for you to conduct the research titled "*Assessing the effectiveness of the Treatment Advocate Strategy in Tracking lost to follow up clients on Antiretroviral Therapy in Sauti Yetu Project within Temeke Municipality*". In responding to the aforementioned letter, the Municipal Director for Temeke has granted permission for you to conduct the research as per the request.

You will be provided with appropriate support needed to accomplish your study goal.

I wish you all the best.


 PILI D. MTAUCHILA
For: MUNICIPAL DIRECTOR
TEMEKE

For: Municipal Director
 TEMEKE

CC: Director, Postgraduate Studies, MUHAS

CC: Dean, School of Public Health and Social Sciences, MUHAS