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DEPARTMENT OF PEDIATRICS AND CHILD HEALTH

**PREVALENCE AND DRIVERS OF LOSS TO FOLLOW-UP AMONG ADOLESCENTS
WITH TUBERCULOSIS AT MULAGO NATIONAL REFERRAL HOSPITAL**

BY

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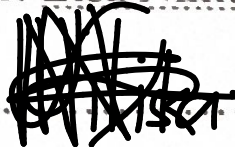
**A DISSERTATION SUBMITTED TO THE DIRECTORATE OF RESEARCH AND
GRADUATE TRAINING AS A REQUIREMENT FOR THE ATTAINMENT OF
MASTERS OF MEDICINE IN PAEDIATRICS AND CHILD HEALTH**

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DECLARATION AND APPROVAL

I, LISA NIMUSIIMA, declare that the information given in this dissertation entitled PREVALENCE AND DRIVERS OF LOSS TO FOLLOW UP AMONG ADOLESCENTS WITH TUBERCULOSIS AT MULAGO NATIONAL REFERRAL HOSPITAL, is my original work and that no part has been plagiarized, nor has it been presented to any other university for any academic award, publication or otherwise.

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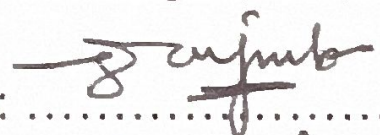
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DEDICATION

I dedicate this dissertation to God Almighty for His grace and strength; to my parents, whose unwavering love, sacrifice and encouragement have been my foundation; to my husband for his endless patience and support and belief in me every step of the way; and to my mentor Dr. Angella, whose constant reassurance and gentle guidance have made the journey a little smoother.

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To my beloved family, my parents, and my husband, thank you for your endless love, encouragement, and sacrifice.

To my sister Belinda, a researcher who has consistently guided the refining my research.

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OPERATIONAL DEFINITIONS

Adolescent: An individual aged between 10 and 19 years, as defined by the World Health Organization

Drug-Sensitive Tuberculosis (DS-TB): Tuberculosis caused by *Mycobacterium tuberculosis* that is susceptible to first-line anti-TB drugs, including isoniazid and rifampicin (WHO, 2013).

Loss to Follow-Up (LTFU): A patient who did not start treatment after being diagnosed or whose treatment was interrupted for two or more consecutive months following enrollment on treatment at Mulago National Referral Hospital.

Rural: Areas outside Kampala and Wakiso District.

Urban: Areas within Kampala and Wakiso District.

TABLE OF CONTENTS

DECLARATION AND APPROVAL.....	i
DEDICATION	ii
ACKNOWLEDGEMENT	iii
OPERATIONAL DEFINITIONS	iv
ACRONYMS AND ABBREVIATIONS.....	viii
ABSTRACT.....	ix
CHAPTER ONE	1
INTRODUCTION	1
1.1 Introduction.....	1
1.2 Problem statement.....	2
1.3 Justification	3
1.4 Research questions.....	4
1.5 General Objective	4
1.5.1 Specific Objectives	4
1.6 Conceptual Framework.....	5
1.6.1 Narrative	6
1.7 Theoretical framework.....	7
1.7.1 Narrative	7
CHAPTER TWO	9
LITERATURE REVIEW.....	9
2.1 Epidemiology of Adolescent Tuberculosis.....	9
2.2 Prevalence of Loss to Follow-Up.....	10
2.3 Factors Contributing to Loss to Follow-Up	10
2.3.1 Individual-level factors	11
2.3.2 Interpersonal Level Factors.....	12
2.3.3 Health System Factors	12
2.3.4 Community-level Factors.....	12
2.3.5 Policy Level Barriers	13
2.4 Implications for Public Health	13
CHAPTER THREE.....	14
METHODS	14
3.1 Study Design.....	14

3.2	Study setting.....	14
3.3	Study Population.....	15
3.4	Eligibility Criteria	15
3.4.1	Inclusion Criteria.....	15
3.4.2	Exclusion Criteria	16
3.5	Sampling Technique.....	16
3.5.1	Quantitative Component	16
3.5.2	Qualitative Component	17
3.6	Study variables.....	18
3.6.1	Dependent variables;.....	18
3.6.2	Independent variables.	18
3.7	Study Procedure.....	18
3.8	Data management.....	19
3.8.1	Quantitative data	19
3.8.2	Qualitative data	19
3.9	Data Analysis	20
3.10	Ethical Consideration.....	20
CHAPTER FOUR.....		22
RESULTS.....		22
4.1	Prevalence of Loss to Follow-up among Adolescents with TB.	22
4.11	Socio-demographic characteristics of Participants	22
4.12	Prevalence of Loss to Follow-up	22
4.13	Treatment interruption	23
4.2	Drivers of Loss to follow-up among adolescents with TB at Mulago National Referral Hospital 24	
4.2.1	Characteristics of Interview Participants	24
4.2.2	Individual-Level Factors	25
4.2.3	Interpersonal Level Factors.....	29
4.2.4	Health System-Level Factors	31
4.2.5	Community-Level Factors	32
4.2.6	Policy-Level Factors	33
CHAPTER FIVE		34
DISCUSSION.....		34

5.1	Prevalence of Loss to Follow-Up Among Adolescents with TB	34
5.3	Study strengths.....	39
5.4	Study limitations	39
CHAPTER SIX.....		40
CONCLUSION AND RECOMMENDATIONS		40
6.1	Conclusion	40
6.2	Recommendations.....	40
REFERENCES		41
APPENDIX I: CONSENT FORMS FOR ADOLESCENTS 18 TO 19 YEARS.....		45
APPENDIX II: CONSENT FORM FOR GUARDIANS OF ADOLESCENTS BELOW 18 YEARS. (English version).....		48
APPENDIX III: ASSENT FORM FOR ADOLESCENTS BELOW 18 YEARS.....		51
APPENDIX IV: CONSENT FORM FOR HEALTH CARE WORKERS.....		54
APPENDIX V: PHONE CONTACT SCRIPT FOR REACHING ADOLESCENTS LOST TO FOLLOW- UP (LTFU).....		57
APPENDIX VIII: QUANTITATIVE DATA EXTRACTION TOOL.....		59
APPENDIX VI: IN-DEPTH INTERVIEW GUIDE FOR ADOLESCENTS		60
APPENDIX VII: KEY INFORMANT INTERVIEW GUIDE		63
APPENDIX VIII: RESEARCH ETHICS COMMITTEE APPROVAL FOR RESEARCH.....		66
APPENDIX IX : MULAGO HOSPITAL ADMINISTRATION CLEARANCE		68

ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
DS-TB	Drug-Sensitive Tuberculosis
HIV	Human Immunodeficiency Virus
IDI	In-Depth Interview
IRB	Institutional Review Board
KII	Key Informant Interview
LTFU	Loss to Follow-Up
MOH	Ministry of Health
NTLP	National Tuberculosis and Leprosy Program
REC	Research Ethics Committee
SEM	Socio-Ecological Model
STATA	Software for Statistics and Data Science
TB	Tuberculosis
WHO	World Health Organization

ABSTRACT

Background: Adolescents with tuberculosis (TB) face unique obstacles across individual, interpersonal, health system, community, and policy levels, increasing their risk of loss to follow-up. The World Health Organisation classifies TB cases as pediatric (0–14 years) or adult (15+ years), obscuring the distinct profile of adolescents (10–19 years). Despite therapeutic advances, adolescents have loss to follow-up (LTFU) rates twice those of adults, reflecting unmet care needs.

Objective: To determine the prevalence and drivers of LTFU among adolescents with TB at Mulago National Referral Hospital.

Methods: A sequential mixed-methods study was conducted. Phase 1 involved retrospective review of TB registers (July 2023 – June 2025) to calculate LTFU prevalence. Phase 2 comprised in-depth interviews with purposively sampled adolescents who had been lost to follow-up, stratified by age, sex, and residence, plus key informant interviews with healthcare providers and community health workers. Quantitative data was analysed using STATA, and the qualitative data was analysed thematically using the Socio-Ecological Model.

Results: Among 123 adolescents, the prevalence of LTFU was 9.8% (12/123). Most participants (75.6%) completed treatment, while 9.8% were lost to follow-up, 10.6% transferred out, and 4.1% died. The median duration in care before LTFU was 172 days (IQR: 60–182.5 days). Qualitative findings revealed multi-level drivers: individual (transport and distance barriers, treatment burden, side effects, school commitments); interpersonal (stigma, peer influence, lack of family support); health system (limited provider support, strict clinic appointments, drug stockouts); community (weak facility–community linkage, cultural and religious beliefs); and policy (reduced donor funding for community programs).

Conclusion: One in ten adolescents with TB at Mulago Hospital was lost to follow-up. Drivers of LTFU span multiple levels, with transport costs, side effects, stigma, and health system inflexibility being prominent. Multi-level interventions, including decentralising TB services to lower-level health facilities, expanding national TB programs to include all adolescents, adolescent-friendly clinic models, and targeted social media campaigns, are urgently needed to improve treatment completion and align with the 2030 WHO End TB Strategy.

CHAPTER ONE

INTRODUCTION

1.1 Introduction

Tuberculosis (TB) is a primary global health concern. It remains one of the leading causes of morbidity and mortality among vulnerable populations, including adolescents, with 10.8 million people suffering from the disease in 2023. (WHO, 2024). Adolescents face a vulnerable and yet often overlooked demographic, accounting for approximately 12% of global TB cases (WHO, 2024)

Despite all the advancements in treatment for Tuberculosis, adolescent patients continue to experience disproportionate treatment outcomes, with LTFU rates approximately double those observed in adult populations (L. A. Enane et al., 2019). In Sub-Saharan Africa, where health system gaps are prevalent, adolescent loss to follow-up rates exceed 15% (Snow et al., 2017)

Uganda's national TB surveillance systems currently fail to adequately capture disease prevalence among 10-19-year-olds, with inconsistent documentation of therapeutic results. Major urban centers, including the capital city, exhibit distinctive challenges, including social discrimination, excessive clinic delays, and conflicting obligations like schooling that may compromise treatment continuity. Despite these documented barriers, research investigating treatment LTFU patterns in urban environments remains strikingly limited (Waako et al., 2013).

Adolescence is characterized by significant biological and psychosocial development, during which individuals often face concurrent challenges including social influences, educational stressors, insufficient TB-related knowledge, and inadequate support systems—all of which may negatively impact treatment adherence and retention in care (Belchior, Mainbourg, & Ferreira-Gonçalves, 2016). Individuals lost to follow-up prior to treatment initiation demonstrated significantly elevated mortality (48.1/1,000 person-years), more than double the post-diagnosis rate (22.9/1,000 person-years) during the first six months of TB care (Birhane, Mekonnen, Dingeta, & Teklemariam, 2023).

Mulago National Referral Hospital was selected for this study as Uganda's largest tertiary TB care center. Informal reports reveal systemic barriers such as stigmatization of adolescents in adult

wards, and inconsistent tracking during clinic transitions, issues that align with documented gaps in TB programs.

This mixed-methods study examined the epidemiology of treatment LTFU and its underlying determinants among adolescent TB patients at Mulago National Referral Hospital. It combined quantitative analysis of LTFU prevalence with qualitative exploration of contributing factors. The findings will inform adolescent-friendly TB care strategies in Uganda and similar high-burden settings, aligning with WHO's End TB strategy targets for reducing treatment abandonment.

1.2 Problem statement

Tuberculosis remains a leading infectious killer of adolescents globally, with 130,000 annual cases and disproportionately high mortality where treatment adherence fails. Despite this burden, TB programs overwhelmingly neglect adolescents, focusing instead on adults and young children, a critical service gap that perpetuates transmission and drug resistance. In Uganda, rural studies in Mayuge and Iganga Districts reported 10.5% LTFU rates among adolescents (Waako et al., 2013), which leaves a significant gap in understanding the dynamics of LTFU in urban settings. Urban data from Mulago National Referral Hospital showed a 9.2% LTFU in children less than 15 years, encompassing a broader pediatric population and masking the true crisis for 10–19-year-olds (Becker et al., 2023). This gap is clinically consequential because untreated adolescents face 48.1 deaths/1,000 persons (Birhane et al., 2023), fuel community transmission, and risk developing MDR-TB (Nidoi et al., 2021).

Urban adolescents face compounding risks, including clinic overcrowding, stigma, and competing school demands, yet no studies have quantified their LTFU prevalence or drivers at Mulago, Uganda's largest referral hospital. Without this evidence, national programs cannot design targeted interventions, perpetuating cycles of preventable death and TB spread. This study will close that gap, providing data to halt these avoidable losses.

1.3 Justification

Current TB programs in Uganda and globally fail to address adolescent-specific needs adequately. The WHO's 2022 TB guidelines lack urban-adolescent-specific recommendations, despite evidence that urban LTFU rates are 48.6% higher than in rural areas (Snow et al., 2017). Uganda's National TB and Leprosy Program (NTLP) allocates less than 5% of its budget to adolescent care (Partnership, 2023), and has no standardized protocols for youth-friendly TB services, such as flexible clinic hours, peer support groups, or tailored counseling. This oversight persists even though adolescents are at high risk of defaulting on treatment due to developmental challenges like growing autonomy, peer influence, and pubertal changes. Without targeted guidelines, healthcare workers are ill-equipped to retain this high-risk group in care.

This mixed methods study directly addresses these gaps by providing the first comprehensive data on LTFU prevalence and its multi-level drivers among urban adolescents at Mulago National Referral Hospital, a large TB referral center. At the policy level, the findings will have immediate programmatic impact, informing the design of adolescent-sensitive interventions such as adolescent-friendly clinic models and peer-support programs. By aligning with WHO's End TB Strategy, this work contributes to global targets for reducing TB mortality by 90% by 2030.

1.4 Research questions

1. What is the prevalence of loss to follow-up among adolescents receiving treatment for TB at Mulago National Referral Hospital?
2. What are the drivers of loss to follow-up among adolescents with TB at Mulago National Referral Hospital?

1.5 General Objective

To determine the prevalence and drivers of loss to follow-up among adolescents with TB at Mulago National Referral Hospital.

1.5.1 Specific Objectives

1. To determine the prevalence of loss to follow-up among adolescents receiving treatment for TB at Mulago National Referral Hospital.
2. To explore the drivers of loss to follow-up among adolescents with TB at Mulago National Referral Hospital.

1.6 Conceptual Framework.

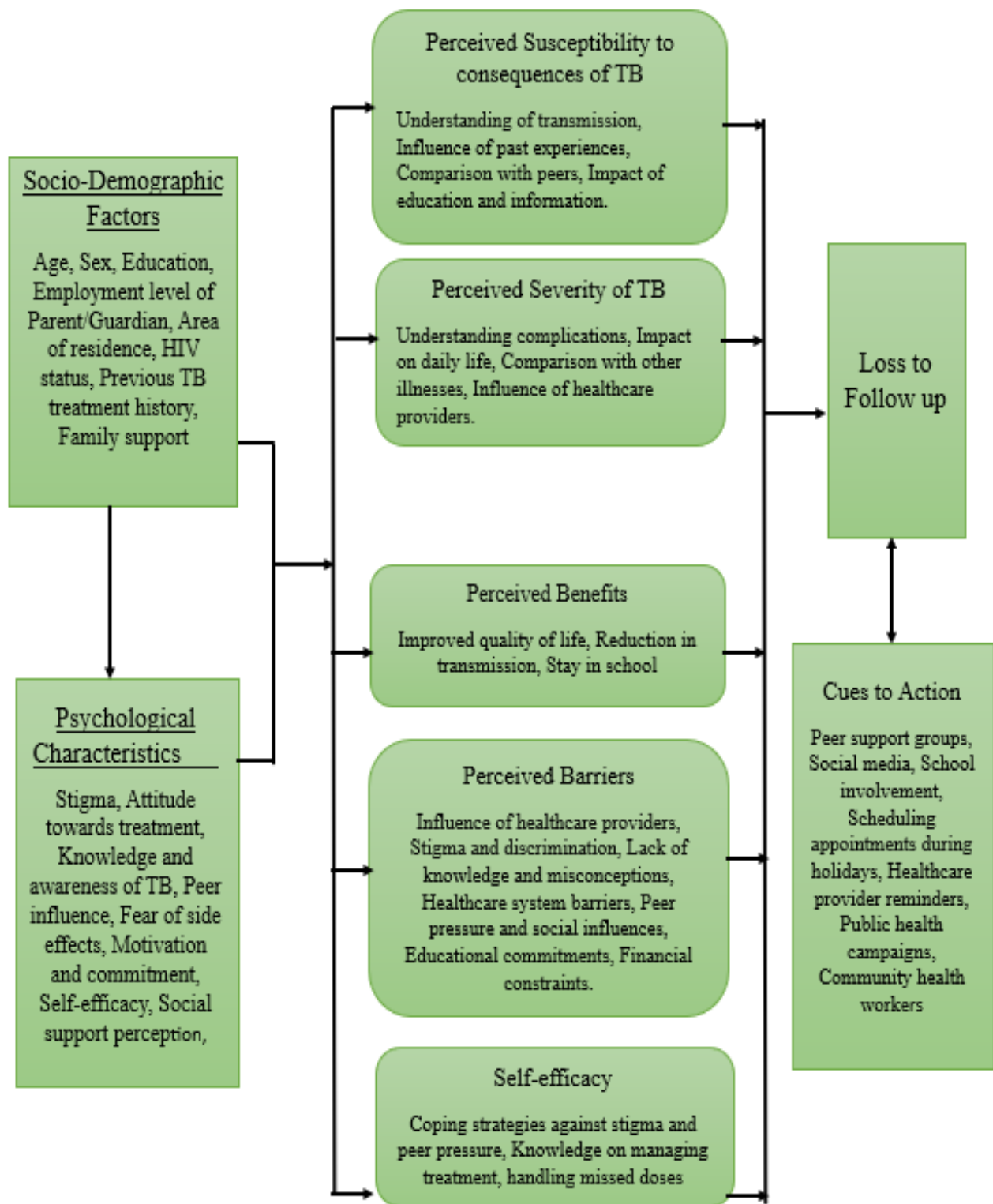


Figure 1: A Conceptual Framework on loss to follow-up among adolescents with Tuberculosis

1.6.1 Narrative

The conceptual framework for this study on loss to follow-up (LTFU) among adolescents with tuberculosis (TB) at Mulago National Referral Hospital was adapted from the Health Belief Model (HBM) (CDC, 2024). It emphasises key components that influence adolescents' engagement with TB treatment. Perceived susceptibility and perceived severity are foundational elements, shaping adolescents' awareness of their risk for TB and the seriousness of the disease. Understanding the potential health consequences of untreated TB can motivate them to seek and adhere to treatment. Perceived benefits highlight the advantages of completing treatment, such as improved health outcomes and reduced transmission risk. In contrast, perceived barriers are likely to identify obstacles that may hinder adherence, including stigma, lack of knowledge, and insufficient support. Self-efficacy reflects how adolescents' confidence affects their ability to manage their treatment regimen and their empowerment to overcome challenges. Lastly, the cues to action serve as triggers that encourage adolescents to engage with healthcare providers and adhere to their treatment plans, coming from sources like reminders, family support, and educational initiatives.

1.7 Theoretical framework

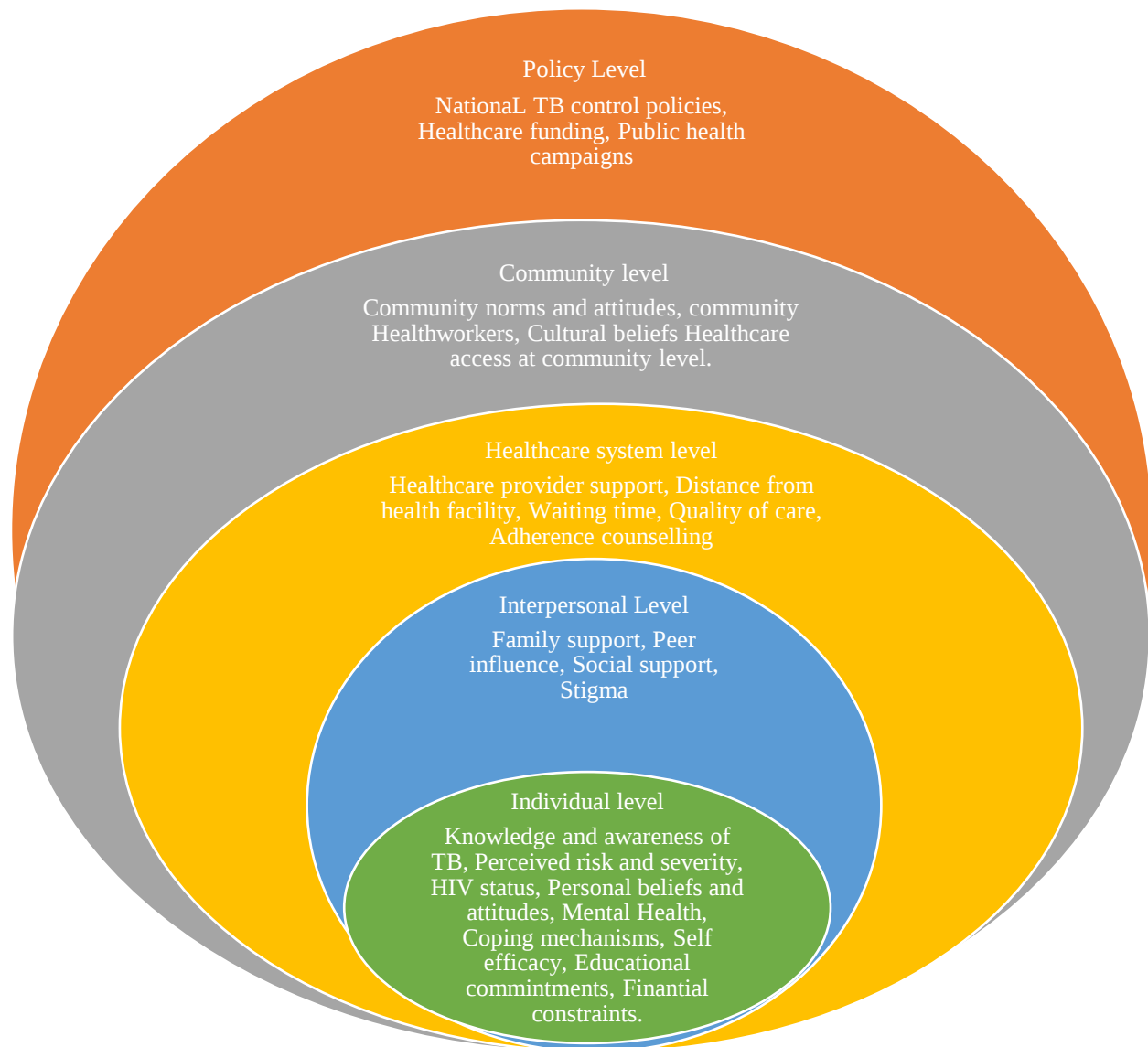


Figure 2: A theoretical framework on the multilevel drivers of loss to follow-up among adolescents with TB, based on the Social Ecological Model.

1.7.1 Narrative

This theoretical framework is based on the Social Ecological Model (SEM) framework (CDC, 2024) to understand the multiple levels of factors that drive loss to follow-up among adolescents with TB at Mulago National Referral Hospital. It highlights how personal, social, healthcare, and policy-related elements will likely affect LTFU in adolescents. At the individual level, factors such

as understanding, beliefs, self-confidence, and psychosocial factors like stigma and mental well-being affect the likelihood of the adolescent becoming lost to follow-up. Close relationships with family, friends, and health workers are likely to affect the way adolescents engage with treatment adherence and follow-up. Healthcare infrastructure, the availability of peer supporters, long waiting times, and distance from the health facility could also influence how adolescents perceive health services at the healthcare system level and ultimately contribute to loss to follow up. At the community stratum, three key elements significantly impact medication: compliance, economic disadvantage, culturally-embedded health beliefs, and population-level perceptions of healthcare. These community characteristics may disproportionately affect adolescents, increasing their risk of treatment interruption. Health policy frameworks at national and sub-national levels create structural conditions that either facilitate or impede consistent treatment engagement. Restrictive policies regarding clinic hours, medication access, or transportation reimbursements may inadvertently create systemic barriers for adolescents attempting to maintain regular care. This complex interplay operates across the five interdependent levels. The convergence of factors across these levels creates a cumulative effect on LTFU.

CHAPTER TWO

LITERATURE REVIEW

2.1 Epidemiology of Adolescent Tuberculosis

Tuberculosis (TB) remains a leading cause of adolescent mortality in high-burden countries, yet this age group (10–19 years) remains a 'blind spot' in global TB surveillance. Globally, the TB incidence rate reduced by 8.3% from 2015 to 2023, way below the WHO Target of 50% (WHO, 2024). Adolescents face unique biological and social vulnerabilities that amplify their TB risks.

The actual adolescent-specific data on tuberculosis (TB) remains uncertain because the World Health Organisation's (WHO) classification system has historically neglected the adolescent age group, categorising tuberculosis cases simply as either children (ages 0–14) or adults (ages 15 and older) (Seddon, Chiang, Esmail, & Coussens, 2018). Consequently, information regarding adolescents with TB primarily comes from single-centre or national studies, where cases are frequently broken down into different age groups.

The occurrence of TB infection tends to rise during adolescence in regions where tuberculosis (TB) is highly prevalent, as they become more exposed to *Mycobacterium tuberculosis* (Middelkoop et al., 2011). The likelihood of developing TB disease, which is at its lowest for children aged 5 to 9 years, escalates throughout adolescence (Seddon et al., 2018). Historically, before the advent of anti-TB treatments and the rise of HIV, it was estimated that the chance of progressing from TB infection to TB disease increased from 3.8% in children aged 5–9 to 6.4% in those aged 10–14 and reached between 10–13% for those aged 15–24 (Marais et al., 2004).

A study in South Africa showed *Mycobacterium tuberculosis* infection was associated with older age, for increasing age group [12–14, 15–17, and 18–19 vs. 10–11 years], having a household TB contact, and increasing community-level HIV prevalence, for increasing HIV prevalence category. In high-HIV settings like Uganda, adolescents face dual burdens: a Cape Town study found HIV co-infection tripled TB risk in 15–19-year-olds (Middelkoop et al., 2011).

2.2 Prevalence of Loss to Follow-Up

Loss to follow-up is defined as a patient who did not start treatment or whose treatment was interrupted for two consecutive months or more (Organization, 2013). The prevalence of LTFU varies significantly across different settings and populations.

A systematic review of tuberculosis programs in high-burden low- and middle-income countries demonstrated wide variations in treatment discontinuation, with reported loss to follow-up rates ranging from 4% to 38%. The highest prevalence of treatment LTFU was consistently observed in African and Asian settings (MacPherson, Houben, Glynn, Corbett, & Kranzer, 2013).

A study conducted in Botswana's capital demonstrated significantly higher treatment LTFU rates with a risk twice that of adults receiving comparable care (L. Enane et al., 2016). In South Africa, research in Cape Town demonstrated that 15.6% of adolescents and young adults prematurely stopped their treatment, with older adolescents (ages 15-19) and young adults (ages 20-24) with HIV co-infection experiencing poorer treatment (Snow et al., 2017).

A study done in Iganga District, Uganda, found a TB prevalence of 160 per 100,000 and an incidence of 235 per 100,000 person-years among adolescents aged 12-18 years (Waako et al., 2013). Significant geographic disparities emerge in treatment adherence patterns, with rural Uganda (Iganga District) demonstrating 10.5% LTFU compared to 15.6% in urban South African settings (Cape Town) (Waako et al., 2013), a 48.6% relative increase in urban LTFU rates (Snow et al., 2017), suggesting urban centres may exacerbate loss to follow-up.

In Kenya, a 17% loss to follow-up rate was found among adolescents with Tuberculosis (Nduba et al., 2018). Research conducted at Kampala's Mulago National Referral Hospital (2016-2021), analyzing pediatric TB treatment outcomes, identified an overall 9.2% LTFU rate. However, the study's broad age inclusion criteria (0-15 years) did not specifically assess the loss to follow-up patterns among adolescents (Becker et al., 2023).

2.3 Factors Contributing to Loss to Follow-Up

Adolescent treatment adherence is shaped by multi-level determinants spanning from individual characteristics, social relationships, community contexts, health system structures, and policy

environments. Across resource-limited settings, patient age, geographical accessibility to healthcare services, educational attainment, availability of familial support, and health system characteristics collectively elevate the likelihood of treatment interruption among TB patients (Opperman & Du Preez, 2023).

2.3.1 Individual-level factors

Factors like smoking, a low level of education, and living in urban areas can make it more likely that an individual will miss their appointments and not stick to their treatment plans. Additionally, socioeconomic status of adolescent or their family plays a role, with lower income levels correlating with higher rates of LTFU in Uganda. (Nidoi et al., 2021)

In East Africa, poverty intersects with age and gender: Ugandan males aged 15–19 with low education had 3 times higher LTFU odds (Kibuule et al., 2020). A Kenyan cohort study in Saiya County (Nduba et al., 2018) identified significant predictors of treatment attrition among adolescent TB patients, with orphaned status, older age, and lack of school enrollment collectively increasing LTFU risk by 40% compared to peers without these risk factors (Nduba et al., 2018). This highlights how fractures in social safety nets amplify the risk of LTFU.

Hormonal fluctuations during puberty can exacerbate mood instability, leading to inconsistent motivation for self-care (Patton et al., 2018). For example, adolescents may skip medications due to emotional distress or frustration with long-term treatment regimens. Additionally, body image concerns, such as weight gain from HIV antiretrovirals or visible side effects of TB drugs, can trigger treatment avoidance, particularly when peer perceptions are prioritized (Ferris France et al., 2023). These biological transitions intersect with psychological development, creating unique adherence challenges that are not typically seen in younger children or adults.

In East Africa, particularly in Uganda, limited data exist on the prevalence of LTFU among adolescents with TB. However, studies from neighboring countries showed that adolescents represented a high-risk group for LTFU due to various socio-economic and healthcare-related challenges (Soedarsono et al., 2021). Adolescents living with HIV who initiated antiretroviral therapy have higher rates of loss to follow-up in the older age group, 15-19, compared to those who started treatment between 10-13 years old. As they transition from younger to older adolescents or older adolescents to young adults, the rates of loss to follow-up increase (Kranzer et al., 2017).

2.3.2 Interpersonal Level Factors

Stigma manifests differently for adolescents: fear of school exclusion and peer rejection causing adolescents to lose the desire to continue with treatment (Chanda & Sichilima, 2018). Another study also revealed that patients with negative attitudes towards treatment, limited social support, and low satisfaction with health services were more likely to discontinue follow-up care (Soedarsono et al., 2021).

Patients who face TB alone, from families without support or a close community, are more likely to give up when faced with drug side effects, difficulty accessing health services, or psychological stresses and disengage from care. (Opperman & Du Preez, 2023)

2.3.3 Health System Factors

A study conducted in Luwero and Nakaseke, both urban and rural districts in Uganda, respectively, revealed that adolescents expressed a diminished trust in public health systems, describing clinics as “hostile spaces” with 3 hour waiting times, unwelcoming, judgmental, and unhelpful health workers as the factors contributing to loss to follow up (Muttamba et al., 2021).

In addition, having insufficient healthcare infrastructure, like space to review TB patients separately, shortages of trained healthcare providers, and long waiting times, does not encourage patients to come back for care. (Sullivan, Esmaili, & Cunningham, 2017)

Drug stockouts have also worsened outcomes of Tuberculosis, with 28% of Ugandan TB facilities reporting rifampicin shortages in 2022 (MOH, 2022).

2.3.4 Community-level Factors

Strong cultural beliefs and the perception of TB care services by society influence LTFU, with some communities’ traditional beliefs affecting medical treatment. This led to prioritizing alternative remedies over hospital-based care (Buregyeya et al., 2011). A study done in Iganga and Mayuge Districts in Uganda showed that TB is often misunderstood, with some individuals associating it with witchcraft, further discouraging adolescents from seeking medical care (Buregyeya et al., 2011).

Misinformation on treatment has been attributed to nonadherence to the set treatment protocols and patient dropouts from follow-up care (Khaitan et al., 2022)

Community health workers reduce loss to follow-up rates by 22% (Sinha, Shenoi, & Friedland, 2020). They play a critical role in reaching adolescents where they are to understand their dynamics and provide home-based adherence support and follow-up reminders. Still, their availability and effectiveness depend on available funding and program sustainability (Sinha et al., 2020). Funding, therefore, affects healthcare access and influences loss to follow-up.

2.3.5 Policy Level Barriers

National TB control policies, healthcare funding, and public health campaigns shape treatment outcomes, including loss to follow-up. Only 5% of Uganda's TB budget targets adolescents (Partnership, 2023). Limited funding for adolescent-focused TB programs results in inadequate adherence counseling, outreach services, and psychosocial support (WHO, 2024). The lack of adolescent-friendly TB Health services means the adolescent is ignored. They are seen in adult care settings and suffer the challenges of being treated as an adult, which may not address their unique social and psychological needs (Muttamba et al., 2021).

2.4 Implications for Public Health

Adolescents with TB not only suffer individual health outcomes like lost to follow up, treatment relapse, but also affect the broader public health efforts aimed at controlling TB transmission. A Ugandan cohort found 12% of LTFU adolescents returned with MDR-TB (Nidoi et al., 2021), confirming that adolescent loss to follow-up fuels drug resistance.

CHAPTER THREE

METHODS

3.1 Study Design

A sequential mixed-methods design was used, combining quantitative analysis of retrospective data with a qualitative exploration of adolescents' experiences of TB treatment and follow-up.

3.2 Study setting

We conducted this study at Mulago National Referral Hospital in Kampala, Uganda, focusing on two specific Tuberculosis clinics within the hospital: the Ward 15 outpatient children's clinic and the Ward 5 clinic.

The Ward 15 outpatient clinic caters to adolescents aged 10-14 years. It operates from Monday to Friday, from 9:00 a.m. to 3:00 p.m. At the clinic, patients are diagnosed clinically, radiologically, or by laboratory findings, and treatment and follow-up are provided for adolescents with TB up to 14 years old. The clinic is run by a medical officer and headed by a paediatrician, who reviews critically ill adolescents. Other clinicians, including Senior House officers, Medical officers, and nurses, are also involved in the care of the adolescents. The clinic operates every day and receives an average of 15 to 20 adolescents monthly, totalling 360 to 480 adolescents for the 2-year study period.

Older adolescents, 15-19, are managed at the Ward 5 outpatient clinic, which receives an average of 5 to 10 adolescents per month, totalling 120 to 240 adolescents in this age group for the study period. The patients are cared for by two Medical officers, nurses, pharmacists, and laboratory personnel. A senior house officer reviews patients with diagnostic and management challenges reported by the medical officer.

Once a patient visits the clinics, they are triaged, weighed, nutritionally assessed, and then reviewed by a clinician. A diagnosis is made clinically, radiologically, or bacteriologically confirmed, and the patient is registered in the outpatient register. The patient's name, address, contacts, disease classification, treatment regimen, HIV status, and diagnostics are recorded in the register. After the clinician reviews the patient and TB is diagnosed, the patient is prescribed anti-TB medication and scheduled for follow-up visits, weekly during the intensive phase and then monthly during the continuous phase.

3.3 Study Population

The target population included all adolescents aged 10–19 years with TB in Kampala, Uganda. The accessible population comprised those treated at Mulago Hospital’s TB clinics between July 2023 and June 2025. The study population consisted of all eligible adolescents aged 10-19 years diagnosed with TB attending the Ward 15 and Ward 5 outpatient clinics at Mulago National Referral Hospital in Mulago’s registers for the quantitative aspect of the study.

For the qualitative aspect of the study, we purposively sampled adolescents with LTFU to provide insight into the individual, interpersonal, health system, community and policy level factors that contributed to their disengagement from TB care, including age, sex, and area of residence. Key informants were also purposively selected based on their direct involvement in adolescent TB care. The selected cadres, nurses, medical officers, senior house officers, and the community health worker represent key stakeholders across the TB care cascade. Their daily responsibilities include diagnosis, treatment, adherence counseling, clinical supervision, and community follow-up. Their insights were essential for understanding both facility-level and community-level factors influencing loss to follow-up.

3.4 Eligibility Criteria

3.4.1 Inclusion Criteria

Quantitative study.

1. Adolescents who were registered and received treatment for tuberculosis at Mulago National Referral Hospital between July 2023 and June 2025.
2. Adolescents aged 10-19 years with TB who received treatment at Ward 15 and Ward 5 outpatient clinics.

Qualitative study

1. Adolescents aged 10–19 years who were classified as lost to follow-up did not start treatment after being diagnosed or whose treatment was interrupted for two or more consecutive months following enrollment on treatment at Mulago National Referral Hospital.
2. Adolescents who were registered and received TB treatment at Ward 15 or Ward 5 clinics, Mulago National Referral Hospital, between July 2023 and June 2025.

3. Adolescents 10-17 years who provided assent with an adult informed consent from a parent or primary caregiver, and adolescents 18 and 19 who provided informed consent.

Key informants

1. Health workers, including nurses, medical officers, senior house officers, and a community health worker who are directly involved in TB care for adolescents at Ward 15 or Ward 5 clinics, Mulago National Referral Hospital.
2. Health workers who had been managing adolescents in the TB clinic for at least 6 months before the study period.

3.4.2 Exclusion Criteria

Quantitative study

1. Adolescents with incomplete medical records, including age, sex, address, and date of initiation on TB treatment.

Qualitative study

1. Adolescents with cognitive impairments that hinder their ability to participate in interviews.

3.5 Sampling Technique.

3.5.1 Quantitative Component

We selected records retrospectively from the paper-based TB registers kept at the Ward 15 Children's Clinic and the Ward 5 TB outpatient Clinic from July 2023 to June 2025.

The sample size for estimating the prevalence was calculated using the Kish and Leslie formula for a single proportion in a finite population:

$$n = \frac{Z^2 \times p \times (1-p)}{e^2} \quad n = \frac{Z^2 \times p \times (1-p)}{e^2}$$

Where n is the Required sample size, Z is the Z-score for 95% confidence level set at 1.96, p is the expected prevalence of LTFU (9.2%, based on Becker et al., 2023) and e as the Margin of error (0.05 for $\pm 5\%$)

Calculation: $n = \frac{(1.96)^2 \times 0.092 \times (1-0.092)}{(0.05)^2} = 129$ participants
 $n = \frac{(0.05)^2 (1.96)^2 \times 0.092 \times (1-0.092)}{1} = 129$ participants

Since Mulago Hospital’s TB registers are expected to contain approximately 400 eligible adolescents (based on historical data from Becker et al., 2023), the finite population correction was applied.

$$n_{\text{adjusted}} = n \left(\frac{N-1}{N} \right) = 129 \left(\frac{1400-1}{1400} \right) = 129 \times \frac{1399}{1400} = 128.9 \approx 129$$

=98 participants

The adjusted sample size of 98 adolescents was the minimum required to estimate LTFU prevalence with 95% CI $\pm 5\%$. However, the study included all eligible adolescents, from Mulago’s TB registers (July 2023–June 2025), ensuring higher precision and allowing for subgroup analyses (e.g., by age, sex, HIV status).

3.5.2 Qualitative Component

We used a purposive sampling approach. Twelve adolescents considered lost to follow-up were selected for in-depth interviews, and data saturation was achieved. Additionally, we interviewed six key informants from the TB clinics. The adolescents and key informants were stratified to ensure varied perspectives. The adolescents were stratified by age category, sex and residence to include rural or urban areas as shown in Table 1, and the Key informants were stratified by cadre as shown in Table 2.

Table 1: Sample size estimation for in-depth interviews

	Male		Female	
Age category	Rural	Urban	Rural	Urban
10-13	2	2	2	2
14-17	2	2	2	2
18-19	2	2	2	2

Table 2: Sample size estimation for Key informant interviews

Key Informant	Target Sample
Senior House Officer	1
Medical Officer	2
Nurses	2
Community Health Worker	1

3.6 Study variables

3.6.1 Dependent variables;

Loss to Follow-Up (LTFU) was defined as the proportion of adolescents with TB who did not start or interrupted their treatment for two consecutive months or more.

3.6.2 Independent variables.

3.6.2.1 Quantitative Variables

- The Demographic variables included age, sex, location (urban or rural, HIV status, disease classification, previous TB treatment history, date of initiation on TB treatment, and referral status.

3.6.2.2 Qualitative variables

- Individual Level factors explored included Knowledge and awareness of TB, Perceived risk and severity, Personal beliefs and attitudes, Transportation costs, Mental Health, school commitments, coping mechanisms, Knowledge and awareness of TB, attitudes towards TB treatment, and financial constraints.
- Interpersonal Level factors included family support, peer influence, and stigma.
- Healthcare system-level factors included healthcare provider support, distance from health facility, waiting time, quality of care, strictness of clinic appointments and drug availability.

3.7 Study Procedure

We used trained research assistants under the supervision of the principal Investigator for the data collection process. The research team underwent orientation on the study protocol and a practice session to familiarise themselves with the data collection process.

Quantitative data was collected retrospectively from the TB registers. The data collected encompassed demographics, treatment start dates, addresses, disease classifications, patient classifications, follow-up appointment records, types of diagnoses, and treatment outcomes recorded in the TB patient registers. We developed and used a standardised data extraction form to collect information from the TB registers maintained at the Ward 15 children's and Ward 5 outpatient clinics. All the information in the registers was systematically reviewed to ensure accuracy.

After collecting the quantitative data, we selected the Key informants and adolescents lost to follow-up, and conducted in-depth and key informant interviews using a semi-structured interview guide. The adolescents identified as LTFU were first contacted via telephone using contact information from the registers. We reached each key informant at their work station and scheduled a convenient time for the interview. They will be conducted at ward 15 and ward 5, guided by the Key Informants workstation. The interviews were guided by pre-tested interview guides to ensure consistency and reliability in the data collection process. All interviews were audio-recorded and shared with the principal investigator. A meeting with the Principal Investigator followed to address any challenges encountered during data collection.

3.8 Data management

3.8.1 Quantitative data

We used the Kobo Collect software to minimise missing data during data entry. Files missing sociodemographic variables, including age, gender, address, and date of initiation on TB treatment, were excluded. Data collected from the registers with Kobo Collect was entered and uploaded onto a server, exported into Microsoft Excel, and cleaned. We analysed the data using STATA Version 16 software.

3.8.2 Qualitative data

We transcribed the audio recordings from the in-depth and Key informant interviews verbatim and proofread each of them to ensure accuracy. The transcriptions were securely stored on a password-protected computer and accessed only by the Principal Investigator. The generated transcripts were then imported into NVivo 2020, where data analysis was done. We familiarised ourselves through repetitive reading of the transcripts, and then developed codes and themes.

3.9 Data Analysis

Objective 1- Prevalence of loss to follow-up among Adolescents with TB

Prevalence Calculation

The prevalence of loss to follow-up among adolescents was calculated as the proportion of adolescents who missed treatment for two or more consecutive months between July 2024 and June 2025.

$$\text{Prevalence} = (\text{Number of adolescents lost to follow-up} / \text{Total number of adolescents initiated on treatment}) \times 100.$$

We used descriptive statistics to thoroughly understand the study population's characteristics and analysed them to summarise key socio-demographic variables.

For all categorical variables such as sex, disease classification, type of patient (new case, relapse, treatment after failure), nutritional assessment, HIV status, and TB drug regimen, the data were analysed, and frequencies and proportions were obtained. We presented the data in bar graphs and tables. All continuous variables, such as age, duration of TB treatment (months), and distance to the health facility, were also analysed and presented as means with their standard deviations (SD). The missed appointments, follow-up visits attended, and days of loss to follow-up, comprising discrete variables, are displayed as medians with their interquartile range.

Objective 2- Drivers of loss to follow-up among Adolescents with TB at Mulago National Referral Hospital.

All audio recordings of the interviews word-for-word were transcribed word-for-word. These transcriptions were checked for precision, and any discrepancies were corrected by re-listening to the tapes. Using thematic analysis, we coded the data independently, highlighting the keywords and phrases on TB LTFU. We then examined these codes, refined, and arranged them into broader themes and subthemes that reflected this study's key findings. We also identified and selected quotes from the transcripts. Once the codes, themes and quotes were established, we were able to interpret the findings on drivers of loss to follow up among adolescents with TB.

3.10 Ethical Consideration

We obtained administrative approval from the Department of Paediatrics, Mulago National Referral Hospital. We also obtained approval from the School of Medical Research and Ethics

Committee (SOMREC). (Mak-SOMREC-2025-567). Written informed consent was obtained from adolescents above 17, and assent was obtained from all adolescents below 18. Throughout the study, we emphasised respecting participants' autonomy and preventing coercive pressure. Participants were informed of their right to withdraw from the study at any time without facing any repercussions. The principle of beneficence also guided the study, ensuring that it produced a beneficial outcome for the community. To safeguard the confidentiality and privacy of participants, all information was anonymised and securely stored. We eliminated personal identifiers during the data analysis. Data was kept in password-protected files on secure servers, with all physical documents securely stored. Only through the Principal Investigator could data be accessed.

CHAPTER FOUR

RESULTS

4.1 Prevalence of Loss to Follow-up among Adolescents with TB.

4.11 Socio-demographic characteristics of Participants

A total of 123 adolescents were involved in this study. Of these, nearly half, 51.2% (63/123), were female. The majority of participants, 74.8% (92/123), reside in urban areas. The mean age of participants was 14.9 years (± 3.1). Most participants were HIV negative, 88.6% (109/123), while nearly half of the adolescents had bacteriologically confirmed pulmonary tuberculosis (48.8%, 60/123). The majority, 97.6% (120/123), were new TB cases (*Table 1*).

4.12 Prevalence of Loss to Follow-up

The prevalence of loss to follow-up (LTFU) among adolescents with tuberculosis was 9.8% (12/123). Among participants lost to follow-up, the median duration in care from treatment initiation to the last clinic visit was 172 days (IQR: 60–182.5 days)

Table 1: Background characteristics of participants

Characteristic	Frequency (n=123)	Percentage (%)
Age (years)		
10 – 13	45	36.6
14 – 17	41	33.3
18 – 19	37	30.1
Sex		
Female	63	51.2
Male	60	48.8
Residence		
Rural	31	25.2
Urban	92	74.8
HIV Status		
Negative	109	88.6
Positive	7	5.7
Unknown	7	5.7
TB Classification		
Extrapulmonary TB	26	21.1
Pulmonary - Bacteriologically confirmed	60	48.8
Pulmonary - Clinically diagnosed	37	30.1
Patient Type		
New	120	97.6
Relapse	1	0.8
Treatment after failure	2	1.6
Treatment Outcome		
Completed	93	75.6
Died	5	4.1
LTFU	12	9.8
Transferred	13	10.6

4.13 Treatment interruption

The median time from diagnosis to treatment initiation was 0 days (IQR: 0–0 days). Most adolescents-initiated TB treatment on the same day they were diagnosed. Overall, three-quarters of the adolescents completed treatment (75.6%, 93/123) (*Figure 2*). Treatment interruption ≥ 2 months occurred in 10.1% (8/79) of participants, with most interruptions lasting for at most 2 months (75%, 6/8).

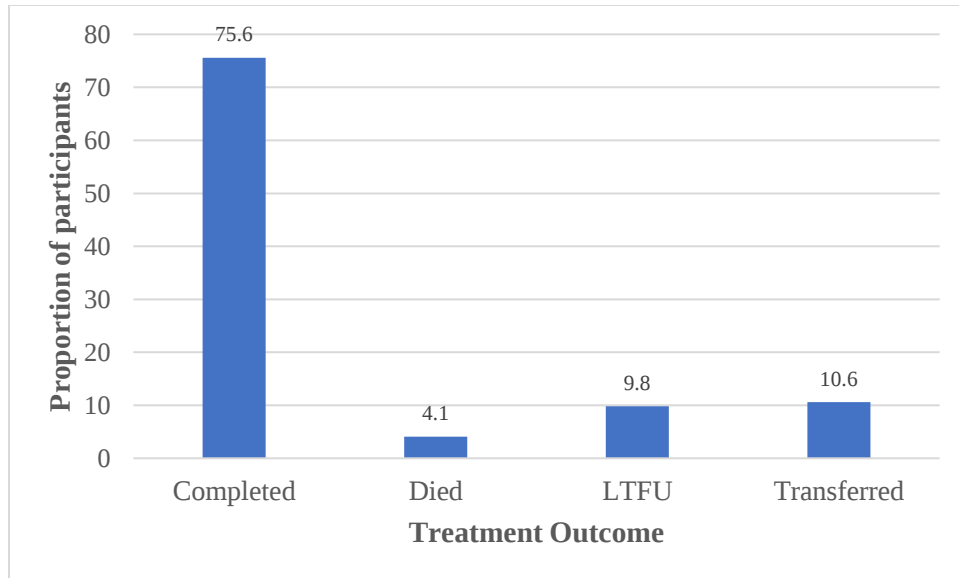


Figure 2: Treatment outcome of participants

4.2 Drivers of Loss to follow-up among adolescents with TB at Mulago National Referral Hospital

4.2.1 Characteristics of Interview Participants

A total of 12 in-depth interviews were conducted with adolescents aged 10–19 years who had been lost to follow-up from TB treatment at Mulago National Referral Hospital. The participants included both males and females from urban and rural areas around Kampala. Their ages were distributed across the adolescent spectrum to capture diverse experiences. We also conducted key informant interviews with six healthcare workers, including senior house officers, medical officers, nurses, and a community health worker, to gain a broader perspective on the health system challenges.

The analysis of the interview transcripts revealed a complex web of factors leading to LTFU, which we organised using the Socio-Ecological Model. The drivers of loss to follow-up were identified at the individual, interpersonal, health system, community, and policy levels. The main themes and sub-themes are summarised in Table 3 below, supported by illustrative quotes from participants identified by unique codes, e.g., Adolescent 04 for the 4th adolescent interview and Key informant interview 01 for

Table 3. Thematic presentation of drivers of loss to follow-up among adolescents with TB at Mulago National Referral Hospital.

Individual-level factors	Transport and distance barriers
	Treatment burden and side effects of TB medication
	School commitments
	Emotional and Psychological responses to TB diagnosis.
	Breakdown in post-discharge communication
	Age of the adolescent
Interpersonal level factors	Stigma
	Peer influence
	Lack of family support
Health system-related factors	Poor communication and inadequate information from health workers.
	Strict clinic appointments
	Limited drug availability.
Community-level factors	Weak community facility linkage and follow-up systems
	Cultural and religious beliefs
Policy-level factors	Reduced donor funding for community programs.

4.2.2 Individual-Level Factors

At the individual level, adolescents' personal circumstances, knowledge, and beliefs were significant determinants of loss to follow-up. The most frequently cited barrier, mentioned by nearly all participants, was transport and distance barriers. Other sub-themes mentioned included side effects, school commitments, emotional and psychological responses to TB diagnosis, inadequate TB information and education, and the age of the adolescent.

Transport and distance barriers

The most frequently mentioned driver of loss to follow up, echoed by 10 out of 12 of the adolescents, was the lack of money for transport and the long distance to reach Mulago Hospital.

This was a source of great frustration to the adolescents and their primary caregivers, some of them relying on churches and relatives for transport.

"Transport would sometimes be delayed. I would have to get it from different people, relatives. My parents didn't have enough money, and we had to wait to come to the clinic" (Adolescent 02, female, 16yrs).

"To come to Mulago, I have to wake up at 5 in the morning. The whole journey is almost three hours. It costs a lot of money. My father is a farmer. Some weeks, we just don't have the money for transport. So we missed the appointment" (Adolescent 10, male 17yrs).

"Distance is another factor that contributes to loss to follow up. Since Mulago is a referral hospital, adolescents come from different regions. Transport becomes difficult" (Key informant 3-Nursing officer).

Treatment burden and side effects of TB medication.

The physical experience of taking TB drugs was a major hurdle. The size, number of tablets, along with side effects like dizziness and changes in urine colour, contributed to loss to follow-up. The long duration of TB treatment led to a sense of exhaustion, causing some adolescents to simply give up treatment.

"I was also tired of taking tablets all the time. Every day, morning and evening, swallowing those big tablets. It was exhausting. I just wanted a break. So I took a break from the clinic and the medicine" (Adolescent 07, female, 13yrs).

"When I first took the medicine, the next day I saw my urine was orange. I was so scared. I thought, 'This medicine is poisoning me. My urine is not normal. I stopped taking the medicine that day. I thought I was dying. I stopped coming back to the clinic" (Adolescent 10, male, 17yrs).

A senior house officer (Pediatric resident) confirmed this pattern, explaining,

"The orange urine scares them, and they stop the medication. They stop coming to the clinic to pick up more medication because that will make their urine turn back to orange."
(Key informant 06-Senior house officer)

School commitments.

More than half of the adolescents mentioned the demands of school, especially for those in boarding schools, as a significant barrier driver of loss to follow-up. Appointments often clashed with exams, forcing a difficult choice, as some adolescents highlighted.

"Sometimes the appointment days they gave me were during my exams. I had my mock exams, and my PLE was coming. My teachers are very strict. If you miss an exam, they punish you. I didn't want to tell them I had TB. So I chose to miss. (the appointments)"
(Adolescent 07, female, 13yrs).

A community health worker noted the complexity of the balance between attending school and keeping track of the clinic appointments, stating,

"Adolescents often return to school once they start feeling better. After that, attending clinic appointments becomes hard. Some cannot obtain permission to leave school, while others fear disclosing their TB status to school authorities, so they miss appointments"
(Key informant 04- Community healthworker).

Emotional and psychological responses to TB diagnosis

For a few adolescents, their thoughts and perception about how severe TB is shaped their initial hesitant response to treatment and ultimately loss to follow-up. An 11-year-old described her initial shock and denial.

"I didn't take medicine at first because I thought, "What is the point? I am going to die anyway." I told my mother, "I don't want medicine. I just want to stay home." I refused to come to the hospital for three weeks. I just stayed in bed, crying." (Adolescent 11, female, 11yrs)

They get lost to follow up, especially those clinically diagnosed, as they tend not to accept the diagnosis. On attempts to call, when they realise that the number is from the hospital, they either don't pick up, or they don't respond well" (Key informant interview 01-Medical Officer).

Breakdown in post-discharge communication.

A recurring theme in both adolescent and key informant interviews was the breakdown in communication between the health system and patients after they left the facility. Many adolescents could not be reached for follow-up because of inaccurate or unavailable contact information. A medical officer explained the frustration of trying to trace patients:

"Some parents of adolescents don't have phones. So usually they get lost to follow up, maybe they're discharged on the ward, and they don't let us know that they have been discharged, we can't find them, and they are lost to follow up" (Key informant 01-Medical Officer).

"The numbers do not go through; most of the time, and some patients don't have phones, so we can't reach them to follow up" (Key informant 02- Nursing Officer).

Age of the adolescent.

The age of the adolescent emerged as a factor influencing loss to follow-up, particularly for younger adolescents who were dependent on their parents or caregivers for support. Healthcare workers noted that younger teenagers, those who could not independently navigate the health system, were especially vulnerable to falling out of care, as a medical officer explained,

"Usually, the young teenagers, those who can't actually even bring themselves to the hospital, are the ones lost to follow-up. Those who need a parent to come along with them" (Key Informant 01-Medical Officer).

4.2.3 Interpersonal Level Factors

Relationships with family, friends, and the community profoundly influenced loss to follow up among adolescents. The main sub-themes were stigma (both enacted and self-stigma), peer influence and lack of family support.

Enacted stigma.

Many adolescents experienced direct discrimination from the people around them- family, friends and community after their diagnosis became known. This rejection led them to hide their condition and avoid the clinics and their treatment. A 13-year-old female described how her family ostracised her:

"They (her family) started to segregate the things I use. The plates- they would give me my own. The clothes, they would wash mine separately. Even when sitting, they would sit a bit far from me. So when my mum travelled for months, I took advantage and didn't come for my appointments" (Adolescent 03 female, 19yrs).

" They fear being judged by neighbours or relatives, so they hide, stop medicine and the appointments so they can be seen as 'normal'" (Key informant 03-Nursing officer).

Self-stigma.

The fear of being stigmatised, even before it happened, caused adolescents to internalise shame and secrecy, leading them to withdraw from care and get lost to follow up, as a 13-year-old explained.

"I thought that if they (other people) knew about my illness, they would not come towards me. They would tell others that that girl has TB, don't go near her. That made me skip medicine and appointments sometimes because I didn't want to be seen as sick" (Adolescent 01, female, 13 yrs).

A key informant described how secrecy within the family compounded the problem:

"They fear disclosing that they have TB. In fact, even their immediate family members may not know. So because of this secrecy, the hiding makes them come for appointments only when it's convenient" (Key informant 02-Nursing officer).

Peer influence

The most damaging form of peer influence was the spread of false information about the medication and peers' perception of TB illness. A 15-year-old female recalled,

"At school, people used to say that if you take medicine all the time, it can damage your liver. I started to get scared, so I stopped taking the medicine" (Adolescent 05, female, 15yrs)

A medical officer confirmed the power of these peer dynamics:

"I had a 17-year-old boy who told me his friends laughed at him when they saw him taking medicine. They said, 'You are always sick. You are weak.' He felt ashamed, so he started hiding his medicine. Then he stopped taking it altogether and got lost to follow up" (Key informant 01-Medical Officer)

Lack of family support

For orphans and adolescents living with disengaged or neglectful relatives, the daily burden of remembering medication, finding transport money, and maintaining motivation fell entirely on their young shoulders. An 18-year-old orphan, living alone and working as a mechanic, described his complete isolation:

"My parents died when I was young. I live alone, work alone, and come to the hospital alone. Sometimes I forget to take my medicine because no one is there to remind me. Sometimes I feel like giving up because no one cares" (Adolescent 12, male, 18yrs).

A key informant explained,

"Adolescents who have supportive families—parents or grandparents who remind them to take medicine, who bring them to the clinic—they do well. But those without support struggle, and eventually get lost to follow up" (Key informant 03-Nursing officer).

4.2.4 Health System-Level Factors

The organisation of care and the interactions with healthcare providers within the health system presented significant obstacles.

Poor communication and inadequate information from health workers

About half of the adolescents often felt that their specific needs were not addressed and that communication with health workers was inadequate, as shared by adolescents and key informants.

"When I went to the clinic, I would only see the person who records (records personnel), then they'd send me to pick up the medicine. I did not get a chance to explain my challenges. Maybe I would have kept coming back for reviews" (Adolescent 11, female, 15yrs).

"The nurse gave me the medicine and said I should take it every day. They didn't tell me about the orange urine or what to do if I feel sick. If they had explained everything at the beginning, I would not have stopped taking the medicine and coming to the clinic" (ADOL10, male, 17yrs)

Strict Clinic appointments

The rigid, inflexible appointment system at the hospital did not accommodate the realities of adolescents' lives, especially school. This inflexibility forced the adolescents to choose between their education and their health, as mentioned by this 15-year-old.

"I am in a boarding school. My parents could pick me up from school on the exact day of the appointment. And then when you reach the clinic beyond midday, you are late, so sometimes, if I knew we would be late, we would just miss(appointments)" (Adolescent 11, female, 15yrs)

Limited drug availability

Stock-outs of medication, requiring multiple trips to the hospital, placed an additional financial and emotional burden on a few families and contributed to LTFU. One participant shared his frustrating experience:

"There was a time I came, and medicine was not enough, so they gave me a prescription for 5 days and told me to come back. It happened about 3 times. It was such a burden" (Adolescent 10, male, 17yrs).

4.2.5 Community-Level Factors

The broader community context, including the presence of community health workers to address challenges of LTFU, cultural and religious beliefs, played a significant role in shaping adolescents' experiences, contributing to loss to follow-up.

Weak community linkage and follow-up systems

While community health workers (CHWs) exist in some areas, a critical disconnect prevents them from effectively supporting adolescents with TB. Because patients are diagnosed and treated at health facilities like Mulago Hospital, CHWs in the patients' home communities are often unaware of their existence and cannot track those lost to follow-up and provide the support they need. A key informant explained the disconnect:

"The challenge is that they (community health workers) exist, but they do not know the children in their communities who are suffering from this disease, since they are diagnosed from various places" (Key informant 01-Medical Officer).

Another key informant described the intended role of CHWs and why it is not being fulfilled:

"The community health worker is supposed to do contact tracing, especially for those contacts for whom we don't test and are found positive, and those who get lost to follow up, but now that there was the change with the USA foreign policy, those CHWs stopped working, because there were no finances" (Key informant 02-Nursing officer).

Cultural and religious beliefs

Deeply held cultural and religious beliefs within the community significantly influenced how adolescents and their families responded to a TB diagnosis. In many cases, these beliefs conflicted

with medical explanations of the disease, leading families to abandon hospital treatment in favour of traditional or spiritual remedies. Key informants described,

"Community people have different perspectives on illnesses. They would say that that is 'Ente yabaana'(malnutrition) or 'Olwenyanja'(malnutrition with oedema). Those are the diseases they associate TB with. They will not accept that diagnosis and miss appointments. They will first go and try the local way" (Key informant interview 02-Nursing officer).

"Born-again Christian patients, when you tell them that it's TB, they will receive the drugs, but they won't take them and instead take the child to church. Till when the church surrenders, and then they came back to the hospital, but initially they called it 'mizimu' (ghosts). They would rather pray for the child than this 'medical thing'"(TB) (KII03-NO).

4.2.6 Policy-Level Factors

Adolescents and healthcare workers identified critical gaps at the policy level that undermined efforts to keep young people in care. These factors, often beyond the control of individual clinics or families, created systemic drivers of loss to follow-up among adolescents.

Reduced donor funding for community programs

The most significant policy-level factor affecting loss to follow-up was the reduction in donor funding for community health programs. Recent cuts were attributed to the shifts in the United States foreign aid policy, have crippled outreach initiatives that were essential for tracing patients lost to follow up. A nurse explained the direct impact of these funding cuts on patient care:

"We used to have a community linkage facilitator. She used to go to the places where those people stay, especially with adolescents who are positive on Expert (GeneXpert) and support them in completing treatment. But it is not done nowadays because of the donor funding cuts" (Key informant interview 02-Nursing Officer).

CHAPTER FIVE

DISCUSSION

This study set out to determine the prevalence and drivers of loss to follow-up (LTFU) among adolescents with tuberculosis at Mulago National Referral Hospital. We used a sequential mixed-methods design, combining a retrospective review of TB registers with in-depth interviews and key informant interviews.

5.1 Prevalence of Loss to Follow-Up Among Adolescents with TB

The prevalence of loss to follow-up among adolescents with TB at Mulago National Referral Hospital was 9.8% (12 out of 123 participants). This means that approximately one in every ten adolescents who started TB treatment did not complete it, with their treatment interrupted for two or more consecutive months.

Our finding is comparable to a previous study conducted at Mulago Hospital between 2016 and 2021, which reported a 9.2% LTFU rate among children under 15 years (Becker et al., 2023). However, that study did not disaggregate data for adolescents specifically, making it difficult to know whether younger children or older adolescents had higher rates of treatment interruption. Our study filled this gap by focusing exclusively on the 10–19-year age group, showing that adolescents experience LTFU at a rate similar to the broader pediatric population but with unique underlying drivers.

When compared to other settings, our prevalence of 9.8% falls within the range reported in similar contexts. A systematic review of TB programs in low- and middle-income countries found LTFU rates ranging from 4% to 38%, with the highest rates observed in Africa and Asia (MacPherson et al., 2013). Our finding is lower than the 15.6% reported among adolescents in Cape Town, South Africa (Snow et al., 2017), and lower than the 17% reported in Kenya (Nduba, van't Hoog, Mitchell, Borgdorff, & Laserson, 2018). However, it is similar to the 10.5% LTFU reported among adolescents in rural Uganda (Waako et al., 2013). The variation across studies may reflect differences in health system structures, geographic access to care, and the availability of adolescent-friendly services.

The median duration in care before loss to follow-up was 172 days (approximately 5.7 months). This is notable because the intensive phase of TB treatment lasts for the first two months, after which patients enter the continuation phase. Our findings suggest that while most adolescents remained in care during the initial phase, loss to follow-up occurred later in treatment, often during the continuation phase when clinic visits become less frequent. This pattern has been observed in other studies, where patients who feel better after the intensive phase may mistakenly believe they are cured and stop attending follow-up visits (Tola, Azar, Shojaeizadeh, & Garmaroudi, 2015).

Another important observation from our quantitative data was that the median time from diagnosis to treatment initiation was zero days, meaning that most adolescents started treatment on the same day they were diagnosed. This is a positive finding, reflecting efficient linkage to care at Mulago Hospital. However, highlights that the problem of LTFU is not about initiating treatment, but rather about sustaining engagement over the full course of therapy.

The relatively low proportion of HIV co-infected adolescents (5.7%) in our sample may be because HIV-positive adolescents are often managed at specialised HIV clinics and may not be captured in the TB registers. However, among those who were HIV positive, the risk of LTFU may be higher, as has been documented in other studies (Kranzer et al., 2017)

With about 10% of adolescents LTFU, there is a risk of ongoing symptoms, disease progression, and drug-resistant TB. A Ugandan study found 12% of adolescents lost to follow-up returned with MDR-TB, which is harder and costlier to treat (Nidoi et al., 2021). Their loss also hinders achieving the WHO goal of reducing TB mortality by 90% by 2030.

5.2 Drivers of Loss to Follow-Up Among Adolescents with TB

Using the Socio-Ecological Model (SEM) as a guiding framework, we identified drivers at the individual, interpersonal, health system, community, and policy levels.

5.2.1 Individual-Level Drivers

Transport and distance barriers emerged as the most frequently mentioned drivers of loss to follow-up, cited by nearly all adolescents interviewed. This finding is consistent with studies from other low-resource settings, where distance to health facilities and the cost of transport are consistently identified as major barriers to TB treatment adherence (MacPherson et al., 2013; Tola

et al., 2015). In our study, adolescents described the long journey to Mulago, sometimes taking three hours or more, and the transport burden. While TB medication is provided free of charge, the cost of transport to collect that medication is not covered, creating a paradoxical situation where free medicine remains out of reach for those who cannot afford the journey.

Treatment burden and side effects of TB medication were another major barrier. Adolescents described fear and confusion when they experienced dizziness or the characteristic orange urine. This finding aligns with studies from Ethiopia and South Africa, where inadequate counselling on side effects was associated with treatment interruption (Birhane et al., 2023; Opperman & Du Preez, 2023)

School commitments were a significant barrier, especially for adolescents in boarding schools or those facing exams. Many described having to choose between attending clinic appointments and attending school. This finding is consistent with research from Kenya and South Africa, where school attendance was a major competing priority for adolescents on TB treatment (Nduba et al., 2018; Snow et al., 2017). The inflexibility of clinic appointment schedules, which are typically held during school hours on weekdays, exacerbates this conflict.

Emotional and psychological responses towards TB medication were also a recurring theme. Adolescents described feeling overwhelmed by the number and size of tablets, and exhausted by the daily routine of taking medication. Some stopped treatment once they started feeling better. This phenomenon, known as "treatment fatigue" or "premature cessation," has been well documented in TB literature (Soedarsono et al., 2021; Tola et al., 2015). Some described being so afraid of dying that they delayed starting treatment altogether. This fear was often rooted in prior knowledge from school or community messaging that portrayed TB as a "killer disease." This finding echoes studies from Botswana and Kenya, where fear of death was a barrier to treatment initiation (L. Enane et al., 2016; Nduba et al., 2018)

Age of the adolescent was noted by key informants as a factor, with younger adolescents (10–14 years) being more vulnerable to loss to follow-up because they were dependent on caregivers who might not be available or willing to bring them to the clinic. This finding is consistent with research from South Africa, where younger adolescents had higher rates of treatment interruption compared to older adolescents (Kranzer et al., 2017)

5.2.2 Interpersonal level drivers

Stigma was a powerful driver, operating at both enacted and self-stigma levels. Enacted stigma included direct discrimination from family members—such as being given separate plates and having clothes washed separately—and from peers who avoided them. Self-stigma involved internalised shame that led adolescents to hide their diagnosis and withdraw from care before experiencing direct rejection. These findings are consistent with studies from Botswana and Zambia, where stigma was a major barrier to treatment adherence (Chanda & Sichilima, 2018; L. Enane et al., 2016)

Peer influence drove LTFU through rumours like TB medication damages the liver or is associated with HIV and ridicule from friends, leading adolescents to hide medication or stop clinic visits. This finding aligns with studies from Botswana and Kenya, where peer judgment and misinformation were major barriers to adolescent TB adherence (L. Enane et al., 2016; Nduba et al., 2018)

Lack of family support was critical for adolescents without a supportive family structure. Orphans and those living with disengaged relatives described having no one to remind them to take their medicine, no one to encourage them when they felt like giving up, and no one to help with transport. The absence of this support left them to navigate treatment alone and fall out of care. This finding aligns with research showing that family support is one of the strongest predictors of treatment adherence (Opperman & Du Preez, 2023)

5.2.3 Health System-Level Drivers

Distance from the health facility was a major barrier, particularly for adolescents from rural areas. As a national referral center, Mulago serves patients from across the country, and the long distances made regular attendance nearly impossible for some. This finding is consistent with studies from Ethiopia and South Africa, where distance was associated with higher LTFU rates (Birhane et al., 2023; Snow et al., 2017)

Limited healthcare provider support was another barrier. Adolescents described feeling unheard and rushed during clinic visits, with no opportunity to discuss school conflicts or side effects. Some

noted they were not adequately counselled about what to expect from treatment, leaving them unprepared for side effects like orange urine. This finding echoes research from Uganda, where poor communication between health workers and patients contributed to treatment interruption (Muttamba et al., 2021)

Strict clinic appointments and limited drug availability emerged as significant health system drivers of loss to follow-up. A few adolescents described being told they would not receive medication if they came on a different day from their assigned appointment, a rigid policy that failed to accommodate school exams, transport delays, or other competing priorities. Additionally, drug stockouts compounded the problem; some adolescents reported making trips to the hospital only to receive a few days' supply of medication, requiring them to return repeatedly. Studies from Uganda and Ethiopia have similarly shown that inflexible appointment systems and drug shortages are associated with higher LTFU rates (Birhane et al., 2023; Muttamba et al., 2021)

5.2.4 Community-Level Drivers

Weak community-facility linkage and follow-up systems meant that CHWs who could have provided home-based support were often unaware of adolescents in their communities on TB treatment. When adolescents missed appointments, there was no system in place to follow up at home. Key informants noted that this was partly due to funding cuts. This finding is consistent with research showing that community-based support can improve adherence, but only with effective coordination (Sinha et al., 2020).

Cultural and religious beliefs played a significant role. Some families believed spirits or curses caused TB and sought help from traditional healers or religious leaders instead of the hospital. This led to delays in seeking care or complete abandonment of treatment and loss to follow-up. This finding aligns with studies from Uganda, where cultural beliefs about TB being caused by witchcraft are common and contribute to poor health-seeking behaviour (Buregyeya et al., 2011).

5.2.5 Policy-level factors

Reduced donor funding for community programs was identified by key informants as a critical factor that undermined efforts to prevent loss to follow-up. Recent cuts in donor funding, attributed

to shifts in the United States foreign aid policy, have led to the loss of community linkage facilitators who previously supported adolescents in completing treatment. Without these community-based supports, adolescents who missed appointments were not traced, and those facing challenges at home were not identified early.

5.3 Study strengths

1. The study used a mixed-methods design, which combined quantitative prevalence data with qualitative insights, providing a more complete understanding of Loss to follow-up.
2. Adolescent-centred sampling, which captured diverse experiences by stratifying participants by age, sex, and residence (urban/rural), ensuring representation of subgroups.
3. Multi-level perspective using the Socio-Ecological Model revealed interconnected drivers at individual, interpersonal, health system, community, and policy levels.

5.4 Study limitations

1. The study relied on existing patient records, some of which contained inaccurate, incomplete, or missing data. To mitigate this limitation, we selected age, sex, area of residence, and treatment initiation date as missing data, and made effort to capture this information from other sources- TB treatment appointment book and pharmacy records.
2. As the research took place at Mulago National Referral Hospital, the results may not apply to all adolescents with TB in Uganda, particularly those receiving treatment in private health facilities where access to care and medical practices may vary, including socio-economic differences. However, the population may be reasonably representative since Mulago Hospital is a national referral hospital.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This study found that the prevalence of loss to follow-up (LTFU) among adolescents with TB at Mulago National Referral Hospital was 9.8%, meaning approximately one in ten adolescents were lost to follow-up. The drivers of LTFU were multi-level and interconnected. At the individual level, transport and distance constraints were the most common barriers, followed by side effects and school commitments. At the interpersonal level, stigma and lack of family support were powerful drivers. Health system factors included limited information from health workers and strict clinic appointments. The community-level drivers included cultural and religious beliefs that conflicted with medical care. Policy-level gaps, such as reduced donor funding for community programs, further contributed to loss to follow-up. Using the Health belief model, these findings suggest that LTFU is driven by low perceived severity once symptoms improve, high perceived barriers such as stigma and transport challenges and insufficient cues to action from the health system.

6.2 Recommendations

1. The Ministry of Health should expand National TB programs and policies to cover adolescents up to 19 years explicitly.
2. The MoH should provide adolescent-friendly services & conduct campaigns, including training health workers in youth communication and side-effect counselling; run TB campaigns on social media and in schools.
3. Ministry of Health and health workers should decentralise TB services for diagnosis, drug refills, and follow-up to the lowest-level health facilities to cut transport costs and reduce school absenteeism.
4. Health facility administration and health workers should provide for flexible clinic hours – establish Saturday or after-school TB clinics so adolescents don't miss school.

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APPENDIX I: CONSENT FORMS FOR ADOLESCENTS 18 TO 19 YEARS.

Study Title: PREVALENCE AND DRIVERS OF LOSS TO FOLLOW UP AMONG ADOLESCENTS WITH TUBERCULOSIS AT MULAGO NATIONAL REFERRAL HOSPITAL.

Investigator: The principal investigator is Dr. Lisa Nimusiima, who is affiliated with the Department of Pediatrics and Child Health at Makerere University College of Health Sciences. Tel. number 0785724830 Email: lisa.nimusiima1@gmail.com.

Please read this form carefully and feel free to ask any questions.

Background and rationale for the study

Tuberculosis (TB) remains a major health challenge for adolescents in Uganda. While TB treatment is effective, adolescents struggle to complete their full course of medication due to various barriers. Currently, there is limited information on how often adolescents discontinue treatment (loss to follow-up) at Mulago National Referral Hospital and what specific challenges they face. This study aims to determine how many adolescents (10–19 years) starting TB treatment at Mulago Hospital do not complete it, and to understand the reasons why some adolescents stop treatment. By sharing your experiences, you will contribute directly to shaping better TB services for young people in Uganda. Your insights could help design more youth-friendly clinics, improve treatment support, and save lives by reducing treatment abandonment.

The interview duration is estimated to take about 30 to 45 minutes.

Study Procedure. If you agree to participate in this study, a member of the study team will conduct an audio-recorded interview, during which questions will be asked to understand the adolescent's treatment practices and the factors that influence them.

Who will participate in the study? All adolescents (10- 19 years) lost to follow-up at Mulago Ward 5 and 15 outpatient clinics between July 2023 and June 2025, provided the adolescent below 18 has assented and the parent or guardian has given informed consent. The adolescents aged 18 and 19 have provided informed consent.

Risks. Some questions may be personal or sensitive, which could cause slight discomfort. However, participation is voluntary, and you may not answer any uncomfortable question.

Benefits: There are no direct medical, financial, or other personal benefits for you or your child as a result of participating in this study. However, the findings will contribute to improving the care of adolescents and reducing their rates of LTFU from TB treatment. It will also help the Ministry of Health implement adolescent-friendly treatment policies.

Confidentiality. All information collected about the adolescent during this study will be kept strictly confidential and will only be accessible to the research team. While the study results may be published, your child's identity will not be disclosed. Additionally, the Makerere University School of Medicine Research and Ethics Committee may request access to identifying information for ethical review purposes, but this information will not be made public.

Cost. You will not incur any cost or be paid for participating in this study.

Compensation for Participation: There will be no payment for participating in the study.

Reimbursement: To acknowledge your time and effort, you will receive 20,000 Ugandan shillings as reimbursement for your transport and your time.

Alternatives and Voluntariness: Participation in this study is completely voluntary for both you and the adolescent. The adolescent is free to participate of your own free will and have the right to withdraw at any time without penalty. Choosing not to participate or withdrawing from the study will not affect the adolescent's access to care at the health facility in any way.

Questions about the study You are free to ask any questions related to the study to the Principal Investigator Dr. Lisa Nimusiima, Tel. number 0785724830 Email: lisa.nimusiima1@gmail.com.

Questions about your rights or any ethical issue. You may contact Professor Ocamia Ponsiano, the chairman School of Medicine Research and Ethics Committee on telephone number +256772-421190.

Dissemination of Results: You will receive feedback on the study findings from the Principal Investigator through the clinic where the study is conducted. The findings of this study will also

be disseminated in form of a report that will be submitted to the department of Pediatrics and child health of Makerere University. The findings will also be disseminated in conferences, abstract presentations and a peer-reviewed journal.

Ethical Approval: The Makerere University School of Medicine Research and Ethics Committee (SOMREC) has reviewed and approved this study.

Statement of consent

..... has described to me what is going to be done, the risks, the benefits involved and my rights regarding this study. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name.....Signature/thumbprint of
participant..... Date Time (AM/PM)

Name.....Signature of witness..... Date
..... Time (AM/PM)

Name.....Signature of interviewer
Date Time (AM/PM)

APPENDIX II: CONSENT FORM FOR GUARDIANS OF ADOLESCENTS BELOW 18 YEARS. (English version)

Study Title: PREVALENCE AND DRIVERS OF LOSS TO FOLLOW-UP AMONG ADOLESCENTS WITH TUBERCULOSIS AT MULAGO NATIONAL REFERRAL HOSPITAL.

Investigator: The principal investigator is Dr. Lisa Nimusiima, who is affiliated with the Department of Pediatrics and Child Health at Makerere University College of Health Sciences. Tel. number 0785724830 Email: lisa.nimusiima1@gmail.com.

Please read this form carefully and feel free to ask any questions.

Background and rationale for the study

Tuberculosis (TB) remains a major health challenge for adolescents in Uganda. While TB treatment is effective, adolescents struggle to complete their full course of medication due to various barriers. Currently, there is limited information on how often adolescents discontinue treatment (loss to follow-up) at Mulago National Referral Hospital and what specific challenges they face. This study aims to determine how many adolescents (10–19 years) starting TB treatment at Mulago Hospital do not complete it, and to understand the reasons why some adolescents stop treatment. By sharing your experiences, you will contribute directly to shaping better TB services for young people in Uganda. Your insights could help design more youth-friendly clinics, improve treatment support, and save lives by reducing treatment abandonment.

The interview duration is estimated to take about 30 to 45 minutes.

Study Procedure. If you agree to participate in this study, a member of the study team will conduct an audio-recorded interview, during which questions will be asked to understand the adolescent's treatment practices and the factors that influence them.

Who will participate in the study? All adolescents (10- 19 years) lost to follow-up at Mulago Ward 5 and 15 outpatient clinics between July 2023 and June 2025, provided the adolescent below

18 has assented, and the parent or guardian has given informed consent. The adolescents aged 18 and 19 have provided informed consent.

Risks. Some questions may be personal or sensitive, which could cause slight discomfort. However, participation is voluntary, and you may not answer any uncomfortable questions.

Benefits: There are no direct medical, financial, or other personal benefits for you or your child as a result of participating in this study. However, the findings will contribute to improving the care of adolescents and reducing their rates of LTFU from TB treatment. It will also help the Ministry of Health implement adolescent-friendly treatment policies.

Confidentiality. All information collected about the adolescent during this study will be kept strictly confidential and will only be accessible to the research team. While the study results may be published, your child's identity will not be disclosed. Additionally, the Makerere University School of Medicine Research and Ethics Committee may request access to identifying information for ethical review purposes, but this information will not be made public.

Cost. You will not incur any cost or be paid for participating in this study.

Compensation for Participation: There will be no payment for participating in the study.

Reimbursement: To acknowledge your time and effort, you will receive 20,000 Ugandan shillings as reimbursement for your transport and your time.

Alternatives and Voluntariness: Participation in this study is completely voluntary for both you and the adolescent. The adolescent is free to participate of their own free will and has the right to withdraw at any time without penalty. Choosing not to participate or withdrawing from the study will not affect the adolescent's access to care at the health facility in any way.

Questions about the study. You are free to ask me any questions related to the Principal Investigator whose name, telephone number, and address are at the top of this form.

Questions about your rights or any other ethical issue; For questions regarding your rights or any other ethical issue, you may contact Professor Ocamo Ponsiano, the chairman of the School of Medicine Research and Ethics Committee, at the telephone number +256772-421190.

Dissemination of Results: You will receive feedback on the study findings from the Principal Investigator through the clinic where the study is conducted. The findings of this study will also be disseminated in the form of a report that will be submitted to the Department of Pediatrics and Child Health of Makerere University. The findings will also be disseminated in conferences, abstract presentations, and a peer-reviewed journal.

Ethical Approval: The Makerere University School of Medicine Research and Ethics Committee (SOMREC) has reviewed and approved this study.

Statement of consent

..... has described to me what is going to be done, the risks, the benefits involved, and my rights regarding this study. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name.....Signature/thumbprint of
participant..... Date Time (AM/PM)

Name.....Signature/thumbprint of
witness..... Date Time (AM/PM)

Name.....Signature of interviewer
Date Time (AM/PM)

APPENDIX III: ASSENT FORM FOR ADOLESCENTS BELOW 18 YEARS

Study Title: PREVALENCE AND DRIVERS OF LOSS TO FOLLOW-UP AMONG ADOLESCENTS WITH TUBERCULOSIS AT MULAGO NATIONAL REFERRAL HOSPITAL.

Investigator: The principal investigator is Dr. Lisa Nimusiima, who is affiliated with the Department of Pediatrics and Child Health at Makerere University College of Health Sciences. Tel. number 0785724830 Email: lisa.nimusiima1@gmail.com.

Please read this form carefully and feel free to ask any questions.

Background and rationale for the study

Tuberculosis (TB) remains a major health challenge for adolescents in Uganda. While TB treatment is effective, adolescents struggle to complete their full course of medication due to various barriers. Currently, there is limited information on how often adolescents discontinue treatment (loss to follow-up) at Mulago National Referral Hospital and what specific challenges they face. This study aims to determine how many adolescents (10–19 years) starting TB treatment at Mulago Hospital do not complete it, and to understand the reasons why some adolescents stop treatment. By sharing your experiences, you will contribute directly to shaping better TB services for young people in Uganda. Your insights could help design more youth-friendly clinics, improve treatment support, and save lives by reducing treatment abandonment.

The interview duration is estimated to take about 30 to 45 minutes.

Study Procedure. If you agree to participate in this study, a member of the study team will conduct an audio-recorded interview, during which questions will be asked to understand the adolescent's treatment practices and the factors that influence them.

Who will participate in the study? All adolescents (10- 19 years) lost to follow-up at Mulago Ward 5 and 15 outpatient clinics between July 2023 and June 2025, provided the adolescent below 18 has assented and the parent or guardian has given informed consent. The adolescents aged 18 and 19 have provided informed consent.

Risks. Some questions may be personal or sensitive, which could cause slight discomfort. However, participation is voluntary, and you may not answer any uncomfortable questions.

Benefits: The findings will contribute to improving adolescents' care and reducing their LTFU rates from TB treatment. It will also help the Ministry of Health implement adolescent-friendly treatment policies.

Confidentiality. All information collected about the adolescent during this study will be kept strictly confidential and will only be accessible to the research team. While the study results may be published, your child's identity will not be disclosed. Additionally, the Makerere University School of Medicine Research and Ethics Committee may request access to identifying information for ethical review purposes, but this information will not be made public.

Cost. You will not incur any cost or be paid for participating in this study.

Compensation for Participation: There will be no payment for participating in the study.

Reimbursement: To acknowledge your time and effort, you will receive 10,000 Ugandan shillings as reimbursement

Alternatives and Voluntariness: Participation in this study is entirely voluntary. You can participate of your own free will and have the right to withdraw at any time without penalty. Choosing not to participate or withdrawing from the study will not affect your access to care at the health facility.

Questions about the study You are free to ask me any questions related to the study to the Principal Investigator whose name, contact is at the top of this from..

Questions about your rights or any ethical issue. You may contact Professor Ocamo Ponsiano, the chairman School of Medicine Research and Ethics Committee on telephone number +256772-421190

Dissemination of Results: You will receive feedback on the study findings from the Principal Investigator through the clinic where the study is conducted. The findings of this study will also be disseminated in a report that will be submitted to the Department of Pediatrics and Child

Health of Makerere University. The findings will also be communicated in conferences, abstract presentations, and a peer-reviewed journal.

Ethical Approval: The Makerere University School of Medicine Research and Ethics Committee (SOMREC) has reviewed and approved this study.

Statement of consent

..... has described to me what is going to be done, the risks, the benefits involved, and my rights regarding this study. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name.....Signature/thumbprint of
participant..... Date Time (AM/PM)

Name.....Signature/thumbprint of
witness..... Date Time (AM/PM)

Name.....Signature of interviewer
Date Time (AM/PM)

APPENDIX IV: CONSENT FORM FOR HEALTH CARE WORKERS

Study Title: PREVALENCE AND DRIVERS OF LOSS TO FOLLOW-UP AMONG ADOLESCENTS WITH TUBERCULOSIS AT MULAGO NATIONAL REFERRAL HOSPITAL.

Investigator: The principal investigator is Dr Lisa Nimusiima, who is affiliated with the Department of Pediatrics and Child Health at Makerere University College of Health Sciences. Tel. number 0785724830 Email: lisa.nimusiima1@gmail.com.

Please read this form carefully and feel free to ask any questions.

Background and rationale for the study

Tuberculosis (TB) remains a major health challenge for adolescents in Uganda. While TB treatment is effective, adolescents struggle to complete their full course of medication due to various barriers. Currently, there is limited information on how often adolescents discontinue treatment (loss to follow-up) at Mulago National Referral Hospital and what specific challenges they face. This study aims to determine how many adolescents (10–19 years) starting TB treatment at Mulago Hospital do not complete it, and to understand the reasons why some adolescents stop treatment. By sharing your experiences, you will contribute directly to shaping better TB services for young people in Uganda. Your insights could help design more youth-friendly clinics, improve treatment support, and save lives by reducing treatment abandonment.

Duration: The interview is estimated to take about 30 to 45 minutes.

Study Procedure. If you agree to participate in this study, a member of the study team will conduct an audio-recorded interview with you, during which questions will be asked to understand the adolescent's treatment practices and the factors that influence them.

Who will participate in the study? Health workers involved in treating adolescents with Tuberculosis at Mulago National Referral Ward 5 and 15 outpatient clinics between July 2023 and June 2025.

Risks. Some questions may be personal or sensitive, which could cause slight discomfort. However, participation is voluntary, and you may not answer any uncomfortable questions.

Benefits: Participating in this study does not directly benefit you. However, the findings will contribute to improving the care of adolescents and reducing their rates of LTFU from TB treatment. They will also help the Ministry of Health and other stakeholders to design and implement adolescent-friendly treatment policies.

Confidentiality. All information collected about the adolescent during this study will be kept strictly confidential and will only be accessible to the research team. While the study results may be published, your child's identity will not be disclosed. Additionally, the Makerere University School of Medicine Research and Ethics Committee may request access to identifying information for ethical review purposes, but this information will not be made public.

Cost. You will not incur any cost, nor will you be paid for participating in this study.

Compensation for Participation: There will be no payment for participating in the study.

Reimbursement: To acknowledge your time and effort, you will receive 20,000 Ugandan shillings as reimbursement.

Alternatives and Voluntariness: Participation in this study is entirely voluntary. You are free to participate of your own free will and have the right to withdraw at any time without penalty. Choosing not to participate or withdrawing from the study will not affect the adolescent's access to care at the health facility.

Questions about the study. You are free to ask me any questions related to the study to the Principal Investigator whose name and contact is at the top of this form.

Questions about your rights or any ethical issues. You may contact Professor Ocamo Ponsiano, the chairman of the School of Medicine Research and Ethics Committee, at the telephone number +256772-421190

Dissemination of Results: You will receive feedback on the study findings from the Principal Investigator through the clinic where the study is conducted. The findings of this study will also be disseminated in a report that will be submitted to the Department of Pediatrics and Child Health of Makerere University. The findings will also be disseminated in conferences, abstract presentations, and a peer-reviewed journal.

Ethical Approval This study has been reviewed and approved by the Makerere University School of Medicine Research and Ethics Committee (SOMREC).

Statement of consent

..... has described to me what is going to be done, the risks, the benefits involved and my rights regarding this study. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name.....Signature/thumbprint of
participant..... Date Time (AM/PM)

Name.....Signature/thumbprint of
witness..... Date Time (AM/PM)

Name.....Signature of interviewer
Date Time (AM/PM)

APPENDIX V: PHONE CONTACT SCRIPT FOR REACHING ADOLESCENTS LOST TO FOLLOW-UP (LTFU)

Purpose: This guide is for the research staff contacting adolescents (or their caregivers) who were lost to follow-up after initiating TB treatment at Mulago National Referral Hospital. The goal is to invite them to participate in a qualitative interview to understand the drivers of Loss to Follow-up.

Phone Script for Initial Contact

Step 1: Greet and Identify

Hello, my name is [Researcher's name], and I am calling from Mulago National Referral Hospital. Am I speaking with [Adolescent's Name] or their caregiver?

If not available:

May I know when would be a better time to reach them?

Step 2: Explain the Reason for the Call

Thank you. I'm part of a research team working on a study about tuberculosis care among adolescents who received treatment at Mulago Hospital.

We are contacting some young people who may have stopped treatment or missed follow-up visits. We want to learn more about their experiences so we can help improve services and support for other adolescents.

Step 3: Emphasise Voluntary Participation and Privacy

Your participation is completely voluntary. Anything you share will be kept private and used only for research purposes. Whether or not you take part will not affect your access to care or services at the hospital.

We are inviting [Adolescent's Name] to do a short interview, in person, at a time that works for you. Your transport will be refunded, and there will be a small token of appreciation for your time.

Step 4: Confirm Interest and Availability

Would you (or your child) be willing to hear more about the study and decide if you would like to take part?

If YES:

Great, thank you! We can agree on the best time for the interview, and I will share more information about the study.

[Confirm or collect phone number, and preferred time.]

If NO:

That is completely okay. If you change your mind later, you are welcome to contact me at [Research Assistants Contact Info]. Thank you for your time.

APPENDIX VIII: QUANTITATIVE DATA EXTRACTION TOOL

Variable	Data Section	Notes
Patient No.	Unique identifier	
Age	10-19 years	(Exact age)
Sex	Male/Female	
Residence	Urban/Rural	(Write Exact address)
HIV Status	Positive/Negative/Unknown	
TB Classification	Pulmonary- Bacteriologically confirmed, Pulmonary Clinically diagnosed, Extrapulmonary TB	
Patient Type	New/Relapse/Treatment after failure	
Treatment Start Date	DD/MM/YYYY	
Treatment Outcome	1) Completed 2(LTFU. 3) Transferred 4)Died	
Last Clinic Visit Date	DD/MM/YYYY	
Contact Number		

APPENDIX VI: IN-DEPTH INTERVIEW GUIDE FOR ADOLESCENTS

Introduction Script

This study aims to determine how many adolescents (10–19 years) starting TB treatment at Mulago Hospital do not complete it, and to understand the reasons why some adolescents stop treatment. By sharing your experiences, you will contribute directly to improving TB services for young people in Uganda. Your information could help design more youth-friendly clinics, improve treatment support, and save lives by reducing treatment abandonment.

We want to learn about your experience with TB treatment to help you and other adolescents. There are no right or wrong answers. Your participation in this study is voluntary, and you can stop anytime. This interview will take about 30 minutes."

Social-demographic Characteristics.

Age Sex ☐ Male ☐ Female

Place of Residence.....

I. Individual Level Factors.

1. Can you tell me how you first found out you had TB?
2. How do you feel about your TB diagnosis?
3. Can you tell me what you know about TB and its treatment?
4. As an individual, what factors stopped you from starting TB treatment or attending the TB clinic at Mulago National Referral Hospital?

Probe for:

- *Self-stigma*
 - *Stress*
 - *Perception of side effects*
 - *Education/work commitments*
 - *Financial challenges, eg, lack of transport*
5. For those living with HIV: How does your HIV treatment affect how you take your TB medication and attend the TB follow-up clinic?
 - *Probe: how HIV treatment facilitates or hinders TB treatment adherence.*

II. Interpersonal Level factors

What factors regarding your relationships with other people stopped you from starting TB treatment or attending the TB clinic at Mulago National Referral Hospital?

Probe for:

- *Reaction by friends and family members towards the TB diagnosis?*
- *Negative influence from friends and family? (negative perception about TB medicines)*
- *Lack of support from family members during treatment*
- *Stigma from friends and family*

III. Healthcare System Level Drivers of LTF

What factors within the health care system made it difficult for you to start TB treatment or continue attending the TB clinic at Mulago National Referral Hospital?

Probe for:

- *Negative experience with the clinic staff.*
- *Limited counselling on adherence at the clinic*
- *Long distance to the hospital*
- *Non-flexible clinic appointments (not aligned with school /work schedule, frequent appointments)*

IV. Community-level Factors

What factors within the community made it difficult for you to start TB treatment or continue attending the TB clinic at Mulago National Referral Hospital?

Probe for:

- *Fear of negative reaction from the community in relation to TB treatment?*
- *Cultural or religious beliefs in relation to TB and its treatment*

Are there community health workers to help you with your treatment?

IV. Policy Level Factors

1. Have you heard of any national campaigns or messages about TB? What do you think of them?
2. Do you feel there is enough support, e.g, free medicines, to help adolescents complete TB treatment?
3. What changes do you think the government can make to help adolescents complete treatment?

V. Closing. Is there anything else that you would like to share before we close?

Thank you for your time and ideas.

APPENDIX VII: KEY INFORMANT INTERVIEW GUIDE

Introduction Script:

This study aims to determine how many adolescents (10–19 years) starting TB treatment at Mulago Hospital do not complete it, and to understand the reasons why some adolescents stop treatment. By sharing your experiences, you will contribute directly to improving TB services for young people in Uganda. Your information could help design more youth-friendly clinics, improve treatment support, and save lives by reducing treatment abandonment.

We want to learn about your experience caring for and treating adolescents with TB. There are no right or wrong answers. Your participation in this study is voluntary, and you can stop anytime. This interview will take about 30 minutes."

Participants

Role: ☐ Senior House Officer ☐ Medical Officer ☐ Nurse ☐ Community Health worker ☐ Other.....

Age Sex ☐ Male ☐ Female

Length in the current position.....

I. General Clinic Operations

1. How are adolescents currently identified and enrolled in TB treatment at this facility?
2. What systems are in place to track their treatment progress?

II. Individual level factors

In your view, what individual factors lead to the loss to follow up of adolescents attending the TB clinic at Mulago National Referral Hospital?

Probe for:

- *Self stigma*

- *Stress*

- *Perception of side effects*

- *Unfavorable education/work commitments*

- *Financial challenges, eg, lack of transport*

III. Interpersonal level factors

In your view, what factors at the interpersonal level lead to loss to follow-up of adolescents attending the TB clinic at Mulago National Referral Hospital?

Probe for:

- *Reaction by friends and family members towards the TB diagnosis?*
- *Negative influence from friends and family? (negative perception about TB medicines)*
- *Lack of support from family members during treatment*
- *Stigma from friends and family*

IV. Healthcare system factors

From your experience, what health system factors lead to the loss to follow up of adolescents attending the TB clinic at Mulago National Referral Hospital?

Probe for:

- *Negative experience with the clinic staff.*
- *Limited counselling on adherence at the clinic*
- *Long distance to the hospital*
- *Non-flexible clinic appointments (not aligned with school /work schedule, frequent appointments)*

V. Community-level factors

From your experience, what community-level factors lead to the loss to follow up of adolescents attending the TB clinic at Mulago National Referral Hospital?

Probe for:

- *Fear of negative reaction from the community in relation to TB treatment?*

- *Cultural or religious beliefs in relation to TB and its treatment*
- Availability of community health workers.*

VI. Policy-level factors

In your view, what policy-level factors lead to the loss to follow up of adolescents attending the TB clinic at Mulago National Referral Hospital?

Probe for:

- *National campaigns on awareness about TB treatment*
- *National protocols for managing adolescents with TB*
- *Availability of drugs*

What changes do you think the government can make to improve the loss to follow up of adolescents in our setting?

Closing:

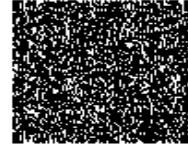
Is there anything else about adolescent TB care and loss to follow-up you would like to share?

Thank you for your time and ideas.

APPENDIX VIII: RESEARCH ETHICS COMMITTEE APPROVAL FOR RESEARCH



24/09/2025
To: LISA NIMUSIIMA
0



Review Type: Initial Review

Re:Mak-SOMREC-2025-567: PREVALENCE AND DRIVERS OF LOSS TO FOLLOW UP AMONG ADOLESCENTS WITH TUBERCULOSIS AT MULAGO NATIONAL REFERRAL HOSPITAL

I am pleased to inform you that at the 205 convened meeting on 08/07/2025, the MAK School of Medicine REC (Mak-SOMREC) meeting voted to approve the above referenced application.
Approval of the research is for the period of 24/09/2025 to 24/09/2026.

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for review and approval prior to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of 24/09/2026 in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by MAK School of Medicine REC (Mak-SOMREC):

No.	Document Title	Language	Version Number	Version Date
1	CONSENT FORM FOR GUARDIANS OF ADOLESCENTS BELOW 18-CLEAN COPY	English	3.0	2025-09-22
2	CONSENT FORM FOR HEALTH CARE	English	3.0	2025-09-22

	WORKERS-CLEAN COPY			
3	CONSENT FORM FOR ADOLESCENTS 18-19-CLEAN COPY	English	3.0	2025-09-22
4	ASSENT FORM CLEAN COPY	English	3.0	2025-09-22
5	KEY INFORMANT INTERVIEW GUIDE-CLEAN COPY	English	3.0	2025-09-22
6	IN-DEPTH INTERVIEW GUIDE-CLEAN COPY	English	3.0	2025-09-22
7	PROTOCOL CLEAN COPY	English	3.0	2025-09-22
8	Application for waiver of informed consent	English	1.0	2025-09-04
9	COVID-19 & EBOLA risk management plan	English	1.0	2025-06-01
10	Data collection tools	English	1.0	2025-05-30

Yours sincerely,



Prof. Ponsiano Ocama
For: MAK School of Medicine REC (Mak-SOMREC)

APPENDIX IX : MULAGO HOSPITAL ADMINISTRATION CLEARANCE

TELEPHONE: +256-41554008/1
FAX: +256-414-5325891
E-mail: admin@mulago.or.ug
Website: www.mulago.or.ug



MULAGO NATIONAL REFERRAL HOSPITAL
P. O. Box 7051
KAMPALA, UGANDA

IN ANY CORRESPONDENCE ON THIS
SUBJECT PLEASE QUOTE NO.....

5th November 2025.

Dr. Lisa Nimusiima
Principal Investigator
Department of Paediatrics and Child Health
Makerere University

Dear Dr. Nimusiima,

RE: ADMINISTRATIVE CLEARANCE TO CONDUCT A STUDY AT MULAGO NATIONAL REFERRAL HOSPITAL.

The Mulago Hospital Management is pleased to inform you that you have been offered clearance to conduct the study titled **MHREC 3045: "Prevalence and Drivers of Loss to follow up among Adolescents with Tuberculosis at Mulago National Referral Hospital"**.

The above clearance is granted to you on the following conditions;

- That you will follow the research ethical processes
- Agreed to comply with all institutional policies and regulations of Mulago National Referral Hospital
- Agreed to provide end of study report and acknowledge Mulago hospital in all publications
- Submit a copy of filled in participant compensation log after recruiting one quarter of the approved research sample size.

Administrative clearance is valid for one (1) year effective from 4th November 2025 to 3rd November 2026.

By copy of this letter, we reiterate our commitment to support this study.


DR. BYANYIMA ROSEMARY
EXECUTIVE DIRECTOR
MULAGO NATIONAL REFERRAL HOSPITAL

Copied to;

1. Incharge – Ward 15-MNRH
2. Incharge – Ward 5-MNRH

Vision: "To be the leading centre of Health Care Services"