# MAKERERE UNIVERSITY

# COLLEGE OF HEALTH SCIENCES

# SCHOOL OF PUBLIC HEALTH

## HEALTH-RELATED QUALITY OF LIFE AND ASSOCIATED FACTORS OF POST-PULMONARY TUBERCULOSIS LUNG DISEASE PATIENTS TREATED FROM MULAGO NATIONAL REFERRAL HOSPITAL, KAMPALA – UGANDA


**BY**

**WAFULA ISAAC**
**No. 2021/HD07/3490U**

**SUPERVISORS**

**DR. AGGREY DAVID MUKOSE**

**DR. CHRISPUS MAYORA**


**A RESEARCH DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT FOR THE REQUIREMENTS OF THE AWARD OF A MASTER OF PUBLIC HEALTH DEGREE OF MAKERERE UNIVERSITY**

**FEBRUARY, 2024**

## DECLARATION

**I, Wafula Isaac,** declare that the information given in this dissertation is the Original of my own and has never been submitted to any other institution for consideration, publication, or other use. I, therefore, submit it to Makerere University School of Public Health Higher Degree Research and Ethics Committee as partial fulfilment of the requirement for the award of a Master of Public Health.

Signature ..... Date 23/02/2024

## APPROVAL

This is to acknowledge and consent that the study titled *"Health-Related Quality of Life and Associated Factors of post-Pulmonary Tuberculosis Lung Disease Patients Treated from Mulago National Referral Hospital"* by Wafula Isaac was written under our supervision and it is now ready for submission to Makerere University School of Public Health as partial fulfilment for the award of Masters of Public Health.

**Supervisors' Signatures**

1. **Dr. Aggrey David Mukose**

Department of Epidemiology and Biostatistics

School of Public Health, Makerere University, Kampala

Signature: ..... Date: 23rd February 2024

2. **Dr. Chrispus Mayora**

Department of Health Policy Planning and Management

School of Public Health, Makerere University, Kampala

Signature: ..... Date: 23/02/2024

## ACKNOWLEDGEMENT

First and foremost, I thank God for blessing me with the strength and courage to carry out the research project.

I would like to extend my greatest appreciation to my supervisors: Dr. Aggrey David Mukose and Dr. Chrispus Mayora for their tremendous support, guidance, and encouragement during the time of working on the research project.

Special appreciation goes to my family members especially my Mother Ms. Nantale Hadijah and friends especially Dr. Akampurira Ian and Mr. Masete Ivan for the support and encouragement they have given to me. May God bless you and reward abundantly.

I would like to extend my sincere gratitude to Mulago Hospital Administration, the medical staff of the chest clinic and the research assistants for the support accorded to me.

Finally, I appreciate the study participants for agreeing to take part in this study.

## DEDICATION

This book is dedicated to my daughter Wafula Val Promise, my wife Mrs. Wafula Jane Bisando, Claver Sheperd Ahabyona and the MPH class of 2023

Thank you for the overwhelming love, patience, assurance and support during this time without which I could not have made it.

## TABLE OF CONTENTS

DECLARATION ..... i

APPROVAL ..... ii

ACKNOWLEDGEMENT ..... iii

DEDICATION ..... iv

LIST OF TABLES ..... viii

LIST OF FIGURES ..... ix

OPERATIONAL DEFINITIONS ..... x

LIST OF ACRONYMS ..... xi

**CHAPTER ONE: INTRODUCTION AND BACKGROUND ..... 1**

1.1 Introduction ..... 1

1.2 background ..... 4

**CHAPTER TWO: LITERATURE REVIEW ..... 5**

2.1 The prevalence of post-tuberculosis lung diseases ..... 5

2.2 Clinical patterns of post-Pulmonary TB lung diseases ..... 6

2.3 Health-related quality of life among patients with post-ptld. ..... 8

2.4 Measuring quality of life ..... 10

2.5 Factors Associated with the Health-Related Quality of Life of Tuberculosis Survivors ..... 11

**CHAPTER THREE: PROBLEM STATEMENT, CONCEPTUAL FRAMEWORK AND JUSTIFICATION ..... 13**

3.1 Problem Statement ..... 13

3.2 Justification ..... 14

3.3 Significance of the Study ..... 14

3.4 Conceptual Framework ..... 15

**CHAPTER FOUR: RESEARCH QUESTIONS AND OBJECTIVES ..... 17**

4.1 Research Questions ..... 17

1.2 Study Objectives ..... 17

4.2.1 General Objective ..... 17
4.2.2 Specific Objectives ..... 17
**CHAPTER FIVE: METHODOLOGY ..... 18**
5.1 Study Design and Approach ..... 18
5.2 Study Area ..... 18
5.3 Study Population ..... 19
5.3.1 Inclusion Criteria ..... 19
5.3.2 Exclusion Criteria ..... 19
5.4 Sample Size Determination ..... 19
5.5 Sampling procedure ..... 20
5.6 Study Variables ..... 20
5.6.1 Dependent Variable ..... 20
5.6.2 Independent Variable ..... 21
5.7 Data Collection Methods and Tools ..... 23
5.8 Field Implementation ..... 24
5.8.1 Field Reconnaissance Visit ..... 24
5.8.2 Recruitment and Training of Research Assistants ..... 25
5.8.3 Data Collection Procedure ..... 25
5.8.4 Quality Assurance and Control ..... 26
5.9 Data Analysis ..... 27
5.10 ethical considerations ..... 30
5.11 Dissemination of Study Findings ..... 30
**CHAPTER SIX: RESULTS ..... 31**
6.2 Socio-demographic characteristics and treatment-related patient characteristics ..... 32
6.3 Factors associated with the level of HRQoL (summary scores) of post-PTLD patients attending the chest clinic at MNRH. ..... 38
6.3.1 Factors associated with physical-related quality of life among post-PTLD patients ..... 38
6.3.2 Factors associated with the mental component score (MCS) in post-PTLD patients ..... 43
**CHAPTER SEVEN: DISCUSSION OF THE STUDY FINDINGS ..... 47**
**CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS ..... 52**

8.1 CONCLUSIONS ..... 52

8.2 RECOMMENDATIONS ..... 53

**REFERENCES ..... 55**

**Annex ..... i**

Annex I: Data Collection Tools ..... i

Tool 1: Consent Form ..... i

Tool 1: Questionnaire ..... iii

Tool 3: The SF-36 Questionnaire ..... vii

Annex II: Clearance forms ..... xiii

Research Clearance Letter Makerere University School of Public Health, Research and Ethics Committee xiii

Research Clearance Letter: Mulago National Referral Hospital ..... xiv

Annex III: Work Plan ..... xv

Annex IV: Budget ..... xvi

## LIST OF TABLES

*Table 1: Clinical patterns of post-PTB chronic respiratory disorders..... 7*

*Table 2 shows the summary of independent variables and their measurement..... 21*

*Table 3: below shows how to score the HRQOL questionnaire..... 28*

*Table 4: below shows how to generate the 8 sub-domains of HRQOL..... 28*

*Table 5 below shows the Socio-demographic characteristics of the respondents..... 33*

*Table 6: Shows HRQoL summary scores..... 37*

*Table 7: Shows factors associated with PCS..... 38*

*Table 8: Shows factors associated with MCS..... 43*

## LIST OF FIGURES

*Figure 1 showing Conceptual framework for HRQoL and related determinants adopted from Wilson & Cleary, (1995)* ..... *16*

*Figure 2: Above shows the study participants' selection and inclusion in the study* ..... *31*

*Figure 3: proportions of specific post-PTB respiratory diseases at the Mulago chest clinic between 1st May 2022-31st May 2023* ..... *36*

*Figure 4: Shows the post-PTLD symptom burden among the study participants* ..... *36*

## OPERATIONAL DEFINITIONS

**Pulmonary tuberculosis (PTB):** Any bacteriologically confirmed or clinically diagnosed case of TB involving the lung parenchyma or the tracheobronchial tree, including tuberculous intrathoracic lymphadenopathy (mediastinal and/or hilar), without radiographic abnormalities in the lungs. Miliary TB is classified as PTB because there are lesions in the lungs. A person with both PTB and extrapulmonary TB is also classified as having PTB. (WHO., 2021)

**Post-pulmonary TB lung disease (post-PTLD):** is an overlapping spectrum of disorders that affects large and small airways (bronchiectasis and obstructive lung disease), lung parenchyma, pulmonary vasculature, and pleura as a result of having pulmonary TB (Allwood et al., 2020).

**Post-Pulmonary TB Lung Disease patient:** this is a patient who was successfully treated for PTB and who presents with respiratory symptoms (MOH., 2017).

**Health-related quality of life (HRQoL)** is an individual's perceived physical and mental health over time.

**TB Cured:** Pulmonary tuberculosis (TB) patient with bacteriologically confirmed TB at the beginning of treatment who was smear- or culture-negative in the last month of treatment and on at least one previous occasion.

**FEV1:** Forced expiratory volume in one second; the volume of air exhaled in the first second under force after a maximal inhalation(Torén et al., 2021).

**FVC:** Forced vital capacity; the total volume of air that can be exhaled during a maximal forced expiration effort.

## LIST OF ACRONYMS

| | |
|---|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| COPD | Chronic Obstructive Pulmonary Disease |
| CRD | Chronic Respiratory Disease |
| HIV | Human Immune deficiency virus |
| HRQOL | Health-related Quality of Life |
| HTA | Health Technology Assessment |
| LMICs | Low and Middle-Income Countries |
| MCS | Mental Component Summary |
| PCS | Physical Component Summary |
| post-PTB | post-Pulmonary Tuberculosis |
| post-PTLD | post-Pulmonary tuberculosis lung disease |
| TB | Tuberculosis |
| TSR | Treatment Success rates |
| WHO | World Health Organization |
| FEV | Forced Expiratory Volume |
| FVC | Forced Vital Capacity |
| CXR | Chest X-Ray |
| CT | Computerized Tomography |

## ABSTRACT

**Introduction**: By the end of 2020, there were approximately 155 million TB survivors globally. TB survivors have up to three times increased risk of mortality from post-Pulmonary TB lung complications compared with the general population, with a prevalence of lung impairment between 18% and 87%. Currently, health systems, especially in Africa, do not recognize that TB care extends beyond treating the initial infection, which leaves the majority of survivors at a higher risk of both clinical and socio-economic consequences even after a microbiologic cure of TB. In Uganda, the burden of post-PTB lung disease, and the health and well-being of TB survivors is poorly understood partly because of a lack of literature, and this contributes to poor health service provision in this sub-population

**Objectives:** The study intended to determine the health-related quality of life of post-PTB lung disease patients and their associated factors in Mulago National Referral Hospital from 1st May 2022 to 31st May 2023.

**Methods:** This study employed a cross-sectional design and utilized quantitative methods to determine the proportion of post-PTLD patients among the general patient population attending the chest clinic at MNRH, their clinical patterns using patient files, their health-related quality of life (HRQOL) (Physical and Mental composite domains) using the SF36v2 questionnaire, and factors associated with HRQOL among these patients. For the post-PTB lung disease patients who met the eligibility criteria and were sampled, interviewer-administered questionnaires were used to collect quantitative data. Before data collection, informed consent was obtained to confirm participants' willingness to participate in the study. Data was entered into Ms. Excel and analysed using STATA software version 16.

**Study findings:** One hundred thirty-three patients with post-PTLD lung disease were included in the study. Post-PTLD lung disease accounted for almost 16 % (173/1086) of the patients who attended the chest clinic.

The mean physical composite score (PCS) among post-PTLD patients for this study was 54.8 units while the mean mental composite score (MCS) was 57.3units

Factors associated with an increase in mean values of PCS included monthly income between (54 and 134 USD) (ARC=7.35, p-value=0.009) and more than 134 USD (ARC=11.91, p-value<0.001), having family support during treatment (ARC=11.40, p-value=0.002), and receiving

counselling (ARC=8.39, p-value=0.001). Age of at least 50 years (ARC=-8.7, p-value=0.028), COPD (ARC=--10.82, p-value<0.001), drinking alcohol (ARC=--9.04, p-value=0.003), being self-employed (ARC=-7.43, p-value =0.023) and smoking (ARC=-7.29, p-value=0.048) were associated with a decrease in the mean scores of MCS

**Conclusions:** The mean scores of physical and mental components of health-related quality of life were generally fair. There was a strong positive correlation between the physical component score and the mental component score. Monthly income greater than 54 USD (Ushs.150, 000) having family support during treatment, and receiving counselling were significantly associated with increased mean values of PCS. Age of at least 50 years, having COPD, drinking alcohol, and smoking significantly decreased the mean scores of MCS.

**Recommendations:**

The study recommends that the care of pulmonary tuberculosis should not be limited to the treatment of initial infection with anti-tuberculous medications. Clinicians should actively screen PTB survivors at risk of developing post-PTB lung complications (diseases) and offer appropriate care at the earliest time of contact to improve their health-related quality of life. Clinicians should emphasize the importance of quitting alcohol consumption and smoking by patients with post-PTLD. Patients with post-PTLD who smoke or consume alcohol should further be prioritized for rehabilitation and equipped with copying mechanisms to modify these risky practices.

# CHAPTER ONE: INTRODUCTION AND BACKGROUND

## 1.1 INTRODUCTION

Pulmonary tuberculosis (PTB) is increasingly being recognized as an important risk factor for chronic respiratory disease (CRD). Tuberculosis (TB) patients continue to have symptoms related to chronic physical, psycho-social, and pulmonary function impairment beyond the completion of treatment (Nightingale et al., 2021). Studies have reported persistent respiratory symptoms among TB survivors 3 – 18 years after completion of treatment (Banu Rekha et al., 2009; Barennes et al., 2010). In 2020, it was estimated that there were 155 million tuberculosis survivors alive globally, the largest proportion of whom were in the Southeast Asia region. Of these tuberculosis survivors, 18% were treated in the past 5 years and 8% were treated in the past 2 years (Dodd et al., 2021). Such high numbers imply that more people are at risk of or are suffering from post-pulmonary tuberculosis lung diseases (post-PTLD).

In sub-Saharan Africa, it was estimated that 2–2.5 million people with pulmonary tuberculosis illnesses (post-PTB) are treated and cured every year (WHO, 2020). However, these people are also up to three times more likely to die compared with the general population, with a prevalence of lung impairment between 18% and 87% (Allwood et al., 2020). The prevalence of post-PTLD is further worsened by an aging population, tobacco smoking, household air pollution, and nutritional impairment (Muñoz-Torrico et al., 2020). Post-PTLD negatively impacts many survivors' Health-Related Quality of Life (HRQoL) (Meghji et al., 2020a), in addition to TB disease affecting it (HRQoL) both before and during treatment (Yasobant et al., 2022). The HRQoL after TB treatment is much better than at the start but still lower than the general population (Chamla, 2004). It deteriorates further among TB survivors with post-PTB lung complications. The TB survivors have reduced economic productivity compared with healthy individuals as a result of reduced physical functionality leading to lost wages in the middle of increased medical expenditures. (Gupte et al., 2019; Soriano et al., 2020).

In addition to indicating the consciousness of patients regarding their physical and mental health, HRQoL measures their overall health status in multiple domains for individuals and groups, including physical functioning, role-physical, bodily pain, general health, vitality, social

functioning, role-emotional, and mental health. HRQoL is multidimensional and can thus be affected by multiple factors related to socio-economic status, individual characteristics, and experiences, among others. Studies have reported that TB survivor's HRQoL is associated with age, education, cigarette smoking, and number a of symptoms (Chamla, 2004; Guo et al., 2010). The HRQoL of individuals varies depending on their experiences and the general context of life. If this context is understood, it is possible to improve their HRQoL after treatment completion. If not, the survivors are at increased risk of, among others, long-term respiratory morbidity, recurrent tuberculosis, and stigma – which all undermine the quality of care and support provided during treatment. This illustrates the urgent need for post-PTB treatment support.

It should be noted that HRQoL varies for each individual, some have a better quality of life than others, hence the need for targeted individual support. Follow-up of patients to determine their health status (including mental well-being or lung damage) after completion of their treatment is necessary. Unfortunately, patient care often ends alongside treatment completion. To provide this support, it is necessary to measure their HRQoL and investigate associated factors so that targeted interventions to address specific factors are designed.

Despite advances in the care of patients with tuberculosis leading to a significant reduction in TB morbidity and mortality globally, post-TB morbidity remains one of the most important causes of chronic lung disease (Allwood et al., 2020; Meghji et al., 2021; Nightingale et al., 2023). However, its impact is insufficiently documented especially in low and middle-income countries where clinical services, research, and advocacy remain inadequate. This is majorly attributed to inadequate published literature in these settings.

Physically, many TB survivors experience health problems mostly arising from respiratory complications of TB-related lung damage. For instance, (Jung et al., 2015) found that prior exposure to PTB was a significant risk factor for chronic airway obstruction that necessitated regular follow-up of lung function. Similarly,(McCree, Mer, Roos, Quinn, & Van Aswegen, 2019) in a feasibility pilot study found that the majority of the TB survivors had reduced exercise capacity. These complications impact not only their physical wellbeing, but also their social and economic productivity such as employment challenges, strained relationships, and societal misconceptions that may contribute to poor quality of life (Allwood et al., 2020; Nightingale et

al., 2023). Mentally, the psychological toll of TB, including the fear, anxiety, and social stigma associated with the disease, impact negatively on their mental health (Allwood et al., 2020; Chin et al., 2019). The misconceptions associated with TB carry persistent social stigma even after the completion of treatment and individuals may face discrimination and isolation hindering them from building social connections (Meghji et al., 2021). Although the true burden of each of these complications remains poorly described, a growing literature describes the shortened survival of post-PTBLD patients. Mortality rates for TB survivors may be as high as three times more than TB naïve people while prevalence estimates for lung impairment after pulmonary TB vary from 18–87% depending on the population studied (Ravimohan, Kornfeld, Weissman, & Bisson, 2018; Romanowski et al., 2019).

Despite available evidence of post-PTLDB morbidity and mortality, the majority of countries globally are yet to fully incorporate post-TB care in their national programs to address the challenges faced by patients. For instance, Uganda has no standardized guidelines on how patients with post-TB lung problems ought to be evaluated and managed. Currently, available guidelines are limited to assessing and managing lung-related damage rather than the impairment in physical functioning and mental health well-being(MOH, 2017). Furthermore, there are no elaborate plans on how to address the challenges in physical functioning and mental wellbeing in these survivors. This could be partly due to the paucity of published data to inform clinicians and policy makers on how TB impairment affects the health-related quality of life lived by these TB survivors (Nuwagira et al., 2022).

This study therefore sought to address the existing information gaps through a cross-sectional design that quantified the proportion of patients with post-TB lung disease, the clinical patterns of post-PTB lung disease patients, their level of health-related quality of life, and factors associated with their quality of life at Mulago national referral hospital.

## 1.2 BACKGROUND

In Uganda, the TB treatment success rates (TSR) are estimated to be 80% (Izudi et al., 2020). The cure rates remain unacceptably low, with rural areas reportedly achieving a 66.7% treatment success rate and urban areas, 81.1% (Musaazi et al., 2017).

There are no standard guidelines on how post-PTB Lung disease patients can be evaluated and treated in Uganda. Health workers have been guided to repeat a TB evaluation according to standard TB diagnosis practices (sputum examination and chest x-rays) (MOH, 2017). If the sputum is positive for TB, the patient is managed as retreatment. If TB tests are negative the patients are to be further re-evaluated for post-PTB lung diseases namely bronchiectasis, chronic obstructive pulmonary disease (COPD), pulmonary hypertension, and colonization with fungal infections such as aspergillosis. In most cases, these patients have residual lung damage which prompts health workers to retreat as bacteriologically negative TB. Many patients are thus treated this way several times exposing them to, sometimes unnecessary, courses of repeated empiric anti-tuberculosis chemotherapy, which has toxic effects. Indeed, post-PTB lung disease patients' HRQoL is negatively affected, by the illness and the repeat treatments.

Further review of the manual for the management and control of tuberculosis and leprosy in Uganda, revealed that there were no specific guidelines on the evaluation of the mental well-being of post-PTB patients. The focus was limited to assessing lung-related damage. This study postulates that the limited follow-up of post-PTB patients has led to the post-PTB lung complications being poorly understood and the extent and nature of these complications not being well studied. This limited knowledge contributes to poor health service provision for this sub-population.

Understanding the burden and health-related QoL among these TB survivors provides an essential foundation for developing targeted strategies aimed at providing rehabilitation care, and psychosocial support in addition to managing long-term complications of the disease (Nuwagira et al., 2022). Although health system changes are certainly needed to effectively manage post-PTB complications, in the short term, individuals need to be equipped with the resources needed to cope with the stresses of prolonged respiratory illness resulting from active TB to post-treatment complications. HRQoL indicates the consciousness of patients regarding their physical and mental health. Therefore, by quantifying and understanding their HRQoL, it is possible to enhance the provision of healthcare services to post-PTB lung disease patients.

# CHAPTER TWO: LITERATURE REVIEW

This section provides reviewed literature in line with the study subject and specific objectives. It gives a broad global picture of the post-tuberculosis lung disease situation including clinical patterns and narrows it down to Uganda's context. It also discusses how HQRoL affects post-TB lung disease and associated factors

## 2.1 THE PREVALENCE OF POST-TUBERCULOSIS LUNG DISEASES

Although appropriate pulmonary TB (PTB) treatment can achieve a microbial cure, the burden of ill health after TB, including post-TB lung disease (PTLD) which had been long neglected is now increasingly gaining global recognition (Byrne, Marais, Mitnick, Lecca, & Marks, 2015. ). People with post-tuberculosis lung disease have reduced health-related quality of life and reduced physical activity including reduced exercise tolerance (Hanekom, Pharaoh, Irusen, & Daniels, 2019). A systematic review and meta-analysis by (Romanowski et al., 2019) regarding long-term all-cause mortality among patients treated for pulmonary tuberculosis revealed that mortality was almost four times higher for the patients in comparison with the general population. PTLD is increasingly being recognized as a significant contributor of chronic respiratory disease in both children and adult populations in SSA where the prevalence of TB is unacceptably high. For instance, an estimated 4-6% of population in SSA is thought to have chronic respiratory problems attributed to PTLD (Sarkar, Srinivasa, Madabhavi, & Kumar, 2017; Soriano et al., 2020). Whereas health systems in SSA treat and cure over 2 million people with PTB annually, there is no assessment of health and well-being beyond the narrow classification of treatment outcomes, and no services have been targeted at the long-term post-TB health needs of these individuals (WHO, 2020). This poor service provision can be attributed to a lack of a proper understanding of the health and well-being of this patient group.

Uganda is among the world's 30 high HIV/TB burden countries with an HIV prevalence of 6.2% and an annual TB incidence of 253 cases per 100,000 (Ario et al., 2022; WHO, 2023). Among all TB cases, HIV prevalence is estimated at 45% (MOH, 2017). However, like the majority of other countries in SSA, the care of patients with PTB never goes beyond the classification of treatment outcome. Even when it is known that PTB may directly contribute to poor lung function due to parenchymal destruction, interstitial lung disease, loss of alveolar surfaces, and primary vascular

processes, culminating in patients with complex medical needs (Gingo et al., 2014; Maharani, Karima, & Kamilia, 2022). In addition to the physiological and anatomical damage described above, people who have survived TB often suffer significant economic and psychological consequences including stigma, and are unwilling to share their experiences at other clinics for fear of being labeled infectious, yet they cannot be attended to at the TB treatment unit because they were cured (Knapen, Vancampfort, Moriën, & Marchal, 2015). Fortunately, international literature is starting to recognize post-PTB sequelae, through among others, studies assessing the HRQoL of post-PTB lung disease patients. This study intended to quantify the proportion of PTLD among patents attending the chest clinic at Mulago NRH to address the existing information gaps as a foundational step to addressing the health challenges encountered in this patient group.

## 2.2 CLINICAL PATTERNS OF POST-PULMONARY TB LUNG DISEASES

Post-PTB respiratory disorders are anatomical and pathophysiological changes in the chest, which are secondary to complications of pulmonary TB. These changes may result in pulmonary dysfunction, which can vary, from minor abnormalities to severe breathlessness, increasing the risk of death from respiratory causes. Some presentations may be completely asymptomatic. Post-PTB respiratory disorders are heterogeneous and affect large and small airways (bronchiectasis and obstructive lung disease), lung parenchyma, pulmonary vasculature, and pleura (Allwood et al. 2021). Multiple patterns of pathology can be seen within a single patient, between or within areas of the lung. The post-PTB respiratory disorders' spectrum is quite wide as shown in *Table 1 below*. This summary in the table below will be used to guide the identification of post-PTB lung disease patients.

*Table 1: Clinical patterns of post-PTB chronic respiratory disorders*

| Compartment | Clinical Patterns | Suggested Definition |
|---|---|---|
| Airways | Tuberculosis-associated obstructive lung disease | Airway obstruction (FEV1/FVC ratio <0.7 OR <LLN) thought primarily related to small airway disease |
| | Bronchiectasis | CT definition – evidence of airway dilatation > diameter of the adjacent vessel, or non-tapering, or CXR definition – evidence of ring shadows and tramlines |
| Parenchyma | Cavitation | A gas-filled space either within an area of pulmonary consolidation or surrounded by a thin wall |
| | Parenchymal destruction | Extensive destruction of lung tissue, with a gas-filled space/collapsed parenchyma occupying the volume of ≥1 lobe |
| | Fibrotic change | Areas of parenchymal scarring with associated volume loss |
| | Aspergillus-related lung disease | Evidence of aspergilloma on imaging or chronic pulmonary aspergillosis on imaging and blood testing |
| Pleural | Chronic pleural disease | Evidence of pleural thickening on CXR or CT imaging |
| Pulmonary vascular | Pulmonary hypertension | Elevated pulmonary artery pressures, as estimated using Doppler echocardiography or measured at right heart catheterization |

**Source: Allwood et al., 2021**

* FEV1, forced expiratory volume in 1 second; CT, computerized tomography; CXR, chest radiograph.

There are a few studies that describe the course, type, and severity of lung disorders in post-PTB patients. Most information available is from studies that targeted active pulmonary TB patients. (Khosa et al., 2020) conducted a prospective cohort study on pulmonary TB patients, focussing on clinical and microbiological characteristics, and found them with mostly chronic airway obstruction and reduced lung volumes after 52 weeks of follow-up. (Allwood et al., 2021) reported a high burden of residual inflammatory changes including consolidation, ground glass change, and nodules among HIV-uninfected, non-diabetic, adult patients with pulmonary TB at diagnosis.

Studies that targeted post-PTB patients also describe the course, type, and severity of lung disorders in post-PTB patients. However, the studies reviewed were prospective. (Akkara et al., 2013) targeted adult-cured pulmonary TB patients and reported the presence of pulmonary vascular disease and advanced cor-pulmonale; bronchiectasis and fungal diseases. The CXR conducted here showed varying degrees of lung destruction, with 38% of the patients having Wilcox Grade II involvement, and varying degrees of obstructive airway disease with restrictive pattern and reversibility. Another prospective study by (Meghji et al., 2020b) in HIV-positive and HIV-negative adults expected to complete treatment for pulmonary TB, found moderate-to-severe cystic bronchiectasis in 12.7% of their respondents with a higher prevalence in HIV-negative (18.9%) as compared to HIV-positive (8.5%) ones. They also found 1.3% of their respondents with mycetoma and 0.8% with Aspergillus immunoglobulins. Based on the above findings, studies on post-PTB lung diseases targeting post-PTB patients are few, and thus an information gap is evident on whether the presentation of post-PTB lung diseases is different among the active pulmonary TB cases and cured ones.

Data on the clinical patterns of post-PTB respiratory disorders on the other hand is quite limited in Uganda. However, consideration of the above treatment success rates highlights the possibility that a significant number of Ugandans are exposed to TB or its severe form (MDR-TB) for a long period, and thus more likely to develop lung complications that last beyond the treatment. (Jones et al., 2017) reported that 30% of those attending the TB clinic at Mulago National Referral Hospital, had a form of post-PTB respiratory disorder and 12% of those attending general chest clinics also had one as the main presenting problem. Understanding the prevalent clinical patterns is essential especially in low-resource settings like Uganda to developing cost-effective and targeted healthcare programs that optimize treatment outcomes among individuals with PTLD.

### 2.3 HEALTH-RELATED QUALITY OF LIFE AMONG PATIENTS WITH POST-PTLD.

WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and about their goals, expectations, standards, and concerns (WHO, 2018). At the individual level, HRQOL includes physical and mental health perceptions (e.g., energy level, mood) and their correlates, including health risks and conditions, functional status, social support, and socioeconomic status. QOL is becoming an important

approach to addressing those dimensions of health(Guyatt et al., 1993). Pulmonary tuberculosis has substantial adverse impacts on patients' quality of life. Patients' perceived HRQoL is decreased in all patients who are diagnosed with PTB (Kittikraisak et al., 2012). While HRQoL improves as pharmacological treatment progresses, perceptions of both mental and physical quality of life remain below the population normal(Aggarwal, Gupta, Janmeja, & Jindal, 2013). Whereas it is anticipated that further improvements in HRQoL could naturally occur over time in the absence of active disease, evidence from a population of multi-drug resistant (MDR) TB proposes the contrary. Studies by (Sharma, Yadav, Sharma, Saini, & Koushal, 2014), and (Laxmeshwar et al., 2019) found that decreased perception of HRQoL was still prevalent up to 18 months after the patients were deemed cured of TB. Exercise capacity in post-PTB populations predominantly ascertained through the 6-min walk test (6MWT), has been assessed in several studies (Godoy et al., 2012; Pontororing et al., 2010). The impact of PTB on walking distance varies depending on age and the severity of the disease. Studies investigating the change in exercise capacity during active treatment have reported improvements when compared to baseline. However, in cross-sectional studies, when compared to a normal population, the 6MWT distance (6MWD) is significantly reduced in PTB patients, even in those patients who had successfully completed their pharmacological treatment regimen.

The association between PTB and lung function impairment has been understood for several years. Pulmonary tuberculosis has recently been identified as an independent risk factor for the development of chronic obstructive pulmonary disease (COPD), in major population-based studies such as the Pravalencia de EPOC en Columbia (PREPCOL) and Proyecto Latinomericano de Investigación Obstrucción Pulmanar (PLATINO) studies (Menezes et al., 2007). Consequences of PTB include permanent scarring, bronchiectasis, and pleural fibrosis (Chakaya, Kirenga, & Getahun, 2016). During the treatment of active PTB, lung function impairment is usually restrictive. This may persist or develop into an obstructive pattern (Chakaya et al., 2016). A systematic review estimated that patients older than 40 years of age are three times more likely to develop COPD when they have a history of PTB (Byrne et al., 2015). Albeit PTB is a risk factor for COPD, the spirometric values are often influenced by concurrent risk factor exposure, such as smoking, biomass fuel exposure, dust, and childhood respiratory illness, making it difficult to distinguish pure obstructive abnormalities from other lung structural abnormalities without full

body plethysmography (Chakaya et al., 2016). Studying the health-related quality of life among TB survivors is essential not only in providing insights into the impact of tuberculosis beyond the clinical aspect but also enables clinicians to understand how TB survivors perceive their well-being, daily functioning, and emotional state post-treatment (Godoy et al., 2012). Understanding the psychosocial aspects is particularly important as TB survivors may face stigma, discrimination, and mental health issues even after successful treatment. However, there is limited published literature regarding the quality of life in terms of the physical and social functional capacity of these individuals. This study therefore investigated the perceived health-related quality of life among PTLD patients at MNRH to address the existing knowledge gaps that could contribute to the development of more patient-centered healthcare policies at the facility.

### 2.4 MEASURING QUALITY OF LIFE

There are many tools used to measure HRQoL; These include; the 36 Item Short-Form (SF-36®) Survey (Rand, 2004), the EuroQoL 5 Domain (EQ-5D) tool (EuroQoL, 2016). The EQ-5D descriptive system is a preference-based HRQL measure with one question for each of the five dimensions including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The SF-36 is a set of generic, coherent, and easily administered quality-of-life measures that rely upon patient self-reporting and have been widely used. The SF-36 includes eight health domains: physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role-emotional (RE), and mental health (MH). The eight domains are aggregated into two different component summaries, the physical component summary (PCS), which includes PF, RP, BP, and GH, and the mental component summary (MCS), which includes VT, SF, RE, and MH.

Both tools (SF-36 and EQ-5D) have been used extensively in the realm of economic evaluation and health technology assessment (HTA) since their results can be converted to numerical values. This allows researchers to compare changes in HRQoL in one type of patient with those in other types of patients. More specific tools exist for certain disease areas such as HIV-QL31 for HIV or EORTC QLQ-C30 for cancer. This study used the SF-36 tool to measure HRQoL. It is one of the most common instruments for assessing HRQoL among active TB cases (Lins & Carvalho, 2016) and may be appropriate for post-PTB lung disease patients as well. It is a well-documented questionnaire for the evaluation of HRQoL in both healthy people and sick patients. However, it

should be noted that although the SF-36 has been validated in different populations, its validity is not well studied among post-PTB lung disease patients.

## 2.5 Factors Associated with the Health-Related Quality of Life of Tuberculosis Survivors

An assessment of HRQoL primarily focuses on factors that fall under the purview of healthcare providers and healthcare systems. This study represents an attempt to determine how variables within the dimension of health (e.g., a disease or its treatment) relate to particular dimensions of life that have been determined to be important to people who have post-PTB respiratory disorders. This study will focus on several factors that are known to affect the quality of life of TB patients, including social support, medical factors, psychological factors, demographic factors, and educational and counseling programs (Darvishpoor Kakhki & Masjedi, 2015). Because of the scarcity of information from the literature review on the factors associated with HRQoL among post-PTB lung disease patients, the study is working under the assumption that factors for active TB patients and post-PTB ones are similar. The quality of life of TB patients is related to the psychological domain, environmental conditions, social relationships, and physical conditions (physical domain). Quality of life is also closely connected to patient conditions like Age, sex, income, emotional connections, and duration of treatment.

Age; the influence of age on QoL of patients with post TB lung disease has not been substantially studied. However, in other chronic conditions that have applied SF36, advanced age has been associated with poor quality of life. For instance, (Knapen et al., 2015) observed that advanced age worsened the quality of life among patients with major depressive disorders. Scholars argue that aging may bring about a range of other health conditions that may worsen an individual's ability to perform daily activities hence, influencing HRQoL (Wu & Harden, 2015; Wurz & Brunet, 2016).

The type of TB based on the resistance pattern is a well-established factor in determining the quality of life of survivors after treatment. From existing literature, patients who have been treated for more extreme forms of TB (MDR-TB and XDRTB) tend to exhibit the most adverse forms of PTLD. The extended courses of complex treatment using more potent drugs with severe side

effects combined with low treatment success rates in this sub-group leads to physical discomfort and decreased functioning hence a lower self-perceived quality of life.(Singla et al., 2018)

Psychological factors like post-PTLD-related stigma can have a negative impact on the mental health of patients, leading to feelings of shame, guilt, and low self-esteem. It can also contribute to anxiety and depression. Stigma can also affect patients' adherence to treatment which derails treatment outcomes. It is therefore important for healthcare providers, policymakers, and communities to work together through social systems like the family to address and reduce TB-related stigma to support patients in improving treatment outcomes. (Munro et al., 2007)

While progress has been made in understanding the burden of post-TB lung complications, there are still many unanswered questions and gaps in our knowledge, particularly regarding mental health among these patients in Uganda. Therefore, this study seeks to further elucidate the underlying determinants of HRQoL among this sub-group which knowledge will improve the well-being of individuals affected by these post-PTLDs.

# CHAPTER THREE: PROBLEM STATEMENT, CONCEPTUAL FRAMEWORK AND JUSTIFICATION

## 3.1 PROBLEM STATEMENT

Uganda is one of the thirty World Health Organisation (WHO) designated countries with a high burden of TB/HIV (WHO, 2021). Its TB treatment outcomes are still poor, with an 80% treatment success rate for TB patients (Izudi et al., 2020), a 70% treatment success for TB/HIV co-infected patients, and 64% for Multi-Drug Resistant (MDR) TB (MOH, 2021). This implies that a significant proportion of TB patients live with the disease for a long time, and thus are naturally more likely to develop TB-related respiratory complications, even when they finally complete treatment. (Jones et al., 2017) reported that 30% of the attendees of the respiratory clinic at Mulago National Referral Hospital had a history of pulmonary TB. This indicates that TB survivors contribute significantly to the growing national burden of chronic respiratory diseases, which receive little attention in LMIC health care delivery systems (Quaderi & Hurst, 2018).

Currently, national guidelines on post-PTB lung disease patients are limited to assessing lung-related damage (MOH, 2017), leaving out mental well-being, including HRQoL, yet it, like in active TB patients, influences treatment adherence and outcomes (Aggarwal, 2019). Therefore, there is no elaborate effort to address the quality of life of post-PTB lung disease patients. As a result, TB survivors in Uganda are likely to suffer a lower HRQoL, higher healthcare use, and reduced economic productivity compared with healthy individuals. Much effort has been on measuring HRQoL in TB patients at the expense of the post-PTB ones (Aggarwal, 2019; S. M. B. Kisaka et al., 2016). Few HRQoL studies have been conducted in Uganda, targeting post-PTB lung disease patients. Studies in similar settings have demonstrated that post-PTB lung disease patients have a generally poor HRQoL compared to the general population and therefore more studies on the determinants of HRQoL in this sub-group in Uganda are needed.

The relationship between HRQoL and post-PTB lung disease patients has not been well studied in Uganda. This study seeks to investigate the HRQoL among post-PTB lung disease patients and associated factors. This information provides an essential foundation in developing targeted strategies aimed at providing rehabilitation care, and psychosocial support in addition to managing long-term complications of the disease.

## 3.2 JUSTIFICATION

There is a growing number of post-PTB lung disease patients in Uganda, in the context of a not-so-supportive policy environment. As a result, targeted interventions and practices are also lacking, resulting in, among others, prolonged respiratory illness, high medical costs, and reduced economic productivity among TB survivors (Gupte et al., 2019; Soriano et al., 2020). Measurement of HRQoL presents an opportunity to further comprehend and measure the exact impact of post-PTB respiratory diseases, and in so doing, inform the development of tailored and evidence-based interventions to manage them, and the formulation of suitable policy frameworks. Improving their quality of life is an effective way of addressing the unique contexts from which individual post-PTB lung disease patients come. To apply this concept, it was necessary to identify and measure mechanisms or factors that improve or lower HRQoL among post-PTB lung disease patients while they are undergoing treatment for TB-related respiratory complications.

## 3.3 SIGNIFICANCE OF THE STUDY

It was anticipated from the review of the literature that there was much to learn. Firstly, it was anticipated that certain aspects of both research and practice in post-PTB patient management would be challenged.

Secondly, the circumstances in which the demographic, socioeconomic status, individual characteristics, and experiences of the post-PTB lung disease patients could affect their HRQoL in the context of a national referral hospital of Uganda would be examined, and actionable recommendations proposed to address these issues, to ensure their wellbeing and the provision of quality and targeted health services. Lastly, the findings of this study would directly benefit the National Tuberculosis and Leprosy Programme in informing the address of various health system-related gaps in their post-PTB management interventions, which are currently lacking.

## 3.4 CONCEPTUAL FRAMEWORK

The conceptual framework was adapted from the Revised Wilson and Cleary model for health-related quality of life "Linking Clinical Variables with Health-Related Quality of Life: A Conceptual Model of Patient Outcomes," (Wilson & Cleary, 1995). The factors that explain one's HRQoL are broadly categorized into individual, treatment, and social characteristics, biological function, symptom status, functional status, and health perceptions. As illustrated in Figure 1, these factors are interrelated. Individual and social characteristics can both influence the health domains (biological function, symptom status, functional status, and health perceptions). For example, older age and the presence of persistent symptoms during treatment were related to a lower Physical Component Summary (PCS) score in post-PTB patients (Li et al., 2017). Some factors in the broad categories are also inter-related. For example, one's income level may influence treatment adherence, which may in turn affect the HRQoL. Marital status has been thought to protect one's well-being by providing companionship, emotional support, and economic security. Being married has been associated with physical and mental health. The diagrammatic illustration of the conceptual framework for this study is shown in figure 1.

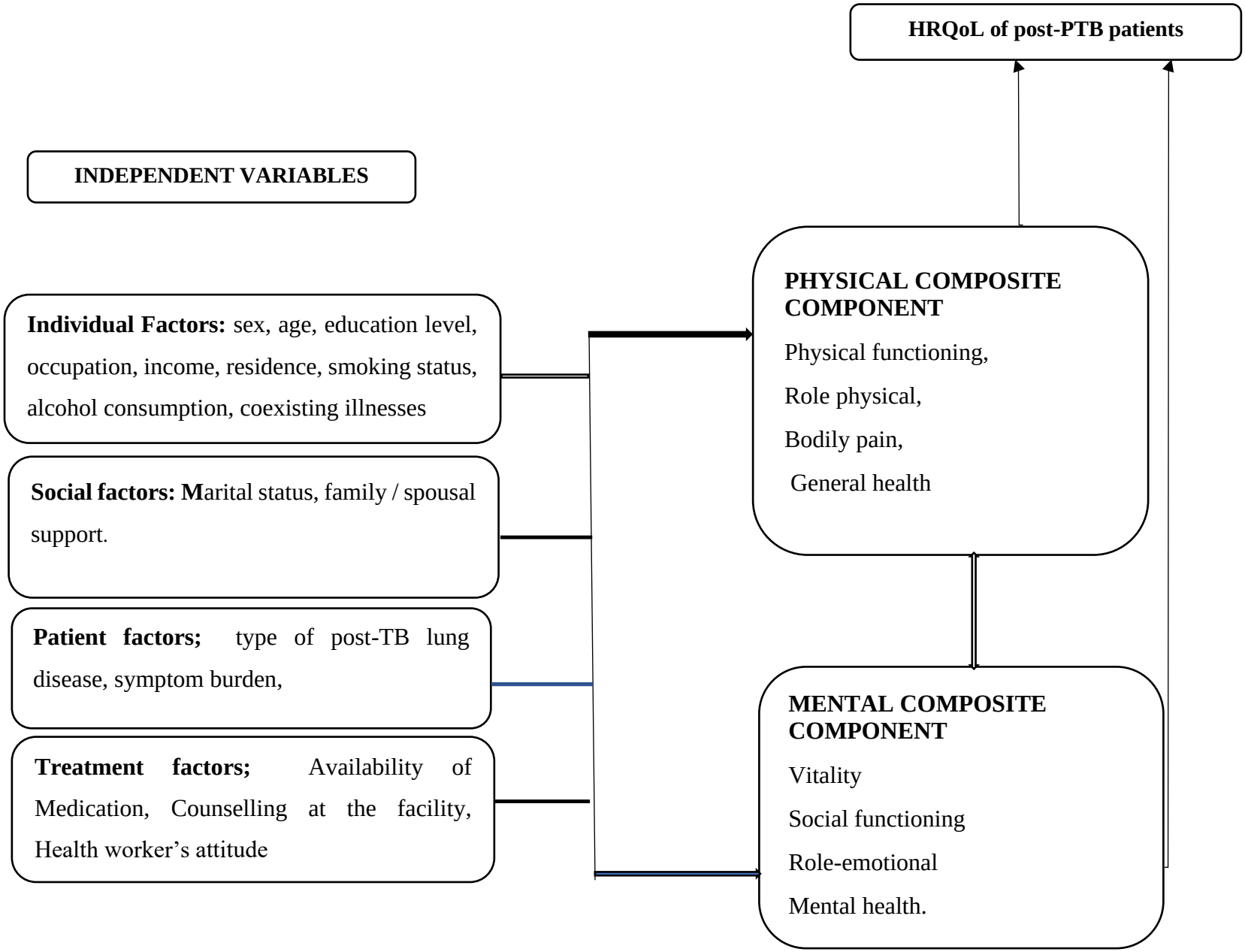



*Figure 1 showing Conceptual framework for HRQoL and related determinants adopted from Wilson & Cleary, (1995)*

# CHAPTER FOUR: RESEARCH QUESTIONS AND OBJECTIVES

## 4.1 RESEARCH QUESTIONS

This study was guided by the following questions;

1. What is the proportion of patients with post-PTB respiratory diseases attending the chest clinic at Mulago NRH?
2. What are the clinical patterns of post-PTLD patients attending the chest clinic at Mulago National Referral Hospital.
3. What is the level of perceived health-related quality of life among post-PTB lung disease patients at Mulago NRH?
4. What are the factors influencing the level of perceived health-related quality of life among post-PTB lung disease patients at Mulago NRH?

## 1.2 STUDY OBJECTIVES

### 4.2.1 General Objective

To determine the health-related quality of life of post-PTB lung disease patients and associated factors in Mulago NRH to aid the development of targeted interventions for managing post-PTB respiratory illnesses and psychosocial support to help address the growing problem of TB-related chronic respiratory diseases in Uganda.

### 4.2.2 Specific Objectives

1. To determine the proportion of patients with post-PTLD patients attending the chest clinic at Mulago NRH.
2. To determine the clinical patterns of post-PTLD patients attending the chest clinic at Mulago national referral.
3. To determine the level of HRQoL of post-PTLD patients attending the chest clinic at Mulago NRH.
4. To identify the factors associated with HRQoL of post-PTLD patients attending the chest clinic at Mulago NRH.

# CHAPTER FIVE: METHODOLOGY

## 5.1 STUDY DESIGN AND APPROACH

In consideration of the study objectives, a cross-sectional design, using quantitative data collection approaches was used. Records were accessed from MNRH and patients were interviewed after calling them and scheduling an appointment with them at the clinic, those whose time for refills and routine assessment fell within the time of data collection were sampled at the time of presentation, home visits were scheduled for those who could not make it to the hospital, phone call interviews were conducted for those who could not be interviewed by all the other options.

Since the outcome (Quality of life of Post TB lung disease patients) and exposure variables existed in the study population at the point the study was carried out, the cross-sectional approach was the most feasible and cost-effective design. Furthermore, the cross-sectional approach enabled the researcher to avoid time constraints associated with long-term follow-ups of the study participants in case longitudinal approaches were used.

## 5.2 STUDY AREA

The study was conducted in the chest clinic of Mulago National Referral Hospital. Mulago National Referral Hospital is a national referral center for the entire country, a teaching hospital for Makerere University College of Health Sciences, and a general hospital for the Kampala metropolitan. The official bed capacity of the hospital is 1,500 beds but due to the ever-increasing number of patients over the years, the actual bed numbers are 1,840 beds inclusive of Kawempe and Mulago although the hospital receives over 3,500 patients daily. The chest clinic is an outpatient-only department, which operates once a week on Tuesdays receiving 15-25 patients on the clinic day. It is managed by a total of 12 Staff including one consultant, three senior house officers, 3 nurses, 2 records officers, and other make-shift personnel like medical interns. The chest clinic of Mulago was selected because it has the expertise of health workers, who handle respiratory illnesses inclusive of various forms of post-TB lung disease, making the target study population easily accessible.

## 5.3 STUDY POPULATION

The study was conducted among adult patients attending the chest clinic of Mulago National Referral Hospital

### 5.3.1 Inclusion Criteria

The study included persons who;

I. Were cured of pulmonary TB in the period between May 2022 and May 2023 at Mulago Hospital;
II. Were diagnosed with any of the post-PTB related lung diseases between May 2022 and May 2023 and are currently getting treatment from Mulago Hospital;
III. Adults aged at least 18 years because they are legally consenting and can report objectively on the outcome

### 5.3.2 Exclusion Criteria

The study excluded persons who;

I. Had life-threatening conditions that would hinder interviews.
II. Those who had had a major thoracic surgical procedure.

## 5.4 SAMPLE SIZE DETERMINATION

The formula by (Yamane et al., 1967) shown below was used to determine the sample size using a 95% confidence interval (Z); and the estimated population from which the sample is drawn (N) is 170. This was determined from a pre-visit to Mulago NRH chest clinic in February 2023, where it was found that 170 post-PTB lung disease patients were recorded in the outpatient HMIS05 registers receiving treatment. This was then adjusted for possible non-response as shown below.

$$n = \frac{N}{1 + \mathrm{N}e^2}$$

Therefore

$$n = \frac{170}{1 + 170 * 0.05^2}$$

n = 119

with an anticipated non-response rate of 10%,

$$n = \frac{119}{0.9}$$

The sample size was 133 participants.

## 5.5 SAMPLING PROCEDURE

A consecutive sampling approach was then applied to select participants for the study.
A list of patients was obtained from the chest clinic by use of the Clinic register. In this register, we retrieved information on the date on which treatment was started, name, age, and contact. Based on this information, eligible respondents were identified and contacted to schedule interview appointments at the hospital. The process of identifying and screening respondents for eligibility and scheduling appointments was repeated until the anticipated sample size was obtained.

## 5.6 STUDY VARIABLES

### 5.6.1 Dependent Variable

The dependent variable was Health Related Quality of Life which was determined using the SF-36 tool described in Section 5.6.2. Data was collected along the eight health domains namely; physical functioning, role physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health.

HRQoL is a continuous variable, which was determined under two summary scores, physical and mental mean scores.

### 5.6.2 Independent Variable

*Table 2 shows the summary of independent variables and their measurement*

| Group | Variable Name | Category | Description of their measurement |
|---|---|---|---|
| Demographic characteristics | Sex | Categorical | This included male and female options only. |
| | Age | Numerical | This was measured in complete life years |
| | Education level | Categorical | This was determined in 4 levels - none, primary (from Primary 1 to 7), secondary (from senior 1 to 6), or tertiary (beyond senior 6) |
| | Smoking history | Categorical | Their current and previous smoking status were assessed. Respondents were asked if they are currently or have in the past 3 years been smoking any of the array of tobacco products. It was measured as "Yes" if they had smoked any of the products or "No" if they hadn't smoked any of the products. |
| | Alcohol consumption | Categorical | Their current and previous alcohol consumption status was assessed. Respondents were asked if they were currently or have in the past 3 years been consuming alcohol. |
| Patient-related factors | Post-PTB lung disease | Categorical | Medical records were reviewed to determine the lung-disease the respondents were diagnosed with and the symptoms they presented with. |
| | Distance from the hospital | Numerical | This was the estimated distance of the respondents' residence to Mulago NRH. It was measured in Kilometres. |
| | Length of time on treatment for post-PTB lung disease | Numerical | This was determined from medical records. It was calculated from the time they were initiated on treatment for the post-PTB lung disease to the time of the interview. It was measured in months. |

| | | | |
|---|---|---|---|
| | Side-effects from the treatment for the post-PTB lung disease | Categorical | These were self-reported effects of the treatment on the respondents. |
| | Coexisting chronic illnesses | Categorical | These were self-reported. The respondents were asked if they had any other pre-existing health conditions other than post-PTB lung disease. Where possible, medical records were also reviewed. |
| | HIV status | Categorical | This was a self-reported status; however, it was verified from medical records. |
| Socio-economic factors | Total monthly income | Numerical | This was the total income from all sources by the respondent. It was measured in Ugandan shillings. |
| | Occupation | Categorical | This was determined under the following categories farmer, student, trader, salaried worker, unemployed, and other (specify). |
| | Marital status | Categorical | This was determined under the following categories – married, single, separated, and widowed. |
| | Family disclosure | Categorical | This was determined by asking the respondents whether a family member was aware of their health situation. It was measured as "Yes" if any family member was aware or "No" if no family member was aware |
| | Family support | Categorical | This was determined by asking the respondents whether their family members or spouse supported their efforts to seek treatment for the post-PTB lung disease. |

| | | | |
|---|---|---|---|
| Treatment-related factors | Conduct of health workers | Categorical | This was determined by asking the respondents what their opinion of the conduct of health workers was. It was measured as good, fair, or bad |
| | Counselling | Categorical | . This was determined by asking respondents about the availability of medicines during their visits. It was measured as "Yes" if received counseling or "No" if they didn't receive counseling. |
| | Availability of drugs | Categorical | This was determined by asking respondents whether drugs were available during their hospital visits. It was measured as "Yes" if drugs were available during their visits or "No" if they were unavailable during visits |

### 5.7 DATA COLLECTION METHODS AND TOOLS

The following methods were used to collect the required data:

a) Questionnaire Administration: The questionnaire collected information on demographic, patient-related, treatment-related, and socio-economic factors in addition to the eight health domains, necessary for determining HRQoL. The purpose of questionnaire administration was to collect information in a non-intimidating way since the respondents were not required to disclose their identities, thus anonymity. The tools included:

i. A five-part questionnaire including demographic, patient-related, Treatment-related factors, and socio-economic sections for the first four parts, and the SF-36 questionnaire for the last part was designed.

ii. The demographic section was the pre-coded section of the tool and collected and recorded data on the factors associated with HRQoL.

It included direct questions and follow-up ones to clarify the direct ones based on the independent variables in Section 5.5.2.

iii. The SF-36 tool section constituted the fifth section of the questionnaire. Below are highlights about the tool and its use:

- The SF-36 questionnaire consisted of eight scales yielding two summary measures: physical and mental health. The physical health measure included four scales of physical functioning (10 items), role-physical (4 items), bodily pain (2 items), and general health (5 items). The mental health measure was composed of vitality (4 items), social functioning (2 items), role-emotional (3 items), and mental health (5 items). A final item, termed self-reported health transition, was answered by the client but was not included in the scoring process.
- The SF-36 offers a choice of recall format at a standard (4 weeks) or acute (1 week) time frame. The respondents were directed to respond to each statement concerning the previous month (4-week recall).
- If a particular situation had not arisen in that time, then the response was determined by how the person thought they would have reacted.

iv. Likert scales and yes/no options were used to assess function and well-being on this 36-item questionnaire.

v. The questions in the tools are provided in Annex 1.

b) **Consultations:** select health workers in the chest clinic were contacted for guidance on where and how to access their patient's records, as well as contacting the patients themselves.

## 5.8 FIELD IMPLEMENTATION

### 5.8.1 Field Reconnaissance Visit

To ensure smooth data collection, prior notice and preparation were crucial. A reconnaissance visit to Mulago NRH was conducted. The relevant hospital staff were informed and oriented about the study; collected the required information about the post-PTB lung disease patients needed to develop the sampling frame, selected study participants; and contacted them or made appointments where necessary or possible. At this point, permission to conduct the study at the hospital had been

sought and hospital leaders were informed in advance of the study schedule before the arrival of the field team.

### 5.8.2 Recruitment and Training of Research Assistants

Four Research Assistants (RAs) with a clinical background were recruited and trained for two days on the research methodology to be followed to avoid information bias when interviewing study participants. These were preferred because it was anticipated that as a result of their background, they were aware of hospital procedures, could easily interpret medical records, and knew how to handle patients, which was key for the collection of this data. In addition to this, they were fluent in Luganda (the common local language spoken in Kampala) and English.

The research assistants were trained on how to install Kobo collect on their mobile phones, and interview patients at the proper time and privately. These had previous experience in conducting interviews in hospital settings, in the use of the study tool and data collection techniques including probing. They were given a briefing on the study objectives and taught how to administer the consent forms.

### 5.8.3 Data Collection Procedure

Data collection was conducted over 30 days period between 1st June 2023 and 30th June 2023, with an anticipated 4 questionnaires administered per day, as outlined in the work plan and detailed schedule of activities presented in Annex III. Data collection entailed the following tasks:

1. Entry meeting with appropriate hospital staff. This was done to inform the hospital administration of our presence and solicit compliance from the hospital staff relevant to our study, which in this case were the staff of the Chest clinic.
2. Extraction of the study participants from the patient records at the hospital. Their contact information, specifically location, telephone, and email in addition to specific medical records were collected.
3. Contacting participants. Calls were made to inform the selected participants about the study and solicit their participation. Participants whose hospital visits fell in the time of the study were interviewed during their visits. For those that didn't, phone interviews or home visits

were conducted where possible. Failure to utilize one of these options led to the exclusion of that participant, who was then replaced as guided by the sampling procedure given in Section 4.5. The interviews took about 30 minutes per participant.

4. Quantitative data was collected from the post-PTLD patients using interviewer-administered smartphone-based questionnaires using the Kobo collect platform. A structured questionnaire was used to collect data through face-to-face interviews and capture information on the Demographic, socio-economic, patient-related, and treatment-related factors.
5. The SF-36 questionnaire was used to collect data on patient's Health Related Quality of Life.

### 5.8.4 Quality Assurance and Control

1. The research assistants underwent a three-day comprehensive training that familiarized them with the skills to collect data from the proposed study population with KoboCollect.
2. The data study tools were pre-tested on 10 post-PTLD patients meeting the inclusion criteria attending clinical care from Entebbe Regional Hospital before their use in the research study. This was done to establish whether the data collection was feasible, as well as to check for any errors in the data collection tool.
3. After pre-testing, arising errors such as skip logic errors were adjusted so that the tool was convenient to collect data
4. Instruments used for data collection were handed over to the researcher at the end of each day for storage and proof-checking.
5. Data collection was done under close supervision of the principal investigator. The tools were independently checked by the principal investigator to ensure they were filled.
6. The anonymity of the study participants was done through the coding of tools.
7. Data validation was done to correct data entry problems such as missed data, double-entered data values, or data entered in the wrong variables.

### 5.9 Data Analysis

The data was coded in Microsoft Excel, cleaned, and exported to Stata Corp version 16.0. Univariate, bivariate, and multivariate analyses were conducted. The data analysis was as follows:

**Objective 1: To determine the proportion of patients with post-PTB respiratory diseases attending the chest clinic at Mulago national referral hospital**

This was calculated as a percentage of patients with post-pulmonary tuberculosis lung diseases at the chest clinic of Mulago NRH. The denominator was the total number of patients who were attending the chest clinic during the study period.

$$\text{Proportion} = \frac{\text{No. of post-PTB patients attending the chest clinic}}{\text{All patients attending the chest clinic during the study period}} * 100$$

**Objective 2: To determine the clinic characteristics of patients attending the chest clinic at Mulago National Referral Hospital.**

Secondary data for each patient was collected from the respective patient files kept in the clinic. Examination of the patient file was done by a medical officer (internist) on ward who reviewed patient files for diagnostic tests done, disease spectrum, and symptoms for each study subject.

**Objective 3: To determine the level of HRQoL of post-PTB lung disease patients attending the chest clinic at Mulago NRH.**

1. To score the SF-36, scales were standardized with a scoring algorithm to obtain a score ranging from 0 to 100. Higher scores indicated better health status and a mean score of 50 was articulated as a normative value for all scales. Scoring SF-36 is summarised in *tables 3 and 4 below*

*Table 3: below shows how to score the HRQOL questionnaire*

| **Question Number** | **Original Response** | **Recorded Value** |
|---|---|---|
| 1, 2, 20, 22, 34, 36 | 1 | 100 |
| | 2 | 75 |
| | 3 | 50 |
| | 4 | 25 |
| | 5 | 0 |
| 3, 4, 5, 6, 7, 8, 9, 10, 11, 12 | 1 | 0 |
| | 2 | 50 |
| | 3 | 100 |
| 13, 14, 15, 16, 17, 18, 19 | 1 | 0 |
| | 2 | 100 |
| 21, 23, 26, 27, 30 | 1 | 100 |
| | 2 | 80 |
| | 3 | 60 |
| | 4 | 40 |
| | 5 | 20 |
| | 6 | 0 |
| 24, 25, 28, 29, 31 | 1 | 0 |
| | 2 | 20 |
| | 3 | 40 |
| | 4 | 60 |
| | 5 | 80 |
| | 6 | 100 |
| 32, 33, 35 | 1 | 0 |
| | 2 | 25 |
| | 3 | 50 |
| | 4 | 75 |
| | 5 | 100 |

*Table 4: below shows how to generate the 8 sub-domains of HRQOL*

| Scale | Number of items | After recording as per table 1. Average the following items |
|---|---|---|
| Physical functioning | 10 | 3,4, 5, 6, 7, 8, 9, 10, 11, 12 |
| Role limitations due to physical health | 4 | 13, 14, 15, 16 |
| Role limitations due to emotional problems | 3 | 17, 18, 19 |
| Energy/fatigue | 4 | 23, 27, 29, 31 |

| | | |
|---|---|---|
| Emotional well being | 5 | 24, 25, 26, 28, 30 |
| Social functioning | 2 | 20, 32 |
| Pain | 2 | 21, 22 |
| General Health | 5 | 1, 33, 34, 35, 36 |

Scores were compiled as a percentage of the total points possible, using the RAND scoring table (STEP I chart). The scores from those questions that address each specific area of functional health status (STEP II chart) were then averaged together, for a final score within each of the 8 dimensions measured. (e.g., pain, physical functioning, etc.)

For example, to measure the patients' energy/fatigue level, add the scores from questions 23, 27, 29, and 31. If a patient circled 4 on 23, 3 on 27, 3 on 29, and left 31 blanks, use Table 1 to score them.

An answer of 4 to Q23 is scored as 40, 3 to Q27 is scored as 60, and 3 to Q29 is scored as 40. Q31 is omitted. The score for this block is 40+60+40 =140. Now we divide by the 3 answered questions to get 46.7%. Since a score of 100 represents high energy with no fatigue, the lower score of 46.7% suggests the patient is experiencing a loss of energy and is experiencing some fatigue.

All the eight categories were scored in the same way. Using this questionnaire at the beginning and during care, we can track the progress of the 8 parameters mentioned in the STEP II chart. (Ware et al., 1996)

The PCS was then finally computed as an average of the scale scores PF, RP, BP, and GH.

The MCS was calculated by averaging the scale scores of VI, SF, RE, and MH.

Each of the final PCS and MCS scores was independently used to determine HRQoL.

A computer database in MS Excel was built to generate the averages automatically.

**Interpretation of scores:** Based on the existing literature, the summary scores were interpreted as generally poor for scores below 50%, fair for scores between 50 and 59.9%, and good for scores of at least 60% (Verkleij et al., 2013)

**Objective 4: To identify the factors associated with the level of HRQoL of post-PTB lung disease patients attending the chest clinic at Mulago NRH.**

Since HRQoL was measured as PCS and MCS which are continuous outcomes, Multivariable analysis was conducted using linear regression to examine factors associated with HRQoL in the post-PTLD group. Two models were constructed as parsimoniously as possible for each measure (i.e., PCS and MCS). Each model had factors that best explain the observed PCS or MCS score. The variables found to be associated with the HRQoL with p-values of less than 0.25 at bivariate analysis, biologically plausible, and those whose associations have been determined from existing literature were included in the analysis. Analysis was entered into the linear regression model. They were then dropped one least significant variable at a time until all independent variables in the linear regression model had a two-sided p-value of less than 0.05. Multicollinearity was assessed using the variance inflation factor and the Bruesh-pagan test was used for assessing heteroskedasticity.

## 5.10 ETHICAL CONSIDERATIONS

Approval to conduct the study was obtained from the Makerere University School of Public Health Research & Ethics Committee (MaKSPH-REC). Permission was sought from the Mulago NRH Director to conduct the study at the hospital premises. Informed consent was sought from each participant after an explanation of the purpose of the study, the benefits of the study, the approximate time of the interview, and assurance of respect for the privacy and confidentiality of the respondents.

## 5.11 DISSEMINATION OF STUDY FINDINGS

The findings from the study were submitted as a thesis report in fulfillment of the requirement of the award of a Master's degree in Public Health at Makerere University. Copies of the report were submitted to Makerere University School of Public Health and made accessible to the public through the Makerere University Institution Repository and to Mulago NRH to help inform targeted interventions for post-PTB lung disease patients seeking health services there.

## CHAPTER SIX: RESULTS

### Objective 1: To determine the proportion of patients with post-PTB respiratory diseases among patients attending the chest clinic at Mulago NRH

One thousand eighty-six patients attended the chest clinic at Mulago National Referral Hospital from 1st May 2022 and 31 May 2023. Four hundred ninety-three (45.4%) had been previously treated for pulmonary Tuberculosis. Slightly over thirty-five percent (173/493) had confirmed diagnoses of post-PTLD. The proportion of post-PTB lung disease patients was 15.9% out of all patients attending the chest clinic in the study period. One hundred thirty-three patients with post-PTLD identified through records were consecutively sampled and scheduled for interviews using phone calls to ascertain their health-related quality of life as illustrated in *Figure 3.*

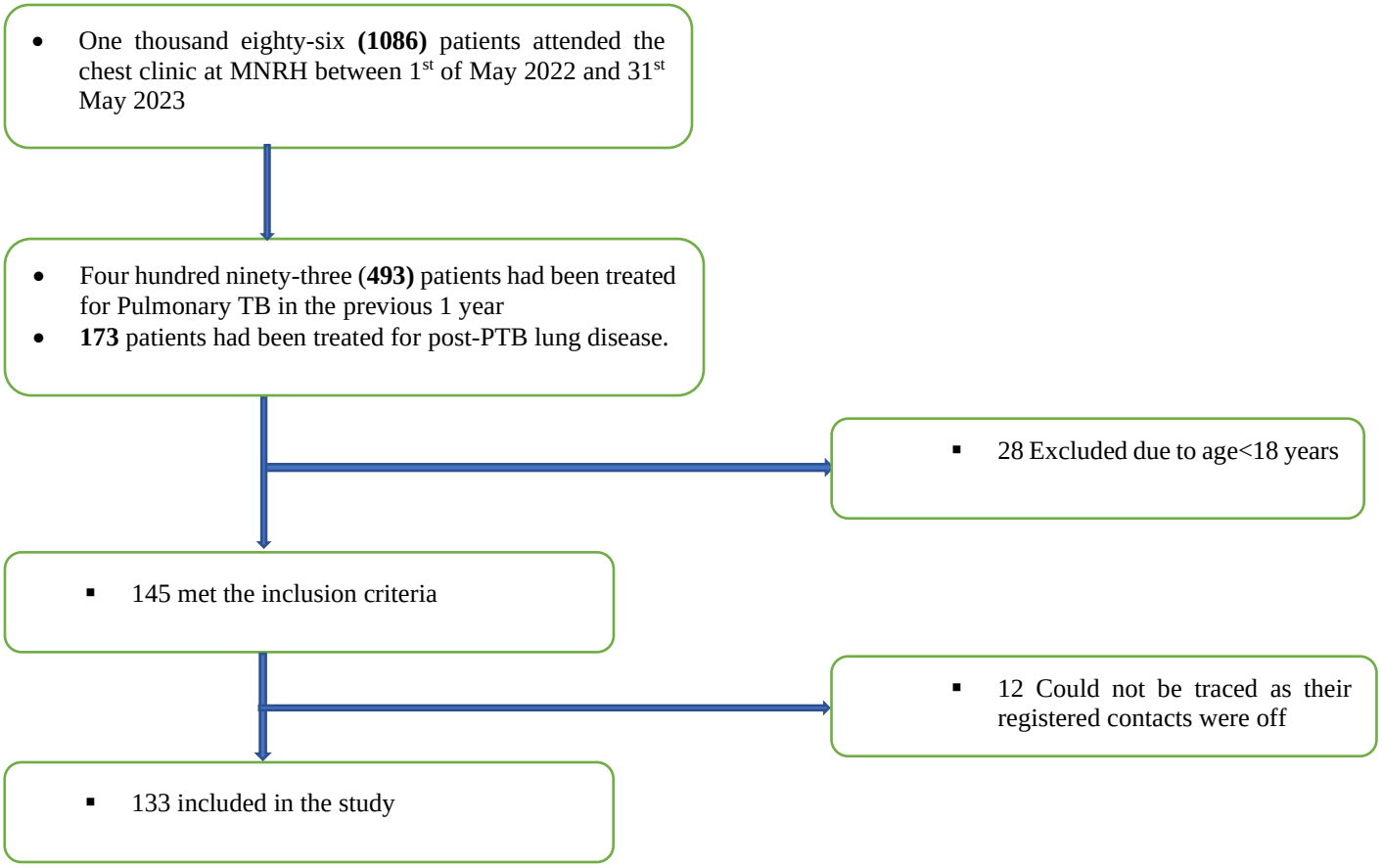



*Figure 2: Above shows the study participants' selection and inclusion in the study*

## 6.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS AND TREATMENT-RELATED PATIENT CHARACTERISTICS

Slightly over half (51.1%, 68/133) of the participants in this study were males, and the rest were females. The mean age of the participants was 39.2 (±12.6) years. Nearly three out of ten (27.8%, 37/133) were aged between 40-49 years, slightly greater than those aged 30-39 years (27.1%, 36/133). Only 21.0% (28/133) of the participants were at least 50 years old as shown in *Table 5*

Almost half of the study participants (66/133) were married at the time of the study, 35.3% (47/133) were single, and 10.5% (14/133) were either divorced or separated while the rest were widowed. The majority of the participants (48.12%, 64/133) had obtained secondary education. Only 3% (4/133) had no education at all. Only 18.8% of the participants (25/133) reported that they were currently smoking. Over 30% (40/133) of the participants reported that they were alcohol drinkers. Slightly over half (51.9%, n=69/133) of the participants in this study earned an average monthly income of less than 200,000 Ugandan shillings. Only 29.3% (39/133) earned at least half a million Ugandan shillings monthly. The majority of the participants in this study (41.3%, 55/133) were unemployed, only 12.0% (16/133) were salaried workers, 37.6% (50/133) were self-employed, and 9.0% (12/133) were peasants.

Regarding treatment factors, the majority of participants (92.5%, 123/133) rated the attitude of health workers as generally good, and the rest rated health workers' attitude towards them as fair. No participant reported poor health workers' attitudes towards them.

The average time of TB completion among the study participants was 5.3 ±3.4 months; the majority of the participants (58.7%, 78/133) had spent less than 6 months following completion of TB treatment. Over 88% of the respondents reported having partner or family support during post-PTLD care.

Financial constraints in accessing post-PTLD were reported in 27.8% (37/133) participants. 33.8% of respondents were HIV positive while the rest were HIV negative. Additionally, 41.4% (55/133) had at least one co-existing chronic illness other than HIV infection. Regarding other co-existing chronic illnesses, Diabetes mellitus was the most frequently reported comorbid condition by the majority (41.4%, 23/55) had diabetes mellitus followed by cardiovascular conditions (Hypertension, Heart failure, and others.), chronic kidney disease (18.2% 10/133), and lastly arthritis was reported by 3.6% (2/55). (9.1% (5/55) had other chronic illnesses.

*Table 5 below shows the Socio-demographic characteristics of the respondents*

| Demographic factors | Frequency n, (N=133) | Percent (%) |
|---|---|---|
| **Sex** | | |
| Female | 65 | 48.9 |
| Male | 68 | 51.1 |
| **Age (years)** | Mean (SD) 39.2± (12.6) | |
| 18-29 | 32 | 24.1 |
| 30-39 | 36 | 27.1 |
| 40-49 | 37 | 27.8 |
| 50+ | 28 | 21.0 |
| **Marital status** | | |
| Single | 47 | 35.3 |
| Married | 66 | 49.6 |
| Divorced/separated | 14 | 10.5 |
| Widowed | 6 | 4.5 |
| **Education level** | | |
| None | 4 | 3.0 |
| Primary | 34 | 25.56 |
| Secondary | 64 | 48.12 |
| Tertiary | 31 | 23.31 |
| **Current smokers** | | |
| Yes | 25 | 18.80 |
| No | 108 | 81.20 |
| **Household smokers** | | |
| Yes | 13 | 9.7 |
| No | 120 | 90.3 |
| **Alcohol drinkers** | | |
| Yes | 40 | 30.2 |
| No | 93 | 69.9 |

| | | |
|---|---|---|
| **Socio-economic Factors** | | |
| **Average monthly income (Ugshs.)** | | |
| <200,000 | 69 | 51.9 |
| 200,000-500,000 | 25 | 18.8 |
| >500,0000 | 39 | 29.3 |
| **Employment status** | | |
| Unemployed | 55 | 41.3 |
| Salaried worker | 16 | 12.0 |
| Self- employed | 50 | 37.6 |
| Peasants | 12 | 9.0 |
| **Treatment factors** | | |
| **Received counseling** | | |
| Yes | 102 | 76.7 |
| No | 31 | 23.3 |
| **Drugs available at the facility** | | |
| Yes | 45 | 33.8 |
| No | 88 | 66.2 |
| **Health workers attitude** | | |
| Poor | 0 | 0 |
| Fair | 10 | 7.2 |
| Good | 123 | 92.8 |
| **Patient-related factors** | | |
| **Time since TB treatment completion (months)** | Mean (SD) 5.3 ± (3.4) | |
| <6months | 78 | 58.7 |
| 6-12months | 55 | 41.3 |
| **Side effects of post-PTLD treatment** | | |
| yes | 24 | 18.0 |
| No | 109 | 82.0 |
| **Presence of family support** | | |
| Yes | 123 | 92.5 |
| No | 10 | 7.5 |
| **Financial constraints in accessing post-PTLD treatment support** | | |

| | | |
|---|---|---|
| Yes | 37 | 27.8 |
| No | 96 | 72.2 |
| **Co-existing chronic disease** | | |
| Yes | 55 | 41.4 |
| No | 78 | 58.6 |
| **HIV status** | | |
| Positive | 45 | 33.8 |
| Negative | 88 | 66.2 |

**Objective 2: Clinical patterns of post-TB lung disease at Mulago NRH**

Post-tuberculous chronic obstructive diseases of the airway (COPD) accounted for the majority of the cases of post-PTLD. Other post-PTLD are shown in *figure 4*

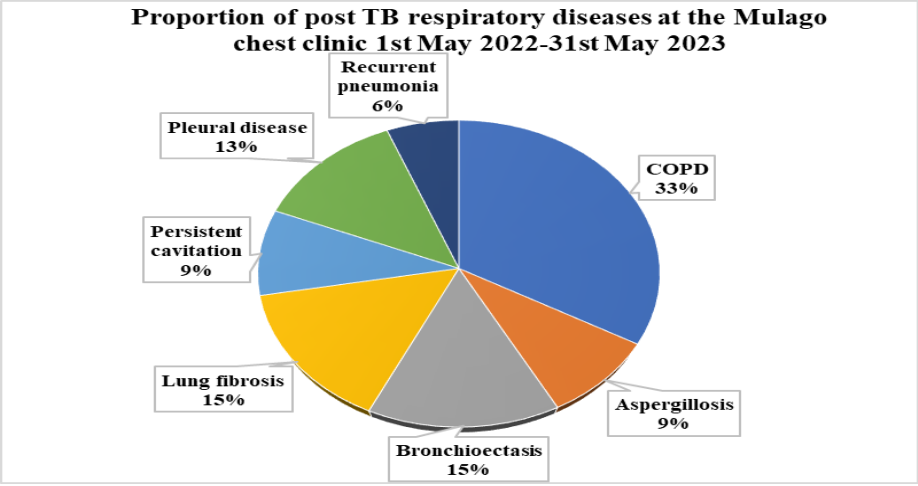
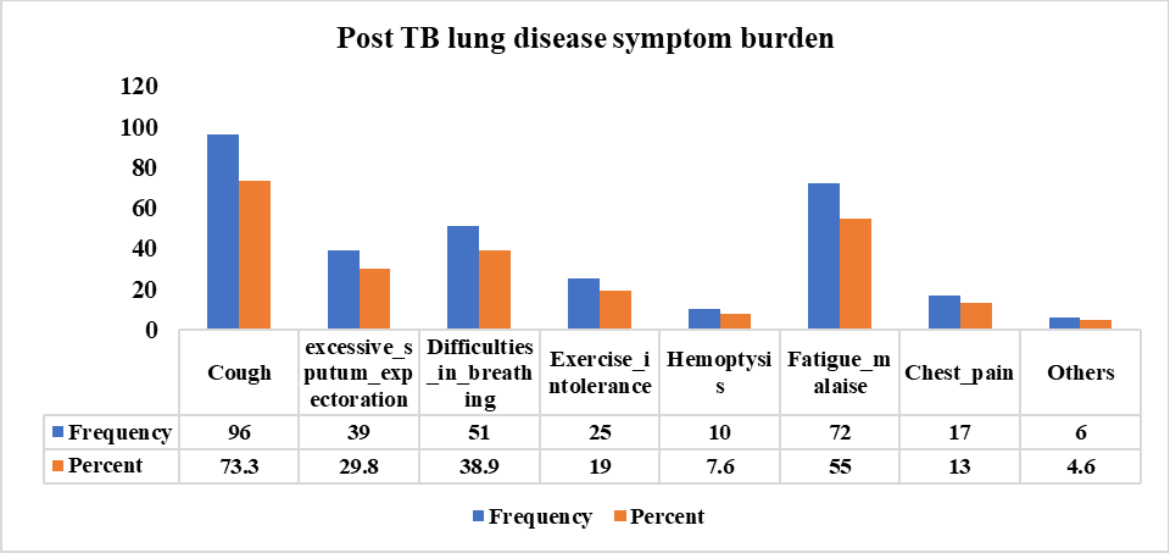



*Figure 3: proportions of specific post-PTB respiratory diseases at the Mulago chest clinic between 1st May 2022-31st May 2023*

This study revealed that cough was the most frequently reported symptom of post-PTB-lung disease by the participants. Almost three-quarters of the patients (96/133) reported bothersome cough at diagnosis. Additionally, over half of the participants (72/1330 reported having fatigue and malaise. Hemoptysis (coughing blood) and chest pain were the least reported symptoms of post-PTLD at diagnosis by 7.6% (10/133) and 13% (17) participants respectively. The post-PTLD symptom burden among the study participants was summarized in *Figure 5*




| | Cough | excessive_sputum_expectoration | Difficulties_in_breathing | Exercise_intolerance | Hemoptysis | Fatigue_malaise | Chest_pain | Others |
|---|---|---|---|---|---|---|---|---|
| Frequency | 96 | 39 | 51 | 25 | 10 | 72 | 17 | 6 |
| Percent | 73.3 | 29.8 | 38.9 | 19 | 7.6 | 55 | 13 | 4.6 |

*Figure 4: Shows the post-PTLD symptom burden among the study participants*

**Objective 3: Health-related quality of life domains**

In this study, emotional well-being had the highest score with a mean of 64.7% (SD 18), followed by pain (62.4%) and social functioning (61.5%). However, general health (49.1%) role limitations due to physical health (48.1%), and role limitations due to emotional health (45.2%) had the lowest scores in the study. Role limitations due to emotional distress were however the most variable HQRoL domain (SD 39.15), while general health had the least variation (17.16). The mean score for the physical component was 54.8%, while the mean score for mental health was 57.3%. The mean scores were generally good (At least 60%) for emotional well-being, social functioning, and pain and fair (50-59%) for physical functioning and vitality (energy and fatigue). However, the scores were poor (below 50%) for role limitations due to physical health emotional distress, and general health as shown in *Table 6*

*Table 6: Shows HRQoL summary scores*

| **Health-related QoL domain** | **Mean (SD)** | **confidence interval** |
|---|---|---|
| Physical functioning | 59.5± (23.9) | (55.4 - 63.6) |
| Role limitations due to physical health | 48.1± (34.4) | (42.2- 54.1) |
| Role limitations due to emotional distress | 45.2± (39.1) | (38.5 - 59.1) |
| Energy/Fatigue | 57.9± (17.4) | (54.9 – 60.9) |
| Emotional well-being | 64.7± (18.0) | (61.6 – 67.8) |
| Social functioning | 61.5 ± (21.3) | (57.9 – 65.2) |
| Pain | 62.4 ± (21.4) | (58.8 – 66.1) |
| General Health | 49.1± (17.2) | (46.2 – 52.1) |
| **Summary composite scores** | | |
| **PCS** | **54.8± (19.6)** | **(51.9 – 57.7)** |
| **MCS** | **57.3± (19.7)** | **(53.9 – 60.8)** |

## 6.3 FACTORS ASSOCIATED WITH THE LEVEL OF HRQOL (SUMMARY SCORES) OF POST-PTLD PATIENTS ATTENDING THE CHEST CLINIC AT MNRH.

The distribution of outcomes of the health-related quality of life i.e., PCS and MCS met the assumption of normal distribution thus allowing analysis using multiple linear regression methods.

### 6.3.1 Factors associated with physical-related quality of life among post-PTLD patients

*Table 7: Shows factors associated with PCS*

| Variable | Unadjusted RC | 95% CI | P-value | Adjusted RC | 95% CI | p-value |
|---|---|---|---|---|---|---|
| **Sex** | | | | | | |
| Female | Ref | | | | | |
| Male | 2.95 | (-2.85 - 8.76) | 0.31 | 1.44 | (-2.12- 5.01) | 0.42 |
| **Age(years)** | | | | | | |
| 18-29 | Ref | | | | | |
| 30-39 | -3.64 | (-11.15-3.87) | 0.34 | -0.57 | (-5.60-4.42) | 0.82 |
| 40-49 | -10.50 | (-18.4 - -2.60) | 0.01 | -2.58 | (-7.88- 2.72) | 0.33 |
| 50+ | -11.74 | (-2.10- -3.37) | 0.006 | -1.99 | (-7.49- 2.79) | 0.28 |
| **Marital status** | | | | | | |
| Single | Ref | | | | | |
| Married | 1.71 | (-4.56-8.00) | 0.59 | -1.40 | (-5.7-2.98) | 0.53 |
| Separated/Divorced | -10.02 | (-20.38-0.34) | 0.058 | -3.83 | (-10.3- -2.6) | 0.25 |
| Widowed | -5.59 | (-19.93- -8.76) | 0.35 | -4.33 | (-13.5-4.8) | 0.34 |
| **Employment status** | | | | | | |
| Unemployed | Ref | | | | | |
| Salaried worker | 13.41 | (4.09-22.73) | 0.005 | 0.17 | (-6.5-6.82) | 0.96 |
| Self-employed | 2.13 | (-4.28-8.54) | 0.51 | -6.16 | (-10.7- -1.6) | 0.008 |
| Peasants | 6.03 | (-4.42-16.48) | 0.255 | -5.05 | (-12.2-1.9) | 0.15 |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Monthly income(Ugshs)** | | | | | | |
| <200K | Ref | | | | | |
| 200k-500k | 8.93 | (2.32-15.54) | 0.008 | 7.35 | (1.88-12.82) | 0.009 |
| >500k | 21.20 | (15.53-26.8) | <0.001 | 11.91 | (6.87-16.96) | <0.001 |
| **Smoking(Yes)** | -11.04 | (-18.2- - 3.8) | 0.003 | -2.28 | (7.46-2.90) | 0.38 |
| **Alcohol Drinkers** | | | | | | |
| No | Ref | | | | | |
| Yes | -18.25 | (-23.6- -12.7) | <0.001 | -10.35 | (-14.5- -6.2) | <0.001 |
| **Post-PTLD COPD** | | | | | | |
| No | Ref | | | | | |
| Yes | -18.91 | (-24.3- -13.5) | <0.001 | -10.97 | (-15.3- -6.7) | <0.001 |
| **Aspergillosis** | | | | | | |
| No | Ref | | | | | |
| Yes | -8.98 | (-17.57- -0.4) | 0.041 | -2.76 | (-8.21- -2.7) | 0.317 |
| **Bronchiectasis** | | | | | | |
| No | Ref | | | | | |
| Yes | -9.66 | (-16.13- -3.2) | 0.004 | | | |
| **Family/Spousal support** | | | | | | |
| No | Ref | | | | | |
| Yes | 23.82 | (13.59-34.1) | <0.001 | 11.40 | (4.25-18.55) | 0.002 |
| **Financial constraints in accessing post-PTLD treatment** | | | | | | |
| No | Ref | | | | | |
| Yes | -14.51 | (-20.5- -8.5) | <0.001 | -2.83 | (-7.27-1.61) | 0.208 |
| **Received Counselling** | | | | | | |
| No | Ref | | | | | |
| Yes | 20.86 | (-26.7--14.9) | <0.001 | 8.39 | (3.30- 13.4) | 0.001 |

| | | | |
|---|---|---|---|
| **Drugs available at the facility** | | | |
| No | Ref | | |
| Yes | -1.06 | (-7.77- -4.53) | 0.61 |

Key : URC = Unadjusted Regression Coefficient

ARC: Adjusted Regression Coefficient

**At bivariate level**

Sex, hypertension, pleural disease, and diabetes were not associated with significant changes in the mean (p-values>0.05)

Patients aged 30-39 years had a non-significant reduction of 3.6 in the mean units of PCS compared to those aged 18-29 years (Unadjusted Regression Coefficient; - 3.64(-11.15-3.87), p-value=0.340). Individuals aged 40-49 years had a significant 10.5 reduction in the units of PCS compared to those aged 18-29 years (URC; -10.50 CI (-18.40--2.60), p-value=0.010). Those aged 50 years and above had a significant 11.7 reduction in the mean scores of PCS compared to those aged between 18-29 years (URC; -13.22 CI (-20.10--3.37), p-value 0.006)

Patients who reported being married were associated with a non-significant increment of 1.7 in the mean of PCS (URC; -1.71 CI (-4.56-8.00), p-value 0.611) compared to those who were single. Those who were separated or divorced had a non-significant 10-unit reduction of PCS compared to single individuals (URC; -10.02 CI (-20.38-0.34), p-value=0.058).

Having primary education was associated with a non-significant increase in the mean units of PCS by 7.7 (URC; 7.71 CI (-8.96-24.37), p-value=0.131) compared to those with no education. Having secondary education was associated with a non-significant 13.8 increment in the units of PCS (URC; 13.84 CI (-2.41-30.09), p-value=0.094) compared to those with no education at all. Having tertiary education was associated with a significant increment of 23.8 PCS units compared to those with no formal education at all (URC; 23.75 CI (7.00-40.51), p-value=0.006).

Of those patients, only salaried workers had a significant increase in mean units of PCS of 13.4 units (URC=13.4 CI (4.09-22.73), p-value=0.005) compared to those who are unemployed.

Those who earned an average of 54-134 US dollars monthly were associated with a significant increment in the mean units of PCS of 8.9 (URC; 8.93 CI (2.32-15.54) p-value=0.008) compared to those who earned less than 34 US dollars monthly. Those who earned an average of more than 134 US dollars monthly were likely to have a significant 21.2 increment in the mean units of PCS (URC; 21.20 CI (15.53-26.87), p-value<0.001) compared to those who earned less than 34 US dollars.

On the other hand, smoking was significantly associated with a reduction in the mean units of PCS by 11.0 (URC; -11.04 CI (-18.26--3.83), p-value=0.003) compared to non-smokers. Alcohol

consumption was significantly associated with a significant reduction of 18.3 in mean units of PCS (URC; -18.25 CI (-23.76--12.72), p-value<0.001) compared to non-alcohol drinkers.

Having COPD was associated with a significant 18.9 reduction in units of PCS (URC; -18.91CI (-24.31--13.51), p-value <0.001) relative to those with no COPD.

**Multivariable level**

After adjusting for other factors, patients who earned between 54 US dollars (200,000Ugx) and USD 134 (500,0000Ugx) monthly were more significantly associated with a 7.4 increment in the mean units of PCS compared to those who earned less than 54 US dollars (200,000Ugx) (ARC 7.35 CI (1.88-12.82) p-value =0.009). Those who earned on average above 134 USD monthly were significantly associated with an 11.9 increment in the units of PCS than those who earned less than USD 34 (ARC; 11.91 CI (6.87-16.96), p-value<0.001).
Alcohol consumption significantly reduced the mean units of PCS by 10.35 (ARC; -10.35, CI (-14.51- -6.19) p-value<0.001) compared to non-alcohol consumers after adjusting for confounders.

On the other hand, after adjusting for other factors, self-employed patients had a significant 6.2 reduction in the mean units of PCS compared to the unemployed (ARC=-6.16 CI (-10.70- -1.62), p-value=0.008). Other employment categories had no significant relationship with PCS.

There was a significant reduction in the mean PCS values of self-employed workers compared to unemployed people (ARC -6.16 CI (-10.7- -1.62) p-value=0.008). There were no significant differences in the mean units of PCS between the unemployed and other categories.

After adjusting for confounders, post-PTB COPD was significantly associated with a 10.9-unit reduction in the mean score of PCS (ARC, -10.97 CI (-15.28- -6.67) p-value<0.001) compared to none post-PTB COPD patients.

Patients who had family support were associated with a significant 11.4 increase in the mean score of PCS compared to those who did not have support (ARC 11.4 CI(4.25-18.55) p-value =0.002) whereas patients who had received counseling had a significant 8.39 unit increment in the mean score of PCS compared to those who had not received counseling (ARC; 8.39 CI(3.30-13.49), p-value=0.01) after controlling for confounders.

### 6.3.2 Factors associated with the mental component score (MCS) in post-PTLD patients

*Table 8: Shows factors associated with MCS*

| Variables | URC | 95%CI | P>t | ARC | 95%CI | P-value |
|---|---|---|---|---|---|---|
| **Sex** | | | | | | |
| Female | Ref | | | | | |
| Male | 2.96 | (-3.78- 9.7) | 0.386 | 2.34 | (-2.71-7.39) | 0.35 |
| **Patient Age (years)** | | | | | | |
| 18-29 | Ref | | | | | |
| 30-39 | -4.84 | (-13.41- 3.7) | 0.266 | -2.38 | (-9.43- 4.66) | 0.504 |
| 40-49 | -10.24 | (-19.2- -1.2) | 0.026 | -3.50 | (-11.0-4.0) | 0. 357 |
| 50+ | -18.50 | (-28.04--8.9) | <0.001 | -8.70 | (-16.4--0.9) | 0.028 |
| **Marital status** | | | | | | |
| Married | Ref | | | | | |
| Single | -3.92 | (-3.27-11.12) | 0.283 | 2.68 | (-3.30- 8.67) | 0.376 |
| Divorced/separated | -9.51 | (-21.38-2.36) | 0.115 | -2.88 | (-11.67-5.90) | 0.517 |
| Widowed | -15.10 | (-31.54-1.34) | 0.071 | -8.21 | (-20.95-4.52) | 0.204 |
| **Drinking Alcohol** | | | | | | |
| No | Ref | | | | | |
| Yes | -17.57 | (-24.30--10.85) | <0.001 | -9.04 | (-14.92--3.16) | 0.003 |
| **Received Counselling** | | | | | | |
| No | Ref | | | | | |
| Yes | 22.17 | (15.14-29.20) | <0.001 | -5.83 | (-13.02--1.36) | 0.111 |
| **Receives Family support** | | | | | | |
| No | Ref | | | | | |
| Yes | 22.19 | (9.94-34.44) | <0.001 | 9.71 | (-0.21-16.63) | 0.362 |
| **Financial constraints** | | | | | | |
| No | Ref | | | | | |
| Yes | -14.54 | (-21.67--7.42) | <0.001 | -3.92 | (-10.19-2.34) | 0.217 |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Monthly Income** | | | | | | |
| <200,000 | Ref | | | | | |
| 200000-500000 | 9.02 | (0.82-17.21) | 0.031 | 7.65 | (-0.08-15.39) | 0.052 |
| 500k+ | 20.06 | (13.02-27.09) | <0.001 | 10.19 | (3.10-17.27) | 0.005 |
| **COPD** | | | | | | |
| No | Ref | | | | | |
| Yes | -18.9 | (-24.3-13.5) | <0.001 | -10.97 | (-15.2- -6.6) | <0.001 |
| **Smoking** | | | | | | |
| No | Ref | | | | | |
| Yes | -14.94 | (-23.2- -6.67) | <0.001 | -7.29 | (-14.5- -0.63) | 0.048 |
| **Employment status** | | | | | | |
| Unemployed | Ref | | | | | |
| Salaried Worker | 15.75 | (4.99-26.5) | 0.004 | 2.63 | (-6.7-11.9) | 0.577 |
| Peasants | 7.82 | (-4.25-19.9) | 0.21 | -2.50 | (-12.3-7.3) | 0.616 |
| **Received family/Spousal support** | | | | | | |
| No | Ref | | | | | |
| Yes | 4.24 | (-7.3-11.4) | 0.17 | 9.707 | (-0.21-19.62) | 0.05 |
| **Received counselling** | | | | | | |
| Yes | Ref | | | | | |
| No | -22.17 | (-29.2- -15.1) | <0.001 | -5.83 | (-13.02-1.35) | 0.11 |
| **Financial constraints in Receiving Treatment** | | | | | | |
| No | Ref | | | | | |
| Yes | -14.54 | (-21.6 - -7.4) | <0.001 | -3.92 | (-10.9 - 2.4) | 0.217 |

**At bivariate level**

Patients aged 30-39 years had a non-significant reduction of 4.8 in the mean score of MCS compared to those aged 18-29 years (URC; - 4.84 CI (-13.41- 3.73) p-value=0.266). Individuals aged 40-49 years had a significant 10.2 reduction in the mean units of MCS compared to those aged 18-29 years (URC; -10.24 CI (-19.2- -1.23) p-value=0.026).

Those aged 50 years and above had a significant 18.5 reduction in the mean units of MCS compared to those aged between 18-29 years (URC; -18.50, CI (-28- -.8.95) p-value <0.001)

Salaried patients were significantly likely to have a 15.7 increment in units of MCS (URC; 15.75 CI (4.99-26.52), p-value-0.007) compared to unemployed patients. Other categories were not significantly associated with MCS

Those who earned an average of 54-134 USD monthly were associated with a significant increment of 9 units in MCS (URC; 9.02 CI (0.82-17.21), p-value=0.031) compared to those who earned less than 54 USD monthly. Those who earned an average of more than 134USD monthly were likely to have a significant 10.2 increment in the mean units of MCS (URC; 20.06 CI (13.02-27.09), p-value<0.001)

Having a supportive family member and receiving counseling at the facility was associated with a significant 22.2 increase in the units of MCS (URC; 22.2 CI (9.94-34.44), p-value<0.001) than those without family support and 22.17 increment of mean MCS units for those receiving counseling (URC; 22.17 CI(15.14-29.20), p-value<0.001) compared to those who were not receiving counseling.

On the other hand, Alcohol drinking was significantly associated with a reduction in the units of MCS by 17.6 (URC; -17.57 CI (-24.30- -10.85), p-value<0.001) compared to non-drinkers, and the same pattern was observed among smokers who showed a significant reduction of 14.9 in units of MCS compared to non-smokers (URC; -14.94 CI (-23.21--6.67), p-value<0.001).

Having COPD was associated with a significant 18.7 reduction of MCS units (URC; -18.72 CI (-25.29- -12.13), p-value<0.001) compared to patients without COPD while financial constraints in accessing post-PTLD treatment significantly reduced the mean scores of MCS by 14.54 units (URC; -14.54 CI (-21.67--7.42), p-value<0.001) as well.

**Multivariable level**

After adjusting for other factors, the age category of 50 and above years was significantly associated with an 8.7 reduction in the mean scores of MCS (ARC; -8.70 CI (-16.43—0.96), p= 0.028) compared to those were 18-29 years. The other age categories did not significantly change the mean scores of MCS.

After adjustment, patients who earned above 134 US dollars monthly (500,000Ugx) were significantly associated with a 10.2 increment in the units of MCS than those who earned less than 54 US dollars (Ugx 200,000U) (ARC; 10.19 CI (3.17-17.27), p-value=0.005). The other age categories did not significantly change the mean scores of MCS.

On the other hand, there was a significantly lower mean value of MCS among alcohol drinkers compared to none alcohol drinkers (ARC = -9.04 CI (-14.92--3.16) p-values=0.003) whereas smoking was associated with a significant 7.3 reduction in the mean units of MCS compared to non-smokers (ARC= -7.29 CI (14.53—0.63)0.048) after adjusting for other factors.

Post-TB COPD was significantly associated with a reduction in mean units of MCS. Post-TB COPD was significantly associated with an -10.8 reduction in the mean score of MCS (ARC, -8.65 CI (-16.92- -4.72) p-value 0.008), after adjusting for confounders.

Lastly, being self-employed was associated with a significant reduction of 7.4 in the mean values of MCS compared to the non-employed (ARC; -7.43, CI (-13.82- -1.04) p-value=0.023) after adjusting for other factors. The mean difference of MCS for Peasants did not significantly change with those who are unemployed.

## CHAPTER SEVEN: DISCUSSION OF THE STUDY FINDINGS

This cross-sectional study sought to determine the proportion of post-PTLD among the patients attending the chest clinic at Mulago National Referral Hospital, the quality of life among patients with post-PTB lung disease, and factors associated with quality of life among patients with post-PTB lung disease. The study revealed that post-PTB lung disease occurred in over one-third of the patients previously treated for TB, and accounted for about one in four patients (15.9%) attending the chest clinic at Mulago Hospital from 1st May 2022 and 30 May 2023. The findings from this study are almost similar to the 38.2% pooled prevalence of post-PTLD from the WHO African region in a meta-analysis by (Maleche-Obimbo et al., 2022). Similarly, a previous study among patients attending a pulmonary rehabilitation program at Mulago National Referral Hospital by (Jones et al., 2017b) reported that up to 30% of the attendees of the respiratory clinic had a history of pulmonary TB. The above findings indicate that TB can potentially cause significant lung damage that results in persistent respiratory problems requiring clinical interventions even after the successful completion of TB treatment. Therefore, the healthcare system needs to monitor and provide appropriate healthcare for individuals with PTB even after successful completion of treatment to improve their productivity and overall quality of life.

Chronic obstructive disease (COPD) was the commonest manifestation of post-PTLD occurring in approximately three out of ten patients with post-PTLD. Other manifestations of post-PTLD observed in this study included restrictive lung diseases such as bronchiectasis (15%), and lung fibrosis (15%), and infectious forms such as Aspergillosis (9%). A study by (Menezes et al., 2007) in Latin America established similar findings despite different populations. In their study, (Menezes et al., 2007) found that over 30% of patients who had suffered from PTB eventually developed chronic airway obstruction.

(Nuwagira et al., 2020) in their study among survivors of multi-drug resistant pulmonary tuberculosis (MDR-TB) found that two in ten survivors of MDR-TB (23%) eventually developed COPD. However, this current study did not establish the post-PTLD prevalence among the patients by their PTB drug resistance patterns. The 33% prevalence of COPD among post-PTLD patients established by this study affirms the existing literature that documents a high prevalence of COPD among post-PTB survivors compared to the 16.2% in the general population (van Gemert et al.,

2015). There is a need to develop and implement effective strategies to diagnose post-PTB lung impairment and improve lung health among survivors of tuberculosis.

More than half of the patients with post-PTB lung disease in this study were males. This was consistent with other previous studies by (Mpagama et al., 2021), (Choi et al., 2021), and (Meghji et al., 2016) in which the majority of the patients presenting with post-PTLD were males. The high risk of post-PTLD observed among males in this study could be explained by the differences in smoking; a risky behavior that was significantly more common in males than females. Over twenty-five percent of the males in this study were more likely to be smokers compared to just 12 % of the females. However, (Katumba et al., 2013)observed poor health-seeking behavior among male PTB survivors hence more likely to develop post-PTLD. Almost three-quarters of the patients reported bothersome cough at diagnosis. This was consistent with a study by (Mpagama et al., 2021) in Tanzania where cough was the most reported symptom of post-PTLD reported in over one-quarter of the patients. This study indicated that cough overlapped with other symptoms like difficulty in breathing, chest pain, sputum expectoration, and hemoptysis which has been established in other studies as well (Mpagama et al. 2021, Ozoh et al. 2021). Therefore, patients who remain with residual symptoms following successful PTB treatment completion should seek early evaluation for a possibility of post-PTLD.

Almost two in every ten participants in this study were active smokers, while another one in ten participants acknowledged that a member of their household was smoking. The proportion of active smokers in this study was slightly lower than the 47% reported by(Mpagama et al., 2021) among patients with post-PTLD. (Mpagama et al., 2021) reported a higher percentage (19%) of passive smokers presenting with symptomatic post-PTLD. Smoking may damage the respiratory system and weaken the lungs' defense mechanisms, making smokers more susceptible to various respiratory infections, including PTB (Jayes et al., 2016). For individuals who successfully recover from active PTB, smoking can hinder the healing process leading to the progression of lung damage (Allwood, Byrne, Meghji, Rachow, van der Zalm, et al., 2021; Byrne et al., 2015). This may lead to the development or exacerbation of post-PTB lung problems such as COPD that may negatively interfere with quality of life as observed in this study.

## Physical and Mental Components of Health-related Quality of Life among post-PTLD Patients

In this study, emotional well-being (64.7%), pain (62.4%), and social functioning (61.5%) generally had good scores, whereas general health (49.1%) and role limitations due to physical health (48.1%) and role limitations due to emotional distress (45.2%) had poor scores. The mean scores for physical component (PCS) 54.7% and mental component (MCS) (57.34%) were generally fair.

There was a strong positive correlation between the mental component and the physical component (0.74). This means that post-PTLD had substantial adverse impacts on patients' quality of life. The mean scores are quite comparable to other studies of a similar nature. A South African study by (Hanekom et al., 2019)found lower mean values of MCS (39.01) and PCS (44.82) whereas an earlier Indian study by Muniyandi et al., (2007) found higher mean values of MCS (68%) and PCS (74%) among patients with post-PTLD. However, the Indian study included patients with asymptomatic post-PTLD, unlike this current study which included respiratory symptoms. It is widely believed that asymptomatic individuals are more likely to live a normal or near-normal quality of life.

## Factors associated with PCS and MCS among post-PTLD patients

The mean values of PCS and MCS were significantly higher for individuals who earned more than USD 134 (>500,000 Ugx) compared to others. As a measure of socio-economic status, monthly income has been found to positively influence treatment adherence and good treatment outcomes in other studies (Mpagama et al., 2021; Muniyandi et al., 2007). High income generally allows individuals to have better access to healthcare services, including regular check-ups, medications, and specialized treatments (Kastien-Hilka et al., 2016; Laxmeshwar et al., 2019). This means that participants with higher incomes were better financially empowered to seek timely medical attention leading to a potentially better quality of life. However, over two-thirds of the participants in this study reported that drugs for their post-PTLD were unavailable at the chest clinic and yet about three in ten patients were financially constrained in accessing post-TB care.

Self-employed participants were associated with a significant reduction in the mean units in health quality of life in both PCS and MCS models compared to unemployed patients. The findings are contrary to what (M. B. Kisaka, 2014) found in patients receiving treatment for PTB where formal

employment was associated with improved quality of life across all treatment phases in both MCS and PCS.

In this study, participants who consumed alcohol were more likely to have reduced quality of life in both PCS and MCS models. This was consistent with findings from a study by (Mpagama et al., 2021) where alcoholism was associated with 40% increased chances of symptomatic post-PTLD (AOR=1.4), and drinking alcohol was associated with overall reduced perceived quality of life. However, contrary to this study, (Menezes et al., 2007) found that social drinking improved the social well-being of post-PTLD patients in rural India. Generally, excessive alcohol consumption may negatively influence the quality of life of individuals by weakening their immune systems, which makes them prone to infections. In the setting of post-PTB infection, physical lung impairment due to PTB may increase the risk for infections where the immune system has been impaired by alcoholism.(Simet & Sisson, 2015)

One-third of the patients in this study had COPD. In both models, having post-TB COPD was associated with reduced quality of life. The results are quite comparable to the study by (Nuwagira et al., 2020) among the survivors of Multidrug-resistant TB at Mulago and Mbarara hospitals. The study established a high prevalence of COPD among the survivors (23%) and reported poor physical score (PCS of 58.6) and mental score (MCS of 52.9)

In the PCS model, having a supportive family member was associated with improved quality of life. After adjusting for other factors, having partner/family support significantly increased the mean value of PCS by over 10 units. A comparison of the mean scores of PCS revealed a significantly higher score (56.58) among patients who reported having family/partner support compared to the respondents who did not report having support in accessing post-TB care (32.76). Whereas no other studies have specifically examined the impact of family or partner support on the quality of life in post-PTLD patients, studies on health-related quality of life in other chronic diseases like cancer support the notion that family support can positively impact the self-perceived quality of life (Katumba et al., 2013; Muliira et al., 2017). Partners and family members are pivots of social support among patients with chronic conditions to physically cope with stress and adversity, which can significantly improve both physical and mental health (Mutumba et al., 2017).

In the MCS model, age beyond 50 years was associated with a significant reduction in the mean score of mental well-being. Compared with other age groups, patients who were 50 years and

above had significantly lower mean scores of MCS compared to those aged less than 40 years. According to (Segal et al., 2018), aging influences mental health through physical health problems, which may create feelings of frustration, anxiety, and depression among older individuals.

Our study indeed observed a difference between the physical and mental composite scores on the SF-36. The PCS score was lower, likely due to the direct impact of post-PTLD lung disease on physical functioning, including breathing difficulties, fatigue, and pain. While MCS scores were higher, indicating better mental health, this doesn't imply a lack of psychological challenges. Post-TB can lead to anxiety, depression, and social isolation, which might not be fully captured by the SF-36 subscales. Interestingly, other studies with post-PTLD patients also report similar discrepancies. (Mahler & Mackowiak, 1995; Zubritsky et al., 2013). Apparent differences between physical and mental scores can be attributed to the fact that physical and mental health are not always directly linked. Some patients might manage chronic physical limitations well emotionally, while others might experience significant mental distress despite less severe physical symptoms.

**Study limitations**

Health-related quality of life is generated through self-reports which are highly subjective and may depend on unverifiable present short-term circumstances or how the patient may be feeling at that particular time. This may introduce a reporting bias, which is a form of information bias. However, this study utilized the expertise of a medical officer and nurses on wards who tried to make the participants report objectively in line with the standard SF36 questionnaire.

This study used the SF36 version 2 tool to design the questionnaire. The questionnaire was quantitative. Qualitative methods like in-depth interviews and focus group discussions may be better at generating deeper explanations of observed HRQoL scores. However, the SF-36 has undergone rigorous psychometric testing, demonstrating high reliability and validity. Therefore, the questionnaire reliably measured the intended study objectives. In addition, its widespread use in various populations and medical conditions indicates that the findings from this study would be reliably compared with results across various studies.

Lastly, this was a facility-based study where the sample size was drawn from patients who attended the chest clinic with symptoms. This study population may not represent the broader population, especially those who did not have access to healthcare or have milder or asymptomatic conditions

and did not seek healthcare from the facility during the time the study was conducted. As a result, the findings may not be generalizable to the general population or specific groups such as asymptomatic post-PTLD patients

# CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS

## 8.1 CONCLUSIONS

1. This study demonstrated that about three in ten patients previously treated and cured of PTB developed post-PTLD. This indicates that post-PTLD is a significant cause of morbidity among PTB survivors
2. The mean scores of physical (54.7) and mental (57.3) components were generally fair compared to the general population as classified by existing literature. The sub-domains of HRQoL scores among post-PTBLD patients were highest in social functioning (61.54), emotional well-being (64.73), and perceived pain (62.44), and lowest in general health (49.10), role limitations due to emotions (45.19) and physical health (48.12)
3. There was a strong positive correlation between the physical component score and the mental component score. This indicates that post-PTLD has an impact on both the physical and mental well-being of the patients.
4. Monthly income greater than USD 54 (UgShs. 200,000), family support, and counseling significantly increased the physical component score of post-PTLD patients in this study while alcohol consumption, COPD, and being self-employed significantly reduced the PCS of post-PTLD patients.
5. Alcohol consumption, age above 50 years, smoking, and COPD significantly decreased the mean score of mental well-being.

## 8.2 RECOMMENDATIONS

**Healthcare providers and facilities**

1. The study recommends that the care of pulmonary tuberculosis should not be limited to the treatment of initial infection with anti-tuberculous medications. Clinicians need to actively screen PTB survivors at risk of developing post-PTB lung complications (diseases) and offer appropriate care at the earliest time of contact to improve their Health-related quality of life.
2. The mental and physical well-being of post-PTLD are positively correlated. To holistically improve the quality of life among these patients, clinicians need to consider implementing interventions that address the physical and mental well-being of these patients as a whole. These may include; psychosocial interventions, counseling, and support groups that can help individuals cope with the emotional distress that usually comes along with chronic diseases such as post-PTLD.
3. Clinicians should emphasize the importance of quitting alcohol consumption and smoking by patients with post-PTLD. Patients with post-PTLD who smoke or consume alcohol should further be prioritized for rehabilitation and equipped with coping mechanisms to modify these risky practices

**Policymakers:**

4. Post-PTLD patients require interventions to improve their socio-economic and living conditions to improve post-TB health outcomes and quality of life. These include policies to enhance the household income of TB survivors to reduce the negative impact of financial constraints in accessing post-TB care and overall quality of life.
5. National TB and Leprosy control program should develop national guidelines outlining a standardized protocol for the post-treatment follow-up of TB patients which should include PTLD surveillance mechanisms after TB chemotherapy to screen TB survivors with an increased risk of developing PTLD. These should then be prioritized for PTLD care programs that are tailored to each individual's social context thus improving treatment outcomes and in the long run HRQoL.

6. The Ministry of Health should initiate a comprehensive health education program to raise awareness among healthcare professionals and the public about the potential long-term consequences of TB and the importance of early screening for PTLD. This can include training modules among others.

7. More funding should be allocated to research to support studies investigating the long-term outcomes of TB treatment. This will contribute to the evidence base for implementing national policies focused on early screening and prioritization of PTLD patients.

**Future studies:**

8. The author recommends further studies with samples of post-PTLD patients across the country. This could help to identify other factors that could be targeted for interventions to improve treatment outcomes.
9. Furthermore, comparative studies among post-PTLD patients and non-post-PTLD patients attending chest clinics around the country should be done to determine if a difference in HRQoL exists among these sub-groups.

## REFERENCES


Aggarwal, A. N. (2019). Quality of life with tuberculosis. *Journal of Clinical Tuberculosis and Other Mycobacterial Diseases*, *17*, 100121. https://doi.org/10.1016/j.jctube.2019.100121

Akkara, S. A., Shah, A. D., Adalja, M., Akkara, A. G., Rathi, A., & Shah, D. N. (2013). Pulmonary tuberculosis: the day after. *The International Journal of Tuberculosis and Lung Disease : The Official Journal of the International Union against Tuberculosis and Lung Disease*, *17*(6), 810–813. https://doi.org/10.5588/ijtld.12.0317

Allwood, B. W., Byrne, A., Meghji, J., Rachow, A., Van Der Zalm, M. M., & Schoch, O. D. (2021). Post-Tuberculosis Lung Disease: Clinical Review of an Under-Recognised Global Challenge. *Respiration*, *100*(8), 751–763. https://doi.org/10.1159/000512531

Allwood, B. W., Byrne, A., Meghji, J., Rachow, A., van der Zalm, M. M., & Schoch, O. D. (2021). Post-tuberculosis lung disease: clinical review of an under-recognised global challenge. *Respiration*, *100*(8), 751–763.

Allwood, B. W., Van Der Zalm, M. M., Amaral, A. F. S., Byrne, A., Datta, S., Egere, U., Evans, C. A., Evans, D., Gray, D. M., Hoddinott, G., Ivanova, O., Jones, R., Makanda, G., Marx, F. M., Meghji, J., Mpagama, S., Pasipanodya, J. G., Rachow, A., Schoeman, I., … Mortimer, K. (2020). Post-tuberculosis lung health: Perspectives from the First International Symposium. *International Journal of Tuberculosis and Lung Disease*, *24*(8), 820–828. https://doi.org/10.5588/ijtld.20.0067

Banu Rekha, V. V., Ramachandran, R., Kuppu Rao, K. V., Rahman, F., Adhilakshmi, A. R., Kalaiselvi, D., Murugesan, P., Sundaram, V., & Narayanan, P. R. (2009). Assessment of long term status of sputum positive pulmonary TB patients successfully treated with short course chemotherapy. *Indian Journal of Tuberculosis*, *56*(3), 132–140.

Barennes, H., Keophithoun, T., Nguyen, T. H., Strobel, M., & Odermatt, P. (2010). Survival and health status of DOTS tuberculosis patients in rural Lao PDR. *BMC Infectious Diseases*, *10*(265). https://doi.org/10.1186/1471-2334-10-265

Byrne, A. L., Marais, B. J., Mitnick, C. D., Lecca, L., & Marks, G. B. (2015). Tuberculosis and chronic respiratory disease: a systematic review. *International Journal of Infectious Diseases*, *32*, 138–146.

Chakaya, J., Khan, M., Ntoumi, F., Aklillu, E., Fatima, R., Mwaba, P., Kapata, N., Mfinanga, S., Hasnain, S. E., Katoto, P. D. M. C., Bulabula, A. N. H., Sam-Agudu, N. A., Nachega, J. B., Tiberi, S., McHugh, T. D., Abubakar, I., & Zumla, A. (2021). Global Tuberculosis Report 2020 – Reflections on the Global

TB burden, treatment and prevention efforts. *International Journal of Infectious Diseases*, *113*, S7–S12. https://doi.org/10.1016/J.IJID.2021.02.107

Chamla, D. (2004). The assessment of patients' health-related quality of life during tuberculosis treatment in Wuhan, China. *International Journal of Tuberculosis and Lung Disease*, *8*(9), 1100–1106.

Choi, H., Lee, H., Ra, S. W., Kim, H. K., Lee, J. S., Um, S. J., Kim, S. H., Oh, Y. M., & Kwon, Y. S. (2021). Clinical characteristics of patients with post-tuberculosis bronchiectasis: Findings from the KMBARC registry. *Journal of Clinical Medicine*, *10*(19). https://doi.org/10.3390/JCM10194542

Darvishpoor Kakhki, A., & Masjedi, M. R. (2015). Factors Associated with Health-Related Quality of Life in Tuberculosis Patients Referred to the National Research Institute of Tuberculosis and Lung Disease in Tehran. *Tuberculosis and Respiratory Diseases*, *78*(4), 309–314. https://doi.org/10.4046/trd.2015.78.4.309

Dodd, P. J., Yuen, C. M., Jayasooriya, S. M., van der Zalm, M. M., & Seddon, J. A. (2021). Quantifying the global number of tuberculosis survivors: a modelling study. *The Lancet. Infectious Diseases*, *21*(7), 984–992. https://doi.org/10.1016/S1473-3099(20)30919-1

EuroQoL. (2016). *About EQ-5D*. https://euroqol.org/eq-5d-instruments/

Guo, N., Marra, F., FitzGerald, J. M., Elwood, R. K., & Marra, C. A. (2010). Impact of adverse drug reaction and predictivity of quality of life status in tuberculosis. *European Respiratory Journal*, *36*(1), 206–208. https://doi.org/10.1183/09031936.00159409

Gupte, A. N., Paradkar, M., Selvaraju, S., Thiruvengadam, K., Shivakumar, S. V. B. Y., Sekar, K., Marinaik, S., Momin, A., Gaikwad, A., Natrajan, P., Prithivi, M., Shivaramakrishnan, G., Pradhan, N., Kohli, R., Raskar, S., Jain, D., Velu, R., Karthavarayan, B., Lokhande, R., … Gupta, A. (2019). Assessment of lung function in successfully treated tuberculosis reveals high burden of ventilatory defects and COPD. *PLoS ONE*, *14*(5). https://doi.org/10.1371/journal.pone.0217289

Guyatt, G. H., Feeny, D. H., & Patrick, D. L. (1993). Measuring health-related quality of life. *Annals of Internal Medicine*, *118*(8), 622–629. https://doi.org/10.7326/0003-4819-118-8-199304150-00009

Hanekom, S., Pharaoh, H., Irusen, E., & Daniels, K. J. (2019). Post-tuberculosis health-related quality of life, lung function and exercise capacity in a cured pulmonary tuberculosis population in the Breede Valley District, South Africa. *South African Journal of Physiotherapy*, *75*(1), 1–8.

Izudi, J., Tamwesigire, I. K., & Bajunirwe, F. (2020). Treatment success and mortality among adults with tuberculosis in rural eastern Uganda: A retrospective cohort study. *BMC Public Health*, *20*(1), 1–10. https://doi.org/10.1186/s12889-020-08646-0

Jones, R., Kirenga, B. J., Katagira, W., Singh, S. J., Pooler, J., Okwera, A., Kasiita, R., Enki, D. G., Creanor, S., & Barton, A. (2017a). A pre–post intervention study of pulmonary rehabilitation for adults with post-tuberculosis lung disease in Uganda. *International Journal of COPD*, *12*, 3533–3539. https://doi.org/10.2147/COPD.S146659

Jones, R., Kirenga, B. J., Katagira, W., Singh, S. J., Pooler, J., Okwera, A., Kasiita, R., Enki, D. G., Creanor, S., & Barton, A. (2017b). A pre–post intervention study of pulmonary rehabilitation for adults with post-tuberculosis lung disease in Uganda. *International Journal of Chronic Obstructive Pulmonary Disease*, 3533–3539.

Kastien-Hilka, T., Abulfathi, A., Rosenkranz, B., Bennett, B., Schwenkglenks, M., & Sinanovic, E. (2016). Health-related quality of life and its association with medication adherence in active pulmonary tuberculosis–a systematic review of global literature with focus on South Africa. *Health and Quality of Life Outcomes*, *14*, 1–13.

Katumba, J., Obore, S., & Kaye, D. K. (2013). Health-related quality of life among patients with ovarian cancer at Mulago Hospital, Uganda. *International Journal of Gynecology & Obstetrics*, *122*(2), 115–117.

Khosa, C., Bhatt, N., Massango, I., Azam, K., Saathoff, E., Bakuli, A., Riess, F., Ivanova, O., Hoelscher, M., & Rachow, A. (2020). Development of chronic lung impairment in Mozambican TB patients and associated risks. *BMC Pulmonary Medicine*, *20*(1), 1–27. https://doi.org/10.1186/s12890-020-1167-1

Kisaka, M. B. (2014). *Health-related quality of life among smear positive pulmonary tuberculosis patients in Mbale District, Uganda*.

Kisaka, S. M. B., Rutebemberwa, E., Kasasa, S., Ocen, F., & Nankya-Mutyoba, J. (2016). Does health-related quality of life among adults with pulmonary tuberculosis improve across the treatment period? A hospital-based cross sectional study in Mbale Region, Eastern Uganda. *BMC Research Notes*, *9*(1), 1–10. https://doi.org/10.1186/s13104-016-2277-y

Laxmeshwar, C., Stewart, A. G., Dalal, A., Kumar, A. M. V, Kalaiselvi, S., Das, M., Gawde, N., Thi, S. S., & Isaakidis, P. (2019). Beyond 'cure'and "treatment success''': quality of life of patients with multidrug-resistant tuberculosis"'. *The International Journal of Tuberculosis and Lung Disease*, *23*(1), 73–81.

Li, C. T., Chu, K. H., Reiher, B., Kienene, T., & Chien, L. Y. (2017). Evaluation of health-related quality of life in patients with tuberculosis who completed treatment in Kiribati. *Journal of International Medical Research*, *45*(2), 610–620. https://doi.org/10.1177/0300060517694491

Lins, L., & Carvalho, F. M. (2016). SF-36 total score as a single measure of health-related quality of life: Scoping review. *SAGE Open Medicine*, *4*, 205031211667172. https://doi.org/10.1177/2050312116671725

Mahler, D. A., & Mackowiak, J. I. (1995). Evaluation of the short-form 36-item questionnaire to measure health- related quality of life in patients with COPD. *Chest*, *107*(6), 1585–1589. https://doi.org/10.1378/chest.107.6.1585

Maleche-Obimbo, E., Odhiambo, M. A., Njeri, L., Mburu, M., Jaoko, W., Were, F., & Graham, S. M. (2022). Magnitude and factors associated with post-tuberculosis lung disease in low-and middle-income countries: A systematic review and meta-analysis. *PLOS Global Public Health*, *2*(12), e0000805.

Meghji, J., Lesosky, M., Joekes, E., Banda, P., Rylance, J., Gordon, S., Jacob, J., Zonderland, H., MacPherson, P., Corbett, E. L., Mortimer, K., & Squire, S. B. (2020a). Patient outcomes associated with post-tuberculosis lung damage in Malawi: A prospective cohort study. *Thorax*, *75*(3), 269–278. https://doi.org/10.1136/thoraxjnl-2019-213808

Meghji, J., Lesosky, M., Joekes, E., Banda, P., Rylance, J., Gordon, S., Jacob, J., Zonderland, H., MacPherson, P., Corbett, E. L., Mortimer, K., & Squire, S. B. (2020b). Patient outcomes associated with post-tuberculosis lung damage in Malawi: a prospective cohort study. *Thorax*, *75*(3), 269–278. https://doi.org/10.1136/THORAXJNL-2019-213808

Meghji, J., Simpson, H., Squire, S. B., & Mortimer, K. (2016). A systematic review of the prevalence and pattern of imaging defined post-TB lung disease. *PloS One*, *11*(8), e0161176.

Menezes, A. M. B., Hallal, P. C., Perez-Padilla, R., Jardim, J. R. B., Muiño, A., Lopez, M. V, Valdivia, G., De Oca, M. M., Talamo, C., & Pertuze, J. (2007). Tuberculosis and airflow obstruction: evidence from the PLATINO study in Latin America. *European Respiratory Journal*, *30*(6), 1180–1185.

MOH. (2017). *Manual for management and control of Tuberculosis and Leprosy in Uganda* (Uganda National Tuberculosis and Leprosy Control Programme, Ed.; 3rd editio). Ministry of Health.

MOH. (2021). *National Strategic Plan for Tuberculosis and Leprosy Control 2020/21 – 2024/25*. National Tuberculosis and Leprosy Control Programme, Ministry of Health.

Mpagama, S. G., Msaji, K. S., Kaswaga, O., Zurba, L. J., Mbelele, P. M., Allwood, B. W., Ngungwa, B. S., Kisonga, R. M., Lesosky, M., & Rylance, J. (2021). The burden and determinants of post-TB lung disease. *The International Journal of Tuberculosis and Lung Disease*, *25*(10), 846–853.

Muliira, R. S., Salas, A. S., & O'Brien, B. (2017). Quality of life among female cancer survivors in Africa: An integrative literature review. *Asia-Pacific Journal of Oncology Nursing*, *4*(1), 6–17.

Muniyandi, M., Rajeswari, R., Balasubramanian, R., Nirupa, C., Gopi, P. G., Jaggarajamma, K., Sheela, F., & Narayanan, P. R. (2007). Evaluation of post-treatment health-related quality of life (HRQoL) among tuberculosis patients. *The International Journal of Tuberculosis and Lung Disease*, *11*(8), 887–892.

Muñoz-Torrico, M., Cid-Juárez, S., Gochicoa-Rangel, L., Torre-Bouscolet, L., Salazar-Lezama, M. A., Villarreal-Velarde, H., Pérez-Padilla, R., Visca, D., Centis, R., D'Ambrosio, L., Spanevello, A., Saderi, L., Sotgiu, G., & Migliori, G. B. (2020). Functional impact of sequelae in drug-susceptible and multidrug-resistant tuberculosis. *International Journal of Tuberculosis and Lung Disease*, *24*(7), 700–705. https://doi.org/10.5588/ijtld.19.0809

Munro, S. A., Lewin, S. A., Smith, H. J., Engel, M. E., Fretheim, A., & Volmink, J. (2007). Patient Adherence to Tuberculosis Treatment: A Systematic Review of Qualitative Research. *PLOS Medicine*, *4*(7), e238. https://doi.org/10.1371/JOURNAL.PMED.0040238

Musaazi, J., Kiragga, A. N., Castelnuovo, B., Kambugu, A., Bradley, J., & Rehman, A. M. (2017). Tuberculosis treatment success among rural and urban Ugandans living with HIV: a retrospective study. *Public Health Action*, *7*(2), 100–109. https://doi.org/10.5588/pha.16.0115

Mutumba, M., Bauermeister, J. A., Harper, G. W., Musiime, V., Lepkowski, J., Resnicow, K., & Snow, R. C. (2017). Psychological distress among Ugandan adolescents living with HIV: Examining stressors and the buffering role of general and religious coping strategies. *Global Public Health*, *12*(12), 1479–1491.

Nightingale, R., Chinoko, B., Lesosky, M., Rylance, S. J., Mnesa, B., Banda, N. P. K., Joekes, E., Squire, S. B., Mortimer, K., Meghji, J., & Rylance, J. (2021). Respiratory symptoms and lung function in patients treated for pulmonary tuberculosis in Malawi: a prospective cohort study. *Thorax*, thoraxjnl-2021-217190. https://doi.org/10.1136/thoraxjnl-2021-217190

Nuwagira, E., Baluku, J. B., Meya, D. B., Philpotts, L. L., Siedner, M. J., Bajunirwe, F., Mpagama, S. G., & Lai, P. S. (2022). Burden, clinical features and outcomes of post-tuberculosis lung disease in sub-

Saharan Africa: A protocol for a systematic review and meta-analysis. *BMJ Open*, *12*(8). https://doi.org/10.1136/bmjopen-2022-062260

Nuwagira, E., Stadelman, A., Baluku, J. B., Rhein, J., Byakika-Kibwika, P., Mayanja, H., & Kunisaki, K. M. (2020). Obstructive lung disease and quality of life after cure of multi-drug-resistant tuberculosis in Uganda: a cross-sectional study. *Tropical Medicine and Health*, *48*(1), 34. https://doi.org/10.1186/s41182-020-00221-y

Quaderi, S. A., & Hurst, J. R. (2018). The unmet global burden of COPD. *Global Health, Epidemiology and Genomics*, *3*. https://doi.org/10.1017/gheg.2018.1

Rand. (2004). *36-Item Short Form Survey from the RAND Medical Outcomes Study | RAND*. http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html

Segal, D. L., Qualls, S. H., & Smyer, M. A. (2018). *Aging and mental health*. John Wiley & Sons.

Simet, S. M., & Sisson, J. H. (2015). Alcohol's Effects on Lung Health and Immunity. *Alcohol Research : Current Reviews*, *37*(2), 199. /pmc/articles/PMC4590617/

Singla, R., Mallick, M., Mrigpuri, P., Singla, N., & Gupta, A. (2018). Sequelae of pulmonary multidrug-resistant tuberculosis at the completion of treatment. *Lung India*, *35*(1), 4–8. https://doi.org/10.4103/LUNGINDIA.LUNGINDIA_269_16

Soriano, J. B., Kendrick, P. J., Paulson, K. R., Gupta, V., Abrams, E. M., Adedoyin, R. A., Adhikari, T. B., Advani, S. M., Agrawal, A., Ahmadian, E., Alahdab, F., Aljunid, S. M., Altirkawi, K. A., Alvis-Guzman, N., Anber, N. H., Andrei, C. L., Anjomshoa, M., Ansari, F., Antó, J. M., … Vos, T. (2020). Prevalence and attributable health burden of chronic respiratory diseases, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet Respiratory Medicine*, *8*(6), 585–596. https://doi.org/10.1016/S2213-2600(20)30105-3

Torén, K., Schiöler, L., Lindberg, A., Andersson, A., Behndig, A. F., Bergström, G., Blomberg, A., Caidahl, K., Engvall, J. E., Eriksson, M. J., Hamrefors, V., Janson, C., Kylhammar, D., Lindberg, E., Lindén, A., Malinovschi, A., Lennart Persson, H., Sandelin, M., Eriksson Ström, J., … Sköld, C. M. (2021). The ratio FEV1/FVC and its association to respiratory symptoms—A Swedish general population study. *Clinical Physiology and Functional Imaging*, *41*(2), 181–191. https://doi.org/10.1111/CPF.12684

van Gemert, F., Kirenga, B., Chavannes, N., Kamya, M., Luzige, S., Musinguzi, P., Turyagaruka, J., Jones, R., Tsiligianni, I., & Williams, S. (2015). Prevalence of chronic obstructive pulmonary disease and

associated risk factors in Uganda (FRESH AIR Uganda): a prospective cross-sectional observational study. *The Lancet Global Health*, *3*(1), e44–e51.

Verkleij, S. P. J., Adriaanse, M. C., Wendel-Vos, G. C. W., & Schuit, A. J. (2013). Longitudinal relation between weight change and quality of life in a community-based population: a prospective cohort study. *European Journal of Public Health*, *23*(2), 285–290. https://doi.org/10.1093/EURPUB/CKS058

Ware, J. E., Kosinski, M., & Keller, S. D. (1996). A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Medical Care*, *34*(3), 220–233. https://doi.org/10.1097/00005650-199603000-00003

WHO. (2020). *Global Tuberculosis Report 2020*.

WHO. (2021). *WHO global lists of high burden countries for tuberculosis (TB), TB/HIV and multidrug/rifampicin-resistant TB (MDR/RR-TB), 2021-2025*.

Wilson, I. B., & Cleary, P. D. (1995). Linking Clinical Variables With Health-Related Quality of Life: A Conceptual Model of Patient Outcomes. *JAMA*, *273*(1), 59–65. https://doi.org/10.1001/JAMA.1995.03520250075037

Yamane, Cochran, Morgan, & Green. (1967). Sample size estimation using Yamane and Cochran and Krejcie and Morgan and green formulas and Cohen statistical power analysis by G* Power and comparisions. *So04.Tci-Thaijo.Org*. https://so04.tci-thaijo.org/index.php/ATI/article/view/254253

Yasobant, S., Nazli Khatib, M., Syed, Z. Q., Gaidhane, A. M., Shah, H., Narkhede, K., Bhavsar, P., Patel, J., Sinha, A., Puwar, T., Saha, S., & Saxena, D. (2022). Health-Related Quality of Life (HRQoL) of Patients with Tuberculosis: A Review. *Infectious Disease Reports*, *14*(4), 509–524. https://doi.org/10.3390/idr14040055

Zubritsky, C., Abbott, K. M., Hirschman, K. B., Bowles, K. H., Foust, J. B., & Naylor, M. D. (2013). Health-related Quality of Life: Expanding a Conceptual Framework to Include Older Adults Who Receive Long-term Services and Supports. *The Gerontologist*, *53*(2), 205. https://doi.org/10.1093/GERONT/GNS093

## ANNEX I: DATA COLLECTION TOOLS

### Tool 1: Consent Form

### A STUDY TO DETERMINE HEALTH-RELATED QUALITY OF LIFE AND ASSOCIATED FACTORS OF POST-PTB LUNG DISEASE PATIENTS TREATED FROM MULAGO NATIONAL REFERRAL HOSPITAL, KAMPALA – UGANDA.

Good morning/afternoon, my name is ……. I am part of a research team from Makerere University School of Public Health. We are assessing the health-related quality of life and associated factors of post-PTB lung disease patients' survivors with post-TB lung disease treated from Mulago national referral hospital. The information generated will assist the Ministry of Health, the hospital administration and other health actors to develop and implement evidence-based interventions to manage post-PTB lung disease interventions.

**Procedure of the Study**

The study is being conducted at Mulago NRH targeting post-PTLD patients attending the Mulago Hospital pulmonology department for respiratory related illnesses. Before you take part in this study, the study must be explained to you and you must be given chance to ask questions. If you agree to take part in the study, you will be interviewed using a questionnaire inquiring about your various individual characteristics and health history to try and determine your quality of life as a result of the post-PTB lung disease you have.

**Benefits of the Study**

Your participation in the study will last for 20 minutes. Acceptance to participate in this study offers both direct and indirect benefits to you. The direct benefits being offering you free and crucial information on your post-PTB lung disease and how to manage it. Indirect benefits will include the improved focus on post-PTB lung disease management by healthcare professionals in your hospital and country at large. The information collected for this study is confidential. Interviews will be conducted in a private, comfortable and secure place of your choosing. The

tools used will be anonymous and the information therein will be safely guarded and only used for study purposes.

**Voluntary Consent**

Taking part in this study is entirely voluntary and if you decided not to take part in it, this will not affect the care of services you receive at any health facility in your area. However, if you participate, you are making a great contribution to the national fight against post-PTB lung disease in Uganda. You will be treated the same no matter your decision. If you agree to take part in this study, you will be asked to sign this form.

**Statement of Consent**

The above information has been clearly explained to me and I have understood it. I do hereby voluntarily agree to participate in this study. If I have any other queries about the study, I may contact …… (Principal Investigator) at …….

I have understood that my participation in this study is voluntary. I know that I may quit the study at any time without any consequences. I also understand that the investigator in charge of this study may decide at any time that I should no longer participate in this study.

If I have questions about my rights as research subjects, I may contact the chairperson of the

Higher Degrees, Research and Ethics Committee,

Makerere University School of Public Health

P.O Box 7072, Kampala, Uganda

I have read and understood the above information. I agree to participate in this study.

_____ _____

Participant Signature Date

_____ _____

Researcher Signature Date

**Tool 1: Questionnaire**

**Assessment of the Health-Related Quality of Life and Associated Factors of POST-PTB Lung Disease Patients Treated from Mulago National Referral Hospital**

**Tool Serial No: ……**

| **Identification** | |
|---|---|
| **Name of respondent:** | |
| **Time since TB treatment completion (in months):** | |
| **Contact** | |

**Section A: Socio-Demographic Characteristics**

| | | |
|---|---|---|
| A01 | Sex of respondent | 1. Male<br>2. Female |
| A02 | How old are you (age in complete years) | …… |
| A03 | What is your marital status? | 1. Single<br>2. Married<br>3. Separated<br>4. Divorced |

| | | |
|---|---|---|
| | | 5. Widowed |
| A04 | What is your highest level of education? | 1. None<br>2. Primary<br>3. Secondary<br>4. Tertiary |
| A05 | Do you smoke tobacco including cigarettes, shisha, pipes or cigars? | 1. Yes<br>2. No |
| A06 | Does any of your household members smoke tobacco including cigarettes, shisha, pipes or cigars? | 1. Yes<br>2. No |
| A07 | Do you drink alcohol? | 1. Yes<br>2. No |

**Section B: Patient Related Factors**

| | | |
|---|---|---|
| B01 | What respiratory disease / lung complication were you diagnosed with after finishing TB treatment? | …… |
| B02 | State at least two (2) symptoms you had at the time of diagnosis. | |
| B03 | When did you start treatment for the post-PTB lung disease mentioned above? | |

| | | |
|---|---|---|
| B04 | Have you experienced any side effects as a result of the treatment you are receiving for the post-PTB lung diseases mentioned above? | 1. Yes<br>2. No |
| B05 | Were your family / partner aware of your TB status during treatment? | 1. Yes<br>2. No |
| B06 | Are they aware of your current situation after completing TB treatment? | 1. Yes<br>2. No |
| B07 | Is your family / partner in support of your seeking further treatment after completing TB treatment? | 1. Yes<br>2. No |
| B08 | Has money ever hindered you from accessing post-PTB respiratory illness treatment? | 1. Yes<br>2. No |
| B09 | How far away from the hospital do you reside? (in km) | |
| B010 | What other chronic illness do you have? | …… |
| B011 | Are you aware of your HIV status? | 1. Yes<br>2. No |
| B012 | If yes, could you please share it with me, if its fine with you? | 1. Positive<br>2. Negative |

**Section C: Socio-Economic Factors**

| | | |
|---|---|---|
| C01 | Which of the following describes your main work status over the past 12 months? | 1. Farmer<br>2. Student<br>3. Trader<br>4. Salaried worker<br>5. Unemployed<br>6. Other (specify) |
| C02 | What is your total monthly income? (in UGX) | …… |
| C03 | | |

## Section D: Treatment factors

| | | |
|---|---|---|
| D01 | Are drugs available during your visit? | 1. Yes<br>2. No |
| D02 | Do you receive counselling during your visits? | 1. Yes<br>2. No |
| D03 | How is the conduct of Health Workers | 1. Good<br>2. Fair<br>3. Bad |

**Tool 3: The SF-36 Questionnaire**

**Please answer the 36 questions of the Health Survey completely, honestly, and without interruptions.**

| No. | Question | 1 = Excellent | 2 = Very Good | 3 = Good | 4 = Fair | 5= Poor Yes |
|---|---|---|---|---|---|---|
| **General Health** | | | | | | |
| 1. | In general, would you say your health is | 1 | 2 | 3 | 4 | 5 |

| | | |
|---|---|---|
| 2. | Compared to one year ago, how would you rate your health in general now? | 1. Much better now than one year ago<br>2. Somewhat better now than one year ago<br>3. About the same<br>4. Somewhat worse now than one year ago<br>5. Much worse now than one year ago |

**The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

| No. | Question | 1 (Yes, limited a lot) | 2 (Yes, limited a little) | 3 (No, not limited at all) |
|---|---|---|---|---|
| 3. | Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports. | 1 | 2 | 3 |

| | | | | |
|---|---|---|---|---|
| 4. | Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | 1 | 2 | 3 |
| 5. | Lifting or carrying groceries | 1 | 2 | 3 |
| 6. | Climbing several flights of stairs | 1 | 2 | 3 |
| 7. | Climbing one flight of stairs | 1 | 2 | 3 |
| 8. | Bending, kneeling, or stooping | 1 | 2 | 3 |
| 9. | Walking more than a mile | 1 | 2 | 3 |
| 10. | Walking several blocks | 1 | 2 | 3 |
| 11. | Walking one block | 1 | 2 | 3 |
| 12. | Bathing or dressing yourself | 1 | 2 | 3 |

**During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

| No. | Question | 1 (Yes) | 2 (No) |
|---|---|---|---|
| 13. | Cut down the amount of time you spent on work or other activities | 1 | 2 |
| 14. | Accomplished less than you would like | 1 | 2 |
| 15. | Were limited in the kind of work or other activities | 1 | 2 |
| 16. | Had difficulty performing the work or other activities (for example, it took extra effort) | 1 | 2 |

**During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

| | | | |
|---|---|---|---|
| 17. | Cut down the amount of time you spent on work or other activities | 1 | 2 |
| 18. | Accomplished less than you would like | 1 | 2 |
| 19. | Didn't do work or other activities as carefully as usual | 1 | 2 |

| | | |
|---|---|---|
| 20. | During the past 4 weeks, to what extent have your physical health or emotional problems interfered with your normal social activities | 1. Not at all<br>2. Slightly<br>3. Moderately<br>4. Quite a bit<br>5. Extremely |

| | | |
|---|---|---|
| | with family, friends, neighbors, or groups? | |
| 21. | How much bodily pain have you had during the past 4 weeks? | 1. None<br>2. Very mild<br>3. Mild<br>4. Moderate<br>5. Severe<br>6. Very severe |
| 22. | During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? | 1. Not at all<br>2. Slightly<br>3. Moderately<br>4. Quite a bit<br>5. Extremely |

**These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

**How much of the time during the past 4 weeks...**

| **No.** | **Questions** | **1 (all of the time); 2 (most of the time); 3 (a good bit of the time); 4 (some of the time); 5 (a little of the time); and 6 (none of the time)** | | | | | |
|---|---|---|---|---|---|---|---|
| 23. | Did you feel full of pep? | 1 | 2 | 3 | 4 | 5 | 6 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 24. | Have you been a very nervous person? | 1 | 2 | 3 | 4 | 5 | 6 |
| 25. | Have you felt so down in the dumps that nothing could cheer you up? | 1 | 2 | 3 | 4 | 5 | 6 |
| 26. | Have you felt calm and peaceful? | 1 | 2 | 3 | 4 | 5 | 6 |
| 27. | Did you have a lot of energy? | 1 | 2 | 3 | 4 | 5 | 6 |
| 28. | Have you felt downhearted and blue? | 1 | 2 | 3 | 4 | 5 | 6 |
| 29. | Did you feel worn out? | 1 | 2 | 3 | 4 | 5 | 6 |
| 30. | Have you been a happy person? | 1 | 2 | 3 | 4 | 5 | 6 |
| 31. | Did you feel tired? | 1 | 2 | 3 | 4 | 5 | 6 |
| 32. | During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? | | 1. All of the time<br>2. Most of the time<br>3. Some of the time<br>4. A little of the time<br>5. None of the time | | | | |

**How TRUE or FALSE is each of the following statements for you?**

| No. | Questions | 1 (definitely) | 2 (Mostly true) | 3 (Don't know) | 4 (Mostly false) | 5 (Definitely False) |
|---|---|---|---|---|---|---|
| 33. | I seem to get sick a little easier than other people | 1 | 2 | 3 | 4 | 5 |
| 34. | I am as healthy as anybody I know | 1 | 2 | 3 | 4 | 5 |
| 35. | I expect my health to get worse | 1 | 2 | 3 | 4 | 5 |
| 36. | My health is excellent | 1 | 2 | 3 | 4 | 5 |

**Thank You**

## ANNEX II: CLEARANCE FORMS

### Research Clearance Letter Makerere University School of Public Health, Research and Ethics Committee

MAKERERE UNIVERSITY
P.O. Box 7072
Kampala UGANDA
Email: sphrecadmin@musph.ac.ug
Tel: +256 -414-543 872/ 031-2-263158
Fax: +256-414-531807
Website: www.sph.mak.ac.ug

**COLLEGE OF HEALTH SCIENCES**
**SCHOOL OF PUBLIC HEALTH**
**Research and Ethics Committee**

MAKERERE UNIVERSITY SCHOOL OF PUBLIC HEALTH APPROVED VALID UNTIL ★ 16 MAR 2024 ★ RESEARCH & ETHICS COMMITTEE P O. BOX 7072, KAMPALA

**16th March, 2023**

Mr Isaac Wafula
Master student, (2021/HD07/3490U)
School of Public Health, Makerere University

**Re: Approval of a research Proposal titled: "Health related quality of life and associated factors of post pulmonary Tuberculosis disease patients treated from Mulago National Referral Hospital, Kampala-Uganda"**

This is to inform you that the Makerere School of Public Health Research and Ethics Committee (MakSPH-REC) has approved your study documents for the above referenced research study.

Please note that your study protocol number with MakSPH-REC is **153.** Please be sure to reference this number in any correspondence with MakSPH-REC. Note that your study was first approved by the MakSPH-REC on **16th/03/2023**, and therefore approval expires at every annual anniversary of this approval date. The current approval is therefore valid until: **16th/03/2024.**

Continued approval is conditional upon your compliance with the following requirements:

1) No other consent form(s), questionnaire and/or advertisement documents should be used. The consent form(s) must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject must be given a copy of the signed consent form.

*Leveraging 100 years of Excellence In Building a Transformed Society*

## Research Clearance Letter: Mulago National Referral Hospital

TELEPHONE: +256-41554008/1
FAX: +256-414-5325591
E-mail: admin@mulago.or.ug
Website: www.mulago.or.ug

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

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

14th April 2023.

**Mr. Wafula Isaac**
Principal Investigator
College of Health Sciences
Makerere University

Dear Mr. Wafula,

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

The Administration and Management of Mulago National Referral Hospital is pleased to inform you that you have been offered clearance to conduct the study titled **MHREC 2457: "Health Related Quality of Life and Associated Factors of Post Pulmonary Tuberculosis Lung disease Patients Treated from Mulago National Referral Hospital, Kampala-Uganda".**

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

Administrative clearance is valid for one (1) year effective from 13th April 2023 to 12th April 2024

The Investigator should ensure to get final approval of the protocol and all accompanying documents from UNCST before starting the study. In case of studies involving drug, approval is obtained from National Drug Authority and for those studies involving medical devices, seek approval from Director General, Ministry of Health.

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

DR. BYANYIMA ROSEMARY
**AG. EXECUTIVE DIRECTOR**
**MULAGO NATIONAL REFERRAL HOSPITAL.**

EXECUTIVE DIRECTOR
MULAGO NATIONAL REFERRAL HOSPITAL
P.O. BOX 7051, KAMPALA

**Copied to;**

1. **Mr. Wafula Isaac – Study Principal Investigator**
2. **Head of Unit- Ward 5&6- MNRH**

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

**ANNEX III: WORK PLAN**

| Activity | May 2023 | Jun 2023 | Jul 2023 | Aug 2023 | Sep 2023 | Oct 2023 | Nov 2023 | Dec 2023 | Jan 2024 | Responsible person |
|---|---|---|---|---|---|---|---|---|---|---|
| Development of the Proposal | | | | | | | | | | Principal Researcher |
| Pretesting questionnaire | | | | | | | | | | Principal Researcher |
| Collection of data | | | | | | | | | | Principal Researcher |
| Data entry and analysis | | | | | | | | | | Principal Researcher |
| Report Writing | | | | | | | | | | Principal Researcher |
| Submission of the report | | | | | | | | | | Principal Researcher |

## ANNEX IV: BUDGET

Budget for the Study to Assess the Health-Related Quality of Life and Associated Factors of TB Survivors Treated from Mulago National Referral Hospital

| Activity | Items Required | Quantity | Unit Cost | Total Cost (UGX) |
|---|---|---|---|---|
| Proposal development | Typing | 40 | 500 | 20,000 |
| | Printing | 40 | 500 | 20,000 |
| | Photocopying | 120 | 100 | 12,000 |
| | Binding | 3 | 3,000 | 9,000 |
| Pretesting data collection tools | Photocopying Consent forms | 120 | 100 | 12,000 |
| | Photocopying questionnaires | 120 | 400 | 48,000 |
| | Transport | 4 | 30,000 | 120,000 |
| | Lunch | 4 | 10,000 | 40,000 |
| Data collection | Android phones for installing Kobocollect and data collection | 130 | 400 | 1,800,000 |
| | Photocopying consent forms | 130 | 100 | 13,000 |
| | Transport (within Kampala) | 4 | 30,000 | 120,000 |
| | Transport for follow-ups outside Kampala | 40 | 80,000 | 3,200,000 |
| | Pens | 1 | 5000 | 5,000 |
| Data analysis | Typing | 1 | 40000 | 40,000 |
| | Printing | 1 | 20,000 | 20,000 |
| Report writing | Printing | 210 | 100 | 21,000 |
| | Photocopying | 420 | 100 | 42,000 |
| | Binding | 4 | 10,000 | 40,000 |
| Report dissemination | Transport | 1 | 15,000 | 15,000 |
| | Lunch | 1 | 5,000 | 5,000 |
| **Total** | | | | **4,820,000** |