#### UNIVERSITY OF THE WESTERN CAPE

**Faculty of Community and Health Sciences** 

# LINKAGE TO CARE AFTER TESTING HIV POSITIVE: A COMPARATIVE ANALYSIS OF MOBILE VERSUS HEALTH FACILITY BASED MODELS IN RURAL SETTINGS, MBEYA-TANZANIA.

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# **Keywords:**

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Health systems

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Tanzania.



### Abbreviations and acronyms

AIDS: Acquired Immune Deficiency Syndrome

AMREF: African Medical Research Foundation

AVERT: An international HIV and AIDS charity, based in the UK

FBO: Faith Based organization

FGD: Focus Group Discussion

CTC: Care and Treatment Center

HIV: Human Immunodeficiency Virus

HTC: HIV Testing and Counselling

IDI: In-depth Interview

NACP: National AIDS Control Program

NGO: Non-Governmental Organizations

MDTC: Mobile Diagnostic and Training Centre

MMRC: Mbeya Medical Research Center

MRHR: Mbeya Regional Hospital Report

MRACP: Mbeya Regional AIDS Control Program

PITC: Provider Initiated Testing and Counseling

PMTCT: Prevention of Mother to Child Transmission

PwP: Prevention with Positives

SSA: Sub Saharan African

STI: Sexually Transmitted Infection

TACAIDS: Tanzania Commission of AIDS

THMIS: Tanzania HIV and Malaria Indicators Survey

UNAIDS: Joint United Nations Programme on HIV/AIDS

VCT: Voluntary counseling and Testing

WHO: World Health Organization.

#### **Declaration**

I Erica Samson Sanga declare that "Linkage to care after testing HIV positive: a comparative analysis of mobile versus health facility based models in rural settings, Mbeya-Tanzania" is my own work, and that all the sources I have used or quoted have been indicated and acknowledged as complete references. The thesis is being submitted for examination, through the School of Public Health at the University of Western Cape- South Africa. This work has not been submitted for any other degree in this or another university

This thesis is written in monograph format with results (Chapters 4-6) written in the form of three manuscripts which have either been published, under review or submitted for publication.

Below is the list of papers:

**PAPER 1: Sanga ES**, Lerebo W, Mushi AK, Clowes P, Olomi W, Maboko L & Zarowsky C. (2017). Linkage into care among newly diagnosed HIV-positive individuals tested through outreach and facility-based HIV testing models in Mbeya, Tanzania: a prospective mixed-method cohort study. BMJ Open. 2017; 7. Doi: 10.1136/bmjopen-2016-013733.

PAPER 2: Sanga ES, Mukumbang FC, Mushi AK, Olomi W, Lerebo W & Zarowsky C. Processes and dynamics of linkage to care from mobile/outreach and facility-based HIV testing models in hard-to-reach settings in rural Tanzania. A sequential explanatory mixed methods study. Submitted .BMC Health Services Research.

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Signature

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## **Dedication**

## To my late mom Hongera Ana Luvanda



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#### **Abstract**

#### Introduction

HIV testing, linkage to HIV care and continuity of care are crucial for proper management of HIV/AIDS. There is increasing interest across sub-Saharan Africa, including in Tanzania, in accessing hard-to-reach populations and remote areas with HIV testing opportunities and linkage to HIV care. Despite the efforts being made by the Tanzanian government to address some of the challenges to improving HIV testing and subsequent linkage to HIV care and treatment services, such as increasing service outlets, linkage to care in Tanzania is still low: studies published in 2009 and 2014 reported linkage rates of 14% at four months and 28% at one year. To our knowledge, there has not been any direct, prospective comparison between mobile and facility-based models of testing in countries like Tanzania, where treatment is only available in a minority of facilities. This study aimed to describe and compare rates and determinants of linkage to care in the first six months following an HIV-positive test result between mobile and facility-based models of HIV testing in Mbeya region, Tanzania.

#### **Methods**

An explanatory sequential mixed method study based on a prospective 2-armed cohort of 1,012 newly HIV diagnosed individuals who tested either at facility-based or mobile/outreach HIV testing sites (n=16) in remote and border areas of Mbeya region, Tanzania, was conducted to describe and compare the rates and determinants of linkage to care. The cohort participants were interviewed using structured questionnaires at 0, 3 and 6 months after diagnosis, to gather information on HIV testing and linkage to care. Quantitative data to describe the populations testing in the two models were collected through register review for 11,733 clients who received HIV testing services in the study sites; the cohort was recruited from amongst these 11,733 clients. A subsample of the cohort also participated in qualitative individual interviews and focus group discussions. Additional qualitative data were collected through interviews with healthcare providers in the study sites, observation/field notes from the sites, and examination of guidelines and reports at the sites. Quantitative data were recorded, cleaned and analyzed using Stata Version

13 (College Station Texas. USA), while qualitative data were analyzed by thematic content analysis, supported by Atlas.ti Software.

#### **Findings**

At six months since diagnosis, 78% (793 out of 1012) of participants enrolled in the cohort had linked into care. Linkage to care was higher from facility-based than from mobile/outreach sites; 84% (CI= 81% -87%, n= 512) of individuals tested at facility-based were linked to care, compared to 69% (CI= 65% -74%, n=281) of individuals tested at mobile/outreach in the same period. Individuals tested at facility-based sites entered HIV care sooner than the individuals tested at the mobile/outreach sites; the median time to linkage was 1 day (IQR: 1-7.5) for facility-based and 6 days (IQR: 3-11) for mobile/outreach sites. Disclosure of HIV status was a significant factor associated with timely linkage to care: participants who disclosed their HIV status had a two and half times earlier rate of linkage to care compared to participants who did not disclose their HIV status (p<0.001). Clients who reported that they tested because they wanted to get treatment for HIV were 25% more likely to link to care (p=0.005). The study showed that more individuals tested at the mobile/outreach site compared to the facility based sites (56% vs 44%, p<0.001), however, HIV prevalence was higher in the facility testing group at 21.5% compared to 7.9% in the mobile/outreach group (p<0.001).

The difference was seen in the HIV testing sites: the mobile sites were actively following people up in their homes, and HIV testing was experienced by study respondents as more friendly and more confidential, while at the facility-based sites testing was passive on the part of the staff, or routine through a PITC approach. Nevertheless, processes and procedures for linkage to HIV care section were similar for all clients, regardless of where they had tested, and all sites appeared to be adhering to national guidelines for testing and linkage to care.

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Qualitative findings of the study revealed that factors facilitating or impeding linkage to care occurred at all levels: patient, provider, health system and contextual. However, patient and health-system related factors were most prominent. The factors that facilitated linkage to care at the individual level were: disclosure of HIV status to someone (spouse, family member, relative or friend), support from family/relatives, and having symptoms of disease at the time of diagnosis. On the other hand, fear of stigma, lack of disclosure, denial, being asymptomatic, and belief in

witchcraft were barriers identified at the level of individuals. At the provider level, support and good patient-staff relationships facilitated linkage, while negative provider attitudes and use of abusive language to patients were reported barriers to successful linkage. Clear referral procedures and well-organized clinic procedures were system-level facilitators of linkage, whereas poorly-organized clinic procedures and visit schedules, overcrowding, long waiting times, and lack of resources (including human resources and equipment) were reported barriers. Distance and transport costs to HIV care centres were important contextual factors influencing linkage to care.

#### **Conclusion**

Timely linkage to care at six months after HIV diagnosis is much higher in Mbeya region in 2017 than was reported in other rural regions only a short time ago. Findings from this study suggest that although mobile/outreach service delivery models bring HIV testing services closer to people in remote and resource-constrained areas, and do increase testing, there is still a significant gap in timely linkage to HIV care compared to sites within established health facilities. The more proactive and client-centred approaches observed at and reported by clients testing at mobile/outreach sites did not result in a comparable rate of linkage to care. In this setting, health system organizational factors, such as on-site services and well-functioning routine procedures, are of particular importance in facilitating linkage to care: these organizational factors, together with the individual-level factors related to reasons for testing and readiness or willingness to accept an HIV diagnosis and seek care, are powerful determinants of linkage. Even though the long waiting times at care and treatment centres could themselves be a significant barrier to the linkage, overcoming stigma, fear, and logistical barriers are of primary importance. Strategies that are more effective are needed to further improve linkage through the mobile/outreach model of service delivery, including increased attention to effectively communicating the importance of linkage to care and adherence to HIV treatment and providing additional support.

# **Table of contents**

Keywords:	
Abbreviations and acronyms	i
Declaration	ii
Dedication	iv
ACKNOWLEDGEMENTS	۰۰۰۰۰۰۰۰ ۱
Abstract	vi
Table of contents	×
List of Tables	xii
List of figures	xiv
CHAPTER ONE	
INTRODUCTION	1
1.0 Introduction	1
1.1 HIV: an uneven and African pandemic	2
1.2. HIV/AIDS epidemic and national response to HIV/AIDS in Tanzania	2
1.3. HIV testing and linkage to care	
1.4. HIV testing and linkage to care guidelines in Tanzania	5
1.5. Mobile/outreach HIV Testing Services in Tanzania	
1.6. Description of study setting: Mbeya Tanzania	<del>6</del>
1.6.1. HIV/AIDS Status and health care services in Mbeya region	
1.6.2. Addressing low rates of HIV testing: Mobile HIV Testing Services in Mbeya Region	
1.7. Rationale of study	<u>c</u>
1.8 Outline of the thesis	10
CHAPTER TWO	11
LITERATURE REVIEW and CONCEPTUAL FRAMEWORK	11
2.0. Introduction	11
2.1. Approaches and guidelines for HIV testing and counseling	11
2.1.1. HIV testing and available approaches	12
2.2. HIV testing at facility-based or clinic setting	13
2.3. Addressing barriers to HIV testing through mobile/outreach and community testing	
programs	14

2.4. Linkage to HIV Care and treatment	15
2.4.1. Poor linkage to care	15
2.4.2. Barriers to successful linkage to HIV care	16
2.4.3. Facilitators of successful linkage to care	17
2.5. Guidelines for HIV testing and HIV management	18
2.5.1. HIV testing guidelines in relation to different HIV testing approaches in Tanzania	18
2.5.2. Guidelines for managing newly-diagnosed HIV clients	19
2.6. Loss of patients between HIV Testing and HIV Care and Treatment Center	20
CHAPTER 3	24
AIMS AND OBJECTIVES, METHODOLOGY AND ETHICAL CONSIDERATIONS	24
3.0. Aims of the study	24
3.1. Specific Objectives:	24
3.2 Study design and overview of project	
3.2.1. Quantitative study	25
3.2.2. Qualitative study	25
3.2.3. Phases of the study	26
3.4. Study setting	29
3.5 Quantitative study	31
3.5.2. Sample size.	
3.5.3. Data collection and data analysis	31
3.5.4 Validity and Reliability	33
3.6. Qualitative study	34
3.6.1. Data collection and data analysis	35
3.6.2. Rigour	35
3.7 Overview of data collected against study objectives	36
3.8. Ethical considerations	38
SECTION II	39
INDINGS	39
Introduction to study findings	39
CHAPTER 4	40
PAPER 1: Linkage into care among newly diagnosed HIV-positive individuals tested throug	
outreach and facility-based HIV testing models in Mbeya, Tanzania: a prospective mixed-m cohort study.	
CONOTE SERVEY.	40

PAPER 2: "Processes and dynamics of linkage to care from mobile/outreach an HIV testing models in hard-to-reach settings in rural Tanzania. A sequential ex methods study"	planatory mixed
CHAPTER 6	89
PAPER 3: Understanding factors influencing linkage to HIV care after testing linkage to HIV care after the HIV care a	<del>-</del>
CHAPTER 7	117
SUMMARY OF FINDINGS AND DISCUSSION	117
7.1 Contributions of this thesis	117
7.2 Summary of findings	118
7.3. Discussion of findings	120
7.3.1 Uptake of HIV testing at mobile/outreach vs. facility sites	120
7.3.2. Linkage to care and time to linkage	121
7.3.3 Processes and dynamics of linkage to care	123
7.3.4 Facilitators and barriers for successful linkage to care at patient, provide and contextual levels	,
7.4. Conclusion	127
CHAPTER EIGHT	
CONCLUSIONS AND RECOMMENDATIONS	128
8.1 Conclusions	128
8.1.1 Study conclusions in relation to the study objectives	128
8.1.2 Overall conclusions	129
8.2. Recommendations	
8.3 Strengths and limitation of the study	131
9. Reference List	133
10. ANNEXES	149
10.1 Ethical approvals	149
10.2. Informed consent-English and Swahili	152
10.3. Questionnaires and interview guides	162
10.4. HIV testing and linkage processes-Scenarios	183
10.5 Paper published on Linkage to Care at BMJ Open. 2017;7. doi: 10.1136/bmjo	open-2016-013733

# **List of Tables**

Table 1.1: Names of sites participating in the study
Table 1.2: Summary of data collected to achieve study objectives
Table 3.1: Names of sites participating in the study
Table 3.2: Summary of data collected to achieve study objectives
Table 4.1: Background characteristics of study subjects by site
Table 4.2: Factors associated with time to linkage by bivariate and Multivariate Cox
regression56
Table 5.1: Research sites and data collection techniques applied
Table 5. 2: Facilitators and barriers to linkage in care by levels
Table 6.3: Research sites and data collection methods
Table 6.2: Characteristics of clients tested at facility vs. mobile/outreach sites over the period of
six months (N=11733)98
<b>Table 6.3.</b> Process/procedures and timelines for a newly diagnosed client at the CTC105
Table 6. 4: Summary of Similarities and differences in facility-based and mobile/outreach
sites

# **List of figures**

<b>Figure 1.1:</b> HIV prevalence among adults aged 15-49 years in Tanzania between 2003-20124
Figure 2.1: Conceptual framework for linkage to care
<b>Figure 3.1</b> : The framework of study phases and research activities
<b>Figure 3.2</b> : Map of the study selected districts in Mbeya region
<b>Figure 4.1:</b> Linkage status.
Figure 4. 2: Survival analysis (KPM)
<b>Figure 5.1:</b> Map of the selected districts in Mbeya region
<b>Figure 5. 2:</b> Conceptualizing the factors influencing linkage to HIV care in Mbeya, Tanzania83
<b>Figure 6. 1:</b> A diagrammatic illustration of the linkage to care process
Figure 7.1: Conceptualizing the factors influencing linkage to HIV care in Mbeya,
Tanzania
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#### **CHAPTER ONE**

#### INTRODUCTION

#### 1.0 Introduction

HIV testing, linkage to HIV care, and continuity of care are crucial for proper management of HIV/AIDS (Hatcher et al., 2013; Wilton & Broeckaert, 2013). Thus, there is increasing interest across sub-Saharan Africa, including in Tanzania, in accessing hard-to-reach populations along major highways or trade corridors, in border areas, and in remote rural areas with HIV testing opportunities and linkages to HIV care and management (Staveteig et al., 2013; Bassett et al., 2015; CDC, 2016).

Mobile and outreach HIV testing can help to achieve universal HIV testing in sub-Saharan African countries. However, despite the efforts being made by the Tanzanian government to address some of the challenges to improving HIV testing and subsequent linkage to HIV care and treatment services, such as increasing service outlets, studies conducted in various regions of Tanzania show that linkage to care is still low. Many factors can interfere with or facilitate successful linkage to and continuity of care. This thesis describes and compares the populations accessing testing at mobile/outreach versus fixed/facility-based testing sites, and compares the processes, dynamics, and outcomes of linkage to care between these two models of HIV testing.

This introductory chapter describes Tanzania's HIV/AIDS response, particularly in relation to testing and linkage to care in the remote, hard-to-reach border region of Mbeya. It situates this response and the challenges of testing and linkage to care in the context of the changing and uneven patterns of the HIV pandemic in Africa and in Tanzania. This introduction sets the stage for the study rationale. The chapter concludes with an outline of the thesis.

#### 1.1 HIV: an uneven and African pandemic

HIV/AIDS is one of the world's main public health problems, and it is estimated that about 36.7 million people are living with HIV/AIDS worldwide (WHO, 2017). Sub-Saharan Africa carries the biggest burden of HIV infection, accounting for more than 70% of global infection, with nearly 1 in every 25 adults (4.4%) living with HIV (UNAIDS, 2014; Kharsany & Karim, 2016). Women living with HIV in sub-Saharan Africa account for 58% of the total number of people living with HIV, with high rates of new HIV infections among young women aged 15-24 (Ramjee et al. 2013; UNAIDS, 2014; AVERT, 2016). Although the number of AIDS-related deaths fell by 39% between 2005 and 2013, Sub-Saharan Africa still accounted for 74% of all the people dying from AIDS-related causes in 2013 (UNAIDS, 2014; Kharsany & Karim, 2016).

In the Sub Saharan Africa, ten countries (Ethiopia, Kenya, Malawi, Mozambique, Nigeria, South Africa, Uganda, Tanzania, Zambia and Zimbabwe) account for more than 80% of all people living with HIV in the region (UNAIDS, 2014b). South Africa and Nigeria account for 25% and 13% respectively, while the East African countries (Tanzania, Kenya, and Uganda) account for 6%, and Ethiopia 3% of all infections in SSA (UNAIDS, 2014; AVERT, 2016; Kharsany & Karim, 2016). In South Africa, the overall HIV prevalence was estimated at 12.7% in 2016, with prevalence differing by provinces, with KwaZulu Natal leading at 16.9%, followed by Mpumalanga and Free State at 14.1% and 14.0 % respectively, while the Northern Cape and Western Cape had the minimum prevalence of 7.4% and 5.0 % respectively (Statistics South Africa, 2016). The Tanzania HIV/AIDS and Malaria Indicator Survey 2011/2012 (THMIS), reported HIV prevalence of 5.1%, with more females infected than males (TACAIDS, 2013; AVERT, 2016). In a similar manner to South Africa, the shape of the HIV epidemic in Tanzania also differs widely from one region to another, with HIV prevalence less than 2% in Manyara, and reaching 14.8% in Njombe region (NACP, 2014; AVERT, 2015).

#### 1.2. HIV/AIDS epidemic and national response to HIV/AIDS in Tanzania

Tanzania has a population of 44.9 million with an average life expectancy of 58.2 years (NBS, 2013; AVERT, 2015). Women are disproportionately represented among people living with HIV in Tanzania, with the Tanzania HIV and Malaria Indicator survey of 2012 (THMIS) showing that

4.4% of women aged 15-24 years were seropositive while the rate among men of the same age was 1.7% (TACAIDS, 2013; NACP, 2014b). In Tanzania, HIV is one of the major underlying contributors to hospital admissions and deaths, and available data indicate that by December 2013, a total of 1,411,829 people were living with HIV/AIDS, and 78,843 people died in 2013 due to AIDS-related diseases (NACP, 2014). Recently, there has been a decline in the epidemic (Figure 1), together with an increased commitment by the Government of Tanzania since the first reported case of HIV/AIDS in 1981 (NACP, 2012).

The National AIDS Control Program (NACP) was established in 1987 as the first response to the HIV/AIDS epidemic. In December 2000, the Tanzania Commission of AIDS (TACAIDS) was established and assigned to coordinate multi-sectoral responses to HIV/AIDS (TACAIDS, 2008). Provision of HIV/AIDS-related counselling services in Tanzania started in 1988 through faith-based organizations (FBOs) and Non-Governmental Organizations (NGOs). In 1989, the government established the first HIV testing sites in the public sector, with a vision of making this a routine practice (NACP, 2007; MOH, 2013; TACAIDS, 2013).

Mobile HIV Testing and Counseling (HTC) was started in the early 2000s to complement existing approaches of HIV testing in the country, and to expand services to remote areas and hard-to-reach communities (NACP, 2012; MOH, 2013). In 2004, Tanzania launched the National HIV/AIDS care and treatment program and provision of care and treatment services for HIV in public health facilities (TACAIDS, 2013). Following on from this, in 2009 TACAIDS developed a National Multisectoral HIV Prevention Strategy (NMPS 2009-2012), which was a major milestone in response to the country's HIV epidemic. Various prevention interventions were integrated to enhance compliance in implementation (TACAIDS, 2013; NACP, 2014). According to current policy guidelines, all testing sites are obliged to establish referral links to further HIV care and treatment centres, as "health care providers should give extra attention to linking the clients with follow up services" (NACP, 2012; MOH, 2013 page 8).

Tanzania's HIV epidemic is attributed largely to heterosexual transmission, with 80% of infections falling in this category (TACAIDS, 2013; NACP, 2014b). Since ART was made available in 2004, the government has strengthened efforts to scale up care and treatment services. It is estimated that

21%-30% of people living with HIV (PLHIV) in Tanzania have registered at the Care and Treatment Center CTC, and 69% of eligible adults were receiving ARVs by 2014 (NACP, 2014). HIV prevalence has decreased significantly from an overall prevalence of 7.0% in 2003/04 to 5.1% in 2011/12, due to increased education on HIV prevention and safe sex practices (NACP, 2014b; TACAIDS, 2013). Fig 1 below illustrates the decline in HIV prevalence in the adult population from 2003 to 2012. While an increase in HIV prevalence would be expected if incidence remains stable and mortality declines, the prevalence in 2016 is reported at 4.7% (AVERT, 2017).

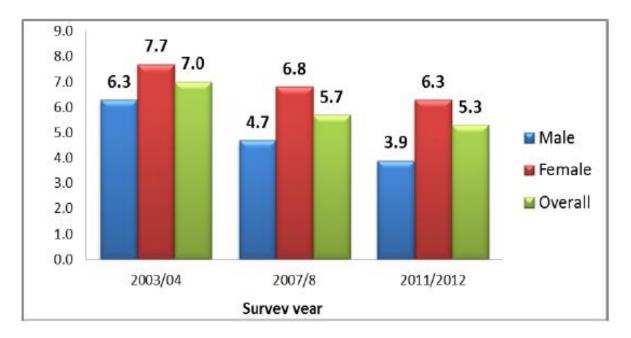


Fig 1: HIV prevalence among adults aged 15-49 years in Tanzania between 2003-2012

Source: Tanzania-UNAIDS-Narrative report 2014

#### 1.3. HIV testing and linkage to care

HIV testing in Tanzania is provided in both health facilities and out-of-facility sites (MOH, 2013). Facility-based approaches include client-initiated counseling and testing, or voluntary counseling and testing (VCT), and provider-initiated counseling and testing (PITC), as well as the Prevention of Mother to Child HIV transmission (PMTCT) program (Kapologwe et al., 2011; MOH, 2013; Layer et al., 2014). Out-of-facility modalities for HIV testing include home-based testing, standalone VCTs, workplace or school-based testing, and community HIV testing through mobile vans

and organized HIV awareness campaigns (MOH, 2009; Njau et al., 2014; Cawley et al., 2015; Sharma et al., 2015).

All individuals diagnosed as HIV positive must be linked to HIV care and treatment immediately (MOH, 2013; Suthar et al., 2013). According to Dombrowski (2013), successful linkage to care is defined as an individual completing a visit with an HIV medical provider within 90 days (three months) of initial HIV diagnosis. At this visit, the CD4 cell count, HIV staging, and an evaluation of the client's need for ART initiation are done (NACP, 2012). Linkage to care is the bridge between HIV testing and HIV treatment care and support (Suthar et al., 2013; Gerdts et al., 2014). Timely HIV diagnosis and effective linkage into care and treatment are keys to improved outcomes (Kranzer et al., 2010; Rio, 2011; Sharma, 2015). Rosen and Fox (2011), defined linkage to care by stages, from registration at the Care and Treatment Center to ART initiation and full engagement in HIV care. Others defined linkage to care as the first visit to a primary health care or an HIV care provider authorized to prescribe ART after HIV diagnosis (Marks et al 2010; Rio, 2011). In this study, linkage to care is defined as attending and completing the first step of registration at the HIV care clinic and receiving an HIV care and treatment card (Rosen & Fox, 2011; Keller et al., 2013).

#### 1.4. HIV testing and linkage to care guidelines in Tanzania

The Ministry of Health and Social Welfare in Tanzania developed the National Comprehensive HTC Guideline, which combines all aspects of HTC into one document. These include VCT, PITC, home-based counselling and testing, outreach HIV testing, and special organized testing events and campaigns, in order to facilitate smooth entry to care and treatment services (NACP, 2014). This was expected to increase access to the care and treatment services through increased service outlets, although the literature demonstrates that referral and linkage remain problematic in Tanzania, with a number of studies showing a linkage of less than 28% within a year (MRACP, 2014; Nsigaye et al., 2009; Simmelink, 2014). The national HTC guidelines (2013) stipulate that after completion of HIV testing, all HIV positive clients should be linked to HIV care at designated centers known as care and treatment centers (CTCs), to assess their need of anti-retroviral therapy (ART), as well as to assess their immediate medical needs, and provide TB screening (NACP, 2012). Depending on CD4 results and clinical staging, the client will either be started on ART or will be followed up regularly to monitor disease progression (NACP, 2012; MOH, 2013). At the

time of the current study, the cut-off point for ART initiation was a CD4 count of 350 cells/ $\mu$ L. Tanzania has since adopted the most recent WHO guidelines for "test-and-treat", where someone who tests positive for HIV is immediately initiated on ART irrespective of their CD4 count (WHO, 2016).

#### 1.5. Mobile/outreach HIV Testing Services in Tanzania

In Tanzania, outreach and mobile testing sites have been implemented to improve on historically low rates of HIV testing (Ostermann et al., 2011; NACP, 2012; MOH, 2013). In response to these low rates, mobile and outreach testing sites have been introduced in Tanzania, reflecting an increased interest in providing early detection of HIV, and subsequent care and support for hard-to-reach populations (NACP 2012; MOH, 2013). Although outreach and mobile testing have increased the rates of HIV testing uptake in Tanzania (Ostermann et al., 2011; Njau et al., 2014), linkage to care from outreach as opposed to from facility-based testing sites has not been evaluated. However, research from South Africa and Kenya suggests that linkage to care may be poorer from outreach testing sites compared to facilities (Bassett et al., 2014; Naik et al., 2015; Muhula et al., 2016). Efforts are being made by the Tanzanian government to improve HIV testing and subsequent linkage to HIV care and treatment services, but studies conducted in various regions of Tanzania shows that linkage to care remains poor (Nsigaye et al., 2009; MRACP, 2014; Simmelink, 2014).

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#### 1.6. Description of study setting: Mbeya Tanzania

Tanzania is an East African country bordering Kenya, Uganda, Burundi, Rwanda, Congo, Zambia, and Malawi. Tanzania's population of about 45 million lives in 30 regions and 125 districts, with more than 80% of people living in rural areas. Mbeya region is situated in the southern part of the country, more than 800 km from Dar-es-Salaam. It has a population of 2,707,410 people, with about 80% of these being self-employed in small-scale business and farming (NBS, 2013). Mbeya region has eight administrative districts divided into ten councils. It is on the highway to Malawi, Zambia and Congo, and has high population mobility which is associated with cross-border business and social interactions, thought to pose a high risk for HIV infection and challenges for continuity of care (MRHR, 2010; MRACP, 2012). The majority of people live in remote hard-to-reach areas with infrastructure problems, including poor roads, and lack of electricity and water

(NBS, 2013; MRACP, 2014). About 23% of people in Mbeya live more than 5 km from a health facility, and 15% are more than 15 km from a health facility (TACAIDS, 2013).

#### 1.6.1. HIV/AIDS Status and health care services in Mbeya region

HIV/AIDS is one of the major public health problems in Mbeya region, and Mbeya has remained among the three regions with the highest prevalence of HIV in the country for over a decade (TACAIDS, 2013; MRACP, 2014). HIV prevalence in Mbeya was found to be as high as 16.6% among adults in the early 2000s (Arroyo et al., 2005).

The majority of health facilities in the rural areas do not offer CD4 testing or HIV treatment services. The region has a total of 430 health facilities in a distribution of 20 hospitals, 36 health centres, and 374 dispensaries. Out of these 430 facilities, 350 facilities provide Prevention of Mother to Child Transmission (PMTCT) services (MRACP, 2014). Mbeya has a total of 312 health facilities where clients can receive HTC services through recommended approaches; however, only 68 of these (21.7%) offer HTC services, posing a challenge to individuals who need to access HIV care services in the region (MRACP, 2014). Access to ART is a challenge for most HIV clients living in rural settings, with distance, poor infrastructure, and poverty being some of the constraints to successful referral of patients to facilities offering CTC services (MRHR, 2010).

#### 1.6.2. Addressing low rates of HIV testing: Mobile HIV Testing Services in Mbeya Region

Despite near universal knowledge about HIV testing and increases in facilities offering HIV testing in Mbeya, rates of HIV testing remain low. Reports up to 2010 showed that about 11.7% of people in the region had tested for HIV at least once in their lifetime (MRHR, 2010; NACP, 2012), while the THMIS found that 67% of adult women and 50% of men in Tanzania had been tested for HIV at least once in their lifetime. By 2013, Tanzania's UNAIDS 2014 progress report found that only 28.4% of people aged 15-49 had taken an HIV test in the past 12 months and knew their results (TACAIDS, 2013; AVERT, 2016).

Among the first Non-Governmental Organizations (NGOs) to deliver stand-alone VCT, outreach HIV testing services, and home-based care services were ANGAZA, which was working with the African Medical and Research Foundation (AMREF), and KIHUMBE (**Ki**kundi cha **Hu**duma

**Mbe**ya), meaning 'home-based care services in Mbeya', a local organization sponsored by USAID. (MRHR, 2010; AMREF, 2012).

Mobile and outreach services, mostly operated by NGOs, usually offer only VCT services. These sites typically do not offer HIV care and treatment services, with the exception of the research mobile laboratory operating under the Mbeya Medical Research Centre (MMRC), which offers CD4-count testing at the point of care. All clients that test HIV-positive must be connected to the nearby facility-based sites for registration or linkage into HIV care and treatment services, for further care and necessary support (MRHR, 2010; MRACP, 2014). There are now several NGOs, working in collaboration with the Mbeya Region AIDS Control Program, that are offering mobile/outreach HIV testing and counseling services in Mbeya including: Walter Reed Program, Mbeya HIV Network, KIHUMBE Oaktree, SHDEPHA, Engender health, ANGAZA, Mango Tree, Lufingo Waviu ('Waviu' is a Swahili word for people living with HIV), PHEDEA, ST JOHN HUS and CARITAS.

There are at least two organizations offering outreach HIV counselling and testing in each district of the Mbeya Region. The Mbeya Medical Research Centre (MMRC) mobile laboratory, also known as the Mobile Diagnostic and Training Centre (MDTC), has been offering CD4-count tests since 2009, covering between eight and twelve sites every three months (MMRC, unpublished data). Available statistics from the Mbeya Regional AIDS Control program annual reports (MRACP) suggest that more people undergo HIV testing at mobile/outreach HIV testing services (56%) compared to facility-based services (44%); however, only about 28% of all people tested were subsequently linked to HIV care (MRACP, 2012, 2014). In the next chapters, we will explore some of the elements influencing linkage to care in the two approaches to HIV testing services.

Despite efforts to reach clients and offer HIV testing services, the main challenge is still the linkage and continuity of care for HIV positive clients, especially in the rural settings. This is because most facilities in remote areas do not have the capacity to offer HIV care services, including HIV staging, CD4-count testing, ART initiation, and other necessary laboratory services (MRHR, 2010; MRACP, 2014). Nevertheless, the annual Mbeya Region Hospital Report (MRHR) shows that there has been a substantial increase in facilities offering HTC services and HIV education campaigns since 2006. HIV testing has improved, and by 2014 about 53.8% of people have ever

tested for HIV and received their results in Mbeya (THMIS, 2011/12; MRHR, 2014). HIV testing accessibility and uptake has improved, but linkage to care remains a challenge.

#### 1.7. Rationale of study

Tanzania has a high and uneven rate of HIV prevalence, with Mbeya region being among the three most-affected regions. There is increasing interest in accessing hard-to-reach populations along the highways and remote rural areas, and linking them to HIV care and management (Grabbe et al., 2010; van Schaik et al., 2010; Medley et al., 2013; MOH, 2013; Bassett et al., 2015).

HIV testing is available through health facilities and community-based HIV testing sites, such as stand-alone VCT, mobile and home-based services, and other outreach testing services like campaigns, door-to-door testing etc. Mobile testing activities have been instituted to increase access and uptake, and available statistics suggest that more people prefer testing at mobile outreach services than at fixed health facilities (MRACP 2012; Meehan 2014). Despite increased HIV testing opportunities, linkage to care remains low, and a comparison of the rates and processes of linkage to care between these models has not been conducted. Moreover, there is little documentation regarding the kinds of the population and the reasons for using different models of HIV testing. Based on other healthcare access models, there are reasons to expect that factors facilitating or inhibiting effective linkage to care would differ between different models of services delivery (Medley et al., 2013; Gerdts et al., 2014; Naik et al., 2015).

There has been little research on overall linkage to care in Tanzania, and to our knowledge, none on whether linkage to care differs between clients diagnosed at mobile/outreach sites compared to health facilities, nor on factors facilitating or inhibiting successful linkage to care between these two models of service delivery (Bassett et al., 2014; Labhardt et al., 2014). These differences may occur at the patient level, at service provider level, at the facility level, or at the level of the health system as a whole. For example, factors enhancing access to testing, such as dedicated outreach staff, may enhance linkage to care for those testing in mobile/outreach facilities, while factors such as geographic distance between patients' homes and testing sites, weak referral systems, and lack of structural links between testing and treatment sites, may lead to disconnects between testing and care (Holzemer et al., 2007; Nsigaye et al., 2009; Leon et al., 2014).

Hence, this study sought to describe and compare the populations accessing testing at mobile/outreach and fixed/facility-based testing sites, and to compare the processes and outcomes of linkage to care between these two models of HIV testing, as well as to identify the factors influencing linkage to care after a positive HIV test result. This study aims to describe and compare rates of linkage to care and to identify and explore the determinants of linkage to care in the 6 months following an HIV positive test result, in mobile and facility-based models of HIV testing in Mbeya region. The findings of this study will inform policy recommendations for HIV testing, linkage and continuity of care in the country.

#### 1.8 Outline of the thesis

After this introductory background chapter, Chapter 2 reviews literature related to HIV testing, linkage to care, and factors influencing the uptake of testing and linkage to care in a conceptual framework, which includes individual, healthcare provider, health system, and contextual levels. Chapter 3 presents the objectives, design and methods of the study, as well as more detail on the study setting within Mbeya region. The findings of the research are reported in Chapters 4, 5 and 6, in the form of manuscripts published in or submitted to peer-reviewed journals. Each manuscript addresses one or more specific study objectives. Chapter 4 presents the major quantitative outcomes of the study: the rates, timelines and determinants of linkage to care in the first six months after HIV diagnosis, between two arms of a cohort of over 1000 newly-diagnosed HIV positive clients who tested at mobile or outreach or facility-based sites. Chapter 5 reports quantitative and qualitative findings about the populations accessing the two models of testing, as well as the processes and dynamics of testing and linkage to care between the two models, while Chapter 6 explores the primary outcomes more deeply by reporting primarily qualitative findings about the facilitators and barriers to linkage to care. Chapter 7 summarizes and synthesizes the findings, and discusses them in relation to the literature, the study objectives, and the conceptual framework. Finally, Chapter 8 offers the conclusions of the study, and recommendations arising from this research.

#### **CHAPTER TWO**

# LITERATURE REVIEW and CONCEPTUAL FRAMEWORK

#### 2.0. Introduction

This chapter reviews the literature about the uptake and modalities of HIV testing and linkage to HIV care after testing HIV positive. The first section reviews different approaches and models of HIV testing, in relation to the Tanzanian national guidelines for HIV testing and HIV management. This section also covers factors that influence uptake of HIV testing. The second section of the literature review concerns the processes for linkage to care in HIV treatment programs. In this section, the factors that influence successful linkage to care are reviewed. In the final section, a conceptual framework that proposes to investigate linkage to care at the individual level, healthcare provider level, health system level, and contextual levels is presented.

#### 2.1. Approaches and guidelines for HIV testing and counselling

HIV testing is an important step for HIV-diagnosed individuals to seek and receive treatment and care, thus contributing to preventing further HIV transmission. As medications and treatment for HIV become widely available, HIV testing and efforts to link HIV-positive individuals to available treatment and care have become important policy priorities in African countries (Staveteig et al., 2013; Gerdts et al., 2014). Despite the fact that more than 90% of people in Africa are aware of HIV and know where to get HIV counselling at testing services, HIV testing uptake is still not optimal (Musheke et al., 2013; Mabuto et al., 2014). Literature shows multiple factors influencing peoples' decision to go for HIV testing, including deterioration of physical health, the death of a sexual partner or child, and availability of treatment (Musheke et al., 2013; Layer et al., 2014). On the other hand, fear of HIV-related stigma, perceived inability of health workers' to maintain confidentiality, long distances to VCT sites, and the psychological burden of living with HIV inhibit uptake of HIV testing, and hence generate the need for expansion and use of alternative models for HIV testing services to improve uptake (Matovu & Makumbi, 2007; Musheke et al., 2013; Mabuto et al., 2014). The World Health Organization (WHO, 2012) underlines that no single HIV testing delivery model will suit different types of epidemics and different intended

beneficiaries, and thus suggests that countries should use a combination of approaches to expand HIV testing services, improve access for hard-to-reach populations, and serve people who are unlikely to seek HIV testing on their own (WHO, 2012; Staveteig et al., 2013). Improving access to tests can help identify people in the acute stage of HIV infection and timely initiation of ART leads to better outcome of HIV management (Hatcher et al., 2013; Wilton & Broeckaert, 2013).

#### 2.1.1. HIV testing and available approaches

HIV tests became available in 1985, some years after the HI virus was discovered to cause AIDS. HIV testing services were initially only available in clinic settings, offered to patients presenting with AIDS-related symptoms. Before treatment for HIV was available, many people questioned the benefit of HIV testing, and the potential harms that might arise following a positive HIV diagnosis (WHO, 2012; Staveteig et al., 2013). With the availability of ART in developing countries, Provider-initiated testing and counselling (PITC) began to be considered and promoted (Staveteig et al., 2013; Kok et al., 2015).

PITC is a strategy where healthcare personnel recommend HIV testing, usually to individuals whose symptoms suggest HIV infection, or whose presumed behaviour suggests exposure (WHO, 2012; MOH, 2013) though as discussed below it is sometimes offered routinely to all clients in health facilities. It was begun in the Antenatal care (ANC) clinics following the finding that ARVs could reduce mother-to-child transmission (MTCT), however, PITC implementation was limited (WHO, 2012). The WHO suggested that PITC should also be prioritized in other clinical settings, like TB, STI and key population clinics (WHO, 2012).

In Tanzania, HIV testing and counselling was introduced for the first time in 1989, but initially offered in the clinic setting only. During the roll-out and scale-up of this service package, and evolution of other testing and counselling approaches including mobile and outreach testing in 2004, VCT services were offered outside clinic settings (WHO, 2012; MOH 2013). The use of different approaches and models of HIV testing service delivery, from health facility-based to mobile/outreach services, have been explored to reduce stigma and discrimination around HIV/AIDS, thus helping people to know their HIV status and access treatment that improves quality of life (WHO, 2012; AVERT 2013).

HIV testing through mobile and outreach services, including but not limited to stand-alone VCTs, workplace testing, door-to-door campaigns, and other outreach testing, was introduced as an alternative model to service delivery in remote areas (NACP, 2012; MOH, 2013). Available evidence shows that a significant percentage of people prefer to test for HIV in the mobile or other outreach services, rather than at facility-based sites (Ostermann et al., 2011; MRACP, 2012). Receiving results immediately after testing was reported to reduce people's anxiety, hence making the initial approach to testing and returning for results a few days later obsolete (USAID, 2009; MOH, 2013).

#### 2.2. HIV testing at facility-based or clinic setting

Facility-based HIV testing is a component of specific health care services offered in clinical settings that could be a place of addressing other health problems as well (Staveteig et al., 2013). The first HIV tests became available in 1985 and it was initially performed only in hospitals or clinic settings. In the public healthcare facilities, HIV testing and counselling (HTC) was made available as part of an integrated clinical service (Meehan et al., 2015; Staveteig et al., 2013).

Multiple factors, including poor access to health facilities, failure of risk-based assessments as the basis for testing, stigma, fear, and practical obstacles, such as transportation and cost were noted to affect uptake for HIV testing (Bassett & Walensky, 2010). Also in Meehan et al., (2015) instances of poor staff attitude and long waiting times were reported as obstacles to HIV testing at public health facilities. Literature shows that uptake of HIV testing has been increasing in the Sub Saharan African countries, due to availability of ART and technology for instance, availability of rapid tests and less invasive testing reduced the burden to the client and care providers and the necessity of returning to the clinic to receive results was removed and thus increasing uptake for HIV testing (Rizza et al., 2012; Staveteig et al., 2013; WHO, 2012).

In health facility settings, Provider-initiated counselling and testing (PITC) or routine HIV testing—refers to HIV testing and counselling recommended at health care facilities as a standard component of medical care. Routine HIV testing in clinic setting was recommended in 2007 by World Health Organization to increase HIV testing uptake and to avoid missed HIV testing opportunities in health care facilities so that more people can be diagnosed, linked to HIV care, and provided ART. This has shown improvement in antenatal care, STIs and Tuberculosis departments (Bassett & Walensky, 2010; Rizza et al., 2012; WHO, 2012).

# 2.3. Addressing barriers to HIV testing through mobile/outreach and community testing programs

Among other advantages of mobile and outreach testing, it was reported that the approach decreased transport costs and other social barriers to HTC access common at the facility-based services (UNAIDS, 2010; WHO, 2012; Medley, 2013). Meehan et al. (2014) reported that Mobile HTC provides an opportunity to target specific populations and settings like the workplace, transport hubs, and communities. Thus, mobile and outreach HIV testing approaches play a major role in reaching groups of people who do not typically access HIV testing services at a clinic. These approaches were also expected to remove structural, logistic and social barriers to HTC, including—in the case of home-based and mobile or outreach HTC—costs associated with transportation to facility-based services (WHO, 2012; Meehan et al, 2014). UNAIDS (2010) reported that such community-based programs have improved HIV testing and linkage to care, as well as strengthening community mobilization and attitudes towards HIV/AIDS in general. In a randomized comparison of home and clinic HIV testing in Uganda, Lugada et al. (2010) found that more people preferred home-based testing than clinic testing; this was also reported in Tanzania and South Africa by MRACP (2012) and Meehan et al. (2014). Studies conducted in South Africa and Tanzania on characteristics and choices of people for different HIV testing approaches showed more men access mobile HIV testing services than clinic testing (Meehan et al, 2014; Njau et al., 2014). This finding emphasizes the importance of taking HIV testing services to the people to enable them to utilize the opportunity (Grabbe et al., 2010; Bassett et al., 2015)

A systematic review of home-based voluntary HIV testing in Sub-Saharan Africa showed high acceptability of outreach and home-based HIV testing models: more than 70% of people tested at HIV testing campaigns and home-based testing services (Sharma et al., 2015). In a study conducted in Cape Town on characteristics of clients accessing mobile compared to clinic testing sites, the clients tested at the mobile HTC reported that they were passing by and took advantage of the opportunity to test, while those who accessed care at the clinic-based site reported that it was because the clinic was closer to home or workplace (Bassett et al., 2015). Distance and travel

cost to the testing site was not statistically significant, although time spent was less in the mobile than the clinic testing sites (Meehan et al., 2014; Naik et al., 2015).

#### 2.4. Linkage to HIV Care and treatment

Effective linkage to HIV treatment care and support is a critical step in the HIV treatment and care cascade (WHO, 2012; Gerdts et al., 2014). All individuals diagnosed as HIV positive at any HIV testing site have to be properly linked to HIV care and treatment for assessment of immediate medical needs (WHO, 2012; MOH 2013). Immediate linkage to HIV treatment, care and timely initiation of ART leads to a better prognosis of the disease, and prevention of transmission of HIV to others (WHO, 2012; Hatcher et al., 2013). There was limited literature on HIV linkage to care at the time of this study, with most literature becoming available in 2014-2017.

A range of factors may facilitate or mitigate the process of linkage in the trajectory of HIV care from the point of diagnosis to initiation of ART. These influences may occur at the level of the patient/individual, the healthcare provider, or the health system, or may be influenced by other factors acting at the structural or contextual level. Interruptions may occur at the level of the individual, such as choosing not to go for a repeat visit (Macpherson et al., 2012; Layer et al., 2014). However, this interruption may reflect a problem in communication or relationship with the care provider, or with the organization of the program or the health system, as well as factors intrinsic to the patient's context, such as family or work commitments, lack of money for transport costs, and long distances to the clinic (Nakigozi et al., 2013; Wachira et al., 2014).

#### 2.4.1. Poor linkage to care

Low or delayed linkage to care leads to HIV positive individuals not benefiting from HIV care. Hence, efforts to improve coverage for HIV care and treatment services are hampered, resulting in increased risk of HIV transmission to others (Hayes et al., 2011; Mugavero et al., 2011; Gerdts et al., 2014) A study conducted in KwaZulu-Natal, South Africa, reported that about 82% of people knew their HIV status, but only 45% had been linked to HIV care and treatment services (Haber et al., 2016). In a study conducted in Los Angeles on testing and linkage to care for 717

HIV positive clients, it was found that about 60% entered into care within 3 - 6 months after HIV results, but 34% of clients had still not entered into care after one year (Oruga et al., 2012). It was also pointed out that people testing in sites with no HIV care facility were more likely to be unlinked to care compared to those testing in sites with HIV care services, and more males were not linked to care than females (Oruga et al., 2012; Wachira et al., 2014). A study conducted in Lesotho pointed out that a community-based HIV testing and counselling approach is widely used in Africa as part of scaling up HIV testing access, but the rates of linkage to care and ART initiation are still low (Labhardt et al., 2016). In another recent study, conducted in Umlazi township, in Durban, South Africa, on linkage to HIV care, it was found that individuals testing at the mobile services were 33% less likely to undergo CD4-count tests than individuals testing at the clinic services (Bassett et al., 2014). The evidence from the literature shows that linkage to care is still a problem in many SSA countries.

#### 2.4.2. Barriers to successful linkage to HIV care

Literature shows that multiple factors may be responsible for delay or failure for linkage to HIV care at different levels (Figure 2: Conceptual framework). Studies conducted in South Africa, Kenya and Tanzania found that fear of stigma, lack of disclosure of HIV status to relatives or other individuals, and being reluctant to enter into HIV care if asymptomatic at the time of diagnosis were the key factors reported as barriers to successful linkage to care at the individual level (Layer et al., 2014; Ostermann et al., 2015; Sharma et al., 2015; Fatoki, 2016;) The authors argued that delay in seeking care after testing HIV positive was more likely to happen in clients who did not expect to get HIV positive results and those who had difficulties in disclosing their status (Medley et al., 2013; Naik et al., 2015).

At the provider level, negative healthcare provider attitudes and limited support were reported to hinder linkage and engagement into care (Govindasamy et al., 2012; Layer et al., 2014). At the program and health system level, the published literature shows a number of factors influencing linkage to care. A study conducted in Mwanza, Tanzania by Nsigaye et al. (2009) on linkage to care and referral systems to HIV care and treatment, showed a very low linkage (14%) at four months after HIV diagnosis. The study pointed out that the 86% of clients diagnosed with HIV who were not linked to care and treatment services had missed opportunities for timely initiation

of antiretroviral therapy, resulting in poor prognosis of the disease (Nsigaye et al., 2009). Respondents in this study expressed a desire for HIV treatment services to be in close proximity to their homes, rather than being referred to the city for further HIV care (Nsigaye et al., 2009). Another study on barriers for linkage conducted in Iringa, Tanzania reported multiple compounding barriers to linkage and progression in the continuum of HIV care, including rigid clinic organizations or practicalities of care at the clinic, congested clinics, poor service, and clinics being out of stock of supplies (Layer et al., 2014).

Availability of alternate healing systems (like spiritual or traditional treatment), long distances to the facility offering HIV care services, and costs related to transport were among the contextual factors associated with delay or failure to linkage into HIV care services (Nsigaye et al., 2009; MacPherson et al., 2012; Mutasa-apollo, 2013; Layer et al., 2014; Genberg et al., 2015).

#### 2.4.3. Facilitators of successful linkage to care

Studies conducted in Kenya, Tanzania, Uganda, Malawi and South Africa on factors facilitating linkage to care indicate that these factors can be grouped at the individual or patient, health provider, health system, and contextual levels (MacPherson et al., 2012; Hatcher et al., 2013; Layer et al., 2014). It has been shown that the disclosure of HIV positive sero-status to the spouse or family members, and social support from significant others, increased the likelihood of enrolling into care at the individual level (Hatcher et al., 2013; Hodgson et al., 2014; Layer et al., 2014). A good relationship between patients and healthcare providers, proper education, and availability of equipment were mentioned as enhancing linkage to care at healthcare provider level (Govindasamy 2012; Nakigozi et al., 2013). Integration of HIV testing and HIV care services, good patient-staff relationships, and short clinic waiting times were some of the factors identified to enhance linkage to HIV care at health system level (Genberg et al., 2015; Naik et al., 2015). At contextual level, short distances to the care and treatment centres, availability of home-based care providers, and community mobilization activities facilitated linkage and engagement into HIV care (Hatcher et al., 2013). Some studies on linkage to care pointed out that enhanced or facilitated linkage to care achieved higher percentage of linkage and timely ART initiation, and ultimately suppression of viral load in individuals diagnosed with HIV (Kapp et al., 2014; Sharma et al., 2015; Ware et al., 2016; Kiene et al., 2017).

#### 2.5. Guidelines for HIV testing and HIV management

Development of global guidelines that ensure the appropriate use of evidence is one of the core functions of the WHO (WHO, 2012). The WHO has been developing and updating HIV prevention, care, and treatment guidelines as the need arises, based on the research and development of antiretroviral treatment of HIV/AIDS (WHO, 2016). The WHO (2012) recommended the use of a combination of strategies for HIV testing and counselling because it was realized that the modalities for HIV testing at the health facility premises will not be able to reach most people, especially those in remote areas. It was recommended that countries should choose a combination of approaches to increase HIV testing uptake, and link HIV positive patients into care for timely initiation of ART (WHO, 2012).

#### 2.5.1. HIV testing guidelines in relation to different HIV testing approaches in Tanzania

Like most African countries, Tanzania follows WHO recommendations for the management of HIV/AIDS (MOH, 2015). For smooth implementation of HIV testing with different approaches, the Ministry of Health and Social Welfare in Tanzania recently drafted the National Comprehensive HIV Testing and Counseling (HTC) guideline, which combines all approaches to HTC into one document. The aim of this guideline is to improve HIV testing, prevention, linkage and enrolment into care, retention and adherence in general HIV care and treatment, and management of comorbidities in HIV/AIDS (NACP, 2014). Home-based and other outreach HIV testing programs have been put in place to improve the low uptake by community members of HIV testing and subsequently linking those individuals to HIV CTCs. Since most of the outreach/mobile HIV testing sites do not have the ability to offer HIV treatment and care services, the National comprehensive guideline for HIV testing and counselling (2013) emphasizes the importance of connecting all HIV positive diagnosed clients into HIV care for the proper management of HIV/AIDS. According to the guidelines, "It is the responsibility of HTC program and providers to ensure that HTC clients and patients are connected with appropriate services following HTC" (MOH, 2013, p-8).

During the time of this study (2014), Tanzania's HIV/AIDS management was still following the previous WHO clinical staging recommendations, that require CD4 counts to complement the clinical stage classification system, with a cutoff point for ART initiation of a CD4 count of 350 (NACP, 2012). The National guideline on management of HIV/AIDS indicates that provision of HTC, including ARVs, should take place at assessed and registered healthcare facilities, which have trained personnel (MOH, 2015). These CTC facilities should also be integrated with other services, such as TB clinics, Sexual and Reproductive Health, Family Planning, PMTCT, social welfare and spiritual support, legal support, and home-based care services (National AIDS Control Program, 2015).

#### 2.5.2. Guidelines for managing newly-diagnosed HIV clients

The 2013 National Standard Operating Procedures for HIV Care and Treatment - Tanzania (NACP, 2013) recommended the following steps for managing HIV diagnosed clients:

#### **Initial clinic visit:**

- Assess patient's needs, record demographic information and patient contact details, issue relevant forms, and direct patient to appropriate point of care.
- Do a confirmatory HIV test if there is doubt of their status, and CD4 cell count or sputum smear if indicated before the patient meets a counsellor and a clinician.
- Specimen/samples (like blood, urine, sputum) for baseline investigation should be done within the facility or sent to a referral laboratory on the same day.

#### **Follow-up visit:**

- Patients recommended for therapy will meet a counsellor/clinician to discuss adherence, dosing, and adverse reaction management.
- Patients will be scheduled for follow-up monthly for the first six months depending
  on an assessment by the clinician. After the patient is clinically stable with good
  adherence for at least six months or more and no history of drug toxicity or recurrent
  OI he/she may see at two-monthly intervals or more as agreed between clinicians and
  the patient.

- During the visits, patients will see a clinician, pick up medication, and meet a counsellor.
- At six months intervals, CD4 counts, and other blood tests will be performed. Patients will be evaluated to assess response to therapy.
- Patients not yet eligible for ART require regular clinical and laboratory assessment (clinical staging and CD4 count) every 6 months.
- All patients should report to CTC if their condition deteriorates even if it is before their next scheduled visit.

# 2.6. Loss of patients between HIV Testing and HIV Care and Treatment Center

A recent and growing body of literature on retention in HIV care between testing and treatment in sub-Saharan Africa reveals a significant loss of patients in every step of the process, from HIV testing to registration at the CTC (Losina et al., 2010; van Schaik et al., 2010; Mugglin et al., 2012; Evangeli, Newell, & McGrath, 2016; Haber et al., 2015). A systematic review for sub-Saharan African countries showed that about one-quarter of HIV positive individuals are lost to care between testing HIV-positive and having a CD4 count done (Sharma et al., 2015). Some clients do not register at any healthcare facility at all, and this is especially true for those who are asymptomatic (Layer et al., 2014; Wynberg et al., 2014). From the initial visit to the healthcare facility to receipt of CD4 count results or clinical staging, about 41% of patients who provide samples for CD4 never return for their results (Elul et al., 2014).

In a systematic review and meta-analysis for sub-Saharan Africa on loss to follow-up between HIV diagnosis and ART initiation, it was found that individuals who were not eligible for ART were more likely to be lost to follow-up compared to clients who were eligible for ART (Mugglin et al., 2012). Elsewhere it was reported that some loss to follow-up occurs in early stages of the care cascade before the clients' ART treatment eligibility is known. It was argued that patients have to complete several visits to the facility before it is decided whether they need immediate care or not, resulting in loss of clients between HTC and HIV care (McGrath et al., 2010; Haber et al., 2015). HIV positive clients living more than 10 kilometres from an HIV care facility are

more prone to drop out of the cascade compared to those living closer to the HIV care facility (Losina et al., 2010; Govindasamy et al., 2011; MacPherson et al., 2012).

#### 2.7. Conceptual Framework for factors influencing successful linkage to care

As shown above, interruptions in successful linkage to and subsequent continuity of care among HIV positive patients may occur at different levels, and a range of factors may enhance or inhibit the process from the point of diagnosis to initiation of ART (Nsigaye et al., 2009; Hatcher 2012). The interruptions or barriers may occur at the level of the patient, due to stigma, being asymptomatic at the time of diagnosis, denial, lack of support from family or friends, or failure to disclose to the spouse and significant others. (Medley et al., 2013; Cummings et al., 2014; Dima, Stutterheim, Lyimo & de Bruin, 2014; Layer et al., 2014). At the healthcare provider level, a poor patient-staff relationship, lack of privacy, and confidentiality concerns may influence a client's decision to enter HIV care (Govindasamy et al., 2012; Nakigozi et al., 2013; Sharma et al., 2015). At the health system level, over-crowded or congested clinics, long waiting hours, poorly organized clinic procedures, and lack of laboratory services, machines and reagents were some of the reported factors negatively influencing linkage and continuation in HIV care (MacPherson et al., 2012; Hatcher at el, 2013; Nakigozi et al., 2013; Wachira at al., 2014; Sharma et al., 2015). Sometimes the wider socio-economic and cultural context may influence a client's decision to enter HIV care, such as long distances to the clinic offering HIV care service, high costs related to transport and work commitments.

Thus, people may be influenced by factors acting at one or more of these levels (Rosen & Fox, 2011; Gerdts et al., 2014; Hodgson et al., 2014; Layer et al., 2014). For example, all HIV positive clients should be given a referral letter or memo for the nearby CTC. However, at the CTC, the clients may require a number of visits before a decision is made regarding whether s/he needs to start treatment or not. An interruption in linkage and continuity may occur at the level of the patient if the client does not to go to a repeat visit, although this interruption may reflect a problem with the organization of the system, or communication from the provider, as well as factors intrinsic to the patient and his/her context, such as family or work commitments, or lack of money for transport costs (Rosen & Fox, 2011; Hatcher at el., 2013; Naik et al., 2015; Sharma et al., 2015). All of these factors and processes may interfere with linkage and continuity of care, therefore efforts must be

made to ensure successful linkage into care by addressing the factors influencing linkage to care at all levels (Gerdts et al., 2014; Maulsby et al., 2015; Katz et al., 2017).



Clients tested at F/facility Clients tested at VCT/Mobile Care and Treatment center System level Health center Patient level District level hospital Inhibiting factors Regional hospital **Inhibiting factors** Number of visits or appointments given Poor Referral system Social demographic factors Fragmentation of HIV related Contextual Provider level Time lapse between registration, to ART eligibility, and to ART initiation Number of visits /appointments Asymptomatic clients (not feeling Lack of feedback and Inhibiting factors Inhibiting factors communication Poor Information to the client Lack of resources Enhancing factors Unskilled staff Long distance to the CTC Good understanding of Poor Staff/patient **Enhancing factors** importance of HIV care Adequate resources (CTCs and Patient being sick or in pain Enhancing factors: Proper **Enhancing factors** Staff) Information, Competent staff Well equipped facilities Availability of equipment's One stop-services Shorter distances to the Good staff/patient relationship CTC Well motivated staff Low costs/free Hatcher et al, 2012; Naik, 2013, Nsigaye et al., 2009;PwP, 2013

Figure 2: CONCEPTUAL FRAMEWORK HIV LINKAGE TO CARE

& Layer at el, 2014

## **CHAPTER 3**

# AIMS AND OBJECTIVES, METHODOLOGY AND ETHICAL CONSIDERATIONS

## 3.0. Aims of the study

This study aims to describe and compare rates and determinants of linkage to care in the first six months following an HIV positive test result, between mobile and facility-based models of HIV testing, in Mbeya region, Tanzania.

## 3.1. Specific Objectives:

- 1. To describe and compare the populations accessing testing at mobile/outreach versus fixed/facility-based testing sites in rural settings of Mbeya.
- To measure and compare time to linkage to care of HIV positive individuals tested at the mobile versus facility services, over the first six months after diagnosis in rural settings of Mbeya.
- 3. To describe and compare the processes and dynamics of linkage to care between mobile and facility-based models.
- 4. To identify factors (patient, provider, health system, and contextual barriers and facilitators) associated with linkage to HIV care services among newly diagnosed HIV positive individuals in the mobile services and facility-based services.

# 3.2 Study design and overview of the project

This study used an explanatory sequential mixed method design, where qualitative methods were applied to explain the results obtained by the quantitative study (Creswell, 2015). Mixed methods study designs have been viewed as a useful alternative to either quantitative or qualitative method alone, as the strengths of one method mitigate the limitations of the other, yielding more informative and useful results (Leech & Ownuegbuzie 2007; Creswell, 2015).

#### 3.2.1. Quantitative study

Quantitative data were collected through a cohort study, in which 1012 newly HIV diagnosed individuals, who tested in either facility-based or mobile/outreach site were enrolled and followed up for a period of six months. Data were collected through documents, guidelines, and records (register books and reports) to gather information related to individuals attending HIV testing services in both mobile and facility-based testing sites. The cohort participants were interviewed using structured questionnaires at different points over the first six months after diagnosis, to gather information on HIV testing and linkage to care. The design allows measuring of the outcomes and determinants of linkage to care over time in the two models of HIV testing service delivery (described in detail in Chapter 4). In addition, the clinic registers for all clients (n=11,733) testing at the study sites over the study period were reviewed, as described in Chapter 5.

#### 3.2.2. Qualitative study

Qualitative data were collected by conducting focus group discussions and in-depth interviews with the individuals enrolled in the cohort study. Additional data were collected through interviews with healthcare providers in the study sites, and observation/field notes from the sites. A descriptive and explanatory qualitative approach was used to describe the processes and dynamics of linkage to HIV care and treatment. Focus group discussions and in-depth interviews were used to collect information from the cohort participants, focusing on what happened from the time of diagnoses to the time of the interview, discussing their experiences of the procedures and timelines of registration, sample provision, and receiving their CD4 results, along with initiation of ART. We also interviewed one or two healthcare providers in each study site to gather information on linkage to care. A qualitative approach was also used to collect information on barriers and facilitators to linkage to HIV care and treatment (refer to Chapter 5).

A qualitative approach captures the voice of respondents and allows participants' experiences, feelings, or concerns to be well understood (Creswell, 2015). This approach was chosen to allow the gathering of information on participant's experiences on HIV testing and linkage to care.

#### 3.2.3. Phases of the study

This study was conducted in two phases:

#### Phase I

The **first phase** comprised a review of documents, guidelines, register books, and records or reports at each site to gather information on individuals testing, referrals, and linkage to care, as documented in the routine records of the 16 study facilities during the study period. In this phase, the study looked at:

- The number and proportions of individuals testing for HIV in the two models of services during the study period.
- Demographic characteristics of people attending facility-based testing versus mobile testing for HIV.
- Documentation, records, reports and availability of guidelines at the selected study sites.

#### Phase II

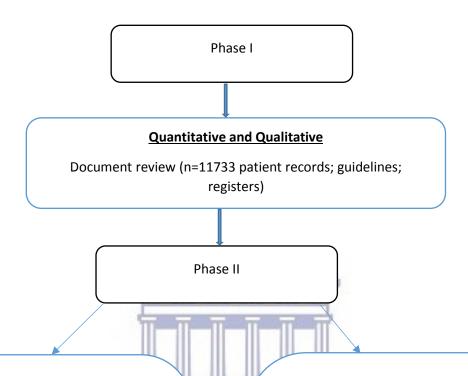
The **second phase** involved enrolling 1012 adult individuals who had recently tested HIV positive into a cohort study and following them for six months to gather information on linkage to care (from diagnosis to registration at a CTC for HIV care). Participants were enrolled in groups based on where they had gotten tested: 1) those tested at fixed public-sector facilities (facility-based), and 2) those tested at mobile, stand-alone VCTs, or any other outreach HIV testing services. In addition, a subsample of the cohort and a sample of healthcare providers were recruited for further interviews. Both quantitative and qualitative data collection methods were used in this phase. In this phase, the study looked at:

- ins phase, the study looked at.
- Demographic characteristics of participants in the cohort.
- The proportion of individuals in each group who linked to HIV Care in the study period.
- The time between HIV positive diagnosis to registration at an HIV care unit.
- Referral systems/procedures in place, and processes of linkage to care.
- Documentation, processes and dynamics of linkage from healthcare providers' and clients' perspectives.

- Timelines from one step to another in the cascade of HIV care (e.g. the time from registration to the provision of blood for CD4, time of results availability, ART initiation etc.)
- Factors (facilitators and barriers) influencing linkage to HIV care.



Figure 3.1: The framework of study phases and research activities



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#### Quantitative

#### At enrollment visit:

Administration of baseline structured questionnaire.

Questions focused on client's profile, reasons for testing and willingness or plans to enter HIV care (n= 1012).

#### At 3 and 6 months:

Administration of second structured questionnaire at 3 months (n= 885) and third questionnaire at six months (n=840), focusing on the process of linkage to care and determining their stage in HIV care.

#### **Qualitative**

Individual interviews with health care providers (n= 1-2 per site, total N= 20) to elicit information on process and procedures of linkage to care.

Individual interviews with newly HIV diagnosed clients at the end of six months (n=10).

Focus group discussions (n= 8 - FGDs) with HIV positive individuals (total N= 68) enrolled in the cohort to discuss:

- Experiences and challenges in HIV care
- Their feelings and opinions about HIV care services in their respective sites.
- Setbacks for successful linkage and continuation in care

## 3.4. Study setting

The study was conducted in four districts of Mbeya Region in 2014. In 2012, the Mbeya region had a population of 2,707,410, consisting of 52% women and 48% men (NBS, 2013). The four study districts were selected to include high HIV-prevalence areas and hard-to-reach populations. Two districts (Kyela and Mbozi) are along the highways and have borders with Zambia and/or Malawi. The population in Kyela district was 221,495 in 2012, while Mbozi had 446,339 residents. High population mobility associated with cross-border business and social interactions is thought to pose challenges to linkage to and continuity of care in these districts. The other two districts (Mbeya Rural and Chunya) have a larger proportion of residents who live 10 km or more from a health facility. The population in these remote districts was 305,319 and 290,478 respectively (NBS, 2013). The HIV prevalence among people tested for HIV in 2014 in the selected districts was Mbeya Rural - 13.0%, Chunya - 9.2%, Kyela - 9.2%, and Mbozi - 8.7%.

The study was conducted at 16 sites (eight facility-based and eight mobile/outreach sites), offering HIV testing and care services. Facility-based sites included hospitals, health centres or dispensaries, while mobile sites coordinated by NGOs used mobile vans or trucks, fixed tents, or offering services at stand-alone HIV testing sites. The eight facility-based sites selected in this study offered HIV testing services, as well as HIV care services (i.e. had a CTC within the same location). Sites had different arrangements for the first step of linkage to care, which is registration. In some facilities, registration was possible on the same day as testing, while other facilities had chosen a single day or two days per week for newly-diagnosed clients to register for HIV care. None of the mobile/outreach sites offered CTC services and had to refer their clients to the closest CTC for further management (HIV staging, laboratory test, and ART initiation). The mobile site from MMRC offered CD4 tests at the point of care but still had to refer newly-diagnosed clients with their CD4 results to nearby HIV care clinics or CTCs for registration and continuation of care. The study followed all study participants enrolled into the cohort for six months including those who did not link into HIV care, with the exception of the 17% of participants who were lost to follow up or died during the study.



Figure 3.2: Map of the study selected districts in Mbeya region Source- Tanzania Census General Report - 29 March 2013

Table 1: Names of sites participating in the study

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Districts	Facility-based	Mobile/outreach	
Kyela district	Kyela Hospital	St John Hus (NGO)	
	Ipinda Health Center	Research mobile lab	
Mbeya Rural	Ifisi Hospital	Kihumbe – Mbalizi	
	Inyala Health Center	Research mobile lab	
Mbozi	Vwawa Hospital	SHDEPHA	
	Tunduma Health Center	Research mobile lab	
Chunya	Chunya Hospital	Kihumbe-Chunya	
	Makongolosi Dispensary	Research mobile lab	

## 3.5 Quantitative study

### 3.5.1. Study population and sampling

The study population comprised adults above 18 years receiving HIV testing at the facility-based and mobile/outreach sites in the four study districts of Mbeya region, all adults registering in CTCs in Mbeya region, and staff working at the mobile and facility-based testing sites and CTCs in Mbeya region.

Four sites in each district (two facility-based and two mobile services) were randomly selected, for a total of sixteen sites to be included in the study. For the quantitative part of the study, all public or mission (faith-based) based, and outreach/mobile sites offering HIV testing services in the selected districts were listed. A total of 27 health facility and four mobile/outreach sites were listed in Mbeya rural, 20 health facility-based and four mobile/outreach sites in Chunya district, 14 facility-based and five mobile/outreach sites in Kyela district, and 29 health facility-based and five mobile/outreach sites in Mbozi district. Four sites in each district (two facility-based and two mobile/outreach) were randomly selected from the list in each district using a table of random numbers. (I.e. a total of 90 facility-based sited and 18 mobile sites from the four study districts were the sampling frame from which a random sample of eight facility-based sites and eight mobile/outreach sites was selected for this study).

## 3.5.2. Sample size

The sample size was calculated using Epi Info software, with a confidence interval of 95% and power of 90%, assuming that the two study groups would have the same number of subjects. We estimated that 30% of individuals tested through mobile/outreach services and 41% of individuals tested at facility-based services were expected to link into HIV care. The estimated sample size was 828; we adjusted this sample size to account for possible dropouts and non-responders (10%) resulting in a total estimated sample size of 900 participants.

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#### 3.5.3. Data collection and data analysis

#### Data collection tools/instruments

The data collection tools in this study included a structured questionnaire that was administered to the participants at three different times (during enrollment at day 0, at three months, and again at six months after diagnosis). Along with this, register books, guidelines, and monthly and annual reports, were used to collect quantitative data. Qualitative data were collected through focus group discussions and individual interviews with the cohort study participants, and an additional 20 individual interviews with healthcare providers in the study sites. All data collection tools (baseline and follow up questionnaires, site records/registers, FGD and in-depth interview guides) are included in Annexure 3.

#### Participant recruitment and enrollment into the study

Recruitment of participants to be enrolled in the study was done at the sites during morning health education sessions on HIV testing and results (normally provided by HIV nurse counsellors). After finishing the session, the nurse counselor introduced the research team to the attendees, then the researcher or research assistant explained the study in brief, and interested individuals were asked to meet with the research assistants in another room for further explanation of the study procedures, including asking for permission to get their test results and follow-up for possible questionnaire administration. Those potentially willing to participate in the study were invited for the enrollment and informed consent discussion and initial questionnaire administration (which occurred either at that time or at another time and place convenient to the participant, within seven days of the testing visit). On the day of enrolment, the participants were provided with an information sheet and informed consent to read, discuss and sign before undertaking any study procedure. The information sheet, consent form, and questionnaires were pretested, reviewed and refined in consultations with clients and healthcare providers at the sites which were not part of the study. These documents (information sheet and informed consent) are included in Annexure 2.

#### Data collection

Data collection was done between August 2014 and July 2015 at the 16 selected study sites (details in chapter 4, 5 and 6). The key outcome variables for the quantitative study were rates of linkage and time variance in the two models of HIV testing. The explanatory variables were factors associated with time variance in the linkage.

#### Data Analysis

Quantitative data were recorded, cleaned and analyzed using Stata Version 13 (College Station Texas. USA). Descriptive analysis methods were used to present the characteristics of participants. Categorical data were analyzed and presented using frequencies and percentage, while numerical was analyzed using the measure of central tendency and measure of dispersion. Normally-distributed data were reported by mean and standard deviation, and skewed data were reported by median and interquartile range. The Chi-square test was used to measure the association between dependent variables and categorical independent variables (age, sex, education, distance etc.). Cox regression was used to measure predictors of time to linkage in HIV care for variables that are time-dependent. Logistic regression was used to identify factors associated with the site of testing (mobile/outreach or facility-based), a likelihood ratio test was used to decide whether to keep a variable in the model if the P-value was <0.05. We compared the ratios and time variance in successful linkage to care using the Kaplan Meier estimator and Log-rank tests. Hazard ratio and corresponding 95% Confidence intervals (CIs) were used to identify factors associated with time-dependent variables. For the entire analysis, the significance level was 0.05.

#### 3.5.4 Validity and Reliability

Validity describes the extent to which a study captures what it is supposed to measure (Roberts, et al., 2006). To ensure validity, the study had a large sample size (1012 participants) and power (90%) sufficient to detect the outcome of interest. The study design used both quantitative and qualitative methods, allowing for substantiation and triangulation of information. The sampling methods used to select the districts and sites, as well as including both sexes of different age groups into the study, minimizes bias and increases the validity of the study. Selection bias was likely to occur because of the voluntary nature of the study. However, recruitment procedures encouraged and invited as broad a range of participants as possible to join the study. Comparison of the study participants' demographic characteristics with those of the general population accessing that testing site helped to indicate whether selection bias was significant. The instruments are questionnaires which are adapted from similar studies conducted in Tanzania by Nsigaye et al. (2009), and in South Africa by Naik (2013). The tools for data collection were pre-tested prior to the study, and the first 15 enrollments and interviews were used as a pilot to offer an opportunity

to discuss the clarity of the questionnaires and procedures with research assistants and enhance validity by allowing the researcher to further improve the data collection tools. Furthermore, the subjects for this study were followed up for six months, and the questionnaire was administered three times at different points (0 months, 3 months and 6 months) to increase the validity of data collected as a reflection of the processes and dynamics of linkage to care. An extensive literature review relevant to the topic was done to interpret the study findings. The data were analyzed using a trusted statistical package, thus increasing the validity of study findings.

Reliability describes how well a test will produce similar results in different circumstances (Roberts et al., 2006). To ensure reliability in this study, the research assistants and field assistants who collected data in the field underwent two days training on the study protocol and questionnaire administration. The researcher ensured that the questionnaire was clear, properly translated, and simple to understand, with most of the questions being closed-ended. The number of interviewers was limited to two trained interviewers per site to ensure consistency. The team regularly debriefed in the field to allow concerns/problems to be shared and addressed consistently. Standard operating procedures (SOPs) were designed for recruitment/enrollment procedures and questionnaire administration, and these were observed and supervised during data collection in the field to enhance reliability. Checking a random sample of 10% of questionnaires for completeness and accuracy and double entry of data after cleaning also increased reliability. The researcher was in the field continuously, visited the sites for questionnaire checking, supervision, and collection of questionnaires in the study sites. In cases of incompleteness of information or misunderstanding, the participant was traced and the data filled in accordingly.

# 3.6. Qualitative study

### Study population and sampling

For the qualitative part of the study, the study population consisted of the newly-diagnosed HIV positive individuals enrolled into the cohort, and the healthcare providers working at the HIV testing section or at the care and treatment centre in the selected study sites. Purposive sampling was used for selection of HIV positive clients from the cohort to take part in the individual interviews and focus group discussions. Selection considered the diversity of characteristics of

patients i.e. gender, age, education level, distance from the HIV care centre, and participants who had already registered at the care and treatment centre.

## 3.6.1. Data collection and data analysis

A total of eight focus group discussions, with 6- 12 participants in each group, were conducted with participants from the cohort for triangulation of information gathered from the quantitative part of the data. For individual interviews, ten participants from the main cohort were purposively selected to gather in-depth information about HIV testing and linkage to care, and their personal experience in HIV care services. One to two health care providers were interviewed and observations were done in each site in order to understand the processes/procedures and operations of the site with regard to HIV testing and linkage to care. The key variables or factors of interest were the factors influencing linkage to care at different levels (individual/patient, healthcare provider, health system, and contextual level). The interview guides are included with other study instruments in Annex 3.

Qualitative data were analyzed by thematic-content analysis (Miles & Huberman, 1994), supported by Atlas.ti Software v7 (Friese, 2013). Data transcripts and interview notes were transcribed and translated into English, categorized and coded according to factors influencing successful linkage to care at different levels, and themes of the study that were formulated in advance. Data from focus group discussions (FGDs) were analyzed and interpreted based on the themes established in advance, as well as emerging themes. The findings from the two arms of the cohort were compared and interpreted and triangulated with the quantitative findings. Data from both FGDs and individual interviews were analyzed by the researcher, and cross-checked by the supervisors.

#### 3.6.2. Rigour

Rigour is being thorough and credible in collecting data. Guba (1981) developed a model of four criteria of Trustworthiness (Credibility, generalizability, dependability, and confirmability) to ensure rigour in qualitative research. Credibility in this study was ensured by collecting information from people who have lived the experience and can provide rich information relevant

to study objectives. Triangulation of methods, data sources, and tools for data collection assisted with consistency and comprehensiveness of the data, thus enhancing credibility. Use of FGDs brought together a group of people who share experiences, which allows further triangulation of information. Study participants were followed up for six months, allowing for prolonged engagement between the subjects and research team; they spent sufficient time together for the subjects to be willing to open up.

In this study, coding and categorization of factors were done according to themes prepared in advance arising from the study objectives, which increased credibility. The interviews and FGDs were conducted in private rooms to offer privacy and freedom of expression to respondents. The researcher determined accuracy and completeness of information by member-checking during individual interviews. The findings in this study are less likely to be transferable to broader populations. According to Krefting (1991), in qualitative research each situation is unique, therefore is less likely for findings to be generalized. However, the researcher provided data and descriptions that are rich enough for other researchers to be able to make a judgment about the transferability of findings to different settings. To ensure dependability, the researcher trained research assistants who collected data in the field, (training for protocol, data collection tools, and questionnaire administration). Questionnaire pre-testing was done before beginning the actual study. To ensure confirmability of this study, the researcher checked the internal coherence of the data/findings. All interviews were audio recorded to make sure that nothing mentioned by the respondent is overlooked.

## 3.7 Overview of data collected against study objectives

#### Table 2: Summary of data collected to achieve study objectives

Objective	
	Data collected
Objective 1: To describe and compare the populations accessing testing at mobile/outreach versus fixed/facility-based testing sites in rural settings of Mbeya	HIV testing models available at the particular site.  Numbers of individuals testing for HIV in the two models of services.  Demographic characteristics of people attending facility-based testing versus mobile testing for HIV.  Proportions of people testing at fixed facilities compared to mobile services among all people tested.
Objective 2: To measure and compare time to linkage to care and loss to follow up of HIV positive individuals tested at the mobile versus facility services three and six months after diagnosis.	Demographic characteristics of participants in the cohort. Proportions of individuals who linked into HIV care in the study period for the two groups. Proportions of individuals lost to follow-up in the two groups. The time from HIV positive diagnosis to registration (link) at HIV care unit in the two groups.
Objective 3: To describe and compare the processes and dynamics of linkage into HIV care in the mobile and facility-based models of HTC service delivery.	Referral systems/procedures and processes of linkage.  Documentation of patterns and procedures of linkage from healthcare providers' and clients' perspectives.  Timelines in the cascade of HIV care (i.e. time between registration to the provision of blood for CD4, time of results availability, ART initiation etc.
Objective 4: Identification and description of factors influencing linkage to care in a group of newly diagnosed HIV positive individuals.	Identify and describe facilitators for linkage into HIV care. Identify and describe barriers for linkage into HIV care at the individual, provider, health system and contextual levels).

#### 3.8. Ethical considerations

The study was approved by the University of Western Cape (UWC) Senate Research committee, the Mbeya Medical Research Center, the Mbeya region Medical Research Ethics Committee (MMREC) and the Tanzanian National Institute for Medical Research (NIMR). The study took place within the routine schedule of volunteers, thus there were no extra visits for interviews. The risks involved were of emotional discomfort and inadvertent disclosure of HIV status. Respondents were well informed that participation in the study is completely voluntary. The aims of the study and methods were clearly explained to all potential study participants. All volunteers were given a study information sheet with details about the study which they read an informed consent form which they signed before any study procedure started. The volunteers were given an opportunity to ask any questions and were all answered before signing the informed consent form. Volunteers were ensured of confidentiality, and each participant enrolled in the cohort was assigned a study number that was used throughout the study. Respondents who participated in FGDs were asked to sign a confidentiality binding form and agreed to maintain confidentiality before the discussion. It was also explained that because the researchers could not guarantee that no one would disclose information from the discussion, it was important for people not to give any information that they feel is sensitive. It was furthermore explained that participants were free to withdraw from the study at any time without any negative consequences. If an interviewer came across an urgent health or other HIV-related problem during the course of the study, s/he was to refer the study participant to the nearest health facility. Otherwise, the study did not interfere with the natural course of activities and health-seeking behaviour of the study participants (Informed consent and information sheet –Annex 2).

# **SECTION II**

# **FINDINGS**

# **Introduction to study findings**

This section presents the findings of the study in the form of three manuscripts which have been published or submitted for publication. This introduction presents an outline of each paper, and the completed manuscripts follow as Chapters 4, 5 and 6. The references for each chapter have been included in the overall bibliography of the thesis, and are not separately included in these chapters. The manuscripts as published are included in the appendixes, with permission from the copyright holders.

Chapter 4 aims to measure and compare time to linkage to care of HIV positive individuals tested at mobile versus facility services over the first six months after diagnosis, in rural settings of Mbeya. Along with this, Chapter 4 looks at factors (patient, provider, health system and contextual factors) associated with linkage to HIV care services among newly diagnosed HIV positive individuals in the mobile services and facility-based services. It addresses Objectives 2 and 4 of the study. Chapter 5 describes and compares the populations accessing testing at mobile/outreach versus fixed/facility-based testing sites, as well as comparing the processes and dynamics of linkage to care. It addresses Objectives 1 and 3. Chapter 6 looks more deeply at Objective 4. It focuses specifically on facilitators and barriers to linkage to care at different levels, including patient, provider and health system levels.

## **CHAPTER 4**

PAPER 1: Linkage into care among newly diagnosed HIV-positive individuals tested through outreach and facility-based HIV testing models in Mbeya, Tanzania: a prospective mixed-method cohort study.

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## **ABSTRACT**

**Objective**: Linkage to care is the bridge between HIV testing and HIV treatment, care and support. In Tanzania, mobile testing aims to address historically low testing rates. Linkage to care was reported at 14% in 2009 and 28% in 2014. The study compares linkage to care of HIV positive individuals tested at mobile/outreach versus public health facility-based services within the first six months of HIV diagnosis.

**Setting**: Rural communities in four districts of Mbeya region, Tanzania.

**Participants**: A total of 1,012 newly diagnosed HIV positive adults from 16 testing facilities were enrolled into a two-armed cohort and followed for six months between August 2014 and July 2015. 840 (83%) participants completed the study.

**Main outcome measures:** We compared the ratios and time variance in linkage to care using the Kaplan Meier estimator and Log-rank tests. Cox proportional hazards regression models to evaluate factors associated with time variance in linkage.

**Results:** At the end of six months, 78% of all respondents had linked into care, with differences across testing models. 84% (95% CI= 81% -87%, n= 512) of individuals tested at facility-based were linked to care compared to 69% (CI= 65% -74%, n=281) of individuals tested at mobile/outreach. The median time to linkage was 1 day (IQR: 1-7.5) for facility-based and 6 days (IQR: 3-11) for mobile/outreach sites. Participants tested at the facility-based site were 78% more likely to link than those tested at mobile/outreach when other variables were controlled (AHR=1.78; 95%CI: 1.52-2.07). HIV status disclosure to family/relatives was significantly associated with linkage to care (AHR=2.64; 95%CI: 2.05-3.39).

Conclusions: Linkage to care after testing HIV positive in rural Tanzania has increased markedly since 2014, across testing models. Individuals tested at facility-based sites linked in significantly higher proportion and modestly sooner than mobile/outreach tested individuals. Mobile/outreach testing models bring HIV testing services closer to people. Strategies to improve linkage from mobile/outreach models are needed.

## Strengths and limitations of this study

#### Strengths

- Prospective adequately-powered cohort study
- Participants from 16 sites
- Participants followed up for six months, with good retention (83%).

#### Limitations

- Some participants may have moved elsewhere during the study and may have accessed care elsewhere; this warrants further investigation.
- Retention was higher in facility-testing arm (87%) than in mobile-testing arm (76%)
- Participant tracking might have enhanced linkage to care.
- Despite a random selection process, all of the facility-based testing sites in our sample had care and treatment centres on site.

### Key words

HIV, Linkage to care, Facility-based HIV testing, Mobile and outreach HIV testing, Mbeya, Tanzania.

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## **INTRODUCTION**

HIV remains a major burden in Sub-Saharan Africa (SSA), with 790,000 deaths associated with HIV in 2014 (AmfAR, 2015). Despite the high prevalence and the increasing numbers of people living with HIV in need of highly active anti-retroviral therapy (HAART), timely linkage to care is generally poor across SSA (Elul et al., 2014; Naik et al., 2015). The Mbeya region is among the three regions in Tanzania with the highest HIV prevalence, with an average of 9% compared to the national average of 5.1%, (TACAIDS, 2013) and AIDS-related deaths are among the three leading causes of death in the area (MRACP, 2012; MRHR, 2010).

Linkage to care is the bridge between HIV testing and HIV treatment, care and support (Gerdts et al. 2014). Timely HIV diagnosis and effective linkage into care and treatment are keys to improved outcomes (Kranzer et al. 2010; Rio 2011). All individuals diagnosed HIV positive must be linked to HIV care and treatment even if local treatment guidelines do not indicate that a person should be started on anti-retroviral therapy immediately (Suthar et al., 2013). CD4 cell count, HIV staging, and evaluation of the client's need for ART initiation need to be done immediately. The Ministry of Health and Social Welfare in Tanzania guideline for initiation of ART is a CD4 count ≤ 500 cells/µL(MOH 2015); however, during the period of this study, the actual cut-off point for ART initiation was a CD4 count of 350. The importance of linkage to care during HIV counselling and testing has been well-advocated in Tanzania; however, available literature indicates that linkage to care after testing HIV positive is still low, with only 14% linkage at 4 months reported in a 2009 study, and only 23% in Ifakara and 28% in Mbeya region in 2014 (MRACP, 2014; Nsigaye et al., 2009; Simmelink, 2014). Low or delayed linkage to care leads to failure of HIV positive individuals to benefit from HIV care. Hence, efforts are hampered to improve coverage for HIV care and treatment services, thus resulting in increased risk of HIV transmission to others (Mugavero et al. 2011; Gerdts et al. 2014). Linkage to care remains at sub-optimal levels in the country due to barriers such as lack of understanding of the importance of care regardless of disease stage, distance from the clinic and transport costs (Nsigaye et al. 2009; Leon et al. 2014; Genberg et al. 2015). Fear of stigma related to HIV, failure to disclose HIV status, being asymptomatic at the time of diagnosis and negative attitudes of health care providers are other factors reported interfering with linkage to HIV care (MacPherson et al. 2012; Govindasamy et al. 2012; Layer et al. 2014).

Mobile and outreach testing sites have been introduced in Tanzania, reflecting an increasing interest in providing early detection of HIV and subsequent care and support in the hard to reach populations and remote areas (Leon et al., 2014; NACP, 2012). Most government health facilities in Mbeya region (the site of this study) offer provider-initiated testing and counselling (PITC) and voluntary counselling services, but only about 21% also offer HIV care and treatment services (MRACP, 2014). On the other hand mobile and outreach services, operated mostly by nongovernmental organizations (NGOs), usually offer only voluntary counselling and testing (VCT) services (MRACP, 2014). These sites do not offer HIV care services, with the exception of the research mobile laboratory operating under the Mbeya Medical Research Centre (MMRC) that offers CD4 testing on site. Clients who test HIV-positive must then go to facility-based sites for registration and other procedures for HIV care and treatment. (MRACP, 2012, 2014).

There has been little research on overall linkage to care in Tanzania, and none to our knowledge on whether linkage to care differs between clients diagnosed at mobile/outreach sites compared to health facilities, nor on factors facilitating or inhibiting successful linkage to care between these two models of service delivery (Bassett et al., 2013; Labhardt et al., 2014). These differences may occur at the patient level, at service provider level, at the facility level or at the level of the health

system as a whole. For example, factors enhancing access to testing, such as dedicated outreach staff, may enhance linkage to care for those testing in mobile/outreach facilities, while other factors such as geographic distance between patients' homes and testing sites and treatment sites, weak referral systems and lack of structural links between testing and treatment sites may lead to disconnects between testing and care (Holzemer et al., 2007; Leon et al., 2014; Nsigaye et al., 2009).

One South African study found that individuals testing at mobile services were 33% less likely to undergo CD4 testing than individuals testing at static clinic services, and only 10% of mobile testers were successfully linked into care versus 72% of clinic testers; (I V Bassett et al., 2013), however, in South Africa nearly all health facilities now offer treatment, care and support. Hence, findings about differences between mobile and facility-based testing and subsequent linkage to care may not be directly transferable to Tanzania, where testing and care are not always available as a 'one stop shop'. Active referral or self-referrals are therefore more common in Tanzanian situations.

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Mbeya region has a total of 312 health facilities where clients can receive testing and counselling (HTC) services through recommended approaches; however, only 68 facilities (21.7%) offer HIV care and treatment service (MRACP, 2014). At least two outreach partners or non-governmental organizations offer HIV counselling and testing in each district of the Mbeya Region. The Mbeya Medical Research Centre MMRC mobile laboratory, also known as the Mobile Diagnostic and Training Centre (MDTC) has been offering CD4 count tests at the point of care (MRHR, 2010). Since 2009, the mobile laboratory has been covering between 8 to 12 sites every three months. Available statistics from the Mbeya regional AIDS control program (MRACP) (MRACP, 2012) suggest that more people undergo HIV testing at mobile/outreach HIV testing services (56%)

compared to facility-based services (44%); however, only about 28% of all people tested were linked into HIV care (Bassett et al., 2014). An earlier study conducted in Mwanza reported that despite increased testing opportunities only 14% of newly diagnosed patients had linked into care 4 months after HIV diagnosis (Nsigaye et al., 2009). Another study on linkage to care conducted in Ifakara showed a linkage of about 23%, indicating that linkage to care is a challenge in Tanzania (Simmelink, 2014).

This article reports new findings on linkage to care and compares the outcomes of linkage and time to linkage into care for individuals tested HIV positive at mobile/outreach sites, versus individuals tested HIV positive at facility-based services over the first six months after diagnosis in rural parts of the Mbeya region. The findings of this study are expected to inform policy makers and other stakeholders in the Tanzanian health care system on the optimization of HIV testing and immediate linkage to care, an issue of critical importance for timely initiation of antiretroviral therapy.

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## STUDY DESIGN AND METHODS

This was a prospective mixed-method cohort study of 1,012 adults who tested HIV positive recruited into a two-armed cohort (health facility-based vs. mobile/outreach HIV testing sites). The study participants were followed for six months to gather quantitative and qualitative information on linkage to care since diagnosis.

# **Study Setting**

The study population comprises rural communities in four of the then eight districts of the Mbeya Region in 2014. In 2012, the Mbeya region had a population of 2,707,410 with 52% women and 48% men (National Bureau of Statistics, 2013). The four study districts were selected to include high HIV prevalence areas and hard-to-reach populations. Two districts (Kyela and Mbozi) are

along the highways and have borders with Zambia and/or Malawi. The population in Kyela district was 221,495 in 2012, while Mbozi had 446,339 residents. High population mobility associated with cross-border business and social interactions is thought to pose challenges to linkage to and continuity of care in these districts. The other two districts (Mbeya Rural and Chunya) have a larger proportion of residents who live 10 km or more from a health facility. The population in these remote districts was 305,319 and 290,478 respectively (National Bureau of Statistics, 2013). The HIV prevalence among people tested for HIV in 2014 in the selected districts were Mbeya Rural -13.0%, Chunya- 9.2%, Kyela- 9.2%, and Mbozi - 8.7%.

All public and mission health facility-based and outreach/mobile sites in the selected districts were listed. A total of 27 health facility and 4 mobile/outreach sites were listed in Mbeya rural, 20 health facility-based and 4 mobile/outreach sites in Chunya district, 14 facility-based and 5 mobile/outreach sites in Kyela district and 29 health facility-based and 5 mobile/outreach sites in Mbozi district. Four sites in each district (2 facility-based and 2 mobile/outreach) were randomly selected from the list in each district using a table of random numbers. The eight facility-based sites selected had a care and treatment centre (CTC) within the facility. Sites had different arrangements for the first step of linkage to care, registration: in some facilities, registration was possible on the same day as testing, while other facilities had chosen a single day or two per week for newly diagnosed clients to register into HIV care. None of the mobile/outreach sites offered CTC services; they had to refer their clients to the closest CTC for further management (HIV staging, laboratory test, ART initiation etc.). The mobile site from MMRC was offering CD4 tests at the point of care, but still had to refer newly diagnosed clients, already with their CD4 results to nearby HIV care clinic or CTCs for registration and continuation of care.

# Sampling

The sampling strategy for testing sites is described above. The sampling framework for the cohort comprised all adults above 18 years receiving HIV testing at facility based and mobile/outreach sites in the four study districts of Mbeya region. The sample size was calculated using Epi Info software with a confidence interval of 95% and power of 90%, assuming that the two study groups would have the same number of subjects. Thirty per cent of individuals tested through mobile

/outreach services and 41% of individuals tested at facility-based services were expected to link into HIV care. The estimated sample size was 828; we adjusted this sample size to account for possible dropouts and non-responders (10%) resulting in a total estimated sample size of 900 participants.

## **Data collection procedures**

Prior to data collection at the clinic, the research team briefed the nurse counsellors at study sites on the study objectives and procedures. In turn, these nurse counsellors introduced the research team to clients. Interested individuals were invited to a private room for detailed explanation, informed consent process, and agreement on a convenient time and place for questionnaire administration. Initial data were collected between August and December 2014. Follow up questionnaire administration continued until June 2015. Eight out of 1,020 individuals who were approached for participating during data collection were not enrolled in the study because two of them were seriously sick and needed hospital admission, three were planning to move out of Mbeya to their home villages after receiving the results and the other three did not come back for enrolment and interviews within seven days of testing and we were unable to track them. Research assistants who underwent two days of training on informed consent and data collection procedures did data collection.

#### **Outcome measures**

The key outcome was the proportion of participants successfully linked to HIV Care and Treatment Centre across the sample and in each arm of the cohort. In this study, "facility-based sites" refers to fixed or static facilities such as hospitals, health centres and dispensaries while "mobile/outreach sites" means all outreach HIV testing services, including campaigns, mobile testing clinics, home visits or special event testing services.

The operational definition for linkage to care in this study is that a newly diagnosed individual has reported to a care and treatment centre, completed the registration process and has been provided with a Care and Treatment Centre (CTC) registration number and clinic card. This definition of linkage to care is based on Rosen and Fox (Rosen & Fox, 2011) and the National AIDS Control

Program in Tanzania(NACP, 2012); it was chosen to allow comparison with earlier studies of linkage to care.

This paper reports on preliminary outcomes for which a structured questionnaire was administered to respondents at enrolment, at 3 months and at 6 months to ascertain time to linkage into HIV care and to explore factors related to linkage to care. Information collected at enrolment included demographic data, date of HIV testing, reasons for testing, plans for linkage into care and plans for disclosure of HIV status to any family member, other relative or friend. All baseline information was self-reported by participants. In follow up interviews at three and six months, we asked about registration/linkage into care, CD4 count testing, ART status and results disclosure status. At these follow-up interviews we also we also reviewed the participants' clinic card to verify the reported dates of linkage, ART initiation and CD4 count results.

## **Data Analysis**

Quantitative data from sites were recorded, cleaned and analysed using Stata Version 13 (College Station Texas. USA). Descriptive analysis methods were used to present the characteristics of participants. Categorical data were presented using frequencies and percentage, while quantitative data were presented using the measure of central tendency and measure of dispersion. Crosstabulation was used to show the distribution of study subject by testing site. We compared the ratios and time variance in linkage to care using the Kaplan Meier estimator and Log-rank tests. Cox proportional hazards regression models were used to evaluate the factors associated with time variance in linkage to care. Statistical significance was declared at p-values less than 0.05 for the entire analysis.

## **Ethical considerations**

The study was approved by the University of Western Cape (UWC) Senate Research Committee, the Mbeya Medical Research Centre, the Mbeya Medical Research Ethics Committee (MMREC) and the National Health Research Ethics Sub-Committee (NatHREC) under the Tanzanian National Institute of Medical Research (NIMR). Participation was voluntary and it was explained to participants that they were free to withdraw from the study at any time without negative consequences. Volunteers were provided with an information sheet containing all details about the study. They signed an informed consent and confidentiality procedures were observed.

# **RESULTS**

# 3.1. Participant characteristics and comparison between facility-based and mobile-based testing models

The cohort of 1,012 HIV positive individuals included 58.5% female participants (56% facility; 61% mobile), with a mean age of 35.8 years (SD 10.5) for facility-based and 35.3 years (SD 10.0) for mobile/outreach participants. By the end of six months follow up overall 83% of participants were still active in the study, 87% in the facility-based arm and 76% in the mobile/outreach arm (p<0.0001). In both testing models, about 60% of participants were married and more than 80% of participants were self-employed with small-scale farming or petty businesses. A detailed listing of the patient characteristics is presented in Table 1. Age, sex, level of education and occupation were not statistically different between the two testing models, while statistical differences in marital status, means of transport, time to reach clinic, income and time to linkage were observed after Chi-square analysis.

# 3.2. Linkage to care at six months

At six months, 78% of enrolled participants were linked to care across both arms. Eighty-four percent (95%CI: 0.81-0.87) of participants tested at the facility-based sites were linked into care within the first six months of HIV diagnosis, compared to 69% (95%CI: 0.65-0.74) from the mobile/outreach-tested group. Figure 1. The interval from the day of HIV testing to the day of registration at a CTC was compared between participants who tested at a health facility and those tested through a mobile/outreach model. The median time to linkage was 1 day (IQR 1-7.5 days) for those who tested at a health facility and 6 days (IQR 3-11 days) for those who tested through any mobile/outreach model.

## 3.3. CD4 cell counts facility-based sites and Mobile sites

Of the 793 clients linked into care, 512 (64.5%) tested in facility-based sites and 281 (35.4%) tested in mobile/outreach sites. Most of the clients (n=774, 97.6%) had a recorded CD4 count. The mean CD4 count among participants who tested in facility-based sites was 279.6 cells/µL (SD, 211.8), whilst among those tested in mobile/outreach sites the mean CD4 count was 288.9 cells/µL (SD,168.8) Student t-test showed no statistical difference in CD4 count at the point of linkage to care between the two testing models (p=0.49).



Table1: Background characteristics of study subjects by site

Variable	Facility-based	Mobile	N	p-value
Gender				
Male	265(43.66)	157(38.77)	422(41.70)	0.122
Female	342(56.34)	248(61.23)	590(58.30)	
Age ,mean (SD)	35.8(10.5)	35.3(10)		0.901
Marital status				
Single	78(12.85)	48(11.85)	126(12.45)	
Married	361(59.47)	252(62.22)	613(60.57)	
Separated	82(13.51)	37(9.14)	119(11.76)	0.002
Divorced	13(2.14)	26(6.42)	39(3.85)	
Widower	73(12.03)	42(10.37)	115(11.36)	
Level of education				
None	104(17.13)	81(20.00)	185(18.28)	
Primary	470(77.43)	299(73.83)	769(75.99)	0.399
Secondary	29(4.78)	24(5.93)	53(5.24)	
Vocational	4(0.66)	1(0.25)	5(0.49)	
Main occupation				
Unemployed	28(4.61)	15(3.70)	43(4.25)	
Student	18(2.97)	3(0.74)	21(2.08)	0.226
Driver	9(1.48)	5(1.23)	14(1.38)	
Employed	18(2.97)	11(2.72)	29(2.87)	3-1
Self employed	530(87.31)	369(91.11)	899(88.83)	
Other	4(0.66)	2(0.49)	6(0.59)	
Means of transport	20			
Walking	163(26.85)	200(49.38)	363(35.87)	
Bicycle	93(15.32)	77(19.01)	170(16.80)	0.0001
Motor cycle	143(23.56)	71(17.53)	214(21.15)	
Public Transport	201(33.11)	55(13.58)	256(25.30)	
Private car	7(1.15)	2(0.49)	9(0.89)	
Time to reach clinic			announced the second	7/
<1 hour	397(65.40)	295(72.84)	692(68.38)	and the second
1-2 hours	157(25.86)	76(18.77)	233(23.02)	0.004
2-5 hours	50(8.24)	26(6.42)	76(7.51)	
>5 hours	3(0.49)	8(1.98)	11(1.09)	Č.
Time to linkage, (days)	1(1-7.5)	6(3-11)		145
Median(IQR)	1(1,10)	-(-1)		0.0001
Income(Tsh)-per month				
<100,000	497(81.88)	320(79.01)	817(80.73)	
100,000-500,000	39(6.43)	56(13.83)	95(9.39)	
500,000-1,000,000	3(0.49)	2(0.49)	5(0.49)	0.0006
>,1000,000	0(0.00)	1(0.25)	1(0.1)	
NA	52(8.57)	21(5.19)	73(7.21)	
Refused to answer	16(2.64)	5(1.23)	21(2.08)	

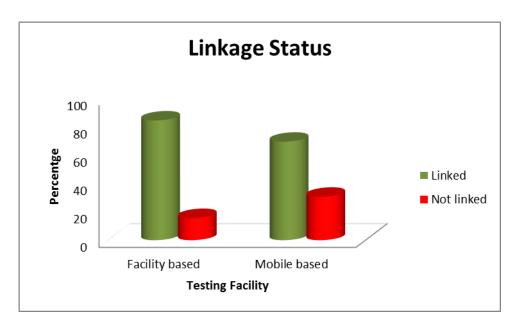


Figure 1: Linkage status for facility-based vs mobile /outreach sites

# 3.4. Time to linkage facility-based and Mobile sites

The time to linkage (registration) was significantly shorter in the facility tested group, compared to the mobile/outreach tested group (p <0.001), Figure 2. Log-rank test showed that there was a significant difference between the two groups (p <0.001). Sensitivity analysis was carried out on the 840 participants who were successfully followed for six months. Cox regression analysis revealed that a person tested at a facility-based site increased the -likelihood of linkage by 61% (AHR=1.61; 95%CI: 1.39-1.85) compared to persons tested at mobile sites. Log-rank test found a significant difference between the two groups (p <0.001).

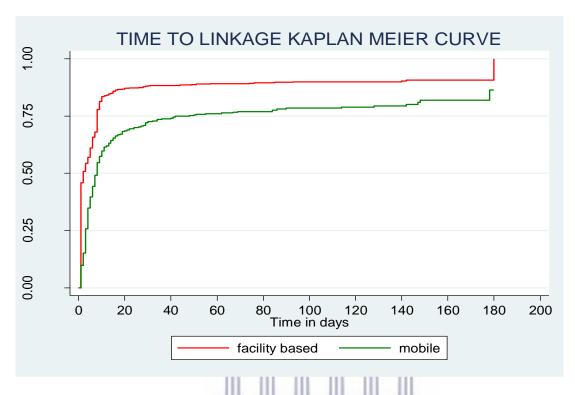


Figure 2: Survival analysis for time to linkage (KPM)

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# 3.5. Linkage from mobile sites with point of care CD4 test versus no CD4 test

Of 405 participants testing at mobile/outreach sites, 182 (44.94%) individuals had tested for HIV at the MMRC mobile site, where CD4 testing was offered at the point of HIV testing, but no registration or ART was provided. 223 (55.06%) individuals tested for HIV at mobile/outreach sites without the availability of CD4 tests, registration and ART. A total of 66.5% of study subjects testing for HIV with an immediate CD4 test and 72% of those testing at a site without CD4 test were linked into care within the first six months; however, this difference was not statistically significant.

## 3.6. Factors associated with time to linkage

Bivariate Cox regression showed that there were several factors associated with likelihood to linkage, and multivariate Cox regression analysis revealed that a person tested at facility-based increases the likelihood of linkage by 78% (AHR=1.78; 95%CI: 1.52-2.07) compared to persons tested at mobile centre when other variables were controlled. Disclosure of HIV status to partners, family, a relative or a friend was found to be a significant factor associated with two and a half times increased the likelihood of linkage to care (AHR=2.64; 95%CI: 2.05-3.39). Participants whose main reported reason for testing was an intention to receive treatment were 25% more likely to link to care (AHR=1.25; 95%CI: 1.06-1.46), Table 2.



Table 2: Factors associated with time to linkage at bivariate and Multivariate Cox regression

Crude HR 95% C			95% CI
Ref		Ref	
0.97	0.84-1.12	0.98	0.84-1.14
Ref		Ref	
0.95	0.81-1.11	0.98	0.83-1.17
1.18	0.95-1.47	1.12	0.87-1.44
1.06	0.65-1.73	1.11	0.66-1.88
Ref		Ref	
1.24	0.98-1.56	1.06	0.83-1.35
1.14	0.85-1.53	0.87	0.64-1.18
1.27	0.84-1.91	1.19	0.78-1.83
1.37	1.02-1.83	1.15	0.82-1.61
The second second			0.86-1.22
			0.88-1.55
0.75	0.37-1.52	1.09	0.54-2.22
Ref		Ref	
	1.49-		1.53-2.07**
لللب	2.003**		5
***	*****	FF397	
Ref	VEKS	Ref 1 0f t	he
1.46	1.22-1.74**	1.01	0.82-1.24
WE	STERM	CAP	E
Dof		Pof	
	1 16 1 50**		0.85-1.203
1.33	1.10-1.38***	1.01	0.03-1.203
Ref	1.07-1.45**	Ref	1.06-1.45**
1.25		1.25	
Ref		Ref	
	0 25-3 54**		2.05-3.39**
	Ref 0.95 1.18 1.06  Ref 1.24 1.14 1.27 1.37  Ref 1.06 0.97 0.75  Ref 1.73  Ref 1.46  Ref 1.35	0.97       0.84-1.12         Ref       0.95       0.81-1.11         1.18       0.95-1.47         1.06       0.65-1.73         Ref       1.24       0.98-1.56         1.14       0.85-1.53         1.27       0.84-1.91         1.37       1.02-1.83    Ref 1.06 0.89-1.25 0.97 0.74-1.28 0.75 0.37-1.52 Ref 1.73 1.49- 2.003*** Ref 1.46 1.22-1.74** Ref 1.35 1.16-1.58** Ref 1.07-1.45** Ref 1.25	Ref       0.84-1.12       0.98         Ref       0.95       0.81-1.11       0.98         1.18       0.95-1.47       1.12         1.06       0.65-1.73       1.11         Ref       1.24       0.98-1.56       1.06         1.14       0.85-1.53       0.87         1.27       0.84-1.91       1.19         1.37       1.02-1.83       1.15         Ref       1.06       0.89-1.25       1.03         0.97       0.74-1.28       1.17         0.75       0.37-1.52       1.09         Ref       1.78       1.78         2.003***       Ref         Ref       1.01         Ref       1.01         Ref       1.22-1.74**       Ref         1.25       1.07-1.45**       Ref         1.25       1.25

<sup>\*\*</sup>Significant at p-value < 0.05

## **DISCUSSION**

This study prospectively measured linkage to care in remote and hard-to-reach areas and populations, and compared successful linkage and time to linkage into HIV care between two HIV testing service delivery models in rural settings of the Mbeya region in Tanzania.

The study was designed and implemented against the background of historically low rates of linkage to care, recent widespread implementation of mobile testing to address low population rates of HIV testing, and evidence from other settings of significantly poorer linkage to care after HIV diagnosis at the mobile/outreach-based testing sites compared to facility-based testing sites.

Our study found that 78% (n=793) of individuals of the overall cohort had registered at care and treatment centres within the first six months after diagnosis, representing a dramatic improvement in linkage to care after HIV diagnosis compared to the recent past in Tanzania (MRACP, 2014; Nsigaye et al., 2009; Simmelink, 2014).

A number of studies on HIV testing and linkage to care in other SSA countries have reported linkage rates of more than 60% (Bassett et al. 2014; Hatcher et al. 2013; Rasschaert et al. 2014; Genberg et al. 2015; Sharma et al. 2015; Muhula et al. 2016). Our encouraging findings likely reflect a combination of the health system and social changes, including reduction in stigma. Our study itself may also have increased linkage to care through regularly contacting and following up HIV positive individuals.

Linkage to care in the group of people tested through the facility-based model was significantly higher compared to the group tested through the mobile/outreach services. More people were linked to care, and they linked modestly sooner in the health facility than mobile clinic arm. This aligns with earlier studies in Kenya, South Africa and systematic review and meta-analysis of community and facility-based HIV testing (Bassett et al. 2014; Genberg et al. 2015; Sharma et al. 2015).

Likewise, a meta-analysis conducted in the United States on entry into medical care after HIV positive diagnosis reported high entry by people testing at clinics and hospitals compared to other community testing settings (Marks, Gardner, Craw, & Crepaz, 2010).

While the improvement in linkage across the overall cohort and the early linkage to the first step of care are encouraging findings, the continued gap in linkage to care between mobile and facility-based testing is important to address. It is possible that some of the respondents lost to follow up in the mobile/outreach arm sought and were linked to care in other sites; however, we believe that significant health system-level barriers must be addressed to ensure timely linkage and, ultimately, retention in care.

Some of the outreach testing activities are done very far from the clinics that offer CD4 testing and HIV care. For example, some clients in Chunya district must travel more than 100 kilometres on a rough road to reach a facility that offers CD4 test services and ART. We suggest an expansion of mobile staging and ART services in remote areas. Furthermore, health care providers should ensure that education and emphasis on the importance of being in HIV care, even if the client does not yet require ART according to local guidelines, are emphasized during counselling.

Disclosure of HIV sero-status to partners and/or family members was strongly associated with earlier linkage to care compared to those who did not disclose to partners, and/or family members/relatives, again corresponding with findings elsewhere (Hodgson et al. 2014; Dima et al. 2014; Ostermann et al. 2015), and highlighting the continued importance of facilitating disclosure and social support.

We found that the majority of participants who reported, "Wanting to receive treatment in case they are infected with HIV" as one of the reason for testing for HIV, tested at facility-based sites. This may suggest that they perceived themselves to be at higher risk, or that they already intended to seek care for their symptoms and that individuals testing at facilities were more willing to link immediately into care because they needed treatment (Layer et al., 2014). This would align with studies elsewhere that have reported higher CD4 counts at mobile sites than at facility-based sites (Bassett et al., 2014); however, while we found slightly higher CD4 counts in the mobile testing arm, this difference was not statistically significant. We therefore think it is important to explore and address health system facilitators and barriers, such as the availability of integrated HIV testing, care and treatment services within the same facility/site.

This interpretation is supported by other findings from our study: a total of 265 individuals, 51.7%, who tested at facility-based sites were able to link on the same day of HIV testing, while only 12%

of those testing through the mobile/outreach model were able to link on the same day. This is likely associated with the availability of HIV testing and HIV care and treatment services within the same compound at facility sites. Not surprisingly, some studies report that CD4 testing at the point of care reduces time for linkage, eligibility assessment and ART initiation, (Hyle et al., 2014; Wynberg et al., 2014), and having HIV testing services and HIV care (CTC) at the same location improves rates of linkage to care and ART coverage (Layer et al., 2014; J Wachira et al., 2014). While Tanzania has made significant progress in increasing testing and linkage to care, our study strongly supports arguments for increasing the proportion of health facilities with care and treatment services from the current low level of 21.7% (MRACP, 2014).

Further analysis of our qualitative and quantitative data will help elucidate these findings. Nevertheless, studies on HIV testing indicate that outreach testing services increase access in remote areas, but linkage to care remains a problem (Kranzer et al., 2010; Labhardt et al., 2014). Our study supports these findings, whilst reporting significant improvements in overall linkage to care since 2009 and 2014.

The strength of this study is that we had a large sample of newly HIV positive diagnosed individuals in the cohort, enrolled from 16 different sites who were followed up for six months from the time of diagnosis. The project team used telephone calls to follow clients on their dates of next visit to the clinic. Use of phone calls may have been one of the factors that facilitated or enhanced linkage to care among the study participants.

The study has some limitations: We were not able to see all clients during the study period, despite efforts to track them through telephone calls by the study team, CTC and community-based health care providers in their respective areas. It may be assumed that the clients might have moved to other places due to prevailing trade routes with extensive cross-border migration; however, our study was not able to ascertain the exact name of linkage site and linkage beyond the study sites. This warrants further investigation. An additional limitation of our study is that the random selection of facility-based sites yielded a sample where all facilities had on-site care and treatment centres.

## **CONCLUSION**

Linkage to care is the bridge between HIV testing and treatment/care services for HIV positive individuals. In comparison with previous studies conducted in 2009, 2012, and 2014 in Tanzania, this study shows that significantly more newly diagnosed HIV positive individuals had linked to care within a short time of testing. We also found that linkage to care within 6 months of HIV testing was significantly higher from health facility-based HIV-testing sites compared to mobile/outreach sites. Finally, though of more modest clinical and population health significance, these individuals were linked into care significantly sooner, particularly at sites where same-day registration for care and treatment was possible. Individuals who had disclosed their HIV status to their partner and/or family members were more likely to link into care earlier than those who did not disclose to anyone. Findings from this study suggest that although mobile/outreach service delivery models bring HIV testing services closer to people in remote and resource restrained areas, there is still a significant gap in timely linkage to HIV care compared to sites within established health facilities. Thus, strategies that are more effective are needed to further improve linkage through this model of service delivery, including increased attention to effectively communicating the importance of linkage to care even for people who do not feel sick. In addition, the availability of care and treatment at facility-based testing sites should be significantly increased from the current low levels of less than 21.7% of public facility-based testing sites offering treatment and care. WESTERN CAPE

## **CHAPTER 5**

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PAPER 2: "Processes and dynamics of linkage to care from mobile/outreach and facility-based HIV testing models in hard-to-reach settings in rural Tanzania. A sequential explanatory mixed methods study"

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NB: A typical day at the testing sites is described in Appendix 10.4

## **Abstract**

### **Background**

Like other countries, Tanzania instituted mobile and outreach testing approaches to address low HIV testing rates at health facilities. Our recently published cohort study found that clients testing at facility-based sites were more likely to link to care than those testing at mobile sites. This paper 1) describes the populations accessing HIV testing at mobile/outreach and facility-based testing sites in hard-to-reach rural settings of Mbeya region, Tanzania, and 2) compares processes and dynamics from testing to linkage to care between these two testing models.

## Methods

An explanatory sequential mixed-method study a) reviewed records of all clients (n=11,773) testing at 8 mobile and 8 facility-based testing sites over 6 months; b) reviewed guidelines; c) applied questionnaires at 0, 3 and 6 months to a cohort of 1,012 HIV newly-diagnosed clients from the 16 sites; d) conducted focus group discussions (n=8) and in-depth qualitative interviews with cohort members (n=10) and health care providers (n=20); e) observed HIV testing sites (n=10) and Care and Treatment Centers (CTCs) (n=8).

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### **Results**

More clients tested at mobile/outreach than facility-based sites (56% vs 44% of 11,733, p<0.001) and were more likely to be younger and male (p<0.001), but more tested HIV-positive at facility sites (21.5 % vs. 7.9% of 11,733, p<0.001). All sites in both testing models adhered to national HIV testing and care guidelines. Staff at mobile sites showed more proactive efforts to support linkage to care, and clients report favouring the confidentiality of mobile sites to avoid stigma. Clients testing at mobile/outreach sites faced longer delays and waiting times at treatment sites (CTCs).

### **Conclusions**

Rural mobile/outreach HIV testing sites reach more and different clients. However, despite more proactive care and confidentiality at mobile sites, clients who tested at facility-based sites were more likely to link to care sooner than those from mobile sites. Our findings highlight a combination of a) patient-level factors, including stigma; and b) well-established procedures and routines for each step between testing and initiation of treatment in facility-based sites. Long waiting times at treatment sites are a further barrier that must be addressed.



## **Background**

In Tanzania, an estimated 1.5 million people were living with HIV in 2013, a 5.1% prevalence amongst the adult population (MOHsw, 2014; UNAIDS, 2014b). HIV testing and successful linkage of people with HIV into HIV care constitute important first steps in effective management of HIV/AIDS, and in reaching the 90-90-90 goal set by the WHO: 90% of people with HIV infection are diagnosed, 90% of those diagnosed start ART, and 90% of those taking ART achieve viral load suppression by 2020, and the goal of an AIDS-free world by 2030 (Haber et al., 2017; UNAIDS, 2014a) In the context of low levels of HIV testing in Tanzania (MOH, 2013; NACP, 2012; Ostermann et al., 2011) the government promoted out-of-facility-based testing services to complement health facility-based voluntary counselling and testing (VCT), which predominantly existed alone until the early 1990s (Kapologwe et al., 2011; Layer et al., 2014; Njau et al., 2014). The out-of-facility-based testing (referred to as the "mobile/outreach testing model" in this study) currently recommended in the country includes home-based testing, workplace or school-based testing, and testing through mobile vans (Cawley et al., 2015; MOH, 2013; Njau et al., 2014).

### Linkage to care

Regardless of how people get to know their HIV status, what is of primary importance is that those who test HIV-positive be successfully linked to HIV treatment and care for further medical care, psychological and social support (Hatcher et al., 2013; MOH, 2013). Linkage to care has been described as the process of assisting individuals with an HIV positive diagnosis to enter into HIV medical care, or the process of engaging newly-diagnosed HIV-infected persons into HIV primary care (Dombrowski, 2013; Philbin et al., 2015; Rio, 2011). It is a crucial step along the HIV continuum of care for better management and prognosis for HIV-positive individuals (S. Gerdts et al., 2014; Haber et al., 2015; Ulett et al., 2009). Linkage to care has been defined as attending at least one clinic appointment within 90 days following diagnosis (Bhatia & Giordano, 2011; Dombrowski, 2013).

Other studies defined linkage to care as attending one or more clinic visit for HIV care within one to six months of diagnosis, or more than two visits within six to twelve months of diagnosis (Keller et al, 2013; Rio, 2011). In this study, we operationalized linkage to care as attending and completing

the first step of registration at the HIV care clinic and receiving an HIV care and treatment card within the first six months after diagnosis (Keller et al., 2013; Rosen & Fox, 2011). Studies conducted in South Africa reported 52.5% and 62.1% clients being linked to care within three months of diagnosis (Govindasamy et al., 2011; Naik et al., 2015) respectively. In Tanzania, a study conducted in Kisesa, a rural area in Mwanza region, showed a linkage of 14% at four months after HIV diagnosis (Nsigaye et al., 2009).

Tanzania's national HIV testing and counselling guidelines (2013) stipulate that after completion of HIV testing, all HIV-positive individuals should be linked to receive appropriate care and treatment care services at designated care and treatment centres (CTCs)(MOH, 2013; NACP, 2012). To this end, all HIV testing sites in Tanzania are expected to establish referral links to these centres (MOH, 2013; NACP, 2012). However, it has been reported that while mobile/outreach HIV testing and counselling (HTC) models are now widely used in Africa, the rates of linkage to care and initiation of antiretroviral therapy (ART) are often low (Bassett et al., 2014; Hatcher et al., 2013; Labhardt et al., 2016). In Tanzania, like other sub-Saharan African countries, poor referral systems, distance and transport costs, poor clinic organization, and inadequate resources pose continuing challenges to linkage to care (Layer et al., 2014; Nsigaye et al., 2009; Simmelink, 2014). In addition, the clients receiving testing at mobile sites may differ from those testing at facilities. We recently reported a two-armed cohort study which found that clients testing at facility-based sites were more likely to link to care than those testing at mobile/outreach sites (E.S. Sanga et al., 2017) This paper seeks to understand this outcome.

This paper's two objectives are 1) to describe the populations accessing HIV testing at mobile/outreach and fixed/facility-based testing sites in hard-to-reach rural settings of Mbeya region, Tanzania, and 2) to compare processes and dynamics from testing to linkage to care between these two testing models.

## **Methods**

This was an explanatory sequential mixed-method study, where qualitative methods were used to complement the quantitative results (Creswell, 2015) in a process evaluation approach (Hulscher et al., 2003), which helped us to (1) compare the populations accessing the two models of testing; (2) describe the linkage to care models; and (2) explore and compare the actual practices by staff and intended users (Hulscher et al., 2003), in order to shed light on the primary outcomes of the cohort study (rates and timelines of linkage to care between the two models) (Sanga et al., 2017). The study reviewed guidelines and records (register books and reports) at 16 mobile and fixed facilities (8+8), to complement a two-armed cohort study of 1,012 newly-diagnosed HIV-positive individuals recruited from these same sites and interviewed with structured questionnaires on HIV testing and linkage to care at 0, 3 and 6 months after diagnosis. We also observed selected sites and conducted eight focus group discussions and ten in-depth interviews with newly HIV diagnosed individuals enrolled in the cohort study, and individual interviews with health care providers (n=20) working at either HIV testing units or CTCs. This paper reports on analyses of additional data from the cohort study to interpret findings previously reported (Sanga et al., 2017) and adds new data on populations accessing the two models of HIV testing and on processes and dynamics of linkage to care. Figure 1 outlines the methods for the objectives reported here.

## Sampling

study were in facilities which also had CTCs.

Multiple sampling techniques were applied to select the study sites and respondents from four districts in Mbeya region, Southern Tanzania. Districts were purposively selected to represent hard-to-reach populations, including two districts on the highway to Malawi and Zambia, and two remote districts. A total of 16 study sites were randomly selected out of 108 sites offering HIV testing services in the four study districts using a random table. These included two facility-based and two mobile/outreach testing sites in each district. Though only a minority of health facilities in the region offer Care and Treatment services, all facility-based sites randomly selected for this

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We reviewed records for all individuals receiving HIV testing services at the study sites between August 2014 and July 2015 (n=11,733). Respondents for qualitative interviews were purposively

selected from the main cohort of adults above 18 years receiving HIV positive testing at the selected facility-based and mobile/outreach sites. Details of cohort construction and recruitment have been reported elsewhere (Sanga et al., 2017).



Figure 1: Methods framework

### Objective 1(phase I)

Compare populations accessing testing at mobile vs facility based sites (Quantitative)

Record review of all clients tested (n=11,733)

### Objective 2 (Phase II)

Document processes, dynamics and outcomes of LTC against conceptual framework of client, provider, health system and contextual levels

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### **Quantitative**

Data from prospective 2armed cohort (n=1,012, recruited from among the 11,733 clients who tested at the study sites over the study period)

Based on structured questionnaires administered at baseline (0 months), 3 months and 6 months post newly testing HIV positive.

#### **Qualitative**

Individual interviews with health care providers (n= 1-2 per site, total N= 20) to elicit information on process and procedures of linkage to care.

Individual interviews with newly HIV diagnosed clients at the end of six months (n=10).

Focus group discussions (n= 8 - FGDs) with HIV positive individuals (total N= 68) enrolled in the cohort

Structured observations at 6 mobile and 4 facility based testing sites and at 8 Care and Treatment Centers

68

The study enrolled 1012 participants evenly divided across the two arms of the study (testing at mobile/outreach vs facility-based HIV testing sites). Cohort retention at 6 months was 83% overall, 87% in the facility-based testing arm and 76% in the mobile/outreach-testing arm. Health workers were purposively selected to include nurse counsellors at HIV testing sites, nurse counsellors and doctors at the care and treatment centre, and in three sites we interviewed the site managers. One day of structured non-participant observation was done by the lead investigator (ESS) at each of the study sites indicated in Table 1, with an assistant at some sites, taking notes of all ongoing activities related to either HIV testing or HIV care. In addition, about 32 hours were spent at eight care and treatment centres observing actual registration and linkage to care activities. The researcher and the assistant compared and compiled their respective notes and observation guides after each day of observation.

### **Data Collection Procedures**

We recruited cohort participants between August and December 2014, and follow-up questionnaire administration continued until July 2015. Participant enrollment was done at the selected study sites with the assistance of the nurse counsellors who introduced the research team to clients during health education sessions. The research team explained the study briefly, and interested individuals were invited to a private room for detailed explanation, informed consent and agreement at a convenient time for questionnaire administration. Data were collected by research assistants who underwent a two-day training on protocol, informed consent, and data collection procedures. Data collection tools were pretested in two sites not selected for this study.

We administered questionnaires and reviewed documents records or registers in all 16 selected study sites, while site observation/field notes, health care providers in-depth individual interviews (IDI), client in-depth individual interviews, and focus group discussions (FGDs) were conducted in some of the sites, as shown in the table below (Table 1). Qualitative interviews and FGDs were conducted in Swahili by the lead investigator (ESS), assisted by four trained research assistants.

Table 4: Research sites and data collection methods

Districts	Type of Site	IDI-HCP	Observation/ Field- Notes	IDI-Client	FGDs
	Facility-base	ed sites			
Kyela	Kyela Hospital	х	х	Х	
	Ipinda Health Centre	Х	х	Х	X
Mbozi	Vwawa Hospital	Х	х		
	Tunduma health Centre	×	х	X	Х
Mbeya Rural	Ifisi Hospital	×	×	Х	X
	Inyala health centre	×	х		
Chunya	Chunya hospital	х	х	Х	X
-	Makongolosi Dispensary	x	х		
	Mobile/outre	each sites			
Kyela	ST JOHN HUS-Kyela	х	х	X	X
	MMRC mobile- Kyela	X	х	X	
Mbozi	SHDEPHA - Mpemba	X	X	Х	
	MMRC Mobile-Mbozi	х			X
Mbeya Rural	KIHUMBE- Mbalizi	x	×	Х	X
	MMRC mobile- Mbeya Rural	×			
Chunya	KIHUMBE- Chunya	×	X	Х	X
	MMRC- Mobile- Chunya	IVERSI	TY of the	X	Х

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## **Data Analysis**

Quantitative data from sites were recorded, cleaned and analyzed using Stata Version 13 (College Station Texas, USA). Descriptive analysis methods were used to present the characteristics of participants (frequencies and percentage for categorical data, measures of central tendency, and dispersion). Cross-tabulation was used to show the distribution of study subjects by the testing site where we had multiple possible categories. Statistical significance was declared at p-values less than 0.05.

Qualitative data were audio recorded and transcribed verbatim in Swahili. The transcripts were translated by two professional translators to English, and each transcript was checked by the first author. The transcripts were analyzed using Atlas.ti version 7, a qualitative data management software (Friese, 2013). The data were analyzed by ESS and FCM using the thematic content analysis approach (Miles & Huberman, 1994). We employed the following steps: (1) free coded the data; (2) identified themes and subthemes; and (3) selected themes that are important for this study.

Our conceptual framework was developed on the basis of existing frameworks and literature on access to care, the conceptual framework included individual, provider, health system and contextual factors (Govindasamy et al., 2012; Hatcher et al., 2013; Hodgson et al., 2014; Rosen & Fox, 2011). We also compared the observed and reported HIV testing and linkage to care processes against the Tanzanian national guidelines (MOH, 2013; MOHsw, 2015).

### **Rigour and Trustworthiness**

To enhance rigour and trustworthiness, we used multiple HIV testing sites and triangulated three different data collections methods with a variety of respondents after piloting, as described above. Research assistants underwent an intensive training for quality assurance. Data analysis was conducted by two of the authors and crosschecked by the last author. Finally, we followed guidelines for reporting qualitative research (Tong et al., 2007).

## **Ethical considerations**

The study received ethical clearance from The University of Western Cape (UWC) Senate Research Committee, the Mbeya Medical Research Centre, the Mbeya Medical Research Ethics Committee (MMREC), the National Health Research Ethics Sub-Committee (NatHREC), under the Tanzanian National Institute for Medical Research (NIMR). Prior to data collection at each clinic, the research team briefed the nurse counsellors about the study objectives and procedures. Interested individuals were invited to a private room for detailed explanation, informed consent process, and agreement on a convenient time and place for the questionnaire to take place. Participation in the study was voluntary, and it was explained to participants that they were free to

withdraw from the study at any time without negative consequences. Volunteers were provided with an information sheet containing all details about the study. They signed an informed consent form, and confidentiality procedures and anonymity were observed.



## **Results**

We first compare the overall client base of the sites comprising the two testing models (Table 2). Next, we compare the two models in terms of the processes and dynamics from HIV testing to linkage into care, subsequently analyzing each approach with regard to the individual, healthcare provider, health system, and contextual levels.

# I Description of individuals tested for HIV at the facility-based and mobile/outreach sites during the study period

We reviewed registers from the 16 study sites to collect information related to individuals attending the sites for HIV testing services, and a total of 11733 individuals received HIV testing services during the study period out of 166,556 individuals who received HIV testing services in the Mbeya region. More people tested at the mobile/outreach sites than facility-based sites (56% vs 44%, p<0.001). The report for Mbeya regional AIDS program reported a proportion of 66.4% testing at the mobile/outreach sites and 33.6% testing at the facility based in 2014. More women (55%) attended HIV testing services than men; and mean age was 33 years, with most clients being married and self-employed in small-scale businesses. Table 2 describes the characteristics of the clients testing in the two models. Chi-Square test showed statistically significant differences in patients' characteristics between facility-based and mobile testing sites, notably that clients testing at mobile/outreach sites were slightly younger (p<0.001) and more likely to be male (p<0.001). We were unable to determine how many clients were linked into care because the registers are filled in immediately after testing and counselling and contained no information on linkage status. However, site staff at all sites reported verbally that all clients tested positive were provided with a referral form to bring to the CTC of their choice. It was also noted that the referral form has a section at the end of the form that was supposed to be cut off by the nurse at the CTC and brought back to the HIV testing section for feedback to the counsellor, but in most sites there was no evidence that these had been brought back to the HIV testing section. It was from this group of 11,733 individuals who came for HIV testing that the cohort of 1,012 newly HIV diagnosed participants were recruited.

Table 2: Characteristics of clients tested at facility vs. mobile/outreach sites over the period of six months (N=11733)

Variable	Facility-based	Mobile	p value
_	(n = 5 234)	(n= 6 539)	
Age			
<25 yrs.	1395 (26.7)	2045 (31.3)	P<0.001
25-39 yrs.	2389 (45.6)	2756 (42.2)	
40-59 yrs.	1147 (21.9)	1360 (20.8)	
>60yrs	303 (5.8)	378 (5.7)	
Gender			
Male	2261 (43.2)	3066 (46.9)	P<0.001
Female	2973 (56.8)	3473 (53.1)	
Marital Status			
Single	1363(26.1)	2063(31.6)	P<0.001
Married	3107(59.6)	3787(57.9)	
Separated	379(7.3)	289(4.4)	
Divorced	34(0.7)	87(1.3)	
Widow	331(6.4)	308(4.7)	
	( /	<b>(</b> ·· )	
Education			
None	160(3.7)	561 (8.8)	P<0.001
Primary	3784(88.1)	4944(77.6)	
Secondary	304(7.1)	700(10.9)	
Post-Secondary	45(1.1)	165(2.6)	
,		(=,	
Occupation		111	
Unemployed	125(2.9)	91(1.4)	P<0.001
Employed	78(1.8)	173(2.7)	
Self Employed	3946(92.1)	5882(92.3)	
Student	UNIV 138(3.2) 11 Y of	228(3.6)	
Ever tested HIV	WESTERN CA	PE	
No	3064(58.5)	3236(49.5)	P<0.001
Yes	2170(41.5)	3303(50.5)	1 30.001
1 53	2170(41.3)	3303(30.3)	
Results			
Negative	4111(78.5)	6023(92.1)	P<0.001
Positive	1123(21.5)	516(7.9)	
To whom planned to disclose			
Spouse/Partner	2758(52.7)	3540(54.1)	P<0.001
Relatives	2291(43.8)	2572(39.3)	
Others	153(2.9)	411(6.3)	
	32(0.6)	16(0.3)	

### II. Mobile (Outreach) HIV testing model

Mobile sites refer to HIV testing services outside of regular health facilities. In this study, they included stand-alone single-purpose, HIV testing sites operating under different NGOs such as Walter Reed Program, Mbeya Medical Research centre, USAID, PACT Tanzania, SHDEPHA Mbeya HIV network, KIHUMBE, and Faith-Based Organization such as the Anglican and Moravian missions. The mobile/outreach teams move from one place to another in the community or work in venues outside of public sector healthcare facilities.

The mobile or outreach HIV testing services include but are not limited to: campaigns; mobile testing clinics using cars or tents; home visits; and workplace, school or special event testing services like World AIDS Day. Most of the mobile/outreach testing sites are coordinated by Non-Governmental Organizations that work in collaboration with the Mbeya Regional Medical Office and the Ministry of Health. All mobile/outreach sites included in the study were working under NGOs and were funded by different organizations, such as the Henry Jackson Foundation through Walter Reed program, USAID, the European & Developing Countries Clinical Trials Partnership (EDCTP) and church organizations. All eight mobile sites had register books for individuals coming for HIV testing, as well as monthly and annual reports in place. The mobile/outreach testing sites had more complete records of the clients attending care in their sites compared to public facility based sites.

### Processes and procedures at the mobile/outreach sites

Our observations and respondent reports revealed that all mobile/outreach sites offer HIV testing, and then refer HIV-positive clients (with a referral letter) to the nearby CTCs for further care. One mobile site from the Mbeya Medical Research Centre offers CD4 testing and HIV staging in addition to HIV testing, then refers the HIV-positive individuals to the nearest CTC. In some of the mobile sites, we observed the care providers assisting the newly-diagnosed client's link into care by escorting them to the CTCs, or by visiting them at home to encourage them to seek HIV care services.

We observed larger numbers of individuals waiting for HIV testing before opening hours in the outreach services compared to the number of clients at the facility-based services. During focus group discussions and individual interviews, when asked the reason for choosing the outreach site for HIV testing, a significant number of respondents reported that they heard announcements when passing by, or they saw the HIV testing truck parking and, seeing many people around, they came and decided to test. Ten clients said they feel more comfortable testing at the mobile site for confidentiality reasons because the service providers in the mobile teams do not come from their community:

I have always been scared to test for HIV for a long time, when I heard that there are specialists from Mbeya town offering free HIV test and other tests. I said let me go and test because no one knows me in that team so even if I am positive nobody in this community will know that I have this [HIV] problem [Female 30 yrs.].

Some participants responded that the entertainment taking place during outreach services and campaigns are what motivated them to come closer, and then they decided to test for HIV.

In the focus group discussions about processes of linkage to care, some clients who tested at the mobile sites expressed their wish that the mobile/outreach site could also offer ART, instead of referring them to the facility-based sites:

The nurse gave me a letter, she said I should come to ... hospital for CD4 test probably I will need ART since I was very weak, the day we went to the hospital there were so many people and the queue was long, I said if KIHUMBE (the site where she tested) was also providing medication (ART) it would have saved me from this distress [FGD<sub>5</sub>].

In the mobile/outreach testing sites, the number of clients would vary depending on the type of activity. For example, at an HIV testing campaign or special events like World AIDS Day, where normally there are advertisements and car announcements and posters inviting people to come to receive free HIV testing, up to 200 people are testing for HIV daily. At these events, there are 2-6 nurse-counsellors, 1-2 doctors and 2-4 other support staff, including recorders, HIV health educators, and drivers. However, when these sites conduct HIV testing at their office (stand-alone VCT site) or on home visits, the number of clients was 20-60 per day, with 2-4 staff on duty. Of the 405 study participants who tested at the mobile sites, 69% (95%CI 0.65% to 0.74%)

successfully linked to HIV treatment and care in a qualified CTC within 6 months (Sanga et al., 2017).

### III. Facility-based HIV testing model

In this study "facility-based sites" refers to fixed or static facilities within the public or mission health sector, like hospitals, health centres, or dispensaries where individuals walk in for HIV testing, or where they came for other illnesses but the care providers advise them to take an HIV test as well. Although only 21% of facilities in Mbeya qualify as CTC's, all eight randomly selected facility-based sites had HIV testing services and CTCs within the campus.

### Processes and procedures at the facility-based site

The eight facility-based sites in this study had an HIV testing section/unit, and a physically separate HIV care section (CTC) within the same campus. Therefore, clients testing HIV positive in these sites also had to be linked to a care and treatment centre for further HIV care services, with a referral letter that had to be taken to the nurse at the CTC section, where the client will register into care. Normally the clients go to the CTC on their own unless there is a situation that needs to be explained to the CTC care provider. For example, if the person is not from the area (was visiting family or friend), they should enter care in their home area, but if they currently have a medical condition that needs doctor's attention, the HIV testing nurse can escort the client to the CTC. At that point, s/he will be given a card with their CTC number that can be linked to the client's file that is stored at the clinic.

The sites had register books for individuals coming for HIV testing or/and coming for entry into HIV care (registration at CTC). However, some sites had incomplete documentation, with missing information about individuals attending HIV testing and HIV care in the register books.

Qualitative interviews revealed that some of the individuals who tested at the facilities did not plan in advance to be tested. For instance, they went to the clinics because they felt unwell and as part of the screening and diagnosis, the health care providers suggested an HIV test. Other clients had been referred from lower-level facilities, like dispensaries, for further management at the higher-

level facilities, and through PITC they were advised to take an HIV test. Similarly, clients who were admitted to the facility for other illnesses got an HIV test as part of management. PITC is done at the outpatient department as well as in the patient's wards, although nurses in the ward may refer the patient to the HIV testing section if the ward does not have a qualified HIV counsellor.

### Linkage to care

With regard to linking HIV positive individuals to care, when an individual tests HIV positive, s/he is provided with a referral letter/form. At the designated CTC, generally in another part of the facility, the client hands the referral letters obtained from the testing sites to the nurse responsible for registering newly-diagnosed HIV-positive individuals. The individuals' details are recorded in a register, and the individuals are provided with a clinic card (CTC-card) detailing their personal information and clinic appointment visits. They have to bring this card every time they attend their clinic or go to any HIV care clinic in the country. The whole procedure of registration takes between 1- 3 hours including waiting time. When this process is complete, the individual is considered to have entered or linked to HIV care. By the end of the study, linkage to care analysis showed that 84% (95% CI 81% to 87%) of participants tested at the facility-based testing sites were linked into care within the first 6 months of HIV diagnosis, significantly higher than the 69% linked from the mobile sites (p<0.001) (Sanga et al., 2017).

With the individual successfully linked to care, they are sent to a clinician for HIV staging, a prescription for CD4 count test, and TB screening (clinicians include medical doctors, assistant medical officers, and clinical officers, all of whom can prescribe or write laboratory requisition in Tanzania). In some sites, the client goes straight to CD4 testing if the services are available on the same day. However, most clinics only do a CD4 test on selected days of the week, meaning that if their doctor consultations fall on a day that the CD4 testing services are unavailable, the clients are told to return on a day the services are available. Clients who had tested at the research mobile laboratory which included CD4 count testing did not have to repeat a CD4 count; the doctors would make care decisions based on the result the client brought from the testing site. In most

cases, CD4 results were available within 3-7 days and clients had to return to the CTC for these results and proceed to the next step: the decision over whether to be started on ART or not.

Every HIV-positive individual is required to attend treatment adherence sessions for at least three days. In some of the sites, the individual could have the adherence sessions while awaiting their lab results. At certain sites, these adherence-counselling sessions are organized for three consecutive days, while at other treatment centres, the adherence counselling sessions are done on the same day each week for three consecutive weeks.

When the CD4 test results are received from the laboratory, the clinician makes the decision of whether or not to start the individual on ART. If the individual has a CD4 count of less than 350 cells, they are initiated on ART. 350 was the cut-off point during the time of data collection; however, recently there has been a circular from the Ministry of Health on HIV treatment, implementing the 'Test and treat' approach, regardless of the CD4 count. The process for the ART-eligible clients to be initiated from the day of registration takes between one and three weeks. By the end of the study, 793 (78%) of the participants were enrolled in CTCs. Among those who were linked into care, 77% were initiated on ART. Participants tested in the facility-based sites were initiated on ART faster than those tested in the mobile site. In the first week since registration, 27 (39%) of those tested in a facility were on ART, compared to 19 (37%) tested in mobile sites. The majority of participants (92%) attended between 3-5 clinic visits/appointments before starting ART (Table 3).

With a CD4 count above 350, individuals were not eligible for ART at the time of this study, unless they had other conditions like TB, or were in HIV stage III and IV. Non-eligible individuals were given an appointment to return after three months, for continuous follow-up and checking of ART eligibility. In some facilities, it is highly recommended that each individual should share their status with a significant other (relative or a friend) to have them as a treatment supporter (accompagnateur). In other sites, this recommendation was not strongly emphasized. Finally, the individual is sent to the pharmacy for their medication to be dispensed. After receiving the medication, the individual returns to the nurse at the registration desk to get the date of their next appointment (**Figure 2**).

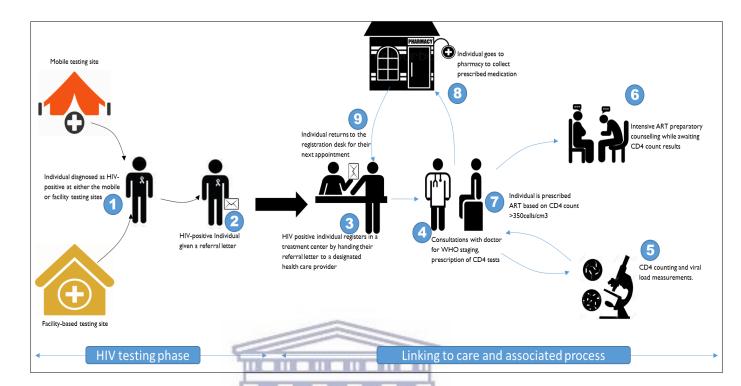


Figure 2: A diagrammatic illustration of the linkage to care process

## Estimated number of clients and staff at the CTC per day

The number of clients at the CTC was high in all sites that offered HIV care and treatment services: between 60 - 120 clients per day in most sites, and more in some sites on some days. In the facility-based sites, the HIV testing sections did not have long queues of people waiting for services. Most of the facilities tested about 10-30 clients per day. In most facility-based testing sites, there were one or two nurse counsellors at the HIV testing station. In all facilities, the section of care and treatment services had 2-6 Nurses, 1-3 Doctors and 2-5 other cadres like lab technicians, pharmacist, recorder etc. Some sites also had Home Based Carers (HBCs) or stable patients in ART known as treatment experts, who were assisting with giving health education on treatment adherence or organizing patients' files. In the health centres and dispensaries, we observed 50-100 clients in the waiting area. These clients are expected to be seen by 2-3 nurses and 1-2 doctors. For this reason, the waiting times at the waiting areas could extend to six hours. This was also reported by health care providers and clients during the in-depth interviews.

Whilst the actual services provided at CTCs are the same regardless of where the client tested, clients coming from mobile/outreach sites experienced more delays at several stages, reflecting the additional challenges of travelling to a new facility with unfamiliar schedules. Table 3 summarizes the processes and timelines at CTCs, comparing clients diagnosed at facility-based and mobile sites, whilst Table 4 summarizes the similarities and differences between the two models of testing.

Table: 3. Process/procedures and timelines for a newly diagnosed client at the CTC

Variables		Total	Facility-based	Mobile	Chi-square P value
		N (%)	N (%)	N (%)	
Time to complete Registration and	other procedure on the first day				
< I hour		5(0.6)	3(0.59)	2(0.71)	P<0.001
I-3 hours		388(48.9)	291 (56.8)	97(34.5)	
3-5 hours		334(42.12)	201 (39.26)	133(47.33)	
> 5 hours		54(6.8)	12(2.34)	42(14.95)	
NA		12(1.5)	5(0.98)	7 (2.49)	
Give Blood for CD4 count on same	lay as registration	1000			
Yes		455(57.4)	278(54.3)	177(62.9)	0.006
No		326(41.1)	229(44.7	97(34.5)	
NA		12(1.5)	5(0.98)	7(2.49)	
Time takes to receive CD4 results					
Same day	,	13(1.6)	11(2.2)	2(0.7)	0.18
2-7 days		742(93.6)	479(93.55)	263(93.59)	
8-14 days	UNIVERSITY	26(3.28)	17(3.32)	9(3.2)	
NA	UNIVERSITI	12(1.5)	5(0.98)	7(2.49)	
Started ART	THE COURSE OF	A TO TO			
Yes	WESTERN C	613(77.3)	402(78.5)	211(75.1)	0.28
No		180(22.7)	110(21.5)	70(24.9)	
How regularly do you check CD4					
Every 3 months		495(69.4)	345(67.4)	150(53.4)	P<0.001
Every 6 months		298(32.6)	167(32.6)	131(46.6)	
Time it takes to start ART from reg	istration				
I-7 Days		234(38.2)	157(39.1)	77(36.5)	P<0.001
8-14 Days		234(38.2)	174(43.3)	60(28.4)	
15-30 Days		93(15.2)	43(10.7)	50(23.7)	
30-90 Days		39(6.4)	23(5.7)	16(7.6)	
>90 Days		13(2.1)	5(1.2)	8(3.8)	
Visit before starting ART					
I-2 visits		38(6.8)	13(3.5)	25(13.5)	P<0.001
3-5 visits		519(92.4)	363(96.3)	156(84.3)	
6-10 visits		5(0.9)	I (0.3)	4(2.2)	

 ${\bf Table~4:~Summary~of~Similarities~and~differences~in~facility-based~and~mobile/outreach~sites}$ 

	Facility-based site	Mobile/outreach sites	
General			
Study working definitions	Facility-based testing sites: fixed or static facilities within the public or mission health sector (e.g. hospitals, health centres or dispensaries) where individuals walk in for HIV testing or other health care services.	Outreach HIV testing sites include but are not limited to mobile testing clinics using cars or tents, home visit workplaces, schools, campaigns or special event testing services like World AIDS Day.  Most mobile /outreach testing sites are operating under Non-Governmental Organizations.	
Funders	Government facilities	Non-Governmental organizations/sponsors	
Client/individual level			
Reason for testing at a particular site	Coming voluntarily for HIV test, or  Coming for medical care and HIV test suggested by staff (PITC), or  referred from lower level facilities, or	People come for HIV testing because they were passing by and saw the tents of track and decide to test, or  Heard the public announcement for free services in their area, or	
	<ul> <li>admitted to the ward and then advised to take a test.</li> </ul>	Coming voluntarily for HIV test because HIV testing services were brought closer to where they live.	
Number of clients tested during the study period  Health care provider level	5234 with 21.5% diagnosed HIV positive.	6539 with 7.9% diagnosed HIV positive.	
Human resource or types of staff available	Nurses: I-2 in VCT Nurses 2-5 at CTC Doctors I-2 doctors at CTC Other staff- lab technician, pharmacy, and recorders I-4	Nurse counsellors 3-6  Home-based carers 1-2  Doctors only at the research mobile  Mobile sites normally have more counsellors, home-based care (HBCs), and peer health educators; they only have doctors in special events	
Client Follow up	PITC actively implemented but no active post-test follow-up of clients.  Some minimal follow-up for clients who are initiated on ART by treatment experts (in facilities where they exist) to ensure that they do not stop treatment.	KIHUMBE, SHDEPHA, and St John Hus sites follow up their HIV positive clients through the Home-based care workers who are paid by the organization.  HBCs sometimes assist clients with the linkage to care process and conduct home visits for support and follow up.  HBC provides the numbers of the clients who are lost to follow-up to the site manager who compiles and writes an annual report for loss to follow-up and sends reports to the regional office	
System level			
HIV testing and HIV care activities	The sites offer HIV testing and HIV care services  Clients come from home following services at the health facility.	The sites offer HIV testing and refer the clients to facility-based CTCs for HIV care services  Conducts mobile/outreach HIV testing, moves from one place to another following people in the community or	
	Clients may come to the site for another sickness, and the healthcare provider may advise the person to test for HIV	their homes	

		Some of the mobile sites (e.g. KIHUMBE) also conduct HIV test in some of their offices in fixed buildings
		During special events and campaigns, music and dancing groups entertaining people are standard
HIV testing place/venue	Fixed buildings like hospitals, health centres or dispensaries (at the HIV testing and CTC section)  In one facility, there was a television set at the CTC clinic	Mobile cars/vans, Fixed buildings/clinics Open areas/grounds Tents
	clients were watching while waiting for services	Tents
Functioning tools/equipment and	Register books	Register books
guidelines	Reports Referral form/letter Patient files	Reports Referral forms Clients tracing forms for HBCs
	Laboratory services available  Guidelines - HIV testing guidelines were not available at the site, but most staff reported being trained on the	No laboratory services except for the research mobile HIV testing guidelines were not available at the site, but most staff reported being trained on the current guidelines
	current guidelines	
Record keeping	Register books and monthly reports in some sites were incomplete	All register books and monthly reports were well kept and complete
Information available	Health education on HIV and HIV treatment adherence sessions	Advertisements of services by local radio stations. Car announcement/public announcements Campaigns
	Posters related to HIV diseases fixed in waiting areas	Flyers with HIV information distributed to community members  Community mobilization and invitation for free HIV testing
Testing algorithms	Use of Determine <sup>™</sup> as primary test if reactive Uni-gold is used for confirmation, However, Elisa test can be done if necessity arises	Use of Determine <sup>™</sup> as a primary test if reactive Unigold is used for confirmation.
		If necessary, they refer clients for Elisa at the nearby hospital or ask the participants to come again after two weeks for re-testing
Referral procedure for HIV positive clients.	Provide referral form to the CTC within the facility.	Provide the referral letter/form and advise the client to link at the facility of their choice.
Same referral forms are used at the facility-based and mobile sites		
Contextual level		
Availability of HIV testing and HIV care services	HIV testing services availability is better compared to availability of HIV care service. In most of the sites (including dispensaries) HIV testing is done, although the distance was still a challenge especially in Chunya and Mbeya rural districts.	HIV testing services are brought closer to clients' homes, however, the challenge was to get care and treatment services.  In some cases, clients needed money for transport to reach a site where they can receive care.

## **Discussion**

This study sought to describe and compare the processes and dynamics of HIV testing and linkage to care among newly-diagnosed individuals testing either at the facility-based or mobile/outreach sites in rural settings of Mbeya, Tanzania. We have described the procedures of linkage and the roles of various actors including patients, providers, and clinic organization in arriving at

successful linkage to care, in relation to national guidelines. The study also compared the populations accessing HIV testing at mobile/outreach versus fixed/facility-based testing sites in rural settings of Mbeya. Identification of characteristics of people, strengths and weaknesses in each model, and the capacities of the overall health system will help strengthen provision of universal testing and linkage to care for HIV-positive individuals (Govindasamy et al., 2011; Hatcher et al., 2013; Njau et al., 2014; Ostermann et al., 2011).

### HIV testing and management guidelines

Both mobile and facility-based HIV testing sites and HIV CTCs attended to the clients in accordance with the National guidelines for HIV testing and HIV management. Although most sites did not have the paper guidelines in place, the staff were trained in and understood their responsibilities with regard to HIV testing and HIV care services. After HIV-positive diagnosis and post-test counselling, the care providers explained the available options for further care and provided the clients with referral letters. The difference was seen in the HIV testing sites: the mobile sites were actively following people up in their homes, and HIV testing was done out of hospital premises, with some activities that attracted more people to come for testing, while at the facility-based sites testing was passive and sometimes by PITC approach. Processes and procedures in the HIV care section were similar for all clients regardless of where they had tested, although those tested at the MMRC mobile site did not have to re-check their CD4 count test. At the CTC, the processes and procedures corresponded to what is reported in other studies (Genberg et al., 2015; Gerdts et al., 2014; Haber et al., 2015).

### Shortage of healthcare workers in HIV care and treatment centres

The improved linkage to care found in our study compared to earlier research in Tanzania are highly encouraging, but staff shortages pose a significant challenge. We noted overcrowding and long waiting periods at the CTC, representing a further barrier to linkage to care to those clients who did follow up after a positive HIV test result and tried to register at a CTC. In Tanzania, only 52% of the government-identified required numbers of health workers are actually available in the health sector, a situation now considered a national crisis requiring continuous and collaborative attention (MOHsw, 2014).

Health worker density in Tanzania ranges from 4/10,000 population to 10/10,000 population (MOHsw, 2014). All of the HIV CTCs included in this study had many clients while the number of staff was low, causing HIV-positive individuals to spend a long time at the clinic waiting for services. This is likely to affect the engagement and retention of patients in HIV care, as reported in other studies (Labhardt et al., 2014; Layer et al., 2014; Wachira et al., 2014). This is particularly challenging for remote areas like the study site, as most of the staff prefer to work in urban areas rather than rural areas with poor working and living environments. Plans are underway to increase the number and capacity of health and social welfare workers at all levels and areas of the country by 2018, and to reduce the shortage of staff from 52% in 2014 to 30% in 2019 (MOHsw, 2014).

### **Choosing where to test**

The study supports findings reported elsewhere that outreach testing methods are effective in improving the uptake of HIV testing, but linkage to care after testing positive is lower in the outreach testing approaches (Bassett et al., 2014; Hatcher et al., 2013). This study found that more people tested at the mobile/outreach sites compared to the facility-based sites. The significantly lower rates of positive HIV test results in this population suggests that most people may be hoping for and expecting confirmation that they are HIV negative. In contrast to both the higher HIV rates and the respondent reporting that they went for HIV testing at the facility based site because they were sick. In the mobile sites, services are provided by care providers who are not from within the community, meaning that people feel their results will remain confidential. This is likely particularly important for individuals who fear that they may learn that they have a positive test result. However, the problem for linkage to care occurs when the client is asked to go for HIV care at the same clinic they were initially avoiding for the testing, echoing similar findings and reasons for choosing testing at outreach services reported in other studies conducted in sub-Saharan African countries (Bassett et al., 2015; Meehan et al., 2015; MRACP, 2012).

### **Dynamics of HIV testing and linkage to care**

The study revealed that different factors at the individual, provider, health system and contextual levels may influence the individual's decision for testing, choices of testing site, and ultimately linkage to care and initiation of ART. More people tested at the mobile facilities than the facility-based sites, but HIV-positive results were more likely in the facility-based testing group. This finding supports the results of our cohort study, where many participants said they went to the facility-based site because they were sick (Sanga et al., 2017). It also reflects the impact of well-implemented PITC. Of note is that nearly all records (over 99%) in both models of testing indicated that clients reported a specific intention to disclose their HIV status. In our cohort study, a markedly smaller proportion (83.5%) reported disclosing their status to someone and status disclosure was found to be a significant factor associated with increased likelihood of linkage to care (Sanga et al., 2017).

At the system or program level, this study reveals some of the tradeoffs between policy objectives of maximizing testing versus maximizing linkage to care. Health systems research suggests that processes from HIV testing to linkage into HIV care may be different in health facility-based and outreach testing models, especially with respect to active referral to help individuals diagnosed with HIV to gain access to treatment and care services(Stuart, Harkins, & Wigley, 2005). This study found that while mobile and outreach sites do indeed reach more people and actively try to facilitate linkage to care after an HIV positive test result more than facility-based sites do, the rates and timeliness of actual linkage to care are longer than for those testing at facility-based sites. This is the case despite the additional access barrier posed by overcrowding and long waiting times once clients arrive at CTCs to attempt to link to care. The mobile/outreach sites were not offering HIV care services. The presence of services in a site, together with standard referral procedures and staff who are motivated to offer and facilitate PITC, appears to outweigh the inconvenience of having to return several times for different stages of the care process, at least for individuals who make it to a facility-based site for an HIV test. This echoes findings reported by other linkage to care studies (Bassett et al., 2014; Medley et al., 2013; Wachira et al., 2014), suggesting that while specific contextual factors must be addressed to remove barriers to both testing and linkage to care in any given site, cross-cutting systemic barriers and facilitators occur across settings.

The study revealed that mobile/outreach sites increased HIV awareness and uptake of voluntary HIV testing, particularly amongst younger and single adults, who are at greater risk of HIV infection. However, challenges remain with linking HIV-positive clients to care. The current referral processes in Tanzania needs to be revisited to allow more active follow-up and assisted linkage to care, as this has been shown to enhance linkage in other areas (Kiene et al., 2017; Ware et al., 2016).

Improvements and streamlining in clinic organization (such as not requiring patients to return multiple times to give a blood sample for a CD4 count, obtain the CD4 count result, be staged and assessed for ART and treatment adherence sessions) would probably further enhance linkage to care. Our study highlights the importance of the system-level factors of availability of services and standard referral and care management procedures. Combined with provider-level adherence to PITC guidelines even in the absence of "going the extra mile" to support patients, these system-level factors facilitate high rates of timely linkage to care for most patients. What has not yet been addressed, however, is what it would take to reach the patients who do not come to HIV care facilities, and who face barriers of stigma, shock at a positive HIV test result, and distance to link to care. Our findings here and in previously published work (Sanga et al., 2017) show that this is a much smaller proportion of the population living with HIV than just some years ago in rural Tanzania (where linkage to care within four months was only 14% (Nsigaye et al., 2009), but there is still a long way to go to reach the 90-90-90 goal and ending AIDS by 2030.

## Strengths and limitations

Process evaluation of this nature determines whether program activities have been implemented as intended. The strength of this study is that it tracks in a stepwise manner the various actions or procedures from HIV testing to linkage into HIV care for newly HIV diagnosed clients, using multiple data sources and methods to triangulate data. Limitations of this study are that because all of the randomly selected facility-based sites in our sample also had CTC facilities within the campus, we were not able to assess how linkage to care from facility-based sites without CTCs

compares to linkage from mobile sites or from facilities offering comprehensive services within a single facility. A further limitation of the study is that, while collecting information on the process and procedure of linkage to care, we did not have access to those individuals who tested HIV-positive but were lost to follow-up, and we were unable to know if they had linked or not.

## **Conclusion**

In this study, understanding the populations accessing HIV testing at mobile or outreach and fixed/facility-based testing sites in hard-to-reach rural settings of Mbeya region, Tanzania, and comparing processes and dynamics from testing to linkage to care between these two testing models in a two-armed cohort followed for 6 months after receiving a positive HIV test result helped to generate useful program-relevant information. The national guidelines for HIV testing and HIV management were observed by the healthcare providers in both models. Despite the more proactive care and clients' appreciation of confidentiality at the mobile sites, clients who tested at facility-based sites were more likely to link to care and to do so sooner because of integration of HIV testing and HIV care services in the same location/spot, as well as that the clients sought HIV testing services because they were sick, and therefore had the desire to start treatment.

This suggests the importance of considering a combination of patient-level factors, notably different reasons for testing and stigma, and well-established procedures and routines for each step between testing and initiation of treatment at all types of HIV counselling, testing and care facilities. Drawing on and further developing existing frameworks and approaches to access to care, this study's findings may inform the development and adaptation of strategies that can respond to the challenges of newly HIV diagnosed individuals and be responsive to the health system realities.

## **CHAPTER 6**

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PAPER 3: Understanding factors influencing linkage to HIV care after testing HIV positive in rural Mbeya, Tanzania: Qualitative findings of a sequential explanatory mixed methods study.

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## **Abstract**

**Background**: In Mbeya region of Tanzania, the rate of linkage into HIV care was estimated at 28% in 2014. This study explored the facilitators and barriers to linkage to HIV care at individual/patient, healthcare provider, health system, and contextual levels to inform the design of interventions to improve linkage to HIV care.

**Methods**: A descriptive qualitative study was conducted between August 2014 and July 2015, nested in a cohort study following 1,012 newly-diagnosed HIV positive individuals for 6 months. Eight focus group discussions and ten in-depth interviews were conducted with recently-diagnosed HIV-positive individuals from the cohort, and a further 20 individual interviews were conducted with healthcare providers. Transcripts were transcribed verbatim in Swahili, translated into English, and analyzed through thematic content analysis supported by Atlas.ti qualitative analysis software. In the discussion, the qualitative findings are interpreted in relation to the quantitative findings of the parent cohort study.

Results: The study identified multiple factors influencing linkage to care. Status disclosure, support from family/relatives, and being symptomatic were reported to facilitate linkage at the individual level. Fear of stigma, lack of disclosure, denial, being asymptomatic, belief in witchcraft, and spiritual beliefs were barriers identified at the individual level. At the healthcare provider level, support and good patient-staff relationships facilitated linkage, while negative attitudes and use of abusive language by healthcare providers to patients were reported as barriers to successful linkage. Referral procedures and well-organized clinic procedures were system-level facilitators of linkage, whereas poorly organized clinic procedures and visit schedules, overcrowding, long waiting times, as well as the lack of resources (including human resources and equipment) were reported barriers. Distance and transport costs to HIV care centres were important contextual factors influencing linkage to care. For most of the factors identified, there was an agreement between the HIV-positive individuals and the healthcare provider respondents.

**Conclusion**: Linkage to HIV care is an important step towards proper management of HIV/AIDS infection. This study found that access and linkage to care are influenced positively and negatively at all levels, but the individual-level and health system-levels barriers were most prominent.

Interventions must address issues around stigma, and improve the capacity of HIV treatment/care clinics to provide a better quality of care, particularly in light of adopting the 'Test and Treat' model of HIV treatment and care recommended by the World Health Organization (WHO).

## Introduction

Sub-Saharan Africa (SSA) bears the highest HIV/AIDS burden in the world, having an estimated 71% (25.8 million) of all the people living with HIV/AIDS in 2014 (UNAIDS, 2014b). In Tanzania, an estimated 1.5 million people are living with HIV, representing a prevalence rate of 5.1% (NACP, 2014; UNAIDS, 2014). Rates of HIV testing is low, particularly in rural areas (Nsigaye et al., 2009; Simmelink, 2014). In 2015, the Ministry of Health and Social Welfare in Tanzania, in collaboration with other stakeholders, drafted the National Comprehensive HIV Testing and Counseling (HTC) guideline, which combines all approaches of HTC into one document. The aim of this guideline was to improve HIV testing, HIV prevention, linkage and enrolment into care, retention and adherence in general HIV care and treatment, and management of comorbidities in HIV/AIDS. In Tanzania, home-based and other outreach HIV testing programs have been put in place to improve the low uptake by community members of HIV testing, and subsequently linking those individuals who test positive to HIV care and treatment centres (CTCs). By increasing the types and number of HIV/AIDS treatment and care service outlets, it was expected that successful linkage to HIV treatment and care among people living with HIV in Tanzania would improve (NACP, 2014b).

Despite an increase in the rates of HIV testing following the expansion of outreach HIV testing approaches (Labhardt et al., 2016), studies conducted in various regions of Tanzania have reported low linkage to care for individuals who test HIV positive (Mayer, 2011). A study conducted in Mwanza (Northern Tanzania) reported a linkage as low as 14% in the first four months after diagnosis (Nsigaye et al., 2009). While improvements are occurring, linkage to care remains poor. According to Simmelink (2014), Ifakara, Tanzania has a linkage rate of 23.1%. Similarly, findings from the Mbeya Regional AIDS control program 2014 report show a linkage rate of 28%. These

rates of linkage to HIV care from various regions in Tanzania are indicative of a generalized problem faced by the Tanzanian HIV and AIDS treatment program.

## Linkage to care: a crucial step in HIV control

Timely and effective linkage to HIV treatment, care and support are crucial for a better prognosis. Hence, the most recent WHO "test-and-treat" guidelines for HIV treatment and care recommend that treatment should be immediately initiated once someone has tested positive for HIV, irrespective of their CD4 count (WHO, 2016). However, treatment initiation can only be achieved if the HIV-positive individual is successfully linked to care and initiated on treatment.

Linkage to care is described as the process put in place to ensure that HIV-positive individuals are successfully entered into HIV medical treatment and care (Rio, 2011; Dombrowski, 2013). The process of linkage to care includes educating patients about the benefits of being in care and providing facilitating services such as referral letters and guidance in selecting a treatment centre (PwP, 2013).

A range of factors may facilitate or hamper the process of linkage in the trajectory of HIV care, from the point of diagnosis to initiation of ART. These influences may occur at the level of the patient/individual, the healthcare provider, the healthcare system, or the system or contextual level. Several studies have explored the barriers and facilitating factors to linkage to care in Kenya, Uganda, Malawi and South Africa (Losina et al., 2010; MacPherson et al., 2012; Govindasamy et al., 2012; Nakigozi et al., 2013; Bassett et al., 2014; Naik et al., 2015). Fear of stigma, lack of disclosure of HIV status to relatives or other individuals, being asymptomatic at the time of diagnosis, and negative healthcare provider attitudes are some of the factors reported as barriers to timely linkage into HIV care (Govindasamy et al., 2012; Layer et al., 2014; Genberg et al., 2015). Factors identified as facilitating linkage were the integration of HIV testing and HIV care services, good patient-staff relationships, and short clinic waiting times (Genberg et al., 2015; Naik et al., 2015). In Tanzania, Layer et al. (2014) explored and classified the facilitating factors and barriers to linkage to HIV care and treatment services. However, the authors of this paper did not find any studies in Mbeya region, a transient and hard-to-reach region of Tanzania where linkage into HIV care is a particular challenge (MRACP, 2014). How these general factors play out in

specific contexts is at the heart of improving practice and outcomes for this highly variable pandemic.

This study sought to explore the barriers and facilitators to linkage into HIV care after testing HIV positive in the hard-to-reach rural settings of Mbeya region, at the individual, provider, system and contextual levels in order to contribute to a deeper, intervention-oriented understanding of the dynamics of linkage to care in Mbeya region, in the southern highlands of Tanzania.

## **Study setting**

The study was conducted in rural communities within Mbeya region of southern Tanzania. This remote and transient region is characterized by higher HIV prevalence than the national average (9% vs. 5.1%). A high proportion of the population lives more than 10 km from a health facility (higher than the WHO-recommended 5km), and the area is characterized by high rates of population mobility for cross-border trade between Tanzania, Zambia and Malawi. Both testing and linkage to care are particularly challenging in these circumstances.

The study was undertaken in four purposively selected districts among the eight administrative districts of Mbeya region: Mbeya Rural, Kyela, Mbozi and Chunya (**Figure 1**). The selected districts included areas of high HIV prevalence and hard-to-reach populations. Two districts (Kyela and Mbozi) are along major highways and have borders with Zambia and/or Malawi, while Mbeya Rural and Chunya districts have a larger proportion of residents who live 10 km or more from a health facility.



Figure 1: Map of the selected districts in Mbeya region

# Characteristics of healthcare provision in relation to HIV care in Mbeya Region

In Mbeya region, about 23% of the inhabitants live within 5 km of a health facility, and 15% are more than 15 km away from a network of health facilities that includes 20 hospitals, 36 health centres, and 374 dispensaries (TACAIDS, 2013). Out of these 490 health facilities, 350 facilities provide Prevention of Mother to Child Transmission (PMTCT) services, 312 provide HIV Counseling and Testing services, while only 68 health provide Antiretroviral therapy (ART) services (MRACP, 2014). The majority of health facilities in the rural areas do not offer CD4 testing or HIV treatment services, although there has been a substantial increase in health facilities offering HIV testing and ART services in this region since 2010 (MRACP, 2014).

## **Design and methods**

The qualitative study reported here is nested within a larger study that aims to document and compare rates, patterns and determinants of linkage to care in the 6 months following an HIV positive test result, between mobile and facility-based models of HIV testing in Mbeya region, Tanzania. To achieve the aim, we adopted a prospective mixed-method cohort design. 1, 012 adults who tested HIV positive were recruited into a two-armed cohort (facility-based vs.

mobile/outreach HIV testing sites) and followed up for six months to gather quantitative and qualitative information on linkage to care since diagnosis. 16 study sites were identified for the study; eight facility-based sites that were offering HIV counselling and testing as well as HIV care and treatment services, and eight mobile/outreach sites which offered HIV counselling and testing, with one (the Research Mobile lab) offering on-site CD4 count test.

In the first phase of the project, we quantitatively compared the outcomes of linkage and time to linkage into care for individuals who tested HIV-positive at mobile/outreach sites, versus individuals tested HIV positive at facility-based services, over the first six months after diagnosis in rural parts of the Mbeya region (Sanga et al., 2017). In the second phase, reported here, we aimed to describe the factors influencing linkage to HIV care services among newly diagnosed HIV-positive individuals in the mobile services and facility-based services, focusing on patient/individual, provider, health system and contextual levels. To this end, we adopted a sequential explanatory mixed methods design (Creswell,2015) based on the prospective cohort study.

We conducted a descriptive qualitative study, which allows a summarisation of specific events experienced by individuals or groups of individuals (Lambert & Lambert, 2013). Ninety-eight study participants were purposively selected from HIV-positive individuals who have been in the HIV care umbrella between 0-6 months, 68 HIV-positive individuals participated in eight focus group discussions (FGDs), each with six to 12 respondents, and in-depth interviews (IDIs) were conducted with another ten HIV-positive individuals. We also conducted 20 in-depth interviews with healthcare providers in the study sites. The respondents for FGDs and IDIs were drawn from a cohort of recently-diagnosed HIV-positive individuals, of whom about 78% reported being linked to care within the first six months of diagnosis (Sanga et al., 2017). The lead investigator (ES), assisted by four trained research assistants, conducted the interviews.

A two-day training session on the data collection methods was held with the research assistants before testing the data collection tools. We piloted the interviews and FGD guides in two sites (health facilities), which were not among the included districts research sites, and adjusted the instruments based on these pilots. The interviews with patients focused on their experiences of being HIV positive, the circumstances around their registration into a treatment/care program, and any challenges or enablers with regard to registration usually considered the first step to linkage

in care. The interviews with healthcare providers asked about the availability of HIV testing and linkage to care guidelines, along with whether these guidelines are being followed, and explored the healthcare providers' perspectives about what inhibits or enables individuals to link into care immediately after testing HIV positive.

Interviews and discussions were audio-recorded and transcribed verbatim in Swahili, and transcripts were then translated into English. Thematic content analysis (Miles & Huberman, 1994) of the translated transcripts was supported by Atlas.ti v7 (Friese, 2013). The analysis involved the following steps: (1) looking for barriers and facilitators at each of the 4 levels; (2) developing themes and subthemes; and (3) selecting relevant themes for the study (Ryan & Bernard, 2003). Finally, in the discussion, the qualitative findings are interpreted, together with the earlier quantitative findings of the parent cohort study (Sanga et al., 2017) to enrich the understanding of both quantitative and qualitative findings.

#### **Rigour and Trustworthiness**

Following Lincoln and Guba (1985) and Shenton (2004), several strategies were employed to enhance credibility, transferability, dependability and confirmability. We adopted a qualitative method with three methods of data collection to explore and complement the findings of a quantitative study. Member checking, by recapping the discussions with validation by the respondents, was done during the focus group discussions. We applied different data collection techniques with a variety of respondents who were selected from multiple HIV testing sites. Dependability was addressed by training and supervision of a small number of field workers, and by ensuring that interviews and focus group transcripts were translated from Swahili to English by two professional translators, and checked by the first author who is fluent in both languages. Data analysis was conducted by two authors, and cross-verified by the last author. For confirmability, we kept an audit trail during the course of the study. Finally, we adopted the relevant guidelines of the 32-item checklist for reporting qualitative research (COREQ) as prescribed by Tong, Sainsbury, & Craig, (2007) to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations.

## **Ethical Considerations**

The study received ethical clearance from the following Ethics review boards: University of Western Cape (UWC) Senate Research Committee, Mbeya Medical Research Center, Mbeya Regional Medical Research Ethics Committee (MMREC), and the National Ethical Committee/ Medical Research Coordinating Committee at the National Institute for Medical Research in Tanzania. Willing participants were provided with an information sheet detailing the nature, aim, and significance of the study. Participation was voluntary, and participants were advised that they were free to withdraw from the study at any time without negative consequences. Willingness to participate was confirmed by signing an informed consent form. Confidentiality and anonymity were ensured by using pseudonyms and numbers to represent participants.

## **Results**

## Study sites and characteristics of respondents

Ninety-eight participants, including 78 recently-diagnosed HIV-positive individuals and 20 healthcare providers, took part in the study in FGDs and IDIs. We conducted the eight focus group discussions with both male and female 18 years and above. The FGDs included both women and men since previous qualitative interviews and community discussions in the area suggested that experiences with health care including for HIV can be discussed openly in mixed-sex groups. The FGDs transcripts as well as observation during the FGDs confirmed that men and women participated approximately equally. We interviewed 30 males and 68 female respondents despite inviting equal numbers of males and females to participate in these interviews. For the ten individual interviews, five male and five female HIV-positive individuals participated. The healthcare providers' interviews included seven site managers or facility in-charge staff, and 13 nurse counsellors. The sample of health care providers included six males and 14 females; in most of the sites, nurse-counselors were female, while we found more male clinicians or site managers.

Table 5.1: Research sites and data collection techniques applied

Districts	Type of Site	No of FGDs	No of IDI-Clients	No of IDIs- HCP
		Facility-based sites		
Kyela	Kyela Hospital	0	1	2
	Ipinda Health Centre	1	1	1
Mbozi	Vwawa Hospital	0	0	1
	Tunduma health Centre	1	1	2
Mbeya Rural	Ifisi Hospital	1	1	1
	Inyala health centre	0	0	2
Chunya	Chunya hospital	1	1	2
	Makongolosi Dispensary	0	0	1
		Mobile/outreach sites	1	
Kyela	ST JOHN HUS-Kyela	1	1	2
	MMRC mobile- Kyela	0	1	1
Mbozi	SHDEPHA - Mpemba	0	0	1
	MMRC Mobile-Mbozi	1	0	0
Mbeya Rural	KIHUMBE- Mbalizi	1	1	1
	MMRC mobile- Mbeya Rural	0	0	1
Chunya	KIHUMBE- Chunya	0	<b>&gt;</b> 1	2
	MMRC- Mobile- Chunya	ALL DE LEE	0	1
TOTAL	T	-8	10	20

## Factors identified as influencing linkage to care

Themes related to factors influencing linkage to care were categorized into four levels based on the conceptual framework used in the study proposal: individual, healthcare provider, health system, and contextual levels. Table 2 below illustrates the various categories into which the emerging themes and factors were classified. We present the identified factors at various levels first, reporting facilitators and then barriers, and then we report the most frequently mentioned factors from focus group discussions, individual patient interviews, and individual healthcare provider interviews.

Table 5.2: Facilitators and barriers to linkage in care by levels

LEVEL	CATEGORIE	CS THEMES/Factors	
Individual	Facilitators	Perceived severity of illness	
		Seropositive status disclosure	
		Social support from family members/relatives and fellow HIV-positive individuals	
	Barriers	Fear of stigma	
		Asymptomatic	
		Denial	
		Poor health literacy	
		Lack or fear of disclosure	
		Belief in witchcraft and traditional treatment	
		Spiritual beliefs	
Health Care	Facilitators	Good patient-healthcare provider relationship	
Provider		Supportive healthcare providers (encouragement)	
	Barriers	Negative attitude from healthcare provider	
Health System	Facilitators	Availability of referral procedures i.e. referral letter/Referral form	
	1	Good service organization	
	Barriers	Poor clinic procedures and visit schedules	
		Clinic over-crowding	
		Long waiting times at the clinic	
		Few care and treatment centres, and inadequate resources	
		Shortage of staff	
	1	Inadequate CD4 testing machines (malfunctioning)	
Contextual	Facilitators	Short distance	
	7	Low transport costs to clinic	
	Barriers	Long distance	
		High transport cost	

#### **Results overview**

While we identified both barriers and facilitators at all levels and from all respondents, we found that individual-level and health system-level factors reported by both HIV-positive individuals and healthcare providers were particularly prominent. With regard to the individual-level factors, most of the HIV-positive individuals mentioned stigma as an important barrier. During the FGDs and IDIs with the HIV-positive individuals, the participants kept steering the discussions toward stigma-related issues. With regard to the health system factors, both the HIV-positive individuals and the healthcare providers emphasized over-crowding and long waiting times at the centres.

All 98 participants invited to participate in the study agreed to do so, and the interviews and FGDs appeared open and free-flowing. During the discussions with the study participants, it was observed that both the HIV-positive individuals and the healthcare providers were very emotional when communicating their concerns, especially the health system-level barriers. We also noticed that in discussing the health system level in one of the sites, while the HIV-positive individuals mentioned that there were times when medication was out of stock, the healthcare providers did not agree that this happens. In spite of this difference in opinion on the issue of medication being out of stock, overall, there was no animosity or antagonism expressed between the HIV-positive individuals and the healthcare providers.

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#### **Individual level**

The individual level includes issues related to the individual's knowledge, attitudes, feelings, experiences and behaviours towards linkage to care or accessing healthcare services.

## Facilitators to linkage to care

Three factors were identified as facilitators to linkage to care at the individual level: Individuals being sick or having symptoms at the time of diagnosis, seropositive status disclosure, and support from family members/relatives.

**Perceived severity of illness or threat:** The individual's perception of their health status, and specifically being sick, was felt to influence linkage to care positively. This is illustrated in the following excerpts:

Initially, I didn't think it was necessary to go [to the hospital] but one day I had a fever. I felt my hands and legs not working at all. I thought I am going to die. I asked my sister to take me to the hospital for medication [IDI - Client<sub>3</sub>: Female - 35 years].

They stay at home until they are seriously sick is when they go to the hospital for registration [FGD<sub>7</sub>].

Seropositive status disclosure: Respondents cited disclosure of seropositive status as an important factor in facilitating linkage to HIV care in HIV-positive individuals. For example, one participant reported:

Most of my relatives know my status after since I told them. They support me. Sometimes they escort me to the clinic [IDI - Client<sub>3</sub>: Female-35 years].

Social and moral support from family members/relatives and from other HIV-positive individuals: Social and moral support from family and relatives were reported to enhance linkage behaviours of HIV-positive individuals in a number of the FGDs and IDIs:

I started suffering so I decided to ask my elder brother to escort me to do the test [HIV] and I was found HIV positive [FGD<sub>3</sub>].

My sister encouraged me, she said it not the end of the world, I will be okay when I start medication, and there are so many people who are in this [HIV] situation [IDI-Client<sub>8</sub>].

At our place Lusungo, we have formed the HIV support group which we meet every 15 of the month to discuss issues and encourage each other... we contribute little money for emergency ...like if someone does not have transport fare we give [FGD<sub>2</sub>].

#### Individual-level barriers to linkage to care

Six factors were salient as barriers to linkage to care from this sub-theme: fear of stigma, denial and being asymptomatic at the time of diagnosis, lack of understanding of the importance of being in care, lack of disclosure, belief in witchcraft and traditional treatment, and spiritual belief.

Fear of stigma: Stigma related to attending HIV care clinics or CTCs was the most frequent factor described by the participants as a barrier to being registered (linked) into HIV care and treatment. This was captured in statements such as the following:

They do not like going to the hospital; some fear that other people will see them at the clinic and know that they are infected  $[FGD_1]$ .

Most of them are because they fear that people will see them at CTC and start pointing fingers [IDI - HCP<sub>2</sub>].

Denial and being asymptomatic: Disbelief of test results, especially when the individual shows no symptoms yet, was reported as a prominent barrier to linkage to care among individuals who had tested positive for HIV:

I was pregnant and I went to the clinic for antenatal care. They [clinicians] tested my blood and told that I am infected with HIV. I did not believe it because I was not sick and had no other health problem apart from being pregnant [IDI - Client9: Female 30 years].

Some clients do not believe they are infected because they are healthy [IDI - HCP<sub>17</sub>].

Poor health literacy (lack of understanding of the importance of being in care): Poor health literacy in the form of lack of understanding of the importance of being in care was an important hindrance to linkage to care. The issue of poor health literacy was mostly reported by the healthcare providers. The patients did not particularly allude to issues related to poor health literacy. Two examples are shown in the following quotes:

Maybe education is still low, they do not understand that is important to start ART care while you are still strong than when you are very weak [IDI - HCP<sub>9</sub>].

Also, some people are just ignorant especially those who do not have any symptoms, they do not see the importance of being in care if they are not sick. [IDI - HCP<sub>5</sub>].

Lack or fear of disclosure: The respondents, both patients and the healthcare providers, identified the lack or fear of disclosure as an important barrier to linkage to care. Participants revealed that HIV-positive individuals sometimes fail to disclose their HIV status to their significant others for fear of consequences, such as intimate partner violence and divorce. This is captured in the following statements:

Many women are facing problems when disclosing HIV status to the men and some lead to divorce [FGD<sub>3</sub>].

They do not tell their partners, so it becomes difficult for them to come to the clinic and they come secretively [IDI - HCP<sub>13</sub>].

**Belief in witchcraft and traditional treatment:** Based on the reports of some of the HIV-positive individuals, it was identified that belief in witchcraft is a challenge to linkage to care among some HIV-positive individuals in rural areas. These experiences were mostly shared by the patients.

When I started getting sick, my in-law took me to a traditional healer, he said I am bewitched. He [traditional healer] started treating me with different herbs, some for drinking and others for bathing. I wasn't getting any better so I told him; I want to go to the hospital [FGD<sub>2</sub>].

He [traditional healer] said it was one of my neighbours in the market who is jealous of me. He [the neighbour] had put something in my store that is causing us to suffer from unknown diseases [IDI - Client 2: Male 42 years].

*Spiritual belief:* It was also reported by some respondents that spiritual belief had a negative impact on linkage to care behaviours of some HIV-positive individuals. This was captured in most focus group discussions with the patients, and some of the key informant interviews with the healthcare providers support this point of view:

You know when there is a problem you become worried so you can come here [clinic] or try other places. They say they pray for you and you will be healed [FGD 4].

Some patients go to the new churches. The pastors in those churches they pray for them and give them holy water to take and they tell them you will be healed [IDI - HCP<sub>3</sub>].

## Healthcare provider level

These are factors related to the relationship between the care providers and the individual, as well as the behaviours of the healthcare providers.

## Healthcare provider facilitators to linkage to care

Two factors were identified as facilitators for linkage to care under this theme: Support or encouragement from healthcare providers, and good patient/staff relationship.

Support or encouragement from healthcare providers: There were similar testimonies from both patients and healthcare providers that support and encouragement from care providers facilitated the registration (linkage) of HIV-positive individuals in the CTC. The role of support and encouragement is captured in these excerpts:

Frankly speaking, the health providers here treat us nicely. They explained to me step-by-step on how to use drugs. I thank them. It is two weeks now since I started the drugs. They are providing good services [FGD<sub>3</sub>].

They [the nurses] even gave me the drugs for preventing chest infection and another disease [IDI - Client<sub>6</sub>: Female 48 years].

Good patient-healthcare provider relationship: A patient who took part in the focus group discussions indicated that a good relationship and service delivery from the healthcare providers could encourage patients to link to care. A good relationship between the healthcare provider and the patient was reported to enhance linkage and continuity in HIV care, as reported in some focus group discussions:

The nurses are very polite and helping us a lot [FGD<sub>1</sub>].

Generally, the service providers are treating us well; we do not have any complain [FGD<sub>4</sub>].

## Healthcare provider barriers to linkage to care

Negative healthcare provider attitude and use of abusive language were reported by the HIV-positive individuals, particularly in one FGD and one IDI. However, on a follow-up visit, the healthcare provider in the site in question claimed that this is related to a shortage of staff at the site: sometimes staff are overwhelmed by responsibilities and work overload, so the patients feel neglected.

**Poor healthcare provider attitude and use of abusive language:** Some participants reported that negative healthcare provider attitudes and the use of disrespectful language and shouting by some of the healthcare providers was an important barrier to linkage to care. It was also reported that patients dropped out of care when mistreated at the clinic. Participants in two of the focus group discussions expressed this in the following statements:

When we reach here [clinic], they look at us like we are not normal human beings, they discriminate against us. They tell us to come very early but you see they start attending to us at 01:00 in the afternoon and sometimes you end up not getting the drugs [FGD<sub>2</sub>].

Truly, shouting can contribute so much, it hurts. You think I am sick then doctor barks or shouts at me, so they decide to stop coming [FGD<sub>6</sub>].

## Health system level

These are the factors related to the health systems and HIV care program implementation in the facility and include the organization of the healthcare services, leadership, resource availability (including human resources), and access to health-promoting services like home-based care or HIV support groups at clinics.

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## Health system facilitators for linkage to care

Two factors were identified as facilitators to linkage to care under this theme: availability of referral procedures (i.e. provision of referral letter/referral form), and the existence of a well-organized clinic system with HIV testing service and HIV care services, as well as possibilities of same-day registration.

Availability of referral procedures: Most of the reports attesting to the availability of referral process were provided by the healthcare providers, although some of the patients provided narratives that support the reports of the healthcare providers. Providing a referral letter/form to enable the registration process of individuals at the CTCs was reported to facilitate linkage to HIV care and treatment. The referral letter is an important document given to HIV-positive

individuals to confirm their seropositive status and facilitate registration into a CTC. The role of the referral letter in the care linkage process is captured in these statements below:

If the client is positive, I refer him/her to CTC with this form (referral form) we have to make sure they are registered in the book [IDI-HCP<sub>1</sub>].

We refer the client we give him/her a referral letter with CD4 results print out and we also do HIV staging so that the CTC clinician can decide on how to continue [IDI-HCP<sub>7</sub>].

It was also revealed that, in some of the sites, the peer health educator escorted the newly diagnosed individual to the clinic.

I sometimes take the letter from here (St John hus site) and I accompany the person to the clinic at Kyela hospital, I take them through all steps [FGD<sub>1</sub>].

Service design or clinic services organization: Both the healthcare providers and the patients agreed that the availability of HIV testing, CD4, counts and HIV care and treatment services within the same facility, organized to provide a complementary service, enabled linkage to care. This provides the possibility for individuals who test positive to be registered and thus linked to care at the CTC, on the same day.

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Normally when I find a positive client, I go to the next room where we keep the documents for registration and the CTC cards, so I register him/her in the CTC register and give them a CTC clinic number with the treatment card [IDI-HCP<sub>12</sub>].

He [the care provider] gave me the letter and asked me to go to room number 10, show this [registration card] to the nurse. They gave me a card then I went into another room to give blood for CD4 [FGD 2].

We have formed the HIV support group which we meet every 15 of the month to discuss issues and encourage each other... we contribute little money for emergency ...like if someone does not have transport fare we give [FGD 2].

## Health system barriers to linkage to care

Five factors were identified as barriers to linkage to care within the health system umbrella. These are Un-organized clinic procedures and visits schedules, clinic overcrowding, long waiting times at the clinic, inadequate CTCs, and shortage of staff.

Disorganized clinic procedures and visit schedules: While it was reported by study participants that healthcare facilities can provide integrated services of testing and treatment/care, which facilitated linkage to care, narratives from patients and healthcare providers indicate that the services might not be available on the same day. Some of the healthcare facilities had a schedule of when testing takes place and when registration to treatment/care occurred. This required patients to make multiple visits to the facility. For example, an individual testing on Friday morning will be given a referral letter to come the next Tuesday for registration, and then they will be told to come on Wednesday or Friday for CD4 testing and then given another appointment to get their CD4 results.

We do CD4 testing on Wednesdays and Fridays, the other days is for in-patients' tests. So if it is Wednesday and the client comes early, they go directly to the CD4 testing section and they are given a date to come for results normally. This could be in about three or four days' time [IDI - HCP<sub>10</sub>].

He gave me some papers (referral form) to go with and show the nurse at the CTC. I went and the nurse said I should come on Tuesday for registration [IDI - Client<sub>2</sub>: Male 42 years].

Clinic overcrowding: Reports from both patients and healthcare providers indicated that clinic overcrowding could constitute a barrier to linkage to care. When patients found a huge crowd of people when they arrived at the clinic, they were tempted to return home. This could lead to the patient failing to become linked to care timeously. This was supported by the discussions among the patients in a focus group.

So even when you tell a client to go and join the queue for registration, he says 'there are too many people, I will come tomorrow' and that is it. They disappear. We don't know whether they go to other clinics or what happens to them [IDI-HCP<sub>9</sub>].

For the matter of staying a long time it is because we are so many, therefore, we take a lot of time [FGD<sub>1</sub>].

Long waiting times at the clinic: This was another frequently mentioned issue from both the patients and healthcare providers. It was revealed that owing to the overcrowding in the CTC, it took a long time for the healthcare providers to consult everyone, leading to long waiting times for patients, and hence a potential barrier to linkage to care.

Patients wait for services for a very long time because the same staff has to go in the wards to assist, and then come here again for HIV client. For example, on Wednesday when they come for adherence treatment classes we can only start with them after 12 noon, and they always complain [IDI - HCP<sub>6</sub>].

We wait for services for a very long time and the waiting place is open when it is raining, we suffer a lot [IDI - Client<sub>1</sub>: Female 33 years].

*Inadequate resources and equipment:* Shortage of resources, such as HIV care centres, staff and CD4 testing machines, were identified as possible barriers to linkage in care. Statements from both healthcare providers and HIV-positive individuals suggest how this resource shortage could interfere with linkage of HIV-positive individuals into HIV care.

There is a severe shortage of staff here; clients wait for CTC services for hours before they are attended to. We are only two nurses and one doctor per shift if one of them is sick or on leave, patients wait up to 4 o'clock in the evening [IDI - HCP<sub>6</sub>].

The problem is, we depend on only this hospital for all people in Chunya, people from Lupa tingatinga and all other villages...and Chunya is big [FGD<sub>4</sub>].

In one district, the recurrent breakdown of the CD4 machine was mentioned as a strong barrier to their linkage with HIV care:

Also, the recurrent problem is with the CD4 machine [breakdown]. Maybe the government can help us by buying a new machine, even two we are so many here who need the service [IDI - Client<sub>1</sub>].

Most of the patients there are delayed due to CD4. This is the only site with a working CD4 machine. We receive patients from Sumbawanga even Nakonde from Zambia because this service is not available in their areas [IDI - HCP<sub>14</sub>].

#### **Contextual level**

Contextual factors refer to matters associated with access to, and affordability of, ART treatment and care services, and this may also include social and cultural factors concerning HIV infection. Depending on how far the individual lives from the clinic, the themes identified under this category could be either a facilitating factor or a barrier. Those who live close to the clinic did not identify access to the clinic facility as a possible barrier to linkage to care. Conversely, those who live further from the care facility saw distance and transport cost to the facility as a potential challenge to linkage to care.

## Contextual facilitators to Linkage to care

**Proximity and low travel cost to the clinic:** Proximity and low travel costs was one of the factors that was reported to facilitate linkage to care in HIV-positive individuals, as reported by some of the participants;

I do not live very far from here, I just get a boda-boda [hired motorbike] and I pay only one thousand [less than half a dollar] and I can even walk if I want to [IDI - Client<sub>6</sub>: Female 48 years].

For me, distance is not a problem, I walk for about ten minutes and am here, sometimes I send my daughter to bring the card for me and put it in the box while am still at home, when I come here I just wait for my turn to take medication [FGD<sub>7</sub>].

## **Contextual barriers for Linkage to care**

Long distance and high transport cost to CTCs: Long distances to the clinic and the high cost of transport were reported by the participants (especially in two districts Chunya and Mbozi) as a deterring factor to linkage to HIV care and treatment.

We refer our clients to either ... hospital [about 10-15 Km] to the ...health centre also about same distance. They say 'I do not have bus fare for now [IDI -  $HCP_{11}$ ].

Transport is very costly. Sometimes, I borrow money from friends and sometimes I come with my bicycle but I do not have the energy to ride for a long distance [IDI - Client<sub>2</sub>: Male 42 years].

Binti-manyanga is far, it is about 100 kilometres from here and the cost of transport is very high about 28000 to 30000 [about \$14] per trip [FGD<sub>4</sub>].



# Discussion: integrating qualitative and quantitative findings in relation to published literature

The study sought to explore the facilitators and barriers to linkage into HIV care after testing HIV positive in the rural settings of Mbeya region, from both facility-based and mobile/outreach sites. The literature on linkage to care indicates that while many studies have explored and described barriers to linkage to HIV treatment in various settings, fewer studies have looked at the facilitating factors, and even fewer have explored both together. In this study, multiple factors were identified as influencing linkage to care in newly-diagnosed HIV positive individuals, and we identified these factors under four levels i.e. individual, healthcare provider, health system, and contextual levels (Figure 2).

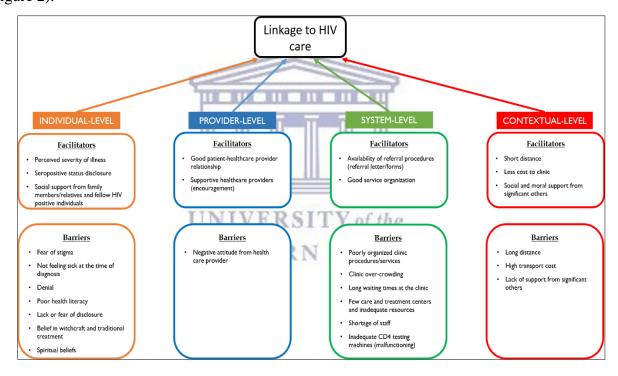


Figure 2: Conceptualizing the factors influencing linkage to HIV care in Mbeya, Tanzania

Based on the findings of this study, as indicated in Figure 2, access and linkage to care plays out at different levels, but the individual-level and health system-levels barriers were most prominent. At the individual level, HIV-positive individuals cited stigma as a very important barrier to linkage to care. This suggests the need for more population-level educational programs and community

HIV-support groups. At the health system level, clinic overcrowding and long waiting times came across strongly from both the HIV-positive individuals and the healthcare providers.

Each of the identified levels of factors is discussed in the section below, with particular attention to integrating the qualitative findings of this study with the quantitative findings from the parent cohort study (Sanga et al., 2017).

#### **Individual level**

At the individual level, the study revealed that having symptoms of disease (being sick at the time of diagnosis), the disclosure of HIV status, and support from family/relatives were facilitators to linkage to care. The findings from the quantitative parent study revealed that disclosure of HIV status was a significant factor associated with timely linkage to care: participants who disclosed their HIV status had a 35% earlier rate of linkage to care compared to participants who did not disclose their HIV status (Sanga et al., 2017). This finding was supported by the HIV-positive individuals and the healthcare providers who participated in the qualitative study. Social and moral support from the HIV-positive individuals' families and spouses, although not identified in the quantitative data as significant to linkage to care, were salient in the qualitative inquiry. This result corresponds to other similar studies on linkage to care (Medley et al., 2013;Cummings et al., 2014; Dima et al., 2014; Hodgson et al., 2014).

In this study, the most frequently reported barriers to linkage into HIV care include fear of stigma related to HIV, lack of disclosure, being asymptomatic at the time of diagnosis, and denial. However, belief in witchcraft and belief in spiritual healing were also reported to hinder linkage into HIV care. Similar findings were identified in other studies on linkage to HIV care in sub-Saharan countries (Hatcher et al., 2013; Hodgson et al., 2014; Layer et al., 2014; Nakigozi et al., 2013; Sharma et al., 2015).

WESTERN CAPE

## Healthcare provider level

We found that healthcare providers' moral and practical support and good patient-staff relationships enhance linkage to HIV care. Conversely, the perceived experience of negative provider attitudes, lack of respect and/or use of abusive language from healthcare providers to

patients was reported by the study participants to impede successful linkage to HIV care. Other studies report corresponding results (Nakigozi et al., 2013; Wachira et al., 2014; Layer et al., 2014). However, in this study, the healthcare providers in some instances suggested that negative relationships with clients are related to a shortage of staff at the site, and high workloads. Existing literature indicates that basic resources, effective management, and supportive supervision issues need to be addressed within a health system in order for patient-centered care of high interpersonal quality to become a priority for healthcare providers (Cowing et al., 2009; Lamarche et al., 2011).

## Health system level

At the health system level, we found the availability of good referral procedures and well-organized clinics services to be important facilitators for linkage to HIV care. Elul et al. (2014), in their study on enhancing linkage to care, reported that availability of CD4 testing at the point of care, and a short message service (SMS) reminder of appointment to patients, was a facilitator to linkage. We also found that in some clinic settings, testing and linkage to care were performed on the same day (same day registration), and sometime CD4 tests were also done on the same day. This helps to explain the finding in the quantitative parent study that those tested at facilities were significantly more likely to have linked to care sooner than those tested at the mobile sites (Sanga et al., 2017).

Healthcare providers in the qualitative study indicated that the mobile clinic staff took measures to promote linkage to care. For instance, one of the healthcare providers running the mobile clinics reported that they situated their mobile laboratory near a health facility, such as a hospital, health centre or dispensary, to link their HIV and TB clients to the existing system for further care. It was also reported by the healthcare provider from mobile/outreach services that the peer educator escorts the newly-diagnosed individuals to the care centre after counselling and testing, to ensure linkage. The quantitative part of the study showed that individuals who tested in facilities had a 78% higher rate of earlier linkage to care compared to those tested in mobile/outreach sites. By adopting the above-mentioned strategies, the linkage to care rates from the mobile testing individual could be improved, as these findings suggest that the disadvantages of testing outside of a multi-service facility are not overcome even by highly motivated and proactive staff action.

Barriers to linkage in care at the health system level included poorly-organized clinic procedures and visits schedules, overcrowding and long waiting time, and lack of resources including staff and equipment at the clinic. While some studies have indicated that having HIV testing services and HIV care available in the same facility improves rates of linkage to care and ART coverage (Layer et al., 2014; Genberg et al., 2015), the integration of these services, if not well coordinated and organized could also constitute a barrier to linkage to care. These factors were similar to some of the health system barriers reported in other HIV care linkage studies (Mayer, 2011; MacPherson et al., 2012; Wachira et al., 2014; Sharma et al., 2015;). However, the qualitative findings reported here, particularly in light of the quantitative findings (Sanga et al., 2017) suggest that even poorly integrated "one-stop shops" are preferable to multiple visits to separate facilities.

#### **Contextual level**

The context level factors that were identified in this study were related to the distance to the healthcare facility, and the cost of transport. For respondents living in close proximity to the clinic, distance and cost were not a challenge. However, it was a significant challenge to respondents who lived further than 10 km from the clinic. Nevertheless, the multivariate Cox analysis of the quantitative part of our study indicated that there was no significant difference between the rates of linkage to care for HIV-positive individuals who lived less than 10kms from the healthcare facility compared to those who lived more than 10kms from the healthcare facility (Sanga et al., 2017). This could be explained by the fact that other barriers at the individual, provider and institutional levels could have influenced the decisions not to register for HIV treatment and care more than the distance. In spite of this finding, long distances from the treatment facility, and cost of transportation were reported by a significant number of the HIV-positive individuals as barriers to linkage and remaining in HIV care. A number of studies have also reported the influence of long distances and transport costs on linkage to care behaviours of individuals diagnosed with HIV (Nsigaye et al., 2009; Govindasamy et al., 2012; Juddy Wachira et al., 2014). Furthermore, some of the HIV-positive individuals reported that short distances to the clinic and low transport cost improved the rate of linkage to care. This is seldom reported in the literature.

Social and moral support from family members, friends, neighbours and significant others were reported to facilitate linkage and retention in HIV care, echoing findings reported by Gerdts et al. (2014) and Genberg et al. (2015). A possible mediator between disclosure of HIV status and early linkage is the perceived social and moral support that the HIV-positive individuals receive from their significant others after disclosure.

## Strengths and limitations

One of the strengths of this study is that various stakeholders (healthcare providers, and HIV-positive individuals), different data collection methods (FGDs and IDIs) and multiple sites (16 sites) were used to elicit relevant information. By triangulating the data source, collection methods and sites, we improved on the trustworthiness of the study. We had mixed-sex FGDs which yielded complementary results and showed that men and women can explore shared as well as divergent experiences. This is a contribution in a field which seldom offers men and women the opportunity to exchange views together. However, the study had some limitations for instance, while we explored the challenges and facilitators for linkage to care, we only interviewed individuals who were already under the care umbrella. We did not have access to those individuals who tested HIV positive but were not registered in care. In addition, we did not delineate the responses of those who tested in the mobile sites from those who tested at the facilities, because both groups were entering care at the health facility-based sites. While we found that the mixed FGDs were rich and gender-specific complementary themes emerged from the individual interviews, we did not conduct separate men's and women's FGDs which may have yielded additional themes.

During this study, it was identified that poor leadership and management at some of the facilities were responsible for poor linkage to care behaviours. Although this study focused on the factors influencing linkage to care, it did not focus in particular on the broader health system issues like health management and leadership. This may require further investigation to address the issues around leadership and health systems management.

## **Conclusion**

The importance of HIV-positive individuals being linked to HIV care has been demonstrated in the literature. The findings of this study indicate that, while there are many barriers to linkage to care, there also exist some facilitating factors. The study showed that individual, healthcare provider, health system and contextual factors might all influence linkage into care, but that individual-level factors (such as stigma), and health system factors (under-resourced and poorly coordinated facilities), are particularly important from the perspective of both patients and providers.

This study was undertaken in part to inform future interventions. Among interventions that could be implemented to address some of the challenges of linkage to care are improved counselling strategies, and the establishment of HIV support groups and community interaction programs to discuss and address HIV stigma-related matters in the community. At the health system level, improvement of inadequate human and other resources, and of HIV care clinic procedures to allow the provision of better quality of care and treatment services to HIV-positive individuals, are urgently needed. Low rates of testing and linkage to care in hard-to-reach and vulnerable populations, such as those, living in Mbeya region, Tanzania, may thus improve to acceptable levels.

WESTERN CAPE

116

## CHAPTER 7

## SUMMARY OF FINDINGS AND DISCUSSION

#### 7.1 Contributions of this thesis

In Chapter 1, we introduced the problem which guided this research:

HIV testing, linkage to HIV care and continuity of care are crucial for proper management of HIV/AIDS. There is increasing interest across sub-Saharan Africa, including in Tanzania, in accessing hard-to-reach populations along major highways or trade corridors, in border areas, and in remote rural areas with HIV testing opportunities and linkages to HIV care and management. Mobile and outreach HIV testing can help to achieve universal HIV testing in sub-Saharan African countries. However, despite the efforts being made by the Tanzanian government to address some of the challenges to improving HIV testing and subsequent linkage to HIV care and treatment services, such as increasing service outlets; available literature and reports in Tanzania show that linkage to care is still low.

Many factors can interfere with or facilitate successful linkage to and continuity of care. This thesis describes and compares the populations accessing testing at mobile/outreach versus fixed/facility-based testing sites, and compares the processes, dynamics, and outcomes of linkage to care between these two models of HIV testing.

The overall aim of the study was to describe and compare rates and determinants of linkage to care in the first six months following an HIV-positive test result between mobile and facility-based models of HIV testing in Mbeya region, Tanzania. We reviewed the literature to understand linkage to care and to identify challenges in linkage to care from mobile testing sites in contexts like South Africa, where treatment is widely available in the public sector. However, to our knowledge, there has not been any direct, prospective comparison between mobile and facility-based models of testing in countries like Tanzania, where treatment is only available in a minority of facilities and where overall testing rates remain low. Similarly, a mixed-method approach combining a quantitative prospective cohort study, records review, and qualitative research with both patients and healthcare providers to explore linkage to care has not been reported in Tanzania and East Africa. The empirical findings on rates, timelines, determinants and dynamics of linkage

to care in the first six months after testing positive for HIV contribute original knowledge to the literature, and to Tanzania's efforts to control and eliminate HIV/AIDS as a major public health problem. Understanding strengths and weaknesses in each approach to testing, in relation to client characteristics and preferences, and the capacities of the overall health system, will help strengthen the provision of universal testing and linkage to care for HIV positive individuals.

#### 7.2 Summary of findings

Results reported in Chapter 4 showed that, at the end of six months since diagnosis, 793 (78%) out of 1012 participants enrolled in the cohort had linked into care. This is a dramatic increase in overall linkage to care since 2009 and 2012 (Nsigaye et al., 2009; Simmelink, 2014; MRACP, 2014). However, the study also found, in line with studies done elsewhere (such as Bassett et al., 2014), that linkage to care was higher from facility-based than from mobile/outreach sites: 84% (CI= 81% -87%, n= 512) of individuals tested at facility-based were linked to care, compared to 69% (CI= 65% -74%, n=281) of individuals tested at mobile/outreach in the same period. This paper also reported that individuals tested at facility-based sites entered HIV care sooner than the individuals tested at the mobile/outreach sites, but that overall, newly diagnosed clients linked to care soon in both models. This also is an important and novel finding. The median time to linkage was 1 day (IQR: 1-7.5) for facility-based and 6 days (IQR: 3-11) for mobile/outreach sites. While the higher rates of timely linkage to care from both models of testing are encouraging, this study nevertheless found that participants tested at the facility-based sites were 78% more likely to link than those tested at mobile/outreach sites, when other variables were controlled (AHR=1.78; 95%CI: 1.52-2.07). The study revealed that disclosure of HIV status was a significant factor associated with timely linkage to care: participants who disclosed their HIV status had a 35% earlier rate of linkage to care compared to participants who did not disclose their HIV status. Clients who reported that they tested because they wanted to get treatment for HIV (suspecting that they were HIV-positive) were 25% more likely to link to care. The difference between the two models of testing and the subsequent linkage to care appears in large part to reflect a more "treatment ready" population testing at facility-based sites, than the population testing at the mobile sites. Nevertheless, the study also confirmed that mobile/outreach testing models bring HIV testing services closer to people, but that more efforts and strategies are needed to improve linkage from mobile/outreach models.

Results reported in Chapter 5 (Paper Two) showed that a total of 11,733 individuals received HIV testing services at either mobile or facility-based testing study sites during the study period. More people (56%) tested at the mobile/outreach site compared to the facility based sites (44%), more women (55%) attended HIV testing services than males and the mean age was 33 years. Most clients were married and self-employed in small-scale businesses. The difference was seen in the HIV testing sites: the mobile sites were actively following people up in their homes, and HIV testing was predominantly done out of hospital premises, with some activities that attracted more people to come for testing, while at the facility-based sites testing was passive on the part of the staff, or routine through a PITC approach. Despite having more people testing at the mobile/outreach sites than the facility-based sites, HIV prevalence was higher in the facility testing group (21.5%) compared to the mobile/outreach group's 7.9%. After post-test counselling, the care providers explained the available options for linkage to care and provided the clients with referral letters to show in the HIV care section. Processes and procedures in the HIV care section were similar for all clients, regardless of where they had tested, but even once they reached a CTC, clients who had tested at mobile/outreach sites showed statistically significant delays in nearly every step of the process, from registration to the clinician's decision to start or not start ART. These likely reflect a combination of having to return to the facility repeatedly and being unfamiliar with the facility procedures and routines. Nevertheless, the proactive, client-centred care at the mobile/outreach sites and respondents' appreciation of the confidentiality and privacy at these sites do not translate into linkage to care equal to that of clients who tested at facilitybased sites.

In Chapter 6 (Paper Three), we sought to explore the multiple factors identified as influencing linkage to care. The study showed that the factors that facilitated linkage to care at the individual level were: disclosure of HIV status to someone (spouse, family member, relative or friend), support from family/relatives, and having symptoms of disease at the time of diagnosis. On the other hand, fear of stigma, lack of disclosure, denial, being asymptomatic, and belief in witchcraft were barriers identified at the level of individuals. At the provider level, support and good patient-staff relationships facilitated linkage, while negative provider attitudes and use of abusive

language to patients were reported barriers to successful linkage. Clear referral procedures and well-organized clinic procedures were system-level facilitators of linkage, whereas poorly-organized clinic procedures and visit schedules, overcrowding, long waiting times, and lack of resources (including human resources and equipment) were reported barriers. Distance and transport costs to HIV care centres were important contextual factors influencing linkage to care. It was noted that access and linkage to care are influenced positively and negatively at all levels, but the individual-level and health system-level factors were most prominent in this setting, rather than healthcare provider and contextual factors.

#### 7.3. Discussion of findings

This section discusses the study findings in relation to the literature and to the policy aims of the Ministry of Health in Tanzania. The discussion is structured according to the objectives of the study and concludes with the conceptual framework.

#### 7.3.1 Uptake of HIV testing at mobile/outreach vs. facility sites

As part of government's response to HIV/AIDS in Tanzania, mobile and outreach HIV testing services were instituted to complement existing approaches of HIV testing in hospital settings in the country, and to expand services to remote areas and hard-to-reach communities. In this study, it was found that HIV testing was higher in the mobile/outreach sites compared to the facility-based sites. In the mobile sites, services are provided by care providers who are not from within the community, and due to this anonymity, people felt their results will remain confidential, echoing similar findings and reasons for choosing to test at outreach services reported in other studies conducted in sub-Saharan African countries (MRACP, 2012; Bassett et al., 2015; Meehan et al. 2014). This underlines the importance of using combined approaches, recommended by the WHO (2012), to increase knowledge of HIV status in people who may not otherwise have tested.

The study showed that the proportion of clients who tested HIV positive was significantly higher amongst those who tested in fixed facilities compared to those who tested in the mobile/outreach sites. A reason for this may be that individuals who tested at the facility had a medical condition that pushed them to seek health care and eventually resulted in an HIV diagnosis. At the mobile site, some clients were passing by or heard an announcement for free HIV testing, and tested just

because there was an opportunity (Ostermann et al., 2011; Meehan et al., 2014). The significantly lower rates of positive HIV test results in the mobile testing group suggests that more people may be hoping for and expecting confirmation that they are HIV negative, in contrast to both the higher HIV rates and the respondent reports of testing because they felt sick at the facility-based sites. HIV-positive individuals in this group may need very high-quality post-testing counseling and further assistance and support with linkage to care. Studies conducted in Uganda, Lesotho and South Africa showed that assisted or facilitated linkage increased rates of linkage among newly HIV diagnosed clients (Labhardt et al., 2014; Sharma et al., 2015; Ware et al., 2016).

#### 7.3.2. Linkage to care and time to linkage

Timely HIV diagnosis and effective linkage into care and treatment are key to improved HIV management outcomes (Kranzer et al., 2010; Suthar et al., 2013). All individuals diagnosed as HIV positive must be linked to HIV care and treatment, even if local treatment guidelines do not indicate that a person should be started on anti-retroviral therapy immediately (MOH, 2013; Suthar et al., 2013). This study showed an overall improvement in linkage to care compared to earlier studies on linkage to care in rural areas and hard-to-reach populations (Nsigaye et al., 2009; MRACP, 2014; Simmelink, 2014), likely due in part to increased community knowledge about HIV/AIDS and the importance of using ART, following the ongoing educational programs in the country. The overall linkage to care has increased significantly since a low rate of 14% was reported in a study published in 2009 (Nsigaye et al., 2009) and 23% in a second study published in 2014 (Simmelink, 2014). The data for the first study was collected in 2006-2008, and for the second study in 2012-2013. Data for the study reported in this thesis was collected between August 2014 and July 2015. The overall retention for this cohort was 83%, which is a very high retention rate for a field cohort study in rural areas. The increase in linkage to care probably reflects a combination of major efforts by government and partners to increase community knowledge about HIV/AIDS and the importance of ART, and significant efforts to improve and standardize the procedures for testing, counselling, referral, registration, and evaluation of need for care across all facilities in Tanzania, including government and NGO programmes. For example, a campaign has been in place since 2013 advocating for people to know their HIV status and educating people about the benefits of using ART. These efforts at outreach to communities and improvement of clinical and organizational practice have been translated into policies and guidelines that are being implemented in the region. This is discussed further in section 7.3.3. below.

Based on the evolution of HIV testing and treatment across Eastern and Southern Africa between 2006 and 2015 and the increases in access to anti-retroviral therapy reported across the region, we believe that it is indeed possible and even likely that linkage to care has increased significantly.

Our study found that linkage to care in the group of people tested through the facility-based approach was significantly higher compared to the group tested through the mobile/outreach services. More people were linked to care, and they linked modestly sooner, in the health facility than mobile clinic arm. The study supports findings elsewhere that outreach testing methods are effective in improving the uptake of HIV testing, but linkage to care after testing positive is lower in the outreach testing approaches (Bassett et al., 2014; Hatcher et al., 2013).

We found that the majority of participants who reported, "Wanting to receive treatment in case they are infected with HIV" as one of the reasons for testing for HIV, tested at facility-based sites (Paper I). The reasons for seeking to test, particularly being symptomatic or suspecting infection, are not only important in deciding where to test, but also strongly influence linkage to care after testing. These findings align with earlier studies in Kenya and South Africa, and systematic reviews and meta-analysis of community and facility-based HIV testing (Hatcher et al., 2013; Bassett et al., 2014; Genberg et al., 2015; Sharma et al., 2015). Studies conducted in South Africa found that delay in seeking medical attention for newly-diagnosed individuals was associated with being asymptomatic, not expecting to get an HIV positive test result, and having difficulty in disclosing their status to others (Medley et al., 2013; Naik et al., 2015). Our findings and their interpretation are in line with these recent studies.

Our study compared not only the proportions of linkage to care, but also looked at the reasons for testing and determinants for linkage into care. Sharma et al. (2015) reviewed different HIV testing modalities, assessing their relative impact in covering the gap of low HIV testing uptake, especially among men, in sub-Saharan Africa. Their study highlighted the importance of expanding HIV testing services, suggesting follow up and support to help HIV-positive clients link to care. It was pointed out that immediate initiation of ART leads to better outcomes and improves the quality of life in people living with HIV.

Disclosure of HIV serostatus to partners and/or family members was strongly associated with earlier linkage to care, compared to those who did not disclose to partners and/or family members/relatives (Hodgson et al., 2014; Ostermann et al., 2015). These findings deepen our understanding of determinants of linkage to HIV care and underline the continued importance of facilitating disclosure and social support. Despite progress in "normalizing" HIV, and increases in testing and linkage in Tanzania and other African countries over a few years, disclosure, stigma and perceived or real lack of support are still very important barriers for linkage and engagement to HIV care (Mbonu et al., 2009; Aransiola et al., 2014).

#### 7.3.3 Processes and dynamics of linkage to care

Both mobile and facility-based HIV testing sites and HIV care and treatment centres attended to the clients in accordance with the National guidelines for HIV testing and HIV management (MOH, 2013; MOHsw, 2015). Recently, the WHO released new guidelines for ART programs, encouraging immediate initiation of treatment for all individuals who are HIV-positive, towards the achievement of the 90-90-90 goal by 2020 (Olney et al., 2016; WHO, 2016). Tanzania is among the countries that have adopted this recommendation, but the rapid changes in management of HIV/AIDS may pose challenges for all facilities trying to follow current guidelines immediately. The fact that the facilities in our study, from districts purposely chosen because they are remote with hard-to-reach populations, were following guidelines is a significant and encouraging finding, associated with dramatic increase in linkage to care outcomes compared to studies done some years ago (Nsigaye et al., 2009; MRACP, 2014; Simmelink, 2014).

The processes and procedures for linkage at the HIV care and treatment centres were similar for all clients, regardless of the site of testing. Since HIV care services such as CD4 count testing, HIV staging, and ART initiation are not available in the mobile /outreach sites, referral procedures, client follow-up and decreasing barriers to access at all levels where linkage can be interrupted is very important. The study showed that after HIV positive diagnosis and post-test counselling, the care providers explained the available options for further care, and provided the clients with referral letters for them to go on their own to the CTCs of their choice. However, there are an increasing number of individuals testing at the mobile sites who may be asymptomatic at the time of diagnosis and are probably not expecting positive test results, meaning that they are less likely

to link with further HIV care. Thus, more efforts, such as client follow-up and assisted linkage (active referral), need to be done, rather than just giving a referral letter and leaving the client to go on their own. A systematic review of HIV testing and linkage to care in sub-Saharan Africa, published after the data collection for this study was completed, pointed out the potential impacts of supporting and following-up HIV-positive clients to ensure they link into care and benefit from ARTs (Sharma et al., 2015). Studies have suggested that the use of combined interventions, like voluntary counselling and testing with point-of-care CD4, active referral system and outreach activities to improve linkage and engagement in the HIV care cascade, may contribute to high impact and success in universal test and treat strategies (Gardner et al., 2011; Rio, 2011; Olney et al., 2016;).

The processes in the two models examined in this study differed. However, one of the important findings is that despite a more proactive and "client-centred" approach in the mobile sites, linkage to care was faster and at higher rates from the facility-based sites. This reflects both the advantages of system-level integration at the sites in this study, as well as the particular challenges faced by clients who are unlikely to come to a facility to test, and who are also unready to receive and act on a positive test result. These findings can inform the development and adaptation of strategies to respond to the challenges of newly HIV diagnosed individuals and can be responsive to the health system challenges to successful linkage to care.

## WESTERN CAPE

# 7.3.4 Facilitators and barriers for successful linkage to care at the patient, provider, health system and contextual levels

Available literature on linkage to care indicates that while studies are increasingly exploring barriers to linkage to HIV treatment and in various settings (Bhatia & Giordano, 2011; Gardner et al., 2011; Rosen & Fox, 2011; Bogart et al., 2013; Wachira et al., 2014; Sharma et al., 2015;), fewer studies have looked at the facilitating factors, and even fewer have explored both together (Hatcher et al., 2013; Layer et al., 2014; Ware et al., 2016). We therefore sought to add to the literature and deepen understanding of linkage to care by exploring the facilitators and barriers to linkage into HIV care after testing HIV positive, from both facility-based and mobile/outreach HIV testing sites.

In this study, we conceptualized a framework of factors reported to inhibit or enhance linkage, based on the available literature (Figure 2 page 23, chapter 3). The data collected from this study showed that multiple factors influence linkage to care in newly HIV positive diagnosed individuals, and we identified these factors under four levels: individual, healthcare provider, health system, and contextual levels. The framework was very useful in identifying areas that need improvement at different levels of the HIV care continuum. This study found that while access and linkage to care are influenced by actors and process at all of the levels in the framework, the individual-level and health system-levels barriers were most prominent.

At the individual level, stigma, denial, lack of disclosure, and being asymptomatic at the time of diagnosis were identified as very important barriers to linkage to care. These findings correspond with other similar studies in HIV (MacPherson et al., 2012; Hodgson et al., 2014; Ostermann et al., 2015; Fatoki, 2016). Factors such as stigma and problems in disclosure are still persistent, despite increased HIV awareness programs and education through radio, television, and posters in Tanzania. We suggest the need for more community-level educational programs and community HIV-support groups, as these strategies have shown potential in alleviating the problem in other recent studies (Hodgson et al., 2014; Ostermann et al., 2015). The fact that some people do not see the importance of seeking medical care when they do not have any symptoms also needs more attention from the healthcare provider's side. During post-test counselling, the importance of being in HIV care and support should be emphasized, whether the client has symptoms of illness or not.

The study revealed that the patient-staff relationship was generally good, and staff are well-trained in HIV care management, which is consistent with their observed ability to do their duties according to the guidelines. In a few sites, clients complained of a poor relationship with staff. However, in this study, the healthcare providers in some instances suggested that while negative relationships with clients do occur, these are related to a shortage of staff at the site, and consequent high workloads. The study findings suggest further research on this aspect is required, and emphasize that basic resources, effective management, and supportive supervision issues need to be addressed within a health system to improve the interpersonal quality of healthcare (Cowing et al., 2009; Lamarche et al., 2011). As years of experience, training and professionalism around HIV/AIDS increases, there is more positive attitude and support from service providers, but still

not enough to overcome stigma, fear, and structural or organizational barriers and inconvenience (Ledda et al., 2017).

At the health system level, clinic overcrowding, poor organization of the clinics, shortage of resources (staff, equipment, reagents), and long waiting times came across strongly from both the HIV-positive individuals and the healthcare providers as a hindrance for linkage to care. Well-organized clinic systems, with HIV testing and HIV care services in one place, and availability of a referral system were reported to facilitate linkage, and these findings align with other studies conducted in Tanzania, Uganda, Kenya and South Africa (Govindasamyet al., 2012; Hatcher et al., 2013; Nakigozi et al., 2013; Layer et al., 2014). Poor linkage and delayed entry into HIV care management after positive HIV diagnosis hamper efforts to improve coverage for HIV care and treatment services (Macpherson et al., 2012; Gerdts et al., 2014). It is therefore important to understand the determinants and factors that may influence successful linkage to care in order to inform strategies that will address the problem of low rates of linkage to care comprehensively along the entire process.

Below is the conceptual framework for factors influencing linkage to care, with the study findings incorporated into the framework.

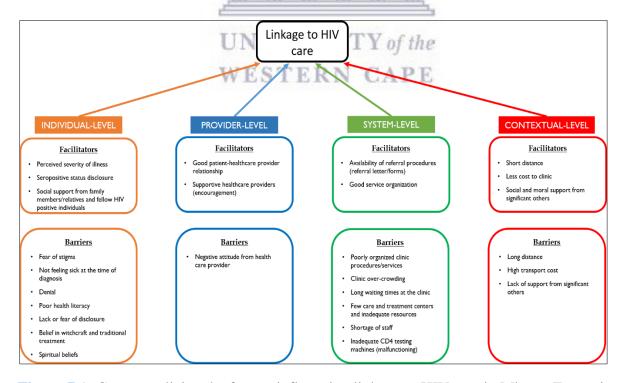


Figure 7.1: Conceptualizing the factors influencing linkage to HIV care in Mbeya, Tanzania

#### 7.4. Conclusion

Early HIV diagnosis, timely linkage to care, and immediate initiation of ART are critical ingredients to achieving the 90-90-90 goal by 2020 (Rio, 2011; Haber et al., 2017). Individuals diagnosed as HIV positive must be linked to HIV care and be initiated onto ART for better outcomes of HIV management, and prevention of further transmission to others. There is a need for special emphasis to link clients who test outside of clinic setting sites into care because these are the people who are more likely not to seek further medical attention. Clients testing at the mobile outreach services had a lower probability of testing positive (only 7% of clients who tested at the mobile sites tested positive, compared to 21% at facility-based sites), meaning that a positive test result may be unexpected for them. This is in comparison to those clients who test in facility-based sites, as they may suspect that they have HIV based on the symptoms that led them to seek or accept testing at a health facility (Paper 1). Since clients testing at mobile sites explicitly mentioned privacy and confidentiality as reasons for avoiding local health facilities, these are the people who need high-quality post-test counselling and support from the healthcare providers and referral system, to ensure that they link into care and benefit from ART.

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## **CHAPTER EIGHT**

## CONCLUSIONS AND RECOMMENDATIONS

#### **8.1 Conclusions**

#### 8.1.1 Study conclusions in relation to the study objectives

This study sought to document and analyze linkage to care in remote areas and hard-to-reach populations in rural Tanzania. At the time of this study, there was limited literature on HIV testing and linkage to care, and reported rates of linkage to care in Tanzania in 2009 and 2012 were very low. The findings of this study contribute to the limited knowledge on linkage to care, comparing two models of HIV testing services through a prospective mixed-method cohort study.

In response to objective 1, describing and comparing the populations accessing testing at mobile/outreach versus fixed/facility-based testing sites, our study found that more people tested at the mobile/outreach sites than at the facility based sites, and that more women than men tested in both arms. This finding reinforces the importance of expanded HIV testing services in out-of-hospital settings.

In response to objective 2, measuring and comparing time to linkage to care and factors associated with early linkage in the models of HIV testing, this study showed a substantial overall improvement in linkage to care compared to earlier studies in rural areas. Nevertheless, linkage to care in the group of people tested through the facility-based approach was significantly higher compared to those who tested at mobile/outreach services. Secondly, the disclosure of HIV serostatus to someone was strongly associated with earlier linkage to care, and HIV testing being sought in order to access treatment was modestly associated with earlier linkage to care. These findings suggest the need for increased strategies focused on facilitating linkage to care and the continued need for programs to normalize HIV in communities to reduce the stigma attached to the disease.

In response to objective 3, describing and comparing the processes and dynamics of linkage to care in the two models, the study findings suggest that while there are differences in the organization of services and the degree of proactive, client-centered care between the two models (with mobile/outreach sites being more proactive), there were no major differences in the processes and procedures of linkage to care in relation to Tanzanian policy and guidelines. All sites adhered well to national guidelines. The qualitative differences observed by the researchers and reported by study participants did not explain the differences in linkage to care between the two models. Once patients arrive at registration, they are managed roughly the same regardless of the testing site, though clients who tested at mobile sites were found to have slight delays at most steps between registration and initiating treatment or care.

In response to objective 4, identification of facilitators and barriers influencing linkage to HIV care services, the study revealed that access and linkage to care may be influenced positively and negatively at different levels (i.e. individual-level, provider-level, health system-level and contextual levels), in line with findings elsewhere. However, individual and health system factors were most prominent in this setting.

#### **8.1.2** Overall conclusions

Overall rates of linkage to care have improved dramatically from the 14% and 28% reported in 2009 and 2014. However, findings from this study suggest that although mobile/outreach service delivery models bring HIV testing services closer to people in remote and resource-constrained areas, and do increase testing, there is still a significant gap in timely linkage to HIV care compared to sites within established health facilities. This study also found that in this setting, health system organizational factors, such as on-site services and well-functioning routine procedures, are of particular importance in facilitating linkage to care: these organizational factors, together with the individual-level factors related to reasons for testing and readiness or willingness to accept an HIV diagnosis and seek care, are powerful determinants of linkage. Even though the long waiting times at care and treatment centres could themselves be a significant barrier to the linkage, overcoming stigma, fear, and logistical barriers are of primary importance. Strategies that are more effective are needed to further improve linkage through the mobile/outreach model of service delivery, including increased attention to effectively communicating the importance of linkage to care and

adherence to HIV treatment and providing additional support. However, if the highly motivated, proactive and supportive health workers identified in the mobile sites are to make a difference, the health system challenges to linkage to care must be addressed.

#### 8.2. Recommendations

In light of the high HIV testing uptake but low linkage to HIV care through the mobile/outreach testing models compared to facility-based testing, we recommend further focused action to improve linkage to care for the people testing in the mobile/outreach HIV testing sites. This should include increased efforts to effectively communicate the importance of linkage to care for people who are asymptomatic at the time of diagnosis, and improvement of referral procedures, support for disclosure to a trusted friend or relative, and follow-up and support to all newly-diagnosed clients. We also recommend further research on the use of assisted or facilitated linkage, since it has shown potential to improve linkage to care in some studies conducted in sub-Saharan African countries.

Multiple level factors were found to influence individuals' decisions and actions influencing linkage to care, and stigma, denial and lack or failure to disclose were particularly important. We echo existing recommendations for improvement in counselling strategies and expansion of community-level educational programs to hard-to-reach populations. While our study did not directly address communities, the findings are in line with suggestions for the establishment of HIV support groups and community interaction programs, to discuss and address HIV stigma-related matters and lack of disclosure in the community.

Considering that in this region more people show a preference for receiving HIV testing at mobile sites, further research is needed to evaluate the possibilities of offering Mobile ART services, as the new WHO guidelines recommend that HIV-positive individuals start ART right away, regardless of CD4 count or the stage of HIV.

Realizing the need to improve HIV care clinics and procedures for the provision of better quality of care and treatment services to HIV-positive individuals, and recognizing the very low number of facilities offering HIV care and shortage of staff in the study area, we encourage the Ministry of Health to accelerate the implementation of policies to address the human resource crisis in the

health sector, and specifically to explore possibilities of increasing the number of CTCs and staff in Mbeya region.

# 8.3 Strengths and limitation of the study

The strength of this study is its longitudinal mixed methods comparative design, with various stakeholders (healthcare providers, and HIV positive individuals), different data collection methods (structured interviews, observation, FGDs, and IDIs) and multiple sites (16 sites) used to elicit information relevant to the study. However, this study had some limitations:

Despite a random selection of sites to be included in the study, all eight facility-based sites had CTCs on the same campus. This limits the generalizability of the findings, as these sites may not be representative of all facility-based testing sites. This selection bias in the study also means that the comparison was between mobile/outreach testing sites and facility-based testing sites with immediately contiguous care and treatment centres.

Due to limited resources, we were able to only follow up participants for six months; it is possible that other participants entered into care later.

Although retention in the cohort was good (76% in the mobile arm and 87% in the facility-based arm), we were not able to reach all clients during the study period, despite efforts to track them through telephone calls by the study team, CTC and community-based healthcare providers in their respective areas. It may be that the clients moved to other places due to prevailing trade routes with extensive cross-border activities, and it is possible that some of them may have sought care elsewhere. This represents a selection bias in the study which may have led to underestimating linkage to care from mobile sites, as all clients lost to follow-up were treated as not linked to care.

In the identification of the challenges and facilitators for linkage to care, the study interviewed individuals who were linked to care. We did not have access to those individuals who tested HIV positive but were not registered in care.

The study design included contacting newly-diagnosed individuals who were enrolled in the cohort for follow-up questionnaire administration. This follow-up may have influenced their decision to

link to care, thus potentially artificially increasing the rates and timeliness of linkage to care in both arms of the study.

The study was unable to compute a possible clustering effect because we did not have a basis on which to estimate clustering/design effects as there were no similar studies conducted in the setting at the time; therefore our assumption was that there was no clustering effect and we set the design effect at 1. However, we are currently undertaking further analysis to look for any significant intraclass correlation coefficient (ICC) and if a significant ICC is found will conduct a further multilevel modelling analysis for an additional manuscript beyond the dissertation.

While we found that the mixed FGDs were rich and gender-specific complementary themes emerged from the individual interviews, we did not conduct separate men's and women's FGDs which may have yielded additional themes.

This study focused on HIV testing and linkage to care but did not focus on the broader health system issues like management and leadership in the sites. This may require further investigation to address issues around leadership and health systems management.

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# 10. ANNEXES

# 10.1 Ethical approvals

- Ethical approval UWC
- Ethical approval Tanzanian IRB





# OFFICE OF THE DEAN DEPARTMENT OF RESEARCH DEVELOPMENT

10 April 2014

#### To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by: Mrs E Sanga (School of Public Health)

Research Project: Linkage to care after testing HIV positive: A

comparative analysis of mobile versus health facility based models in rural settings, Mbeya-

Tanzania.

Registration no: 14/3/14

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias

Research Ethics Committee Officer University of the Western Cape

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A place of quality, a place to grow, from hope to action through knowledge

# THE UNITED REPUBLIC OF TANZANIA MINISTRY OF HEALTH AND SOCIAL WELFARE

Cable Referral Hospital Telephone: 2503456/2503351 Fax 2503577 Email: mrh@muchs.ac.tz



MBEYA CONSULTANT HOSPITAL P. O. BOX 419 MBEYA

Ref. No. MRH/R. 10/18/VOLL.VII/71

02<sup>nd</sup> May, 2014

Dr. Erica Sanga NIMR – Mbeya Medical Research Centre P.O.Box. 2410, Mbeya

RE: LINKAGE TO CARE AFTER TESTING HIV POSITIVE : A COMPARATIVE ANALYSIS OF MOBILE VERSUS HEALTH FACILITY BASED MODELS IN RURAL SETTINGS, MBEYA - TANZANIA

The aforementioned subject is concerned.

The Chairman has, on behalf of the Mbeya Medical Research and Ethics Committee grant an approval of the above mentioned study proposal for one year as from 17<sup>th</sup> April 2014 to 16<sup>th</sup> April 2015.

This approval which was granted by the Mbeya Medical Research and Ethics Committee meeting of 17<sup>th</sup> April bears the following specifications

 The Ethics Committee requires you to correct all typographic errors in the study proposal.

If the Research is completed you are required to submit a final report to Mbeya Medical Research and Ethics Committee

3. At all times you are responsible for Ethical conduct of your research

Kind regards,

Dr. Humphrey Kiwelu MD, MMed, MBA

Secretary: Mbeya Medical Research Ethics Committee.

cc: The Chairman

National Institute for Medical Research (NIMR)

P.O.Box 9653

Dar es Salaam

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# 10.2. Informed consent-English and Swahili

### 10.2.1 INFORMATION SHEET -English

Title: Linkage to care after testing HIV positive: a comparative analysis of mobile versus health facility based models in rural settings, Mbeya-Tanzania.

### What is this study about?

This is a research project being conducted by Erica Sanga at the University of the Western Cape. We are inviting you to participate in this research project because you are a person who can give the necessary information to the research on the experiences and challenge to HIV testing and linkage to HIV care in Mbeya region

The purpose of this research project is to describe and compare the processes and dynamics of linkage to HIV care and management between mobile and facility based models of HTC service delivery in the rural settings of Mbeya

## What will I be asked to do if I agree to participate?

You will be asked to respond to certain question that will be asked by the research with regards to linkage to HIV care, you may also be asked to participate in focus group discussions. The interviews will be conducted at the beginning, then after three months and the last interview will be six, months later.

This is study is conducted in four districts of Mbeya region, and this site is one of the sites selected for the study. In this study Linkage to HIV care means entering/start receiving HIV care and treatment after positive HIV results. The duration of study will be six month from time of enrolment. The interviews will take about 30-40 minutes, and the focus group discussion may take one hour. In the interviews you will be asked of general information like age, marital status, and occupation also you will be asked about the choices of HIV testing and HIV care sites, in

addition you will be asked about your experience in HIV care at this site and your opinion on what should be improved

# Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality The completed interviews will be kept safely by the researcher in a locked cabinet at the Mbeya Medical research centre and will only be seen by me and my supervisor.

I will collect your particulars, name and address, only to simplify tracking you for the second and third interviews and will not disclose them to anyone, apart from the research team. The data collected will be used for the research purposes only. Every study participants will be allocated a study number which will be used to keep the information not your name, and nobody will be able to link the number to your name except the research team. These interviews will not affect your medical treatment and support from the Health Facility or referral hospital.

After study completion if we write a report or article about this research project, your identity will be protected to the maximum extent possible.

#### What are the risks of this research?

There are no known risks associated with participating in this research however you may encounter emotional discomfort due to knowledge of their status and having to talk to the researcher about your health and what is happening after testing HIV positive.

#### What are the benefits of this research?

This research is not designed to help you personally but the information we get from the clients taking part in this study will help the health stake holders and ministry of health in Tanzania to improve access and linkage to HIV care and management in the rural setting of Mbeya region by formulating strategies to mitigate the challenges identified in this study. You will not be compensated with money or food for participating in this study

## Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be

penalized or lose any benefits to which you otherwise qualify. You are free to decline answering any questions you feel uncomfortable answering without being penalized

# What if I have questions?

This research is being conducted by Erica Sanga of Mbeya Medical Research Centre who is a student at the University of the Western Cape. If you have any questions about the research study itself, please contact the Study Coordinator's Name: Erica Sanga Mbeya Medical Research Centre P.O. Box 2410, Mbeya, Tanzania.

Mobile: +255 762 577 041; Email: esanga@mmrp.org; ericass80@hotmail.com or

*The* study supervisor Professor Christina Zarowsky (<u>czarowsky@uwc.ac.za</u>, czarowsky@gmail.com; tel +27 21 959 2809)



## **Dean of the Faculty of Community and Health Sciences:**

Prof Jose Frantz
University of the Western Cape
Private Bag X17
Bellville 7535
ifrantz@uwc.ac.za

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

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# **10.2.2 INFORMATION SHEET- SWAHILI**

# TAARIFA ZA UTAFITI

Jina la utafiti: Kuunganishwa katikahuduma baada ya kugundulika kuwa na VVU: Kulinganisha huduma za vituo vya kuhamishwa dhidi ya vituo vya afya vilivyojengwa katika maeneo ya vijijini mkoa wa Mbeya nchini Tanzania.

## Utafiti huu unahusu nini?

Huu ni utafiti unaofanywa na ndugu Erica Sanga wa chuo kikuu cha Western cape kilichopo nchini Africa kusini, tunakualika ushiriki katika utafiti huu kwa sababu wewe ni mmoja wa watu walio na taarifa muhimu na sahihi kwa ajili ya utafiti unaoangalia uzoefu na changamoto katika upimaji wa virusi vya ukimwi (VVU) na kujiunga na huduma katika mkoa wa Mbeya.

Lengo la utafiti huu ni kuelezea na kulunganisha taratibu, michakato na mipangilio ya kujiunga katika huduma na matibabu kati ya vituo vinavyohama hama na huduma zinazotolewa na vituo vya afya vilivyojengwa katika maeneo ya mbeya vijijini.

# Iwapo nitakubali kushiriki katika utafiti nitatakiwa kufanya nini?

Utaombwa kujibu maswali kadhaa ambayo utaulizwa na mtafiti juu ya upimaji wa virusi vya ukimwi na kujiunga na huduma unaweza pia ukaombwa kushiriki katika kundi dogo la majadiliano

Mahojiano yatafanyika mwanzoni, kisha baada ya miezi mitatu na mahojiano ya mwisho yatafanyika baada ya miezi sita. Utafiti huu utafanyika katika wilaya nne za mkoa wa Mbeya, na kituo hiki kimechaguliwa kama moja ya vituo vya utafiti. Katika utafiti huu kujiunga/kuanza kupata huduma baada ya kupata majibu ya VVU. Utafiti huu utadumu kwa miezi sita kuanzia utakapoingia rasmi kwenye utafiti. Mahojiano haya yanatarajiwa kuchukua takribani dakika 30-40 minutes nakatika mahojiano ya kundi dogo yanaweza kuchukua saa moja.

Katika mahojiano haya utaulizwa maswali ya kawaida mfano umri, hali ya ndoa na shughuli unazofanya, pia utaulizwa kuhusu uchaguzi wa vituo vya upimaji na huduma za matibabu. Zaidi ya hayo utaulizwa uzoefu wako katika kituo hiki cha huduma ya VVU na mawayo yako juu ya kitu gani kiboreshwe.

# Je ushiriki wangu katika utafiti huu utakuw a wa siri?

Tutafanya kila jitihada kutunza taarifa zako binafsi kwa usiri. Kuhakisha tunatunza usiri, mahojiano yaliyokamilika yatawekwasalama na mtafiti kwenye kabati linalofungwa katika kituo cha utafiti wa tiba mkoani mbeya, na yataonwa na mimi na mkaguzi tu.

Nitachukua taarifa zako, jina na anuani ya unapoishi kwa ajili ya urahisi wa kuktafuta kwa ajili ya mahojiano ya pili nay a tatu na sitazitoa taarifa hizi kwa mtu yeyote zaidi ya watafiti. Taarifa zitakazopatikana zitatumika kwa ajili za utafiti tu. Kila mshiriki atapewa namba ya utambulisho ambayo itaumika kutunya taarifa zako na sio kwa jina lako, na hakuna atakayeweaza kunganisha numba na jina lako isipokuwa watafiti. Utafiti huu hautaathiri matibabu yako wala msaada kutoka kituo cha afya au hospitali ya rufaa. Baada ya kwisha utafiti huu iwapo tutaandika taarifa au machapisho kuhusu utafiti huu utambulisho wako utatunzwa katika kiwango cha juu kwa kadri iwezekenavyo.

### Kuna athari gani kushiriki katika utafiti?

Hakuna athari yoyote inayojulikana kwa kushiriki katika utafiti huu, hata hivyo unaweza kupatwana mfadhaiko kwa sababu ya kujua afya yako na ukatakiwa kuzungumza na mtafiti kuhusu afya yako na nini kinatokea baada ya kujua unamaambukizi.

# Kuna faida gani kushiriki katika utafiti?

Utafiti huu haukupangwa kumnufaisha mshiriki moja kwa moja, bali matokeo yatakayotokana na huu utafiti yatasaidia watoaji wa huduma afya pamoja na wizara ya afya nchini Tanzania, kuboresha utoaji wa huduma kwa watu wenye virusi vya ukimwi katika vijiji mkoa wa Mbeya kwa kuandaa mikakati ya kupambana na matatizo yatakayopatikana au kugunduliwa baada ya huu utafiti. Pia hutalipwa pesa wakla chakula kama fidia ya kushiriki katika utafiti.

#### Ni lazima nishiriki katika utafiti au naweza kuacha ushiriki wakati wowote?

Ushiriki wako katika utafiti huu ni huru na wa hiari kabisa. Unaweza kuamua kutoshiriki kabisa na kama ukiamua kushiriki katika utafiti huu unaweza pia kuacha kushiriki wakati wowote. Kama ukiamua kutoshiriki kabisa au ukaamua kujitoa wakati wowote hutapata adhabu wala kupoteza faida yoyote unayostahili. Unaruhusu. Uko huru kukataa kujibu maswali ambayo hujisikii vizuri kuyajibu bila kupata adhabu yoyote

# Itakuwaje kama nikiwa na maswali?

Utafiti huu unaendeshwa na ndugu Erica Sanga wa kituo cha utafiti wa tiba mkoani Mbeya ambaye ni mwanafunzi wa chuo kikuu cha Western Cape kilichopo Afrika yza kusini. Kama una maswali yoyote kuhusiana na utafiti wenyewe tafadhali wasiliana na Mratibu wa utafiti Erica Sanga wa Mbeya Medical Research Center P.O. Box 2410, Mbeya, Tanzania.

Simu: + 255 762 577 041; baruapepe: <a href="mailto:esanga@mmrp.org">esanga@mmrp.org</a>; <a href="mailto:ericass80@hotmail.com">ericass80@hotmail.com</a> au Mkuu wa kituo cha utafiti wa tiba mkoani Mbeya, Dr Leonard Maboko kwa simu namba 2503364 au msimamizi wa utafiti Profesa Christina Zarowsky wa (<a href="mailto:czarowsky@uwc.ac.za">czarowsky@uwc.ac.za</a>, <a href="mailto:czarowsky@gmail.com">czarowsky@gmail.com</a>; tel +27 21 959 2809.

Utafiti huu umepata kibali kutoka kamati la utafiti na maadili chuo cha Western Cape, pia kamati ya maadili ya mkoa wa Mbeya na taifa la Tanzania.

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# 10.2.3 CONSENT FORM- English

Title: Linkage to care after testing HIV positive: a comparative analysis of mobile versus health facility based models in rural settings, Mbeya-Tanzania.

The study has been described	l to me in language that I understand and I fro	eely and voluntarily agree
to participate.		
My questions about the stu	dy have been answered. I understand that	my identity will not be
disclosed and that I may with	ndraw from the study without giving a reason	n at any time and this will
not negatively affect me in a	ny way. IVERSITY of the	
	WESTERN CAPE	
	••••••	•••••
Participant's name	Participant's signature/thumb print	Date
		••••••
Name of witness	Signature	Date
		•••••
Name of researcher	Signature	Date

Thank you for your participation

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### 10.2.4 FOMU YA KUKUBALI KUSHIRIKI

Jina la utafiti: Kuunganishwa katikahuduma baada ya kugundulika kuwa na VVU: Kulinganisha huduma za vituo vya kuhamishwa dhidi ya vituo vya afya vilivyojengwa katika maeneo ya vijijini mkoa wa Mbeya nchini Tanzania.

Nimepewa maelezo ya kina kuhusiana na utafiti huu na ninakubali kushiriki Nimepata nafasi ya kuuliza maswali yote niliyokuwa nayo na yamejibiwa kiasi cha kuniridhisha

Naelewa kuwa naweza kujitoa katika utafiti huu wakati wowote bila kutoa sababu na hili halitabadilisha huduma ninayostahili kupata mimi au familia yangu katika kliniki au kituo hiki.

UNIVERSITY of the WESTERN CAPE

••••••	•••••	•••••
Jina la mshiriki	Sahihi/dole gumba	Tarehe
••••••	•••••	•••••
Jina la Shahidi	Sahihi	Tarehe
	•••••	••••••
Jina la mtafiti	Sahihi	Tarehe

Asante kwa kutusaidia katika utafiti wetu.

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# 10.2.5 FOCUS GROUP CONFIDENTIALITY BINDING FORM-English

Title: Linkage to care after testing HIV positive: a comparative analysis of mobile versus health facility based models in rural settings, Mbeya-Tanzania.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. I agree to be audio-taped during my participation UNIVERSITY of the in the study. I also agree not to disclose any information that was discussed during the group discussion. Participant's name Participant's signature/thumb print Date ..... ..... ..... Name of witness **Signature Date** ••••• Name of researcher **Signature** Date

Thank you for your participation

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### 10.2.6 FOCUS GROUP CONFIDENTIALITY BINDING FORM- Swahili

#### FOMU YA MAKUBALIANO KUTUNZA SIRI YA MJADALA KATIKA MAKUNDI

Jina la utafiti: Kuunganishwa katikahuduma baada ya kugundulika kuwa na VVU: Kulinganisha huduma za vituo vya kuhamishwa dhidi ya vituo vya afya vilivyojengwa katika maeneo ya vijijini mkoa wa Mbeya nchini Tanzania.

Utafiti umeelezwa kwangu kwa lugha ninayoielewa na kwa uhuru na hiari yangu nakubali kushiriki. Maswali yangu kuhusiana na utafiti yamejibiwa. Naelewa kuwa utambulisho wangu hautajulikana kwa yeyote na kwamba naweza kujitoa wakati wowote katika utafiti bila kutoa sababu yoyote na hili halitaniathiri kwa namna yoyote.

WESTERN CAPE

Nakubali kurekodiwa wakati wa ushiriki katika mjadala huu.

Pia ninakubali kuwa sitatoa nje taarifa yoyote iliyojadiliwa katika kundi hili la mjadala.

#### ••••• ••••• ..... **Tarehe** Jina la mshiriki Sahihi/dole gumba ••••• ••••• Jina la Shahidi Sahihi Tarehe ..... ..... ..... Jina la mtafiti **Tarehe** Sahihi

Asante kwa kutusaidia katika utafiti wetu.

# 10.3. Questionnaires and interview guides

# 10.3.1. QUESTIONNAIRE- ROUND ONE-@ ENROLLMENT

Title: Linkage to care after testing HIV positive: A comparative analysis of mobile versus health facility based models in rural settings, Mbeya-Tanzania

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Diuu	110111001		

## READ INFORMATION SHEET AND OBTAIN WRITTEN INFORMED CONSENT

PART I. Health facility information

PARI	1. Health facility information	
1	District	1. Kyela 2. Mbeya Rural
		3. Mbozi 4. Chunya
2	Ward	
3	Street/ Village	
4	Name of street leader/ten cell	ERSITY of the
	Leader/ popular person	DEDAL CARE
4	Name of health facility/site	LERN CAPE
5	Type of health facility/site	1.Hospital
		2. Health Centre
		3. Dispensary
		4. Stand-alone VCT
		5. Mobile/outreach
		6. Other specify
7	Ownership	1. Government
		2. Faith based
		3. NGO
		4. Research center (MDTC)
		5. Other specify
8	Date of interview	Day Month Year

Thank you for agreeing to answer a few questions I'd like to begin by asking you some general demographic questions.

Part II: Demographic and socio-economic information

9	Sex of client	1. Male
		2. Female
10	How old are you?	Age in complete years at last birthday
11	What is your highestlevelof education?  (Circle only one)	<ol> <li>None</li> <li>Primary school</li> <li>Secondary school</li> <li>Vocational training/college</li> <li>University</li> <li>Other (specify)</li> </ol>
12	What is your marital status?	1. Single 2. Married 3. Separated 4. Divorced 5. Widower
13	What is/are your occupation(s) (Past twelve months)? (circle all applied)	<ol> <li>Unemployed</li> <li>Student</li> <li>Driver/transport</li> <li>Employed -government ,NGO, Private sector</li> <li>Self-employed (petty trader, business, peasant)</li> <li>Other (specify)</li> </ol>
	13(a) what is your income per months (estimation)	<ol> <li>1. 10,000 -100,000 (T- shillings)</li> <li>2. 100,000 - 500,000 (T- shillings)</li> <li>3. 5000,000 - 1,000,000 (T- shillings)</li> <li>4. Above 1,000,000 (T- shillings)</li> <li>5. N/A</li> </ol>
14	What means of transport did you use to come to the clinic	<ol> <li>Walking</li> <li>Bicycle</li> <li>Motorbike</li> <li>Vehicle (public transport)</li> <li>Private car</li> </ol>
15	How long did it take you to reach the clinic	1.less than one hour 2.More than one hour 3. two to five hours 4. More than five hours 5. Other (specify)

16	How much money did you use for transport to get to this place?	<ol> <li>Amount in Tshs</li> <li>N/A</li> </ol>
17	Why did you choose to come to this facility/site and not another site (give reasons)	
Part II	I: HIV testing and linkage to care	
18	What were the reason for you testing for HIV (circle all applied)	<ol> <li>Want to know my HIV status</li> <li>Want to get married</li> <li>I'm pregnant</li> <li>I believe is a good thing</li> <li>I want to receive treatment in case am infected</li> <li>Suspicious of partner's behaviour</li> <li>I have been feeling sick</li> <li>I have been involved in risk behaviour</li> </ol>
19	When did the healthcare worker give you the result?	<ul> <li>9. My spouse/partner forced me 10. Other (specify)</li></ul>
20	What is the name of the site where you tested for HIV? (Write the name of site)	3. At the next visit
	20 (a) when did you go for testing (date of testing) (If possible check the date in the client's card, or count exact number of days since testing)	CAPE
21	Are you planning/intending to share your results with your sexual partner/spouse?  21.(a) Why	1.Yes 2.No → 21 (a) 1. Fear for divorce
	(circle all applied)	<ol> <li>Fear for stigma from the relative</li> <li>I don't have a permanent partner/spouse</li> <li>Other, specify</li> </ol>
22	Do you feel/think that you received all the necessary information about your status and where to go for care by the health care provider?  22 (a) If No; what more information	<ol> <li>Yes → 23</li> <li>No → 22 (a)</li> </ol>
	would you like to be told or explained about?	

23	Are you planning/intending to join/register at the HIV treatment and care center (circle only one)	` '
	<b>23.</b> (a) What is the name of the CTC do you intend to register?	
	23.(b)When do you intend to go for registration at the CTC (number of days from today)	
	23.(c) If the answer is No What are the reasons ( <i>Probe for reasons</i> )	
24	23 (d) when did you register (confirm date in client's card)  23 (e) Registration number (check in the card for d & e)  What do you think makes it difficult for someone from entering or joining HIV treatment and care services  (circle all applied)	1. Not understand the importance of being in HIV care  2. Not feeling sick  3. Long distance to the CTC  4. Cost of transportation  5. Insufficient number of health care providers  6. Low motivation of health care providers  7. Long waiting time at the clinic  8. Delay of laboratory results (e.g. CD4)  9. Fear of stigmatization  10. Failure of involving the partner  11. The partner/spouse do not allow  12. Lack of privacy at the Clinic

		13.Other:
25	What do you think makes it easier for someone to enter/join HIV treatment and care services?	(probe)
		99. Don't know

# Ask if the client has any question and respond accordingly

Thank you so much for your time, as we have seen in the participant information sheet, we are going to interview you again after three months, so see you in the next three months. Stay well.

Contacts: for tracing purpos	es: phone number	•••••
If no phone get the Family/t	rusted persons number	
If no phones at all try get the his/her home.	name of a popular neighbor or any	v identifiable thing near
	UNIVERSITY of the WESTERN CAPE	
Initials of research assistant	Date	Signature

#### **10.3.2 QUESTIONNAIRE - ROUND 2** (at three months)

Dtudy Hullion	y number	Site		
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# Title: Linkage to care after testing HIV positive: A comparative analysis of mobile versus health facility based models in rural settings, Mbeya-Tanzania

# Check/confirm participants study number

Take some minutes to chat to the client on other general issues then remind him/her that we had agreed to have another interview with them after three months

PART I. Health facility information

1	District	5. Kyela	
1	District	6. Mbeya Rural	
		7. Mbozi	
	110 010	8. Chunya	
2	Ward	o. Chunya	
	ward		
3	Street/ Village		
4	Name of street leader/ten cell		
	leader		
4	Name of health facility/site	EDGITTY CO.	
5	Type of health facility/site	1.Hospital	
	2 Health Centre		
	3. Dispensary		
		4. Stand alone VCT	
		5. Other specify	
7	Ownership	1. Government	
		2. Faith based	
		3. NGO	
		4. Other specify	
8	Date of interview	/_/_/	
		Day Month Year	
		1	

Thank you for agreeing to answer a few questions

I'd like to begin by asking you to tell me about what has happened in relation to your health and following up on your HIV status. I will also ask you some questions about your experiences at

health facilities and specifically at Care and Treatment Centre (CTC), thinking especially about your most recent visit.

# Write the participant's CTC card number .....

	Process, time line and procedure at the CT	CC
1	What means of transport did you use to	1. Walking
	come to the clinic	2. Bicycle
	come to the chine	3. Motorbike
		4. Vehicle (Public transport)
		5. Private car
2	How long did it take you to reach the alinia	1.less than one hour
	How long did it take you to reach the clinic	2.More than one hour
		3. two to five hours
		4. More than five hours
2	Has someone assumented way to the clinic?	
3	Has someone accompanied you to the clinic?	1. Yes $\rightarrow$ 3.(a)
	2() D. d.: d	2. No → 4
	3.(a) Does this other person	1. Yes 2. No.
	accompanying you know your status	2. No
4		
4	How long (days, weeks, months) did it take	
	you to go and register at the CTC?	
	Fill in exact time, calculate by checking	Mana than and month
	dates in the card	More than one month $\longrightarrow$ (4(a)
	4. (a) If answer is more than one	0.00
1		E 1 A E E E E
	month (ask reasons for delay, do	CAPE
	not make the client feel she has	CAPE
		CAPE
	not make the client feel she has	CAPE
	not make the client feel she has	CAPE
5	not make the client feel she has made a mistake)	CAPE
5	not make the client feel she has made a mistake)  What happened on your first day at the CTC	CAPE
5	not make the client feel she has made a mistake)	CAPE
5	not make the client feel she has made a mistake)  What happened on your first day at the CTC	CAPE
	not make the client feel she has made a mistake)  What happened on your first day at the CTC (mention all events- if possible in series)	
5	not make the client feel she has made a mistake)  What happened on your first day at the CTC (mention all events- if possible in series)  How long (hours) did it take to complete	1. One hour
	not make the client feel she has made a mistake)  What happened on your first day at the CTC (mention all events- if possible in series)  How long (hours) did it take to complete registration and other procedures on your	1. One hour 2. 2-3 hours
	not make the client feel she has made a mistake)  What happened on your first day at the CTC (mention all events- if possible in series)  How long (hours) did it take to complete	1. One hour 2. 2-3 hours 3. 4-5 hours
6	not make the client feel she has made a mistake)  What happened on your first day at the CTC (mention all events- if possible in series)  How long (hours) did it take to complete registration and other procedures on your first day	<ol> <li>One hour</li> <li>2-3 hours</li> <li>4-5 hours</li> <li>More than five hours</li> </ol>
	not make the client feel she has made a mistake)  What happened on your first day at the CTC (mention all events- if possible in series)  How long (hours) did it take to complete registration and other procedures on your	1. One hour 2. 2-3 hours 3. 4-5 hours

		,
	<b>7(a)</b> How many days later did you	
	give blood for the above mentioned	
	tests (count exact number of days)	
8	How long did it take to receive your results	1. Same day
	, ,	2. Two - seven days later
		3. One to two weeks later
		4. Two to four weeks later
		5. More than four weeks later → 8 (a)
		3. Whose than four weeks later > 0 (a)
	Q (a) If more than two weeks, ask for	1. Decults were not ready
	8.(a) If more than two weeks, ask for	<ol> <li>Results were not ready</li> <li>I did not return on time for results</li> </ol>
	reasons of delay	
		3. I had no money for transport
		4. I was sick
		5. Other
13	What happened after receiving your results	
14	Have you started ART	1. Yes → 15
	118 1118 1118 111	2. NO→14 (a)
	14 (a) ask for reasons	
		1. Not eligible for now →14(b)
	<u> </u>	2. Other
	plant and a second	
	<b>14(b)</b> For Pre-ARTs, when is your	TY of the
	next appointment for follow up?	1 1 of the
	WESTERN	CAPE
15	For those on ART, how long did it take for	1. Within one week
	you to start ART (from day of registration)	2. One to two weeks
		3. Two to three weeks
		4. One month
		5. One to three months
		6. More than three months
16	How many time/visits did you attend at the	1. 1-2 visits
	clinic before starting ART?	2. 3-5 visits
		3. 6-10 visits
		4. More than 10 visits
		1. Whole than 10 visits
18	How much was your CD4 count when you	
	started CTC (check in the patient's card)	
19	How much was your CD4 count when you	
1)	started ART (check in the patient's card)	
	bianca interputed scara)	•••••

20	Do you feel any improvement on your health after being on treatment?	<ol> <li>Yes</li> <li>No</li> </ol>
21	What do you think of the convices given to	
21	What do you think of the services given to you by the health care providers from the	
	time you went for HIV testing up to now?	
	<b>21(a).</b> Did you receive a referral letter or Memo from provider at HTC to go with to the CTC?	
	21(b). Did the care provider show/tell you	
	where to go for your next appointment?	
	21(c). What do you think needs to be	
	improved at the site for you to be more comfortable with service provided here?	
22	When are you scheduled for next visit at the	
	clinic	Date, month and year
	22 (a) What helps you/motivates you to	
	abide to your scheduled visit?	TY of the
	<b>22 (b)</b> What hinders/inconveniences you willingness or desire to abide to your	CAPE
	scheduled visits?	CALL
23	Do you face any challenges in dealing with your status	1. Yes→ 23(a) 2. No → 24
	23(a) what are the most frequent challenges	
	Disclosure and Support	
24	Have you told anyone about your HIV status?	<ol> <li>Yes → 24 (a)</li> <li>No → 25</li> </ol>
	24 (a) How are you related to the	1. Spouse/partner
	people you told (circle all applied)	<ul><li>2. Parents</li><li>3. Brother/Sister</li></ul>
	, <b>,</b> ,	4. Uncle/aunt
		5. Other (mention)

25	If you have not told anyone so far, are you planning to tell someone about your HIV status  25 (a) If No why		Yes→ 26 No → 25(a)
26	Do you have any friends or family who are taking ARVs	1. 2.	Yes No
27	Do you know anyone who his/her health has been improved because of using ARVs	1. 2.	Yes No
28	We are organizing a small group discussion, Are you okay discussing these challenge in a small group of 6-8 people who are HIV positive to find out how others deal with same challenges?	1.Yes 2. No	
29	I believe you do remember that we have one more last interview with you after three months to discuss how you are doing and to complete the study, is it still okay if we contact you again for this purpose?	1. 2.	Yes

Ask if the client has any question and respond accordingly
Thank you for your time, see you next time

Initials of research assistant	Signature

### 10.3.3 QUESTIONNAIRE - ROUND 3 (at six months).

Study	number	Site	
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# Title: Linkage to care after testing HIV positive: A comparative analysis of mobile versus health facility based models in rural settings, Mbeya-Tanzania

Take some minutes to chat with the client on other general issues then remind him/her that we had agreed to have another interview with them after six months

Thank you for agreeing to answer a few questions I'd like to begin by asking you some questions on how things went for the past three months and your experience in HIV care services

	A	
	Experiences at the CTC	
1	Did you come alone or you are accompanied	3. Yes
	by some one	4. No
	1(a) Does this other person	3. Yes
	accompanying you know your status	4. No
	UNIVERSI	TY of the
2	Are you now on ART	<ol> <li>Yes <b>2</b>(a)</li> <li>No <b>2</b>(b)</li> </ol>
	2(a)When did you start ART, after	1. Within one month
	registering at the CTC(check in the	2. Two months
	patient's card)	3. Three months
	,	4. Four months
		5. Five months
		6. Sixth months
	<b>2(b)</b> when is your next appointment	
3	How much was your CD4 count when you	
	started CTC? (check in the patient's card)	
	3.(a) How much was your CD4 count when	
	you started ART(check in the patient's	
	card)	
	3.(b) How much is your CD4 count	
	now(check in the patient's card)	
	· · · · · · · · · · · · · · · · · · ·	

4	How are you feeling now	<ol> <li>Very well</li> <li>Better</li> <li>Somehow better</li> <li>Not much improvement</li> <li>No improvement at all</li> </ol>
5	How regularly do you check the CD4 count in this center	<ol> <li>Each month</li> <li>Every three months</li> <li>Every six months</li> <li>Whenever necessary</li> <li>Other specify</li> </ol>
6	How would you rate the care you were given with healthcare provider at the site/clinic?	<ol> <li>Excellent</li> <li>Good</li> <li>Average/fair</li> <li>Not satisfactory</li> <li>Poor</li> </ol>
7	What do you feel needs to be improved at the center for you to be more comfortable with service provided here?	
8	Do you face any challenges in dealing with your status  8.(a) what are the most frequent challenges	2. No → 9
	<b>8.(b)</b> What you think should be done to overcome these challenges	1. 2. 3. 4. Don't know
9	We are organizing a small group discussion, Are you okay discussing these challenge in a small group of 6-8 people who are HIV positive to find out how others deal with same challenges?	1.Yes 2. No

## Ask if the client has any question and respond accordingly

Thank you for taking part in this study and for making it to the third interview, this is the end of this study, however you may still contact me or the study coordinator if you have any question. Stay well



# 10.3.4 FOCUS GROUP DISCUSSION- INTERVIEW GUIDE -

Name	of the site:
Date	Time start:
1.	Do you think there are some people in the community who are reluctant to know their HIV status in this area/community
2.	If yes what are the reasons?
3.	Let's now talk of people who have tested positive for HIV, are there people who are reluctant to join HIV care in this area or who find it difficult to get care?
4.	If yes what are the reasons?
5.	What do you think about the health care providers – do they give enough information and support on joining HIV care and treatment centers?
6.	What else/more information would make it easier to get services from a CTC?
	UNIVERSITY of the
7.	How far (distance) is it for people to get to the nearby CTC (in sites without CTC)
8.	Is distance a constraint in abiding to the scheduled visits at the clinic
9.	Are the any other factors that interfere or are a setback to stayingin care? (mention)
10.	What are your suggestions to improve the service in the HIV care unit (i.e what would you suggest to health care providers, to the government or ministry of health, and to patients and communities?)
Thank	for participation
Time F	Finished:

#### 10.3.5 IN-DEPTH INTERVIEW- INDEX CASES

Study number.....

Title: Linkage to care after testing HIV positive: A comparative analysis of mobile versus health facility based models in rural settings, Mbeya-Tanzania		
Explain to her about this interview, let the participant choose a Nick name and ask for permission to record the interview.		
1. Where did you go for HIV test (name of the site)		
2. When was that (date and month if possible)		
3. Did you get your test results the same day or you had to come on another day		
4. Please tell me on your own words what happened in your life from the day you receive your results until now		
5. Tell me what have you done or tried to do in order to take care of your health after knowing your HIV status		
Encourage the participant to talk by showing that you are following his/her story and probawhenever necessary		
<ul> <li>6. How would you rate the care you were given with healthcare provider at the site/clinic?</li> <li>1. Excellent</li> <li>2. Good</li> <li>3. Average/fair</li> <li>4. Not satisfactory</li> <li>5. Poor</li> </ul>		

**Time start.....** 

Thank you so much for taking part in this study to the end

8. Do you have any question? If yes respond accordingly

7. Is there anything else you would like to advise or suggest to health care providers, to the MOH or the government regarding health services to individuals living with HIV?

# 10.3.6 SITE REGISTER AND RECORDS

a: /E	W	
	acility information	
1	Name of the facility	
2	Site/facility status	Public, private, FBO, NGO
3	Level of Facility/site	Hospital, Health centre, dispensary, stand alone VCT
4	Services type	HTC / CTC or both
5	Number of client attended per month	HTC CTC
5	Date	
B. Clie	ent Information	
1	Sex	
2	Age	
3	Religion UNIV	ERSITY of the
4	Marital status	TERN CAPE
5	Education Level	
6	Occupation	
7	Ever tested before	
8	Results disclosure plan by client	
9	Name of referral site/centre ( if referred)	
10	Client code number	

	• • • • • • • • • • • • • • • • • • • •
Initials of research assistant	Signature

# 10.3.7 HIV LINKAGE TO CARE STUDY -OBSERVATIONAL CHECKLIST

District	Name of the site
Type of facility or site:	Hospital, Health center, dispensary, clinic, stand alone-VCT)
Site ownership: Govern	nment, Private, NGO)
Working places/ space:	Building, tents, Van or car),
Date	Researcher initials

SN	Item/activity	Yes/No	Number or	Explanation or
DIT	item activity	105/110	time (if	comments
			Applicable)	Comments
	HTC with CTC		търнешоте)	
			7	
	HTC without CTC	NUL 118 100	- 10.1	
	Documents			
	(Registers/Records/reports)			
	Waiting area (chairs/benches,			
	television)	_111_111_111		
	Counseling and registration			
	rooms, (Space, privacy)	ERSITY	of the	
	WEST	CEDN C	ADE	
	Estimated number of Clients	LEKN	AFE	
	Number of staff on duty and			
	qualifications.			
		Organization o	f services and t	flow of activities
	Working hours			
	Waiting time			
	Referral processes			
	(explanations and letter)			
	Waiting time for services			
	Step by step for a client			
	coming for HIV testing			
	Step by step for a client			
	coming for registration			
	(linkage).			
	Any other on going activity or			
	event at the site			

# **HEALTH CARE PROVIDER INTERVIEW-English**

Study number	. Site
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Title: Linkage to care after testing HIV positive: A comparative analysis of mobile versus health facility based models in rural settings, Mbeya-Tanzania

	A. Facility/site Informa	tion
1	District	9. Kyela 10. Mbeya Rural 11. Mbozi 12. Chunya
2	Ward	
3	Location	<ul><li>1- Highway/Boarder</li><li>2- Remote</li></ul>
4	Name of health facility/site	
5	Type of health facility	<ol> <li>Hospital</li> <li>Health Centre</li> <li>Dispensary</li> <li>Stand-alone VCT</li> <li>Mobile/outreach</li> <li>Other specify</li></ol>
6	Distance from referral Hospital, centre or CTC	<ol> <li>It is a site with CTC</li> <li>Less than 2 kilometers</li> <li>2 - 5 kilometers</li> <li>6- 10 kilometers</li> <li>More than 10 kilometers</li> </ol>
7	Ownership/status	<ol> <li>Government</li> <li>Faith based</li> <li>Private</li> <li>NGO</li> <li>Other specify</li> </ol>
8	Role of health provider in the site	<ol> <li>Site manager/in-charge</li> <li>Nurse counsellor in-charge</li> <li>Counsellor</li> <li>Doctor/Clinician</li> <li>Laboratory personnel</li> <li>Other specify</li> </ol>
10	Date of interview	//_/ //// Day Month Year

Thank you for agreeing to take part in this key informant interview, please be free to explain to me anything that is important in relation to this study

#### **B.** Facility/site operation

- 1. Please tell me about works of this facility/site what happens to the client from the time he/she registers for service (if possible in series)
- 2. What are the procedures for referral at this facility/site?
- 3. Are there official documents on guidelines/processes for referral at the site?
- 4. How do you follow up clients after HIV positive results? Pre- ART and those on ART
- 5. What works well in following up and retention of clients?
- 6. What doesn't work very well in follow up of clients?
- 7. Are there clients who are reluctant to enter HIV care?
  - 7(a) If yes, what do you think are the reasons?
- 8. In your opinion what makes it difficult for a client to enter or join HIV care?
  - 8 (a) what makes it easier for a client to enter HIV care?
- 9. What do you think can be done to improve things at the site with regard to linkage and continuity in HV care?

	C. Process, time lines and patterns	
1		
	What are your operating hours (time in a day)	
2	Does this facility/site offer HIV Testing	1.Yes
	and Counseling (HTC) services?	2. No : Go to 6
3	Are results for HIV test given to the client	5. Yes
	on the same day	6. No - 4.(a)
	4.(a) When does the client come back for results	<ul><li>6. Next day</li><li>7. Two - seven days later</li></ul>
	back for results	8. One- two weeks later
		9. More than two weeks later
4	What is the HIV testing algorithm used at this facility/site?	7. More than two weeks later
5	Does this site offer Care and treatment	1.Yes
	services	2. No → 14
		3. CD4 Count on site → 8
	18 818 818	1.0 0.0 0.0
6	Do clients give blood samples for CD4	1. Yes → 8
	count and other investigation on the day of	2. No
	receiving HIV positive result?	1 17 0
7	Do clients give blood samples for CD4	$ \begin{array}{c} 1. \text{Yes} \longrightarrow 8 \\ 2. \text{No} \longrightarrow 7(a) \end{array} $
	count and other investigations on the day of registration at the CTC?	
	7 (a) If No when do they come to provide	ITY of the
	blood samples (number of days)	N CAPE
8	How long (days, week, months) does it	1. Same day
	take for the CD4 count results to be	2. 2 - 7 days
	available from the day of sample	3. 1 - 2 weeks
	collection	4. 2 - 4 weeks
		5. More than 1 month
9	Do you have clients who do not return for	1. Yes→9(a)
	their CD4 or any other results?	2. No → 10
	<b>9.</b> (a) what do you think are the reasons?	
10	For clients with CD4 above 350 cell, what	
	happens (mention the steps)	

11	For clients with CD4 below 350 cell, what	
	happens (mention the steps)	
12	How many visits are scheduled for the	5. 1-2 visits
	client with CD4 less than 350 before	6. 2-5 visits
	starting on ART (estimates)	7. 5-10 visits
		8. More than 10 visits
13	How long (days, weeks, months) does it	1. Less than one week
	take for a client eligible for ART to start	2. 1-2 weeks
	treatment? (e.g. CD4 below 350)	3. 2-3 weeks
		4. One month
		5. More than one month
14	If the site is not a care and treatment center	
	(CTC) where do you refer HIV clients for	1
	further care?	2. Is the site with CTC services
20	Do you face any challenges as a health care	1. Yes
	provider in dealing with HIV clients at this	2. No →21
	site	II—II—II
	20.(a)What are the most frequent	
	challenges	
		ш_ш_ш,
	The state of the s	

Ask if the health provider has any question with regard to the study or interview. Thank you for participation and your time. Contacts/ phone number

Initials of research assistant	Date	Signature

## 10.4. HIV testing and linkage processes-Scenarios

How do these procedures play out on a typical day? Below are two scenarios explaining what happens at the mobile site and at the facility based site from the moment the client comes in to the time when all procedures are completed.

#### A day at the research mobile site

The ABC mobile site offers HIV testing, TB screening, cervical cancer screening and CD4 count testing, but does not offer ART, therefore all clients diagnosed HIV-positive must be connected to the nearby Care and Treatment Centre sites for registration and further HIV care and treatment.

This mobile site normally stays in one area for about one to two weeks. Normally one week before its arrival at the area, the field outreach officer goes to the area for preparations, informing the local government authorities, community leaders and the health facility in-charge (where the mobile team will refer HIV positive clients or any other client who may need further medical care. The outreach officer explains about the coming team, the duration of stay and the services that will be offered. This field officer has to make an arrangement or liaise with the nearby health facility staff where the mobile team will have to refer the HIV diagnosed clients for further care or any patient that may need further management in the hospital setting. He will finally fix posters in the public places showing the picture of the truck, the services offered and the time and dates of services.

Sometimes they also do film/video shows in the evenings, showing different events or topics related to HIV, TB, and cervical cancer. There is also the distribution of leaflets HIV, TB and cervical cancer.

#### The staff and activities at the research mobile site

The mobile team has two clinicians, three nurse counselors, two laboratory technicians, the receptions or the person who registers everyone coming for services on a particular day, the education officer, and a driver. There are two tents around the mobile lab, one for the clinicians and the other one for counselors. Usually, the mobile lab parks close to the health facility for easy linking of the clients who need further care. This offers an opportunity to use some of the facility rooms to offer services.

On the day of observation, the mobile lab parked closer to one of the public health center in Kyela district. About 100-150 people were waiting to be attended by the mobile team. There was a queue to the registration desk, they registered their names and other basic personal information, and then depending on the services they come for they are given a small piece of paper with a number and the designated tent for service provision.

We concentrated on the clients who were going to the HIV testing services. The clients who come for HIV testing queued towards the tent of the counselor, one counselor is in a tent and the second counselor is in one of the facility rooms, they go in one by one. Most clients took between 10-20minutes, though some clients took about 30 minutes, The nurse reported that if someone is coming for a repeat test and the results are negative then counselling is short, but for those coming for the first time it takes longer, and even longer if the client did not expect the result they got.

The clients who are HIV negative are counseled on how to stay negative and are advised to come for re-check after three months.

Clients who tested HIV positive were directed to the clinician's tent, where the doctor/clinician expected to examine and assess the need for any medical attention, then a request for CD4 count test and sputum for TB screening plus any other test that might be necessary is made.

The client will go to the lab technician, provide the requested specimen and then wait for results. In most cases the results are available after 2-3 hours, however, clients who provide the samples after 3.00 are advised to come on the next day for their results.

After receiving the results, the clinician will explain to the client the next steps, whether they are supposed to start ART or not and other necessary information depending on the clients' condition. The clinician will then refer the client to the health facility, giving them a referral form, with a copy of lab results to go with, to the facility that offers further care on HIV/AIDS. If the client is also TB reactive, they will be referred to a TB section to continue with treatment. Cervical carcinoma screening and TB screening was also ongoing concurrently with HIV testing as well as the distribution of health information leaflets.

The day ended at 5.30pm. The team then had to prepare for film show that was starting at 7.00pm.

#### HIV testing and linkage at the facility-based site

DEF is one of the facility based sites in Mbeya region. The site offers HIV testing services as well as HIV care and treatment services. The HIV testing and counseling station has one counselor who also assists at the antenatal care clinic when there are no clients for HIV testing.

The care and treatment centers station has one doctor, two nurses, two nurses' assistants, one Home Based Carer and one treatment expert (these are stable patients on ART).

The weekdays in this hospital are divided into different services and activities. Monday is for weekly departmental meeting and report writing of the previous week, and is a treatment initiation day for ART-eligible clients who tested for CD4 on Friday and received their results on Monday. Tuesday is the day for registration of newly diagnosed clients, Wednesday and Friday are CD4 count testing days. Thursday is also a treatment initiation day plus other usual CTC procedures and a clinic for children although recently they have started having a clinic for children on Saturdays. Therefore, the whole week the CTC is quite busy with between 40-80 clients attended every day.

On the day we observed this facility, the HIV testing section was not busy: there were five people waiting for services. The nurse counselor came and allows them to enter one by one into her office for counseling and then testing. The testing is done using Rapid tests, therefore each person stays with the counselor for about 15-30 minutes, less if it is a repeat test. A client who was diagnosed with HIV was given a referral letter and asked to bring it on the day of registration at the care and

treatment section which was on the other side across the open space, she showed the client where to go.

Tuesday is the day of registration into HIV care, on which all clients diagnosed HIV positive in the week or those referred from other testing sites comes to register at this care and treatment center (CTC).

At 09.00am, about 40 -60 clients are sitting outside the CTC. There are only four benches where people were seating. Most people are seating on the floor or on the grasses, these people are waiting for the healthcare providers to finish a brief morning report before they can be attended.

At 9.30 am the treatment expert came to talk to the clients in the waiting area. He asked for their attention and asked those who had come to the clinic for the first time to hand in their referral letters. He collected the letters, put them n a tray and took them inside to the CTC nurse who is responsible for registration. While the clients were waiting to be called in for services, the treatment expert continued with treatment adherence session. He explained that HIV is not a death sentence, if one adheres well to ART they will live a normal life just like other people who are not infected. He explained the procedures at the clinic and allowed questions; he responded to all question related to treatment adherence. For the question that needed medical personnel to respond, he noted them down and asked the doctor to respond. While the treatment session was ongoing, the clients who come for ART pick up and follow up visits were being attended by other care providers. The clients who were already in care had a box where everyone who comes to the

clinic put their cards in the box in order of their arrival. The nurses attend the clients in the order of first in first out.

After completing the session, the new clients are called in to see the nurse who registers them and gives the CTC card numbers (the clients are supposed to come with this card every time they come for a clinic visit or when they are sick and needs medical attention). She also opens a file for each client. The file is used to keep the records and clinical notes from the doctors and laboratory results for the client. All clients go for vital signs and weight check, and they are sent to the doctor for medical examination and HIV staging, then all new clients a given a laboratory request form for CD4 count test to determine their eligibility for ART initiation in the next day (Wednesday, if the client cannot make it they may come on Friday it was also a day for CD4 count test as well).

At around 4.30 pm the waiting area was empty.

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**Open Access** Research

**BMJ Open** Linkage into care among newly diagnosed HIV-positive individuals tested through outreach and facilitybased HIV testing models in Mbeya, Tanzania: a prospective mixed-method cohort study

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#### ABSTRACT

Objective: Linkage to care is the bridge between HIV testing and HIV treatment, care and support. In Tanzania, mobile testing aims to address historically low testing rates. Linkage to care was reported at 14% in 2009 and 28% in 2014. The study compares linkage to care of HIV-positive individuals tested at mobile/ outreach versus public health facility-based services within the first 6 months of HIV diagnosis.

Setting: Rural communities in four districts of Mbeya Region, Tanzania.

Participants: A total of 1012 newly diagnosed HIVpositive adults from 16 testing facilities were enrolled into a two-armed cohort and followed for 6 months between August 2014 and July 2015. 840 (83%) participants completed the study.

Main outcome measures: We compared the ratios and time variance in linkage to care using the Kaplan-Meier estimator and Log rank tests. Cox proportional hazards regression models to evaluate factors associated with time variance in linkage.

Results: At the end of 6 months, 78% of all respondents had linked into care, with differences across testing models. 84% (CI 81% to 87%, n=512) of individuals tested at facility-based site were linked to care compared to 69% (CI 65% to 74%, n=281) of individuals tested at mobile/outreach. The median time to linkage was 1 day (IQR: 1-7.5) for facility-based site and 6 days (IQR: 3-11) for mobile/outreach sites. Participants tested at facility-based site were 78% more likely to link than those tested at mobile/outreach when other variables were controlled (AHR=1.78; 95% CI 1.52 to 2.07). HIV status disclosure to family/relatives was significantly associated with linkage to care (AHR=2.64; 95% CI 2.05 to 3.39).

Conclusions: Linkage to care after testing HIV positive in rural Tanzania has increased markedly since 2014, across testing models. Individuals tested at facility-based sites linked in significantly higher proportion and modestly sooner than mobile/outreach

#### Strengths and limitations of this study

- Prospective adequately powered cohort study.
- Participants followed up for 6 months, with good retention (83%).
- Some participants may have moved elsewhere during the study and may have accessed care elsewhere; this warrants further investigation.
- Retention was higher in facility-testing arm (87%) than in mobile-testing arm (76%).
- Participant tracking might have enhanced linkage

tested individuals. Mobile/outreach testing models bring HIV testing services closer to people. Strategies to improve linkage from mobile/outreach models are needed.

#### INTRODUCTION

HIV remains a major burden in Sub-Saharan Africa (SSA), with 790 000 deaths associated with HIV in 2014. Despite the high prevalence and the increasing numbers of people living with HIV in need of highly active antiretroviral therapy (HAART), timely linkage to care is generally poor across SSA.2 3 The Mbeya Region is among the three regions in Tanzania with the highest HIV prevalence, with an average of 9% compared to the national average of 5.1%,<sup>4</sup> and AIDS-related deaths are among the three leading causes of death in the area.

Linkage to care is the bridge between HIV testing and HIV treatment, care and support.4 Timely HIV diagnosis and effective linkage into care and treatment are keys to

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improved outcomes. 7 8 All individuals diagnosed HIV positive must be linked to HIV care and treatment even if local treatment guidelines do not indicate that a person should be started on antiretroviral therapy immediately.9 CD4 cell count, HIV staging and evaluation of the client's need for antiretroviral therapy (ART) initiation need to be performed immediately. The Ministry of Health and Social Welfare in Tanzania guideline for initiation of ARTi is a CD4 count ≤500 cells; 10 however, during the period of this study, the actual cut-off point for ART initiation was a CD4 count of 350. The importance of linkage to care during HIV counselling and testing has been well advocated in Tanzania; however, the available literature indicates that linkage to care after testing HIV positive is still low, with only 14% linkage at 4 months reported in a 2009 study, and only 23% in Ifakara and 28% in Mbeya Region in 2014. 11-13 Low or delayed linkage to care leads to failure of HIV-positive individuals to benefit from HIV care. Hence, efforts are hampered to improve coverage for HIV care and treatment services, thus resulting in increased risk of HIV transmission to others. 4 14 Linkage to care remains at suboptimal levels in the country due to barriers such as lack of understanding of the importance of care regardless of disease stage, distance from the clinic and transport costs.  $^{11\ 15\ 16}$  Fear of stigma related to HIV, failure to disclose HIV status, being asymptomatic at the time of diagnosis and negative attitudes of healthcare providers are other factors reported to interfere with linkage to HIV care.17-19

Mobile and outreach testing sites have been introduced in Tanzania, reflecting an increasing interest in providing early detection of HIV and subsequent care and support in the hard to reach populations and remote areas.16 20 Most government health facilities in Mbeya Region (the site of this study) offer providerinitiated testing and counselling (PITC) and voluntary counselling services, but only about 21% also offer HIV care and treatment services. 13 On the other hand mobile and outreach services, operated mostly by nongovernmental organisations (NGOs), usually offer only voluntary counselling and testing (VCT) services. 18 These sites do not offer HIV care services, with the exception of the research mobile laboratory operating under the Mbeya Medical Research Centre (MMRC) that offers CD4 testing on site. Clients that test HIV-positive must then go to facility-based sites for registration and other procedures for HIV care and treatment.6 1

There has been little research on overall linkage to care in Tanzania, and none to the best of our knowledge on whether linkage to care differs between clients diagnosed at mobile/outreach sites compared to health facilities, or on factors facilitating or inhibiting successful linkage to care between these two models of service

delivery. <sup>21</sup> <sup>22</sup> These differences may occur at the patient level, at service provider level, at the facility level or at the level of the health system as a whole. For example, factors enhancing access to testing, such as dedicated outreach staff, may enhance linkage to care for those testing in mobile/outreach facilities, while other factors such as geographic distance between patients' homes and testing sites and treatment sites, weak referral systems and lack of structural links between testing and treatment sites may lead to disconnects between testing and care. <sup>11</sup> <sup>16</sup> <sup>23</sup>

One South African study found that individuals testing at mobile services were 33% less likely to undergo CD4 testing than individuals testing at static clinic services, and only 10% of mobile testers were successfully linked into care versus 72% of clinic testers;<sup>21</sup> however, in South Africa nearly all health facilities now offer treatment, care and support. Hence, findings about differences between mobile and facility-based testing and subsequent linkage to care may not be directly transferable to Tanzania, where testing and care are not always available as a 'one stop shop'. Active referral or self-referrals are therefore more common in Tanzanian situations.

Mbeya Region has a total of 312 health facilities where clients can receive testing and counselling (HTC) services through recommended approaches; however, only 68 facilities (21.7%) offer HIV care and treatment service. 13 At least two outreach partners or NGOs offer HIV counselling and testing in each district of the Mbeya Region. The Mbeya Medical Research Centre MMRC mobile laboratory, also known as the Mobile Diagnostic and Training Centre (MDTC), has been offering CD4 count tests at point of care<sup>5</sup> since 2009, covering between 8 and 12 sites every 3 months. Available statistics from the Mbeya Regional AIDS Control program (MRACP)<sup>6</sup> suggest that more people undergo HIV testing at mobile/outreach HIV testing services (56%) compared to facility-based services (44%); however, only about 28% of all people tested were linked into HIV care.21 An earlier study conducted in Mwanza reported that despite increased testing opportunities only 14% of newly diagnosed patients had linked into care 4 months after HIV diagnosis.11 Another study on linkage to care conducted in Ifakara showed a linkage of about 23%, indicating that linkage to care is a challenge in Tanzania. 12

This article reports new findings on linkage to care and compares the outcomes of linkage and time to linkage into care for individuals tested HIV positive at mobile/outreach sites, versus individuals tested HIV positive at facility-based services over the first 6 months after diagnosis in rural parts of the Mbeya Region. The findings of this study are expected to inform policy-makers and other stakeholders in the Tanzanian health-care system on the optimisation of HIV testing and immediate linkage to care, an issue of critical importance for timely initiation of antiretroviral therapy.

<sup>&</sup>lt;sup>i</sup>First line ART in Tanzania is Tenofovir, Lamivudine and Efevirenz. <sup>10</sup>

#### STUDY DESIGN AND METHODS

This was a prospective mixed-method cohort study of 1012 adults who tested HIV positive recruited into a two-armed cohort (health facility-based vs mobile/outreach HIV testing sites). The study participants were followed for 6 months to gather quantitative and qualitative information on linkage to care since diagnosis.

#### Study setting

The study population comprises rural communities in four of the then eight districts of the Mbeya Region in 2014. In 2012, the Mbeya Region had a population of 2 707 410 with 52% women and 48% men.24 The four study districts were selected to include high HIV prevalence areas and hard-to-reach populations. Two districts (Kyela and Mbozi) are along the highways and have borders with Zambia and/or Malawi. The population in Kvela district was 221 495 in 2012, while Mbozi had 446 339 residents. High population mobility associated with cross-border business and social interactions is thought to pose challenges to linkage to and continuity of care in these districts. The other two districts (Mbeya Rural and Chunya) have a larger proportion of residents who live 10 km or more from a health facility. The population in these remote districts was 305 319 and 290 478. respectively.24 The HIV prevalence among people tested for HIV in 2014 in the selected districts were Mbeya Rural 13.0%, Chunya 9.2%, Kyela 9.2%, and Mbozi 8.7%.

All public and mission health facility-based and outreach/mobile sites in the selected districts were listed. A total of 27 health facility and 4 mobile/outreach sites were listed in Mbeya rural, 20 health facility-based and 4 mobile/outreach sites in Chunya district, 14 facilitybased and 5 mobile/outreach sites in Kyela district and 29 health facility-based and 5 mobile/outreach sites in Mbozi district. Four sites in each district (two facilitybased and two mobile/outreach sites) were randomly selected from the list in each district using a table of random numbers. The eight facility-based sites selected had a care and treatment centre (CTC) within the facility. Sites had different arrangements for the first step of linkage to care, registration: in some facilities, registration was possible on the same day as testing, while other facilities had chosen a single day or two per week for newly diagnosed clients to register into HIV care. None of the mobile/outreach sites offered CTC services; they had to refer their clients to the closest CTC for further management (HIV staging, laboratory test, ART initiation, etc). The mobile site from MMRC was offering CD4 tests at the point of care, but still had to refer newly diagnosed clients, already with their CD4 results to nearby HIV care clinic or CTCs for registration and continuation of care.

#### Sampling

The sampling strategy for testing sites is described above. The sampling framework for the cohort comprised all adults above 18 years receiving HIV testing at facility-based and mobile/outreach sites in the four study districts of Mbeya Region. The sample size was calculated using Epi Info software with a CI of 95% and power of 90%, assuming that the two study groups would have the same number of participants. Thirty per cent of individuals tested through mobile/outreach services and 41% of individuals tested at facility-based services were expected to link to HIV care. The estimated sample size was 828; we adjusted this sample size to account for possible dropouts and non-responders (10%) resulting in a total estimated sample size of 900 participants.

#### Data collection procedures

Prior to data collection at clinic, the research team briefed the nurse counsellors at study sites on the study objectives and procedures. In turn, these nurse counsellors introduced the research team to clients. Interested individuals were invited in a private room for detailed explanation, informed consent process and agreement on a convenient time and place for questionnaire administration. Initial data were collected between August and December 2014. Follow-up questionnaire administration continued until June 2015. Eight of 1020 individuals who were approached for participating during data collection were not enrolled in the study because two of them were seriously sick and needed hospital admission, three were planning to move out of Mbeya to their home villages after receiving the results and the other three did not come back for enrolment and interviews within 7 days of testing and we were unable to track them. Research assistants who underwent 2 days of training on informed consent and data collection procedures did data collection.

#### Outcome measures

The key outcome was the proportion of participants successfully linked to HIV CTC across the sample and in each arm of the cohort. In this study, 'facility-based sites' refer to fixed or static facilities such as hospitals, health centres and dispensaries while 'mobile/outreach sites' means all outreach HIV testing services, including campaigns, mobile testing clinics, home visits or special event testing services.

The operational definition for linkage to care in this study is that a newly diagnosed individual has reported to a CTC, completed the registration process and has been provided with a CTC registration number and clinic card. This definition of linkage to care is based on Rosen and Fox 25 and the National AIDS Control Programme in Tanzania; 10 it was chosen to allow comparison with earlier studies of linkage to care.

This paper reports on preliminary outcomes for which a structured questionnaire was administered to respondents at enrolment, at 3 months and at 6 months to ascertain time to linkage into HIV care and to explore factors related to linkage to care. Information collected

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at enrolment included demographic data, date of HIV testing, reasons for testing, plans for linkage into care and plans for disclosure of HIV status to any family member, other relative or friend. All baseline information was self-reported by participants. In follow-up interviews at 3 and 6 months, we asked about registration/linkage into care, CD4 count testing, ART status and results disclosure status. At these follow-up interviews, we also reviewed the participants' clinic card to verify the reported dates of linkage, ART initiation and CD4 count results.

#### Data analysis

Quantitative data from sites were recorded, cleaned and analysed using Stata V.13 (College Station, Texas, USA). Descriptive analysis methods were used to present the characteristics of participants. Categorical data were presented using frequencies and percentage, while quantitative data were presented using the measure of central tendency and measure of dispersion. Cross-tabulation was used to show the distribution of study participant by testing site. We compared the ratios and time variance in linkage to care using the Kaplan-Meier estimator and Log rank tests. Cox proportional hazards regression models were used to evaluate the factors associated with time variance in linkage to care. Statistical significance was declared at p values <0.05 for the entire analysis.

#### **Ethical considerations**

The study was approved by the University of Western Cape (UWC) Senate Research Committee, the Mbeya Medical Research Centre, the Mbeya Medical Research Ethics Committee (MMREC) and the National Health Research Ethics Sub-Committee (NatHREC) under the Tanzanian National Institute of Medical Research (NIMR). Participation was voluntary, and it was explained to participants that they were free to withdraw from the study at any time without negative consequences. Volunteers were provided with an information sheet containing all details about the study. They signed an informed consent, and confidentiality procedures were observed.

#### RESULTS

# Participant characteristics and comparison between facility-based and mobile-based testing models

The cohort of 1012 HIV-positive individuals included 58.5% female participants (56% facility; 61% mobile), with a mean age of 35.8 years (SD 10.5) for facility-based and 35.3 years (SD 10.0) for mobile/outreach participants. By the end of 6 months follow-up overall 83% of participants were still active in the study, 87% in the facility-based arm and 76% in the mobile/outreach arm (p<0.0001). In both testing models, about 60% of participants were married and more than 80% of participants were self-employed with small-scale farming or petty businesses. A detailed listing of the patient

characteristics is presented in table 1. Age, gender, level of education and occupation were not statistically different between the two testing models, while statistical differences in marital status, means of transport, time to reach clinic, income and time to linkage were observed after  $\chi^2$  analysis.

#### Linkage to care at 6 months

At 6 months, 78% of enrolled participants were linked into care across both arms. Eighty-four per cent (95% CI 0.81% to 0.87%) of participants tested at the facility-based sites were linked into care within the first 6 months of HIV diagnosis, compared to 69% (95%CI 0.65% to 0.74%) from the mobile/outreach-tested group (figure 1). The interval from the day of HIV testing to the day of registration at a CTC was compared between participants who tested at a health facility and those tested through a mobile/outreach model. The median time to linkage was 1 day (IQR 1–7.5 days) for those who tested at a health facility and 6 days (IQR 3–11 days) for those who tested through any mobile/outreach model.

#### CD4 cell counts facility-based sites and mobile sites

Of the 793 clients linked into care, 512 (64.5%) tested in facility-based sites and 281 (35.4%) tested in mobile/outreach sites. Most of the clients (n=774, 97.6%) had a recorded CD4 count. The median CD4 count among participants who tested in facility-based sites was 220 (IQR: 114–382), while among those tested in mobile/outreach sites the median CD4 count of 255 (IQR: 174–394). Student's t-test showed no statistical difference in CD4 count at the point of linkage to care between the two testing models (p=0.49).

#### Time to linkage facility-based and mobile sites

The time to linkage (registration) was significantly shorter in the facility tested group, compared to the mobile/outreach tested group (p<0.001) (figure 2). Log rank test showed that there was a significant difference between the two groups (p<0.001). Sensitivity analysis was carried out on the 840 participants who were successfully followed for 6 months. Cox regression analysis revealed that a person tested at a facility-based site increased the 'risk' of linkage by 61% (adjusted hazard ratio (AHR)=1.61; 95% CI 1.39 to 1.85) compared to persons tested at mobile sites. The log-rank test found a significant difference between the two groups (p<0.001).

# Linkage from mobile sites with point of care CD4 test versus no CD4 test

Of the 405 participants testing at mobile/outreach sites, 182 (44.94%) individuals had tested for HIV at the MMRC mobile site, where CD4 testing was offered at the point of testing, but no registration or ART was provided. A total of 223 (55.06%) individuals tested for HIV at mobile/outreach sites without the availability of

Variable	Facility based	Mobile	N	p Value
Gender				
Male	265 (43.66)	157 (38.77)	422 (41.70)	0.122
Female	342 (56.34)	248 (61.23)	590 (58.30)	
Age, mean (SD)	35.8 (10.5)	35.3 (10)		0.9
Marital status				
Single	78 (12.85)	48 (11.85)	126 (12.45)	
Married	361 (59.47)	252 (62.22)	613 (60.57)	
Separated	82 (13.51)	37 (9.14)	119 (11.76)	0.002
Divorced	13 (2.14)	26 (6.42)	39 (3.85)	
Widower	73 (12.03)	42 (10.37)	115 (11.36)	
Level of education				
None	104 (17.13)	81 (20.00)	185 (18.28)	
Primary	470 (77.43)	299 (73.83)	769 (75.99)	0.4
Secondary	29 (4.78)	24 (5.93)	53 (5.24)	
Vocational	4 (0.66)	1 (0.25)	5 (0.49)	
Main occupation				
Unemployed	28 (4.61)	15 (3.70)	43 (4.25)	
Student	18 (2.97)	3 (0.74)	21 (2.08)	0.23
Driver	9 (1.48)	5 (1.23)	14 (1.38)	
Employed	18 (2.97)	11 (2.72)	29 (2.87)	
Self- employed	530 (87.31)	369 (91.11)	899 (88.83)	
Other	4 (0.66)	2 (0.49)	6 (0.59)	
Means of transport				
Walking	163 (26.85)	200 (49.38)	363 (35.87)	
Bicycle	93 (15.32)	77 (19.01)	170 (16.80)	p<0.0001
Motor cycle	143 (23.56)	71 (17.53)	214 (21.15)	
Public transport	201 (33.11)	55 (13.58)	256 (25.30)	
Private car	7 (1.15)	2 (0.49)	9 (0.89)	
Time to reach clinic (hours)				
<1	397 (65.40)	295 (72.84)	692 (68.38)	
1–2	157 (25.86)	76 (18.77)	233 (23.02)	0.004
2–5	50 (8.24)	26 (6.42)	76 (7.51)	
>5	3 (0.49)	8 (1.98)	11 (1.09)	
Time to linkage, median (IQR)	1 (1–7.5)	6 (3–11)		p<0.0001
Income (Tsh)				
<100 000	497 (81.88)	320 (79.01)	817 (80.73)	
100 000-500 000	39 (6.43)	56 (13.83)	95 (9.39)	
500 000-1 000 000	3 (0.49)	2 (0.49)	5 (0.49)	0.0006
>1 000 000	0 (0.00)	1 (0.25)	1 (0.1)	
NA	52 (8.57)	21 (5.19)	73 (7.21)	
Refused to answer	16 (2.64)	5 (1.23)	21 (2.08)	

CD4 tests, registration and ART. A total of 66.5% of study participants testing for HIV with an immediate CD4 test and 72% of those testing at a site without CD4 test were linked into care within the first 6 months; however, this difference was not statistically significant.

#### Factors associated with time to linkage

Bivariate Cox regression showed that there were several factors associated with hazard of time to linkage, and multivariate Cox regression analysis revealed that a person tested at facility-based increase the risk of linkage by 78% (AHR=1.78; 95% CI 1.52% to 2.07%) compared with persons tested at mobile centre when other variables were

Sanga ES, et al. BMJ Open 2017;7:e013733. doi:10.1136/bmjopen-2016-013733

controlled. Disclosure of HIV status to partners, family, a relative or a friend was found to be a significant factor associated with two and a half times increased risk of linkage to care (AHR=2.64; 95% CI 2.05 to 3.39). Of the participants whose main reason to report for testing was an intention to receive treatment 25% were more likely to link to care (AHR=1.25; 95% CI 1.06 to 1.46), table 2.

#### DISCUSSION

This study prospectively measured linkage to care in remote and hard-to-reach areas and populations, and compared successful linkage and time to linkage into HIV care between two HIV testing service delivery

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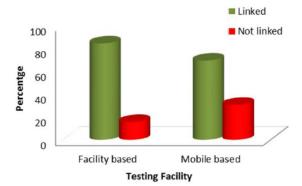


Figure 1 Linkage status.

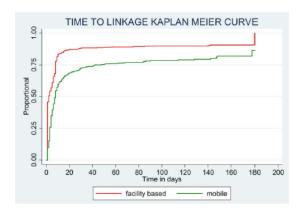


Figure 2 Survival analysis (KPM).

models in rural settings of the Mbeya Region in Tanzania.

The study was designed and implemented against the background of historically low rates of linkage to care, recent widespread implementation of mobile testing to address low population rates of HIV testing and evidence from other settings of significantly poorer linkage to care after HIV diagnosis at the mobile/outreach-based testing sites compared to facility-based testing sites.

Our study found that 78% (n=793) of individuals of the overall cohort had registered at CTCs within the first 6 months after diagnosis, representing a dramatic improvement in linkage to care after HIV diagnosis compared to the recent past in Tanzania. 11–13

A number of studies on HIV testing and linkage to care in other SSA countries have reported linkage rates of more than 60%. <sup>15</sup> <sup>21</sup> <sup>26-29</sup> Our encouraging findings likely reflect a combination of health system and social changes, including reduction in stigma. Our study itself may also have increased linkage to care through regularly contacting and following up HIV-positive individuals.

Linkage to care in the group of people tested through the facility-based model was significantly higher compared to the group tested through the mobile/outreach services. More people were linked to care, and they linked modestly sooner in the health facility than mobile clinic arm. This aligns with earlier studies in Kenya, South Africa and systematic review and meta-analysis of community and facility-based HIV testing. <sup>15 21</sup> 29

Likewise, a meta-analysis conducted in the USA on entry into medical care after HIV-positive diagnosis reported high entry by people testing at clinics and hospitals compared to other community testing settings.<sup>30</sup>

While the dramatic improvement in linkage across the overall cohort and the early linkage to the first step of care are encouraging findings, the continued gap in linkage to care between mobile-based and facility-based testing is important to address. It is possible that some of the respondents were lost to follow-up in the mobile/outreach arm sought and were linked to care in other sites; however, we believe that significant health system-level barriers must be addressed to ensure timely linkage and, ultimately, retention in care.

Some of the outreach testing activities are performed very far from the clinics that offer CD4 testing and HIV care. For example, some clients in Chunya district must travel more than 100 km on a rough road to reach a facility that offers CD4 test services and ART. We suggest expansion of mobile staging and ART services in remote areas. Furthermore, healthcare providers should ensure that education and emphasis on the importance of being in HIV care, even if the client does not yet require ART according to local guidelines, are emphasised during counselling.

Disclosure of HIV sero-status to partners and/or family members was strongly associated with earlier linkage to care compared to those who did not disclose to partners, and/or family members/relatives, again corresponding with findings elsewhere 31-33 and highlighting the continued importance of facilitating disclosure and social support.

We found that the majority of participants who reported, "Wanting to receive treatment in case they are infected with HIV" as one of the reasons for testing for HIV, tested at facility-based sites. This may suggest that they perceived themselves to be at higher risk, or that they already intended to seek care for their symptoms and that individuals testing at facilities were more willing to link immediately into care because they needed treatment.<sup>17</sup> This would align with studies elsewhere that have reported higher CD4 counts at mobile sites than at facility-based sites;<sup>21</sup> however, while we found slightly higher CD4 counts in the mobile testing arm, this difference was not statistically significant. We therefore think it is important to explore and address health system facilitators and barriers, such as the availability of integrated HIV testing, care and treatment services within the same facility/site.

This interpretation is supported by other findings from our study: a total of 265 individuals, 51.7%, who

Variable	Crude HR	95% CI	Adjusted HR	95% CI
Gender				
Male	Ref		Ref	
Female	0.97	0.84 to 1.12	0.98	0.84 to 1.14
Age				
18–30	Ref		Ref	
30-45	0.95	0.81 to 1.11	0.98	0.83 to 1.1
45-60	1.18	0.95 to 1.47	1.12	0.87 to 1.4
>60	1.06	0.65 to 1.73	1.11	0.66 to 1.8
Marital status				
Single	Ref		Ref	
Married	1.24	0.98 to 1.56	1.06	0.83 to 1.3
Separated	1.14	0.85 to 1.53	0.87	0.64 to 1.1
Divorced	1.27	0.84 to 1.91	1.19	0.78 to 1.8
Widower	1.37	1.02 to 1.83	1.15	0.82 to 1.6
Time to reach clinic (h	ours)			
<1	Ref		Ref	
1–2	1.06	0.89 to 1.25	1.03	0.86 to 1.2
2–5	0.97	0.74 to 1.28	1.17	0.88 to 1.5
>5	0.75	0.37 to 1.52	1.09	0.54 to 2.2
Testing site				
Mobile based	Ref		Ref	
Facility based	1.73	1.49 to 2.003*	1.78	1.53 to 2.0
Health improved beca	use of ARV			
No	Ref		Ref	
Yes	1.46	1.22 to 1.74*	1.01	0.82 to 1.2
Any friend/Family taking	ng ARVs			
No	Ref		Ref	
Yes	1.35	1.16 to 1.58*	1.01	0.85 to 1.2
I want to receive treatr	ment			
No	Ref		Ref	
Yes	1.25	1.07 to 1.45*	1.25	1.06 to 1.4
Disclosure of HIV statu				
No	Ref		Ref	
Yes	2.82	0.25 to 3.54*	2.64	2.05 to 3.3

tested at facility-based sites were able to link on the same day of HIV testing, while only 12% of those testing through the mobile/outreach model were able to link on the same day. This is likely associated with availability of HIV testing and HIV care and treatment services within the same compound at facility sites. Not surprisingly, some studies report that CD4 testing at the point of care reduces time for linkage, eligibility assessment and ART initiation, 34 35 and having HIV testing services and HIV care (CTC) at the same location improves rates of linkage to care and ART coverage.17 36 While Tanzania has made significant progress in increasing testing and linkage to care, our study strongly supports arguments for increasing the proportion of health facilities with care and treatment services from the current low level of 21.7%.13

Further analysis of our qualitative and quantitative data will help elucidate these findings. Nevertheless, studies on HIV testing indicate that outreach testing services increase access in remote areas, but linkage to care remains a problem.<sup>22 37</sup> Our study supports these findings, while reporting significant improvements in overall linkage to care since 2009 and 2014. The strength of this study is that we had a large sample of newly HIV-positive diagnosed individuals in the cohort, enrolled from 16 different sites who were followed up for 6 months from the time of diagnosis. The project team used telephone calls to follow-up clients on their dates of next visit to clinic. Use of phone calls may have been one of the factors that facilitated or enhanced linkage to care among the study participants.

The study has some limitations. We were not able to see all clients during the study period, despite efforts to track them through telephone calls by study team, CTC and community-based healthcare providers in their respective areas. It may be assumed that the clients might have moved to other places due to prevailing trade routes with extensive cross-border migration; however, our study was not able to ascertain the exact name of linkage site and linkage beyond the study sites.

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This warrants further investigation. An additional limitation of our study is that the random selection of facilitybased sites yielded a sample where all facilities had on-site CTCs.

#### CONCLUSIONS

Linkage to care is the bridge between HIV testing and treatment/care services for HIV-positive individuals. In comparison with previous studies conducted in 2009, 2012 and 2014 in Tanzania, this study shows that significantly more newly diagnosed HIV-positive individuals had linked to care within a short time of testing. We also found that linkage to care within 6 months of HIV testing was significantly higher from health facility-based HIV-testing sites compared to mobile/outreach sites. Finally, though of more modest clinical and population health significance, these individuals were linked into care significantly sooner, particularly at sites where the same-day registration for care and treatment was possible. Individuals who had disclosed their HIV status to their partner and/or family members were more likely to link to care earlier than those who did not disclose to anyone. Findings from this study suggest that although mobile/outreach service delivery models bring HIV testing services closer to people in remote and resource-restrained areas, there is still a significant gap in timely linkage to HIV care compared to sites within established health facilities. Thus, strategies that are more effective are needed to further improve linkage through this model of service delivery, including increased attention to effectively communicating the importance of linkage to care even for people who do not feel sick. In addition, the availability of care and treatment at facility-based testing sites should be significantly increased from the current low levels of <21.7% of public facility-based testing sites offering treatment and care.

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# Linkage into care among newly diagnosed HIV-positive individuals tested through outreach and facility-based HIV testing models in Mbeya, Tanzania: a prospective mixed-method cohort study

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