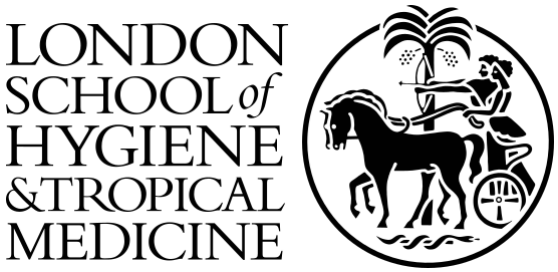

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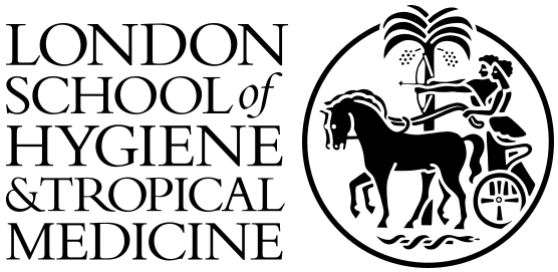

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Critical assessment of the intersection between mental health and Tuberculosis (TB) during TB treatment and beyond in a Sub-Saharan context with a focus on Zambia.

Tila Mwinde Mainga

Thesis submitted in accordance with the requirements for the degree of

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LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

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Abstract

There is a high prevalence of mental distress in people with TB associated with social, economic, and biological factors present from TB investigation through to post TB treatment. However, there is limited research to understand mental health experiences of people with TB and the current working practices to manage mental distress in people with TB by TB health workers. Additionally, little is known about the burden of mental distress in TB survivors in the sub-Saharan region.

This mixed methods PhD aimed to critically reflect on the relationship between TB and mental health from TB investigation through to post TB treatment in Zambia. Study data is drawn from eight urban communities in Zambia. Qualitative methods explored: 1) drivers of mental distress as experienced by people with TB and perceived by TB health workers and stakeholders in Zambia; 2) how health workers manage mental distress in their clients with TB. In one community, quantitative analysis was used to compare the prevalence of mental distress in adult TB survivors to adults with no history of TB.

Findings show that mental distress is prevalent among people with TB in this setting and ranged from mild to severe. Mental distress was driven by multi-layered and intersecting stresses, with the economic stress of poverty being the most powerful driver. TB health workers and stakeholders understood the economic drivers of distress in their clients but had a poor understanding of other causes of distress and no standard management practices for mental distress in their clients. Quantitative analysis indicates that TB survivors do not have a disproportionate burden of mental distress when compared to individuals without a history of TB in this setting. The thesis uses the findings to generate recommendations for comprehensive management of TB and mental distress using the WHO Innovative Care for Chronic Conditions framework.

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I would like to say a heartfelt thank you to everyone that made this possible, starting with my supervisory team. Professor Bond, thank you for being such an amazing mentor. Your kind supportive and pragmatic yet encouraging nature helped me push through, even in the moments when I was ready to give up. Dr Stewart, and Dr Mactaggart thank you for the valuable guidance in measuring and understanding mental health, providing a broader view to the research and being supportive through this whole journey. Mr Scherer, thank you for your guidance, your insights and comments helped me become a stronger academic writer and taught me to think more critically about my data and the literature. To all four of you, thank you for the multiple readings and edits of all the chapters of this thesis. I would also like to thank my advisory team. Mr Schaap, thank you for being such a patient teacher, you were always available to help me think about how to analyse the data. You encouraged me to really understand my quantitative data, while providing a laugh with your straightforward natured humour. Ms Hill, thank you for always being available when I needed any further guidance on mental health.

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Lastly, I would like to thank and appreciate my family for their unwavering support. Thank you Situmbeko for holding my hand every step of this journey, mum for stepping in to mother Kozo and

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Abbreviations

1.	Africa Focus on Intervention Research for Mental health	(AFRIM)
2.	Alcohol Use Disorders Identification Test	(AUDIT)
3.	Antiretroviral Therapy	(ART)
4.	Bio-medical Ethics Committee of the University of Zambia	(UNZABREC)
5.	Civil society organisations	(CSOs)
6.	Common mental health disorders	(CMDs)
7.	Community HIV care Providers	(CHiPs).
8.	Confidence Interval	(CI)
9.	Design, Implementation, Monitoring and Evaluation	(DIME)
10.	Good Clinical Practice	(GCP)
11.	Home Based Care	(HBC)
12.	Human Immunodeficiency Virus	(HIV)
13.	In-depth Interviews	(IDIs)
14.	International Classification of Disease	(ICD)
15.	International Classification of Diseases (11th revision)	(ICD-11)
16.	International Classification of Functional Disability and Health Framework	(ICF)
17.	London School of Hygiene and Tropical Medicine	(LSHTM)
18.	Low- and middle-income countries	(LMICs)
19.	major depressive disorder	(MDD)
20.	Mental Health Gap Action Programme	(mhGAP)
21.	Mini International Neuropsychiatric Interview	(MINI)
22.	Mobile field site	(MFS)
23.	Multi-drug resistant	(MDR)
24.	National Health Research Authority	(NHRA)
25.	National Tuberculosis and Leprosy Programme	(NTLP)
26.	National Tuberculosis Programme	(NTP)
27.	Neighbourhood Health Committees	(NHC)
28.	Non-governmental organisations	(NGOs)
29.	Patient Health Questionnaire	(PHQ-9)
30.	Odds Ratio	(OR)
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39.	WHO Innovative Care for Chronic Conditions	(ICCC)

40. World Health Organization (WHO)
41. Zambia Ministry of Health (MoH)

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Chapter One: Introduction

Background of the Tuberculosis epidemic in Zambia

Pulmonary Tuberculosis (TB) is a communicable respiratory illness and one of the leading causes of death globally (1). Approximately 90% of people who fall sick with TB are from 30 low- to middle-income countries (LMIC), including Zambia (1). In 2020, 59,000 people with TB in Zambia fell ill with TB and 14,800 of them died (1). Zambia has a long standing history with TB, with efforts to eradicate it dating back to the 1960s (2). The Zambia Ministry of Health (MoH) TB notification data, which is data that records people who have been diagnosed with TB (3), show a steady increase in TB notifications of approximately 3% annually between 1964 to 1985 (2). The start of the Human Immunodeficiency Virus (HIV) pandemic in the mid-1980s resulted in a proliferation of TB in Zambia, which was reflected in a 313% increase in the TB notification rate from 124 per 100,000 in 1985 to 512 per 100,000 in the early 2000s (4). Infection with HIV is one of the leading risk factors for TB infection and progression to active disease (5). The World Health Organization (WHO) data estimates an even higher burden than that shown by MoH, for example, WHO data suggests TB notification of 759, rather than 512, per 100,000 population in the year 2000 (6). Other drivers of the TB epidemic in Zambia included widespread poverty and inadequate TB control strategies (2, 4).

According to the WHO data, TB notification rates have declined significantly in the last two decades, starting at 759 per 100,000 population in 2000 to 319 per 100,000 by 2020 (6, 7). This reduction is in part due to initiatives to eradicate TB, including re-establishing the National Tuberculosis and Leprosy Programme (NTLP) previously known as the National Tuberculosis Programme (NTP). The NTP was funded by donors and the government and operated with clear objectives (8). One of the NTP objectives was to implement a WHO recommended information system in all districts that was meant to monitor and evaluate all active case finding (TB screening that is implemented outside of health facilities (9)) and

treatment initiatives (8). Another objective of the NTP was to create a national TB manual and guide for programme staff and general health workers on TB treatment and management (8). For example, guidance in a most recent version of the manual (2017-2021, 5th edition) includes definitions of TB case and treatment outcomes, and guidance on TB screening, diagnosis, management, and treatment in line with the latest international standards (10). The NTP also ensured that treatment centres received uninterrupted supplies of TB medication (8). Other initiatives that helped reduce the TB burden in Zambia included: the adoption of the WHO recommended Direct Observation of Therapy programme; an increase in diagnostic health facilities; a rise in community groups and volunteers who supported people with TB during TB treatment; and the integration of TB and HIV services (2, 4, 11).

The HIV and Tuberculosis Epidemic

HIV is one of the leading drivers of the TB epidemic in Zambia and, according to WHO, Zambia has one of the highest estimated number of incident TB cases among people living with HIV (PLWH) (12). In 2019, 47% of people with TB in Zambia were co-infected with HIV and co-infected individuals accounted for 62% of TB related deaths that occurred in that year (12). In 2019, Zambia had an estimated HIV prevalence of 11.5% amongst adults aged 15-49 (13). The prevalence of HIV is higher among women than men and this difference is even more pronounced among young adults (20-24 years of age) (14). HIV prevalence also tends to be higher in urban versus rural settings (14).

People who are co-infected with TB and HIV are known to have poorer health outcomes than people with either individual condition in Zambia (4). The vulnerability of PLWH to developing TB prompted the integration of TB and HIV services in Zambia, which was piloted though the Pro Test project in 1999 and

rolled out in government clinics in 2005 (11). This integration included: intensified TB case-finding; Isoniazid preventive therapy (medication) for PLWH; HIV testing and counselling; HIV prevention co-trimoxazole preventive therapy for PLWH; and ensuring HIV care and support, including antiretroviral therapy, (ART) for PLWH (11). The integration of HIV and TB services played a key role in improving health outcomes for co-infected individuals in Zambia. For example, between 2006 and 2010 the proportion of people with TB being tested for HIV increased from 23% to 84% while TB related deaths in sputum positive people coinfected with TB and HIV reduced from 13% to 9% (11). A 2013 randomised controlled trial conducted in Zambia and South Africa (Zambia and South Africa TB and HIV reduction study – ZAMSTAR) aimed to assess the effectiveness of two types of TB interventions (community level enhanced TB case-finding and household level TB-HIV care) in reducing TB incidence (15). The household level TB-HIV care interventions was conducted in 16 urban communities in Zambia and included a strategy of combined TB-HIV household level counselling for newly diagnosed people with TB and their households; although not statistically significant, it found an 18% (Odds Ratio (OR) 0·82 95% CI,0·64-1·04) reduction in TB incidence in communities that were part of the intervention (15), suggesting that similar interventions may be of value in TB control in this setting.

There are, however, notable gaps in integrated service provision. For example, a study published in 2021 conducted in 12 urban facilities in Zambia assessing TB case-finding among PLWH in Zambia interviewed 13 key health workers working in the ART departments in these facilities (16). The study findings reveal that 58.3% healthcare workers did not know the number of TB symptoms PLWH had to report to qualify for tuberculosis symptom screen, and only 27% reported receiving specific training in TB preventive treatment (16). Additionally, 83.3% of the healthcare workers reported insufficient stocks of medication for their clients to complete the 6-month TB treatment course (16).

The relationship between Tuberculosis and mental distress

There is evidence that TB and mental health share a complex relationship (17, 18). In this thesis, I explore the relationship between TB and "*mental distress*." Mental distress is a broad concept that includes certain common mental health conditions (for example, depression and anxiety) but also general psychological distress that does not reach criteria for formal diagnosis. Mental, behavioural, and neurodevelopmental disorders are defined by the International Classification of Diseases (11th revision) (ICD-11) as "*syndromes characterised by clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes that underlie mental and behavioural functioning. These disturbances are usually associated with distress or impairment in personal, family, social, educational, occupational, or other important areas of functioning*" (12). These include common non-psychotic disorders, for example, depression and anxiety disorders (19), psychotic disorders, for example, schizophrenia and neurodevelopmental and neurobehavioral disorders, which are disorders that have their onset during the developmental period and persist over a person's lifespan (20). This thesis is not focussed on psychotic or neurodevelopmental disorders, rather it is focused on mental distress that includes non-psychotic mental health conditions such as depression and anxiety disorders and general psychological distress.

TB and mental distress share a syndemic relationship. Singer and Clair (21) define a syndemic relationship as the convergence of two or more conditions that act synergistically to magnify the burden of diseases. The syndemic relationship between TB and mental distress is due to the convergence of biological, social, and behavioural factors that collectively increase the risk for negative health outcomes (18). Shared biological risk factors, for example HIV, work in different pathways to increase the risk of

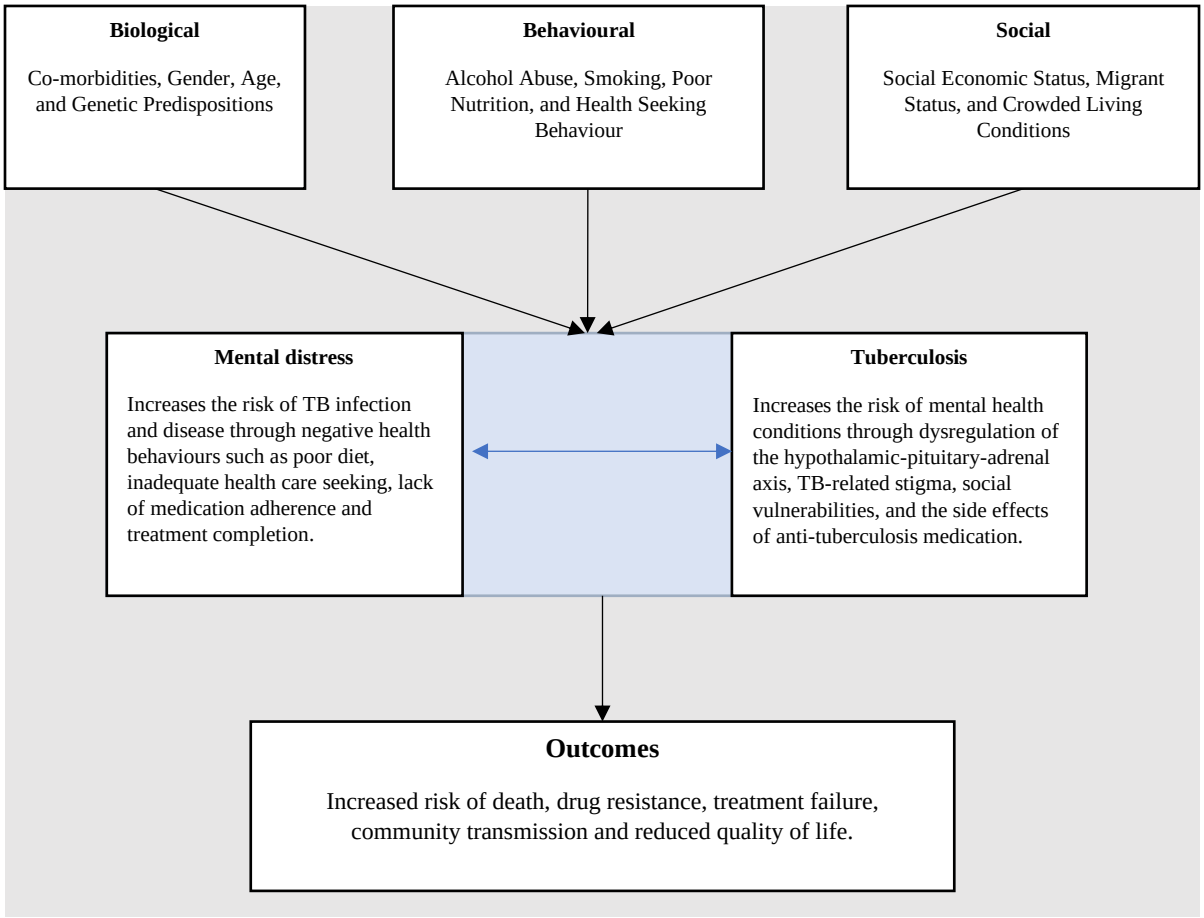
both conditions. HIV increases the likelihood of reactivating latent TB to active TB disease by lowering the immune system (22). HIV has also been shown to biologically induce depression through the release of inflammatory cytokines (23). Social factors, including low socio-economic status, increase the likelihood of living in overcrowded and lower quality housing, which in turn leads to higher risk of TB infection in susceptible individuals from people with infectious TB (24). Similarly, people living in poor quality housing often experience stressors related to their living conditions including, damp, leaks, flooding and inadequate heating, and these stressors were associated with adverse mental health both in the short and long term (25-27).

Behavioural risk factors including smoking and alcohol abuse also increase the likelihood of independently developing mental distress and TB. For example, alcohol abuse, which is often classed as a mental health condition, increases the risk of latent TB activation by impairing the immune system while also increasing the likelihood of an individual being found in social environments that promote the spread of TB (28). On the other hand, there is literature that highlights the causal link between alcohol abuse and depression (29), although the underlying mechanisms remain unclear.

In addition to shared risk factors, mental distress and TB also act as risk factors for each other. More specifically mental health conditions, such as depression can negatively impact health behaviours including diet and health care seeking, thereby serving as a risk factor for TB infection and disease (18). Depression can also increase the likelihood of poor health outcomes among people with TB by disrupting medication adherence and/or treatment completion (18). TB can in turn act as a risk factor for mental distress (17), through TB-related morbidity resulting in reduced quality of life (30, 31), the duration and side effects of TB treatment (17, 32), TB stigma (18, 31, 33, 34), a fear of transmitting TB

disease to others (17), and other potential comorbidities (especially HIV) that are associated with TB (35). In this way comorbid TB and mental distress significantly increase an individual's multi-disease burden, which ultimately leads to poor health outcomes including development of multi-drug resistant (MDR) TB, and death. Figure 1 below is adapted from Sweetland et al. (18) to illustrate the syndemic relationship between TB and mental distress.

Figure 1: Shared Risk Factors and Syndemic Relationship between Mental Health Conditions and TB from (Adapted from Sweetland et al. pp 853 (18)



This thesis triangulates three research areas with the aim of providing a holistic understanding of the mental health and TB nexus in Zambia. The three areas being investigated are: 1) lived mental distress experiences of people with TB; 2) the mental health burden in TB survivors; 3) TB health workers and stakeholder perspectives around mental distress and TB. These three areas and the research gaps the thesis aims to fill are described in the following sections.

Lived mental health experiences of people with Tuberculosis

There are a handful of studies exploring the relationship between mental health and TB in the Zambian setting and, like other research in the region, these studies have focused on investigating prevalence rates of mental distress in people with TB (36-38). Research quantifying mental distress in TB patients is important because it highlights the burden of disease in this population thereby providing evidence for policies aimed at improving health outcomes of people with TB in this setting. However, there is a significant gap in acknowledging and recognizing mental health experiences of people with TB **(Research Gap: 1).** Lived experiences can provide a wealth of insight into the drivers and implications of mental distress on TB treatment outcomes. Lived experiences increase visibility and provide nuances beyond the numbers availed by prevalence studies that allow for the creation of more tailored specific solutions (39). Lived experiences provide contextualised data that enable solutions that are shaped around peoples' social realities (39). For example, a qualitative study in Uganda focused on exploring experiences of young women living with HIV with regards to adherence to ART, revealed how a variety of everyday life occupations influenced their decision to adhere to their medication ranging from more generalizable reasons such as fear of being stigmatised, poor mental health resulting from lack of support, to more context specific reasons like young women prioritizing house chores over taking their medication because they interlaced these chores with their wider identity as young and proper Ugandan

women (39). The findings discovered that these chores were so demanding that they left no time for the young women to take their medication (39). Additionally, incorporating patient perspectives around the experiences of illness forms a critical component of creating compassionate, patient-centred care. For example, a 2012 global systematic review of 32 studies, focused on patient-centred care in chronic disease management, highlights that acknowledging the patient's situation and legitimizing the illness are some of the core components of patient-centred care (40). In this thesis I used qualitative methods to explore mental health experiences of people with TB in Zambia. Qualitative methods lend themselves well to developing quality patient-centred care as they work inductively to build knowledge and understanding of patients' preferences for treatment options and healthcare delivery (41). I discuss the value of qualitative methods for understanding patient experiences in more detail in the methods section.

Burden of physical disease and mental distress in TB survivors

There is growing evidence of the association between previous TB and persistent abnormal lung structure and function, often summarised as post TB lung disease (42). Post TB lung disease is broadly defined as the presence of chronic respiratory abnormality, with or without symptoms, linked to a previous pulmonary TB episode (42). The burden of post TB sequalae is evidenced in the higher mortality rates among TB survivors documented in the literature across different settings. A global 2018 systematic review, consisting of data from ten studies with a total sample of 40,781 individuals and 6,922 deaths, showed that TB survivors had a standardised mortality ratio of 3.76 when compared with the general population or matched controls (43). The most common causes of death post TB treatment included cardiovascular disease (20%), followed by cancer (19%), respiratory illness (14%) and infectious diseases namely TB and HIV (9%) (43). Authors highlighted the complications in interpreting associations

between TB and mortality including confounding factors such as higher prevalence of social economic disadvantages faced by TB survivors when compared to the general population (43).

Post TB lung disease may lead to mental distress due to potential ongoing social and economic stressors. For example, TB survivors (particularly those with post TB lung disease) may experience continued loss of productivity, coupled with compounded health seeking costs brought about by morbidity associated with post TB lung disease. A 2017 study carried out in Malawi, that followed up 405 people with TB for 12 months after they successfully completed their TB treatment, found that employment, incomes, and poverty levels of participants were worsened due to their TB episode (44). These indicators did not recover significantly even a year post TB-treatment completion (44). For example, 72% of participants were in paid work prior to their TB diagnosis compared to 63% one-year post TB treatment completion, and participants reported lower incomes one year post TB treatment completion (median US$44.13) as opposed to before their TB diagnosis (median US$72.20 P value=0.006) (44).

The resulting health and economic implications of post TB lung disease on TB survivors and their families could potentially place a psychological strain on TB survivors (44). Literature from the region is suggestive that post TB lung disease negatively affects the quality of life of TB survivors. Findings from a 2019 study conducted in South Africa, assessing the health-related quality of life of 45 TB survivors, suggests that the mental health scores of participants (39 out of 100) were lower than the normal score of the population (50 out of 100) (45). After conducting a rapid literature review, I determined that there are currently no studies examining the prevalence of mental distress in TB survivors in Zambia, (**Research Gap: 2)** and consequently no recommendations for the management and treatment of mental distress in this population if they carry a disproportionate burden of mental distress. It is important to establish the mental health burden among TB survivors particularly in settings like Zambia

that have some of the highest global TB burdens (12). Poor mental health is linked to higher rates of mortality as documented in a 2015 systematic review and meta-analysis of 203 articles from 29 countries, which found that the pooled relative risk of mortality among individuals with common mental health disorders (CMDs) was over two times that of the comparative population, and additionally, individuals with CMDs were found to have a median reduction in life expectancy of 10 years (46). Furthermore, poor mental health increases economic vulnerability of individuals, as explained by the social drift theory which proposes that individuals with poor mental health may drift into poverty or be pushed further into poverty due to loss of productivity (47). Given the limited mental health resources available in Zambia (48), it is important to establish if the mental health burden in people with a history of TB is significantly higher than that of the general population, thus provide evidence for resources to be channelled appropriately.

In this thesis I use quantitative methods in form of a cross-sectional observational study, to investigate if the burden of mental distress in TB survivors differs from that of individuals who have never had TB before. According to the literature, the cross-sectional study design is the most effective way of assessing and comparing disease prevalence across different sub populations (49, 50). I discuss the rationale behind the use of the cross-sectional observation study in more detail in the methods section.

TB stakeholders and health care workers perspectives on mental health and TB

Zambia has one of the world's lowest ratios of trained mental health personnel per capita, for example, data from the WHO shows that in 2020 the median numbers of mental health workers per 100,000 population in Zambia was 4.26 (48) while, by comparison the ratio in a country with a more established mental health workforce such as the United Kingdom is 201.14 per 100,000 population (51). One of the

key strategies for addressing the scarcity of mental health services in resource limited settings such as Zambia is the integration of mental health services into primary health care through a task sharing approach as recommended by the WHO global mental health action plan (52). Task sharing constitutes of training non-mental health specialists in the primary health care setting to identify and treat mild cases of mental health conditions using simple, evidence-based techniques (53).

Task sharing would result in a degree of integration of TB and mental health services that may lead to economies of scope. Economies of scope refers to the health economics phenomenon in which the unit cost decreases when the variety of products increases (54). There is some evidence that supports the economies of scope in health care. A critical analysis of 19 reviews focused on cost effectiveness of health services integration suggests that there is evidence of cost–effectiveness of some integrated care approaches but caution that the evidence base remains weak (55). With regards to TB and mental health service integration, economic modelling suggests that every dollar spent on task sharing would yield an economic return of between $4 and $43, particularly in high TB prevalence settings (56, 57). More importantly, integrating mental health services into routine TB services could improve patient treatment outcomes as highlighted by a 2021 study with 3,500 people with TB conducted in Pakistan (58). The authors evaluated the impact of mental health integration into TB services on the treatment outcomes of people with TB (58). Their findings show that people with TB who received mental health services in the form of four counselling sessions during their TB treatment period had higher rates of TB treatment completion (92.9%) than those who did not (75.1%) (58).

A 2018 mixed methods global systematic review of 20 studies, which focused on barriers and facilitators of mental health integration into primary health care, highlighted that some of the barriers to

integration are specific to health care workers. These include: a lack of acceptability of mental health as a health priority; mental health stigma; lack of interest and motivation to treat mental health conditions; high work burdens; and a lack of knowledge and skill to screen and treat mental health conditions (59). Understanding primary health workers' perceptions around mental health screening, treatment and management is an integral step of planning integration of services, falling within the first WHO key recommendation from the 2013–2030 comprehensive mental health action plan, which calls for conducting a preliminary situational analysis on treatment and care of mental health conditions at different levels of care (60). A situational analysis highlights opportunities and weaknesses in health systems that could either facilitate or hinder the integration process. For example, a situational analysis to inform mental health integration into primary care, conducted in five countries in Asia and sub-Saharan Africa (Ethiopia, India, Nepal, South Africa, and Uganda), found weaknesses and opportunities for mental health integration (61). The weaknesses included a lack of reliable information on existing treatment coverage for mental health conditions, lack of organisational requirements for mental health care, including specialist mental health professionals and a reliable supply of medication for mental health conditions (61). Additionally, there was low community mental health literacy and no models for multi-sectoral collaborations with traditional or religious healers (61). The health system opportunities included a potential to apply existing models of care from other chronic conditions including TB and HIV, and an extensive network of community-based health workers and volunteers provided a resource to expand mental health care (61).

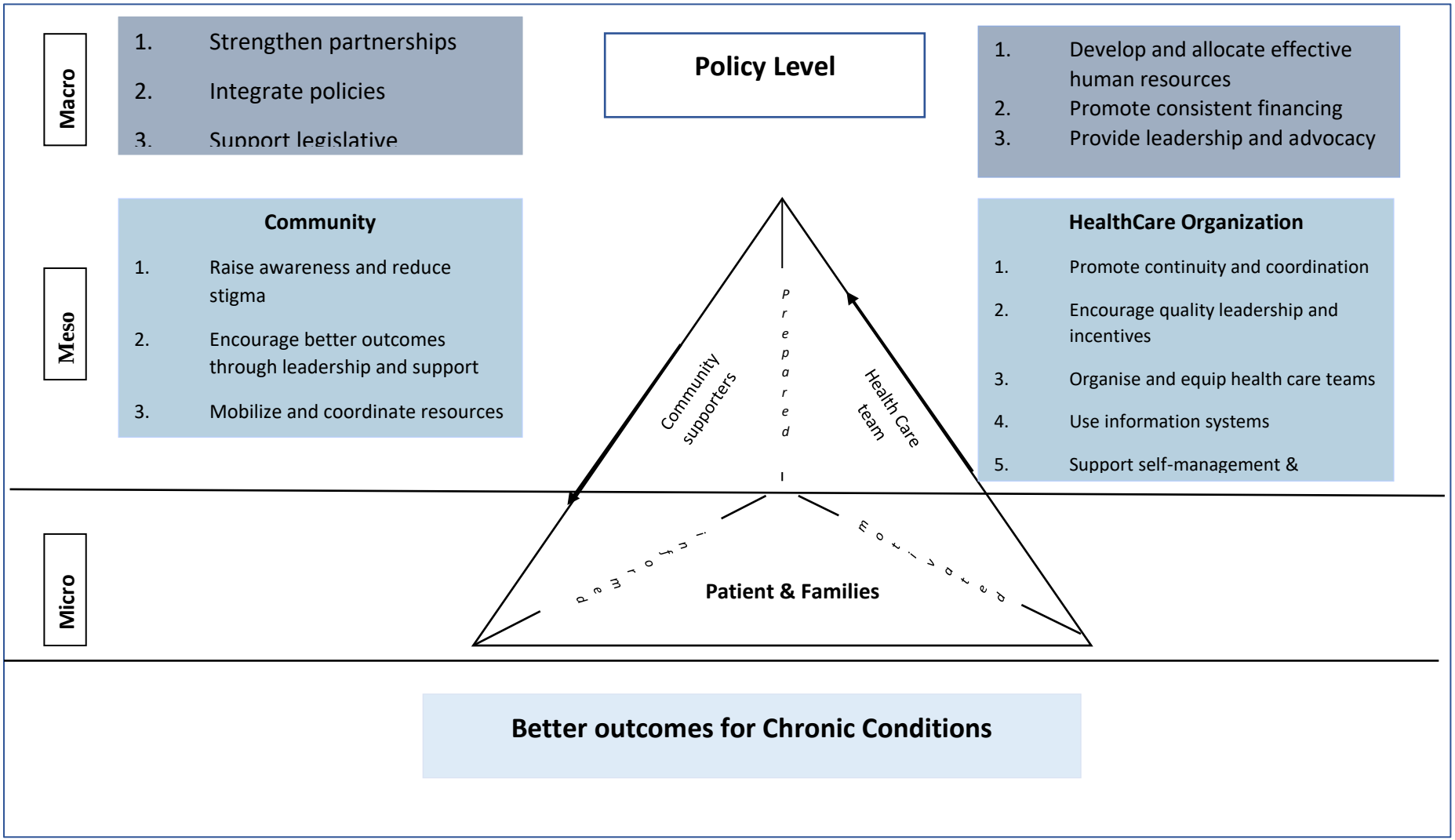
Although health care workers are key players in the integration process, literature exploring TB health workers' and stakeholders' perspectives about the relationship between TB and mental health in the sub-Saharan region is scant. Furthermore, there is limited details on the current practices that health

workers employ in screening and managing mental distress in their clients in this setting. (**Research Gap: 3).** Data on health workers and stakeholders' perceptions around the mental health and TB nexus will be explored using qualitative methods, namely focus group discussions (FGDs) with TB stakeholders and In-depth Interviews (IDIs) with TB health workers.

Theoretical framework and rationale

Figure 2 below provides a summary of the WHO Innovative Care for Chronic Conditions (ICCC) framework that this thesis draws on. The ICCC framework consists of three layers that work collaboratively to support people with chronic conditions to manage their health (62). These are also described as the micro level (that constitutes the patient and their families), the meso level (made up of the primary health care setting and the community) and macro level (which comprises the policy environment) (62). The figure also summarises the different building blocks that make up each level. The following paragraphs provide more detail about the framework in relation to the thesis.

Figure 2: WHO ICCC Framework (62).



WHO Innovative Care for Chronic Conditions (ICCC) framework

The ICCC framework which was created in 2002 to provide guidance on the management of chronic conditions (62). Globally, chronic conditions are becoming more prevalent, in part due to a demographic transition (people are living longer) because of advances in medical science and successful public health measures, but also due to an increase in risk factors associated with chronic conditions including unhealthy lifestyles (63).

Benefits of Innovative Care for Chronic Conditions framework for Tuberculosis and mental distress care.

The ICCC framework provides a model for comprehensive management for people with comorbid TB and mental distress in Zambia. Although TB can be cured, it is still considered a chronic condition because it requires long term management, even more so in cases of multi drug resistant (MDR) TB, recurrent TB episodes, and post TB lung disease resulting from a TB episode (64). Similarly, certain mental health conditions, for example depression, can also be chronic and require long term health management (65). The ICCC framework is ideal because it addresses shortcomings within the primary health systems that hinder effective care of chronic conditions. The ICCC argues that the primary health care system was initially developed in response to handling acute health needs resulting from infectious diseases (62). The hallmarks of this system include testing, diagnosing, relieving symptoms, and expecting a cure (62). Unlike acute conditions, chronic conditions are enduring, and therefore need care that draws on an expanded time frame, where the patient takes on responsibilities in managing their health problems (62). The model argues that the outcome for patients with chronic conditions is the quality of life of the patient and family as opposed to seeking of a cure as is typical of the acute model (62). The health system needs to equip patients with chronic conditions and their families with the skills

needed for managing their conditions in their everyday lives while simultaneously offering broader support that anticipates patient's needs (62).

The Innovative Care for Chronic Conditions framework levels applicable to this PhD

This PhD focuses on meso level analysis by using patient, health worker and stakeholder level data to assess how health workers and the community can provide comprehensive care for people with TB that are experiencing mental distress. At the meso level, the ICCC advocates that health care personnel are provided with expertise and tools they need to help them manage patients with chronic conditions while also having adequate knowledge of the community resources that can support patients with chronic conditions (62). The building blocks of the meso level include: promoting continuity of care across all levels of health services; encouraging quality care through leadership and incentives; organizing and equipping health care teams (including provision of detailed guidelines for care and diagnosis); supporting patient self-management and comorbidity prevention by educating patients; and use of information systems that gather and organize epidemiological and treatment data (62). An example of an intervention targeted at the meso level health facility building blocks is the essential Non-Communicable Disease health intervention project that was carried out in Tanzania and Cameroon (66). The aim of the project was to equip health care teams to effectively manage chronic conditions in their clients and this was done through development of guidelines for management of specific chronic conditions at health facility level, and development of rapid evaluation models for assessing the quality of health care being provided for people with chronic conditions (66).

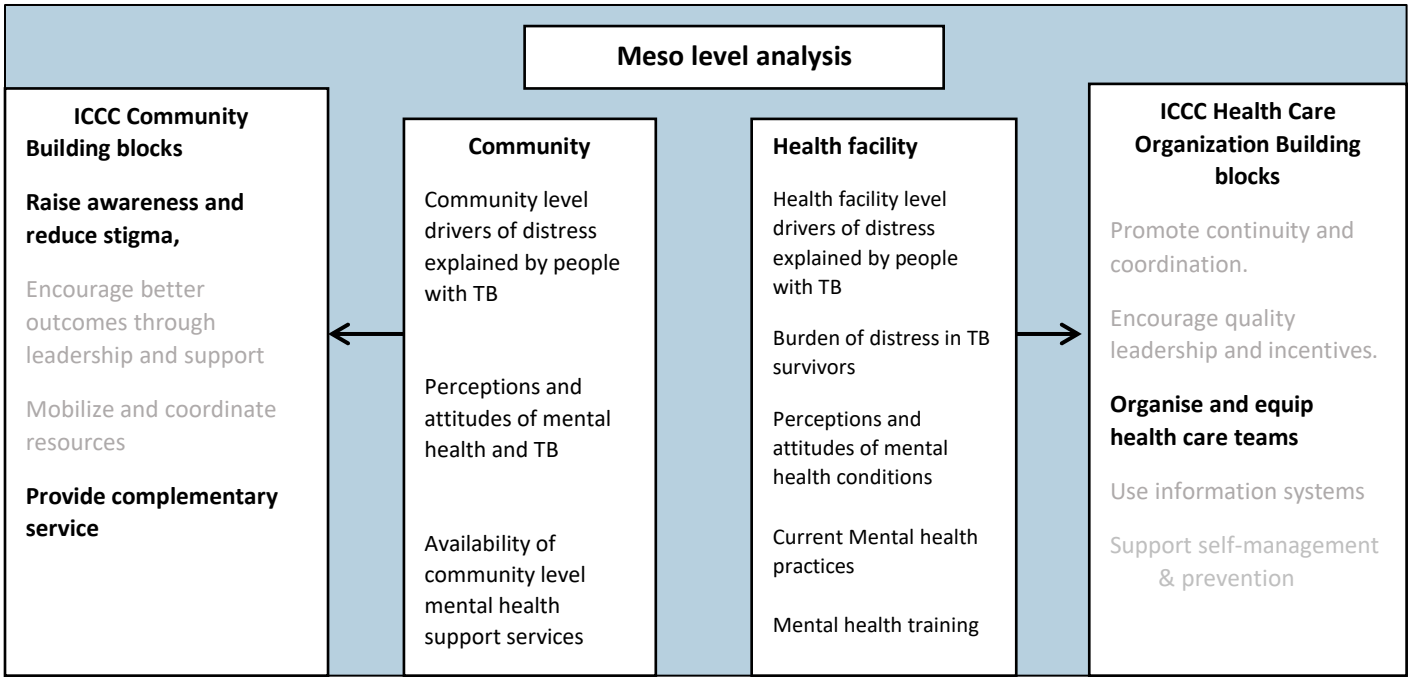
The health workers meso level analysis in this thesis aims to establish how prepared health workers are in providing care for people with TB experiencing mental distress. More specifically, this analysis explores perceptions and attitudes of health care workers with regards to mental distress, their current practices in managing mental distress in people with TB and highlights their mental health training needs. It also draws on patient level data to assess health level drivers of distress during TB investigation and treatment and draws on the prevalence of mental distress in TB survivors to assess if there is need for mental health interventions for TB survivors. The analysis will feed into the "*organising and equipping health care teams*" ICCC building blocks.

The building blocks of the community meso level include: raising awareness about chronic conditions and their associated risk factors; encouraging better outcomes through leadership and support; mobilizing and coordinating resources; and providing complementary preventive and management services (62). In Zambia, two home-based care (HBC) programmes providing support to people living with HIV and people with TB serve as an example of the community mobilization and provision of complementary services building blocks. The programmes were run by community nurses and volunteers and in both programmes the community served as a health care partner (62, 67). The nurses and community health workers provided direct patient care, self-management support, and support to family caregivers (62, 67). The meso level analysis in this thesis will assess if community level supplementary services are available for people with TB, and how conducive the community environment is to support the health needs of people with TB who are experiencing mental distress. It does so by investigating TB stakeholders' perceptions and attitudes of mental health and TB and availability of community level mental health support services. These areas of inquiry will feed into the

"*provision of complementary services and raising awareness*", and "*stigma reduction*" ICCC community building blocks.

The PhD inquiry and associated building blocks are summarised in figure 3 below, with bold text used to indicate what applies to this body of work.

Figure 3: PhD Contribution to ICCC Meso level



Aim: To identify ways of providing holistic care for people with TB in Zambia by critically assessing the intersection between mental health and TB during TB investigation, treatment and beyond in this context.

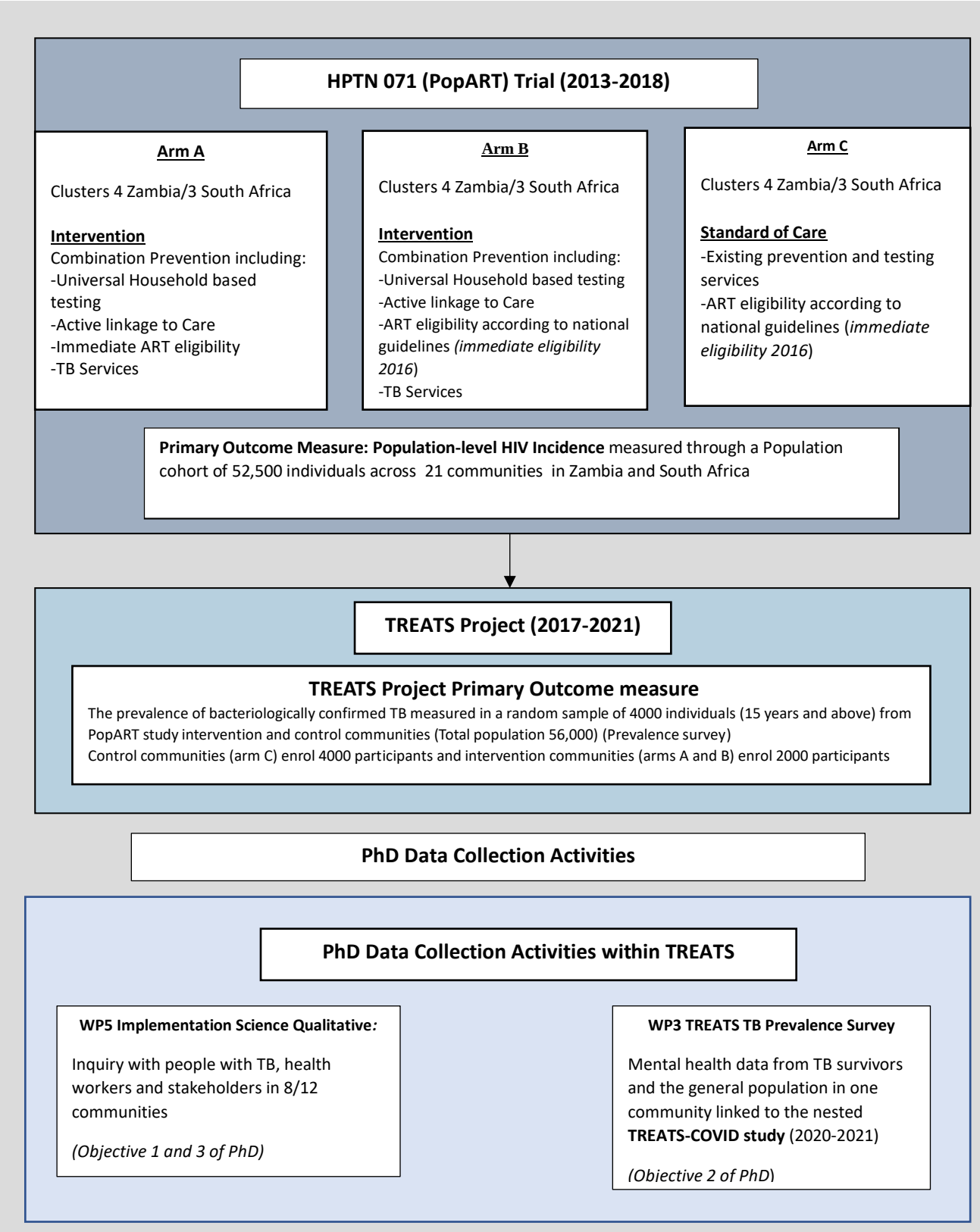
Objectives

1. To critically examine how people with TB conceptualise and experience mental distress (common mental disorders and psychological distress) during TB investigation and treatment in the context of socio-economic factors contributing to the TB and mental distress in Zambia.
2. To investigate prevalence and risk factors of probable mental distress in TB survivors compared with individuals with no history of TB in an urban Zambian community.
3. To explore TB health workers' and stakeholders' conceptualisation, management, and treatment of mental distress in people with TB in the Zambian context.

Study Setting

Figure 4 below provides a visual demonstration of the connection between the studies that contributed to data collection for this PhD study and data collection opportunities for this PhD. These studies are the PopART trial, the TREATS Project, and the nested TREATS-COVID sub study.

Figure 4: Summary of Studies Contributing to this PhD



This PhD, focusing on Zambia, was nested within the TB Reduction through Expanded Antiretroviral Therapy and TB Screening (TREATS) project that was carried out in 12 urban communities in Zambia and 9 communities in South Africa between [2018] and [2022]. TREATS was a follow-on study from the Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART HPTN071) Trial (2014-2018). PopART was a 3-armed randomised control trial that aimed to investigate the impact of a combined HIV prevention door-to-door package, including TB screening and referral, on community level HIV incidence in 21 urban communities organised for the purpose of the trial into seven triplets (68). The intervention was delivered to two arms (arms A and B communities) only. Arm A communities received the full intervention including immediate initiation of ART (68). Arm B communities received the full intervention but followed standard of care for ART initiation (68). Arm C did not receive the PopART intervention and followed the standard-of-care thus serving as the control arm (68). In Zambia, there were four triplets, with each triplet randomly allocated each intervention type and a control. Therefore, in total, there were eight intervention communities and four control communities that were part of the PopART trial. The PopART intervention was delivered by an auxiliary cadre of health care workers known as Community HIV care Providers (CHiPs). The HIV prevention package included: universal voluntary HIV counselling and testing provided at the household level; linkage of HIV infected individuals to care; and, in one trial arm early initiation of ART for all those testing HIV-positive (69). TB interventions in PopART included: TB case finding using a screening questionnaire and sputum diagnosis; training of health facility staff on TB management using the 3i approach (Intensified Case-Finding (ICF)); isoniazid preventive therapy (IPT) and infection control (IC)); establishment of TB active diagnostic support (namely the provision of technical staff); GeneXpert machines in all study hubs; a sputum courier system; and consumables.

The primary outcome for the PopART HIV intervention was HIV incidence measured in a Population Cohort of approximately 2,000 randomly sampled adults per community, aged between 18 and 44 years, constituting a total of 38,474 adults across 21 communities (68). The trial findings revealed that the combined PopART intervention reduced HIV incidence by 20% in the intervention communities (68). The TREATS project aimed to investigate the impact of the PopART intervention on TB incidence and prevalence. The TREATS primary outcomes are still being analysed and prepared for publication.

In Zambia, the 12 study communities are spread across 4 provinces and 5 districts. The selection criteria used by PopART for these communities included having a health facility that offered TB and HIV services, a high HIV prevalence (above 20%), and a total population of about 20,000. The TREATS project, funded by the European and Developing Countries Clinical Trials Partnership (EDCTP) consists of nine work packages, each representing a distinct research activity and are listed below.

1. Work package 1 - Project Management and Internal Communication
2. Work Package 2 – Incidence of Infection Cohort
3. Work Package 3 – TB Prevalence Survey
4. Work Package 4 – Evaluation of new tools
5. Work Package 5 – Implementation Science
6. Work Package 6 – Data Management and Statistical Core
7. Work package 7 – Mathematical Modelling and Economics
8. Work Package 8 – Training and Capacity Development
9. Work Package 9 – Communications, Dissemination and Exploitation

This PhD draws on data from two of these work packages, namely work package 5 *Implementation Science* and work package 3 *Prevalence Survey*.

With the advent of the COVID-19 pandemic in 2020, funding was obtained to conduct a nested study in one Zambian urban community that was part of the TREATS study. The TREATS-COVID study carried out additional activities to measure the prevalence, incidence and spread of COVID-19 in Zambia and to gauge community preparedness. This PhD draws on data from the adjusted prevalence survey linked to the TREATS-COVID study. It should be noted therefore that the quantitative data for the prevalence survey was collected during the COVID-19 pandemic (see methods section for a more detailed discussion of the implications).

TREATS work package 5 (Implementation science)

The TREATS WP5 consisted of quantitative and qualitative components. The quantitative component aimed to measure the effect of the PopART intervention on TB notification among adults residing in the study communities and the clinical characteristics and treatment outcomes of adults with TB among adults residing in the study communities. It also aimed to measure the total number of people with TB screened by HIV status divided by the total risk population screened, change in TB notifications, and reported TB incidence. The qualitative component, where data for this PhD was collected, aimed to assess the delivery of the PopART intervention by describing the comparative experiences of diagnosed TB patients and their households across intervention and control communities, including a comparison of the PopART household interventions and standard of care health facility services. The qualitative work also aimed to explore understandings of TB stigma and popular understanding of TB among community members. The qualitative research was carried out in eight of the TREATS communities

following the initial design of the TREATS project which aimed to compare Arm A and Arm C communities only. Changes to include Arm B communities were made after the PopART primary outcome results showed a significant reduction in HIV incidence in Arm B (68). This change was made after the qualitative research had been conducted and therefore the qualitative data is from eight of the 12 communities (thereby not including the four communities allocated to arm B). Data was collected through FGDs with TB stakeholders and members of the Neighbourhood Health Committees (NHC) and IDIs with TB survivors and TB health care workers.

I designed the mental health component of the data collection tools. The mental health component aimed to explore mental health experiences of TB patients and how TB health workers and stakeholders understood the intersection of mental health and TB in the Zambian context. This data was collected from August 2018 to November 2018. The data was used for objectives 1 and 3 of this PhD, leading to published articles entitled "*Qualitative Study of Patient Experiences of Mental Distress during TB Investigation and Treatment in Zambia,"* and "*Conceptualization, detection, and management of psychological distress and mental health conditions among people with tuberculosis in Zambia: A qualitative study with stakeholders' and TB Health workers."*

TREATS Tuberculosis Prevalence Survey work package 3

The TREATS TB Prevalence Survey work package aimed to measure the prevalence of TB disease through a TB prevalence survey conducted in all 12 TREATS communities in Zambia. The TB prevalence survey began in January 2019 and was completed in December 2021. The survey had a target sample size of 2,000 participants in each of the eight intervention communities and 4,000 in the each of the control

communities. TREATS study activities were conducted at a mobile field site that served as a one stop TB platform which included a truck that contained a digital X-ray and Xpert instrument and tents where study activities were conducted. The study activities included TB screening, testing and administration of a questionnaire. When the additional funding was obtained to extend the prevalence survey in one community to collect data on COVID during the pandemic (the TREATS-COVID study), there was an opportunity to make changes to the questionnaire, and to adjust the prevalence survey tool to include mental health items in the one community.

The subsequent TREATS TB prevalence survey questionnaire, administered in one (Arm C) of the 12 TREATS communities, contained a mental health screening tool that was used in objective 2 of this PhD and purposively included for the PhD. The community where data was collected is a middle to high density urban area in the Central Province of Zambia with a total population of approximately 28,000 people. I chose and adapted the mental health tool to be included in the questionnaire and trained field teams in administration of the questions in the tool.

Structure and methodological approach of the thesis

In this thesis, I have used a mixed methods approach to address my aim and objectives and am doing a thesis by publications. The thesis results chapters therefore comprise of two peer reviewed articles and one manuscript that is ready for submission and is currently being reviewed by the TREATS publication working group as per publication guidelines of the study. Following feedback from the publication working group, this manuscript will be submitted to a journal for peer review.

The first chapter introduced mental health and TB, highlighted the research gaps with regards to this relationship, outlined the aims and objectives of this thesis, and provided details of the study setting. The second chapter examines the literature regarding mental health and TB, with a focus on the prevalence of mental distress among people with TB, drivers of distress during TB investigation and treatment, and integration of mental health care into routine TB care in low resource settings. The third chapter provides a detailed overview of the mixed methods used in this thesis. Quantitative methods included a cross sectional survey while the qualitative methods included FGDs and IDIs. It also explores the strengths and limitations of the mixed methodological approach with regards to this work. The fourth chapter is focused on experiences of mental distress during TB investigation and treatment **(Research gap 1)**. It is informed by qualitative data collected from 80 people with a recent history of TB in eight urban communities in Zambia**.** The fifth chapter investigates if there is a difference in the prevalence of mental distress in TB survivors compared to people who have no TB history**.** It utilises quantitative data collected from 3,393 individuals from one urban community in Zambia. This chapter provides a retrospective perspective on the relationship between TB and mental distress in this setting **(Research gap 2).** The sixth chapter investigates TB stakeholders' and health workers' conceptualisation of the relationship between TB and mental health using qualitative data collected from the same eight urban communities explored in chapter three**.** This chapter also explores TB health workers' and stakeholders' understanding of the drivers and implications of mental distress among people with TB during TB treatment and investigation. It further details current practices in screening and managing mental distress in people with TB in Zambia **(Research gap 3)**. The seventh and final chapter summarises and discusses the findings in context of the existing literature, while highlighting whether the objectives of the thesis have been met. The discussion uses the ICCC model to guide recommendations around holistic mental health care for people with TB in the Zambian setting. By filling the above-mentioned gaps, the discussion focuses on how people with TBs' experiences triangulated with TB stakeholder and

health worker perspectives around the TB and mental health nexus can be used to provide adequate guidance to TB health workers and stakeholders, allowing them to be better prepared to provide needed support to people with TB who are experiencing mental distress in this context.

My role and Contribution to work presented in this thesis

I applied and was fortunate enough to be awarded the Social Science PhD position within the TREATS project. I developed the study protocol with support from my supervisors Professor Virginia Bond, Dr Islay Mactaggart, Nathaniel Scherer, and Dr Robert Stewart. My advisory committee consisted of Ab Schaap, a statistician, who provided critical statistical advice and teaching at various stages of the PhD, and Lesley Hill, a mental health practitioner, who provided input on conceptualisation of mental health concepts from a clinical standpoint.

I designed and chose the aspects of the data collection tools pertaining to this PhD with guidance of my supervisors. I trained the research assistants (RAs) and oversaw all aspects of the qualitative field work. I was also involved in the day-to-day activities of data collection, conducted some of the IDIs and facilitated some of the FGDs. I chose the mental health screening tool included in the TREATS prevalence survey and trained the RAs on how to sensitively administer the tool. I was not able to participate in the quantitative data field work due to Covid restrictions and my own poor health at the time of data collection. I analysed the mental health data, along with other variables of interest to this objective from the prevalence survey.

Multi-authored papers

There are three first-authored papers, (two published and one ready for submission), presented as part of this thesis. Each paper addresses one of the objectives of this PhD. I am the lead author in all three papers, I carried out the analysis, and wrote the drafts of the papers. Co-authors provided substantial input in form of support and guidance during analysis of data, suggestions on content, and language edits. Subsequently, all authors reviewed and approved the final manuscripts prior to submission.

Professor Virginia Bond provided critical conceptual input in the development of this thesis and critically reviewed all the material presented as part of this thesis.

Ethics Clearance

Ethical approval for all TREATS study procedures was obtained from the Bio-medical Ethics Committee of the University of Zambia (UNZABREC) (ref 005-02-18) and the institutional ethics review of the London School of Hygiene and Tropical Medicine (LSHTM) (ref 14985). Further permission to conduct the study was also obtained by the Ministry of Health (MoH) in Zambia through the National Health Research Authority (NHRA). Additional expeditated permission for the TREATS-COVID study was obtained from the NHRA and the LSHTM ethic committee (22606). See Appendices 1, and 2 for information sheets, informed consent forms and ethical clearance letters linked to TREATS and TREATS-COVID, that included the data collected for this PhD.

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Chapter two: Literature Review of Mental Health and Tuberculosis

Understanding the relationship between mental distress and tuberculosis

Mental distress associated with TB includes common mental disorders such as depression, anxiety, and adjustment disorder (1). Findings from studies that were conducted in Bangladesh, Russia, United Kingdom, and China show that patient experiences provide insight into the accumulation of financial losses and the psychological burden endured by people with TB, including a loss of agency, personal relationships, income and ultimately a loss of self-worth all leading to mental health conditions such as depression (2-5). The relationship between TB and mental distress is complex, as both conditions are risk factors for each other while also sharing psycho-social and biological risk factors. In this chapter, I will explore the relationship between mental distress and TB, reflecting on the prevalence, biomedical, economic, and social drivers of mental distress during TB investigation and treatment. The chapter also reflects on the integration of mental health and TB services.

Prevalence of mental distress in people with Tuberculosis

According to the WHO the global prevalence of mental distress is approximately 13% (6) which is similar to the Zambian estimate of 14% established by a 2009 study of 4,466 individuals aged 15-59 (7). There is evidence that people with TB have a disproportionately higher prevalence of depression when compared to the general population (8). However, before considering the evidence on the prevalence of mental distress among people with TB, it is important to first consider that estimates from most research studies are derived from a variety of screening tools and different population subgroups. The differences in reporting style make comparison across studies more complex. The use of different tools for measuring mental distress for a range of health conditions have been shown to yield different prevalences even in the same participants measured at the same time points. For example, a study

assessing the prevalence of depression in a cohort of 100 stroke victims followed up at four time points using 4 screening tools (namely the Beck Depression Inventory, Hamilton Rating Scale for Depression, Visual Analogue Mood Scale, and the Diagnostic and Statistical Manual of Mental Disorders 3rd Edition) found that the prevalence differed according to the assessment instruments (9). The range in the prevalence of depression during the different follow up visits were lowest when measured using the Diagnostic and Statistical Manual of Mental Disorders (3rd Edition) which found 6% to 16% of patients had major depression, while the Beck Depression Inventory, Hamilton Rating Scale for Depression, and Visual Analogue Mood Scale found rates of 23% to 29%, 10% to 14% and 26% to 9% respectively (9). It is also worth noting that screening tools are meant to indicate elevated symptoms and are useful in research to understand estimates of prevalence, but they are not diagnostic, and their results should be interpreted with caution.

The prevalence of mental distress amongst people with TB varies by country. A 2021 systematic review and meta-analysis, which aimed to quantitatively summarize the prevalence of depression among 4,391 people with TB from nine sub-Saharan African countries, found a pooled prevalence estimate of 39.4% (95% CI 30.7–48.2) from 19 studies (8). The review highlighted a broad range of reported prevalence rates of depression from 65% (95% CI 55.7-74.4) in South Africa to 9.3% (95% CI 5.6-13.0) in Zambia (8). This variation could be partly explained by the heterogeneity in the tools being used to measure depression in the different studies and the severity of the depression (mild, moderate or severe) being reported (8). For example, a 2013 study, included in the review, conducted in Ethiopia used the Kessler Psychological Distress Scale-10 and reported prevalence of depression of 19.8% (95% CI 13.6-25.7) and did not report the severity of depression (8). While a second study also conducted in Ethiopia in 2019

using the Patient Health Questionnaire (PHQ)-9 tool found an overall prevalence of 51.9%, (95% CI 47.0-56.8) disaggregated by severity as mild (34.2%), moderate (14.9%) and moderately severe (2.5%) (8).

There are not many studies assessing the prevalence of mental distress in people with TB in Zambia. Those that have been conducted found higher estimates than that of the general population. For example, a 2013 study using the Mini International Neuropsychiatric Interview (MINI) across 16 primary health care centres found a 9.3% (95% CI 5.6-13.0) prevalence of major depressive disorder (MDD) in 231 people with TB with 3.4% (95% CI 1.5–7.3) of these having attempted suicide at least once (10). The prevalence of MDD found in the study is higher than the 2011 and 2015 University of Washington estimate in sub-Saharan Africa of 2.4% (11) reflecting an urgent need for mental health interventions in this population.

Biomedical Drivers of mental distress during Tuberculosis investigation and Treatment.

The global literature highlights biological factors associated with development of mental distress in people with TB. The biomedical drivers include the inflammatory response resulting from TB infection, morbidity associated with TB symptoms, comorbidities, and adverse drug reaction.

The inflammatory response, resulting from cytokines released due to active TB infection, negatively affects the immune systems' response within the central nervous system leading to the dysregulation of the hypothalamic-pituitary-adrenal axis (12, 13). The hypothalamic-pituitary-adrenal axis is a complex interaction of hormones between the hypothalamus, pituitary gland, and adrenal glands. Dysregulation of hypothalamic-pituitary-adrenal axis is characterised by elevated cortisol and blunted

adrenocorticotropin hormones (14) which increase the likelihood of developing depression and has also been linked to suicidal behaviour (15, 16).

TB morbidity was also a common driver of reduced quality of life and psychiatric morbidity as highlighted by the literature (1, 17). TB symptoms are often painful and debilitating and the most common symptoms include a productive cough, chest pains, weakness, weight loss, fever and night sweats (18, 19). MDR TB, which often translates to longer duration and increased severity of the disease had a stronger association with depression (20-23). Co-morbidities, particularly HIV, also had a strong association with depression in people with TB (24, 25). A 2021 systematic review of 19 studies from 8 Sub Saharan African countries found that people with TB with a comorbidity had a 4.19 higher likelihood of experiencing depression as compared to people with TB who had no other chronic illnesses (8). Furthermore, post TB related morbidity could still serve as a driver of mental distress in TB survivors. Some studies investigating the quality of life of people with a history of TB are suggestive of mental health challenges in this population due to chronic respiratory symptoms resulting from their TB episode. These respiratory symptoms can last several years beyond TB treatment completion (2, 26, 27). For example, a study conducted in India found the health quality of life score, which encompasses a mental health score, of 436 TB survivors with respiratory symptoms 1 year after TB treatment was significantly lower than that of the general population (28). Similarly, a long term (14-15 years) post TB treatment study, also conducted in India, found significant impaired health related quality of life in 363 TB survivors compared to the control group (29).

As well as TB morbidity, adverse drug reactions from Anti-TB medication were also highlighted as common drivers of mental distress in people with TB. Some of the adverse drug reactions are

neuropsychiatric complications, although these complications are very unusual as evidenced by a global meta-analysis that calculated a pooled estimate of 1.1% (95%CI 0.2-2.1) for central nervous system related adverse drug reactions in people with TB (30). In addition to neuropsychiatric adverse drug reactions of TB medication, the literature highlights: hepatotoxicity (jaundice and elevated transaminase); gastrointestinal disorders (nausea, vomiting and diarrhoea); allergic reactions (rash); arthralgia and muscle pain as the adverse TB drug reactions more commonly reported by people with TB (31, 32). The morbidity associated with these adverse drug reactions coupled with the long duration of the TB treatment regimen (often a minimum of 6 months) were commonly cited as drivers of depression in people with TB (1, 33). It is worth noting that the prevalence of mental distress differed at various stages of TB treatment. Some studies indicate a decline in mental distress over the treatment period, with the highest prevalence noted immediately after diagnosis and during the intensive phase of TB treatment (first two months) rather than the continuation phase of treatment (last four months). A pooled estimate from three studies examining the prevalence of depression by phase of TB treatment found that people with TB in the intensive phase of TB treatment were 2.32 times more likely to be depressed than those who were in the continuation phase (8). The decreasing prevalence of depression during the TB treatment course could be attributed to less TB morbidity and relief from TB symptoms due the effectiveness of TB medication (34) and a reduction in adverse drug reactions (35).

In summary, biological drivers of mental distress in people with TB were the inflammatory response leading to the dysregulation of the hypothalamic-pituitary-adrenal axis and sympathetic nervous system, morbidity associated with the disease and adverse drug reactions to anti-TB medication. The intensity of mental distress in people with TB often reduced during their TB treatment regimen as people with TB start to feel better and get used to the medication.

The relationship between tuberculosis, poverty, and mental distress

Association between tuberculosis and poverty in Zambia

TB is often described as a disease of poverty, evidenced by the fact that TB infection and disease disproportionately affect individuals in lower socio-economic positions (36, 37). Some of the literature even suggests that, on a national level, TB trends are more closely linked with social and economic factors than the intensity of TB control measures (38). Structural determinants of health offer an explanation to this phenomenon. Structural determinants of health are defined as those conditions that generate or reinforce social stratification in society (39). In the case of TB, the structural determinants of health that lead to a disproportionate TB burden amongst the poor include: rapid unplanned urbanisation leading to overcrowded, poorly ventilated housing; food insecurity and malnutrition; and economic, geographical and cultural barriers to health care access (37). Inequality in the distribution of structural determinants of TB is reflected in all stages of TB pathogenesis. For example, poorer individuals have higher exposure to TB infection and progression to disease due to factors including poor quality housing and malnutrition (37). Additionally, poorer individuals are also more likely to experience economic and geographical barriers to health care access leading to late or inappropriate diagnosis and treatment, which ultimately translate into worse TB treatment outcomes (37).

According to the World Bank economic indicators, Zambia is a LMIC with high levels of income inequality and poverty (40). The poorest 20% of the Zambian population hold only 2.9% of the nation's wealth (40) while the wealthiest 10% of the population hold 51% of the nation's wealth (41). Additionally, approximately half of the Zambian population face multi-dimensional poverty, thereby experiencing

multiple overlapping deprivations (health, education and standard of living) (42). The high rates of poverty are directly correlated with the TB epidemic in the country, which is concentrated amongst lower socio-economic brackets particularly in urban settings. For example, a 2013-2014 TB prevalence survey conducted in Zambia estimated a TB prevalence of 729 per 100 000 population in the lowest wealth category compared to 359 per 100 000 in the highest (43).

Implications of tuberculosis on economically vulnerable households

Like many countries in the region, TB treatment is free in the Zambian public health sector. However, the indirect costs of TB investigation and treatment such as transportation and medical investigation costs are often substantial particularly for poorer households. For example, studies done in South Africa assessing the impact of TB treatment on vulnerable households using multidimensional poverty indicators found evidence that relatively poorer individuals faced both higher absolute and relative TB costs when compared to participants in wealthier quantiles (44, 45). Results from a study assessing the direct and indirect TB related costs showed that in Zambia people with TB spent approximately 16% of their mean monthly income on transportation costs to the clinic while direct medical expenditure for TB investigation averaged 127% of their mean monthly incomes (46). Time opportunity costs resulting from health seeking during TB investigation and treatment often leads to lost income and thereby also negatively affecting the income security of vulnerable households (47, 48). For example, studies conducted in Zambia in 1998 and 2004 found that people with TB missed an average of 18 workdays during TB investigation (46) and an additional average of 48 days during TB treatment (49).

The accumulation of costs has been shown to increase poverty levels, particularly in vulnerable households. Although data is not available for Zambia, a study of 399 Malawian people with TB found that there was a 16.1% increase in the proportion of participants living in poverty pre-illness compared to one year post treatment completion (50). The implications of TB on vulnerable households' economic stability are shown to persist years after TB treatment completion, and once again disproportionately affecting poorer households as they are more likely to experience dissaving (the use of savings, borrowing money or selling of household assets to meet direct and indirect health needs) during TB investigation and treatment (50). Additionally, poorer households are more likely to experience more generational economic implications from TB investigation and treatment, such as schooling disruption for their children (50). Lastly, poorer individuals are at higher risk of experiencing worse TB treatment outcomes including TB reinfection and mortality (51) due to less access to quality health care services, less financial and social support during TB treatment, poorer nutrition, and higher exposure to risk factors of TB. These poor TB treatment outcomes lead to additional, and often catastrophic costs for vulnerable households (52).

The cyclical relationship between tuberculosis, poverty, and mental distress

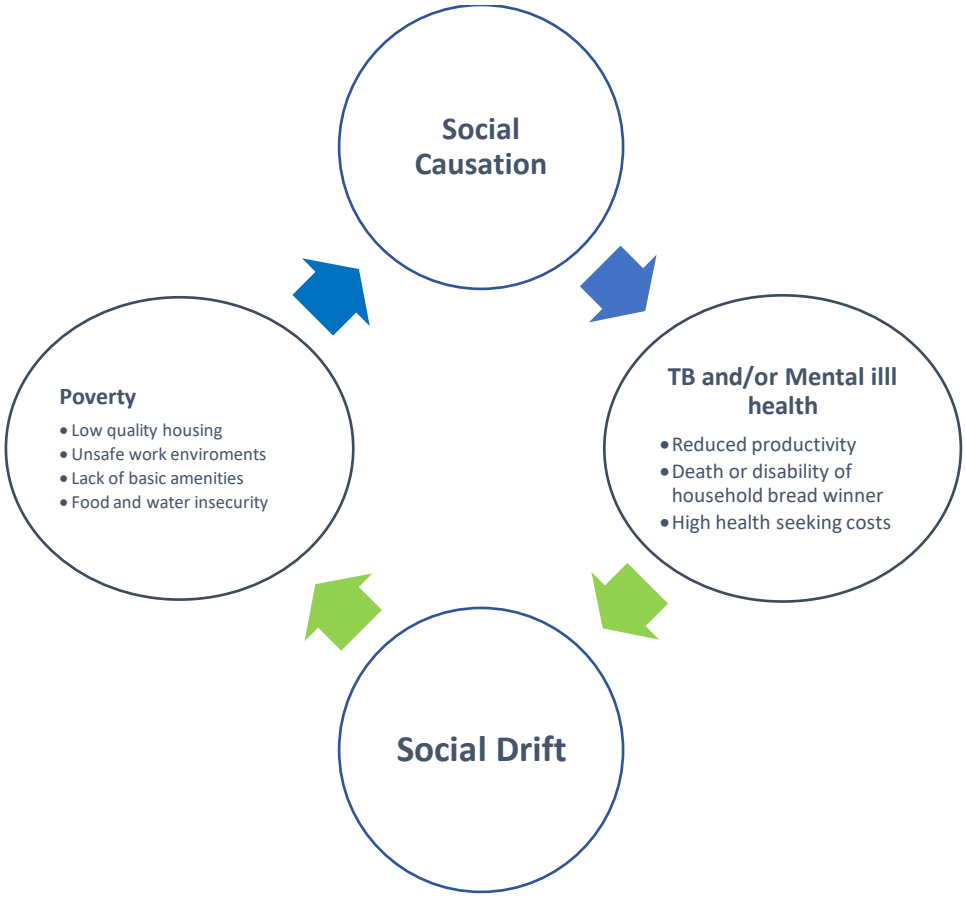
The economic implications of a TB episode undeniably put psychological strain on those experiencing them and thus serve as a driver mental distress in people with TB. Independently of TB, poverty also serves as a risk factor for developing mental distress. For example, the majority of the 115 studies included in a 2010 systematic review show a positive association between mental health conditions and poverty (53). Poorer people are at higher risk of developing mental health conditions due to exposure to poverty induced stressors including social exclusion, decreased social capital, poor nutrition, increased obstetric risks, violence, and trauma. Simultaneously poorer people are also at higher risk of TB infection

or disease due factors such as poor nutrition and living in overcrowded and lower quality housing which create a suitable environment for TB transmission and disease progression (54). Therefore, in high TB burdened settings poorer people are at high risk of independently and jointly developing TB and mental health conditions due to shared risk factors between TB and mental distress including food insecurity and poor-quality housing (37, 53).

Concurrently, TB and mental health conditions can both independently and jointly lead to impoverishment of economically vulnerable households due to reduced productivity levels as a result of morbidity and the direct and indirect health related costs associated with both conditions (55). In this manner TB, mental distress and poverty exist in a vicious cycle, where people living in poverty are at higher risk of developing TB and or mental distress while both conditions simultaneously increase an individual's income vulnerability. This vicious cycle can be explained via the social drift and social causation theories (56). The social drift theory, with regards to mental health and social class, is the theory that a mental health condition leads to a downward drift in an individual's social class (57). While the social causation theory stipulates that adverse social and economic conditions of poverty increase risk for mental illness (56). These processes can happen concurrently as evidenced by a study using longitudinal data from the National Income Dynamics in South Africa (56). The dataset comprised of 11,440 individuals from the general population aged 15 years or older, who were interviewed at 3 time points, in 2008, 2010–2011 and 2012 respectively (56). The study aimed to test social causation and social drift hypotheses using structural equation modelling across the three time points (56). Findings from the analysis show that worse individual economic status at baseline was independently associated with worse depression two and four years later (56). Conversely worse depression at baseline was independently associated with worse economic status two and four years later (56).

In summary the social drift theory demonstrates how people living with mental health conditions and or TB are likely to drift into poverty or be pushed further into poverty due to reduced productivity levels, while the social causation theory highlights how poverty increases the risk of TB and or mental health conditions through specific stressors including social exclusion, decreased social capital, poor nutrition, violence and trauma (55). Figure 5 below, provides a visual illustration of how these two theories relate to TB and mental distress.

Figure 5: TB/CMD and poverty cycle. Adapted from The Mental Health and Poverty Project (53)



Stigma

Stigma is another social process that plays a key role in development of mental distress in people with TB. Daftary et al (2018) argue that TB stigma is partly rooted in policy, and this is exemplified by public control measures that describe people with TB as potential threats to the health of others (58, 59). Public health practices including involuntary testing, certain TB treatment rituals (for example, daily hospital visitations), and confidentiality breaches in clinic settings often reinforce TB stigma (58, 59). The prevalence of TB stigma in Zambia is high. For example, 113 of 138 (81.9%) people with TB reported encountering TB stigma in a 2015 mixed methods study conducted in Lusaka Zambia (60). TB stigma has significant negative implications on people with TBs investigation and treatment trajectory. For example, stigma was the main reason why 46 of 115 (40%) people with TB in a 2018 cross-sectional study conducted in the Copperbelt province of Zambia felt like discontinuing their TB medication (61). Community level drivers of TB stigma are complex and often differ by setting (low-or high- TB burden settings) (59). In Zambia and similar settings in the region, TB Stigma at community level is influenced by the local perceptions of aetiology of TB transmission. For example, the majority of the 300 people with TB that participated in a mixed methods study conducted in a Kanyama clinic in Lusaka Zambia often mixed the biomedical and local aetiology of TB (62). The study findings show that participants believed that TB was transmitted through: eating utensils (51.7%); excessive drinking or smoking 89 of 300 (29.7%); engaging in taboo ‘sexual behaviours (23%); and bewitchment (28.3%) (62). A different study carried out in 2006, in two urban communities in Lusaka and one rural community in southern Zambia, further highlighted how perceptions of TB as a sign of HIV infection also fuelled TB stigma in this setting (63). Findings from the study highlighted that HIV is a highly stigmatised condition and TB symptoms and diagnosis were often assumed as a strategy for patients, families and health workers to hide an HIV diagnosis (63).

In addition to TB stigma, people with TB are likely to experience intersecting stigmas due to the social and biological realities of their condition. For example, the relationship between TB, poverty and mental distress described above implies that people with TB are at higher risk of being in lower socio-economic brackets and developing mental distress. Being poor (64) and mentally ill (65, 66) can be stigmatised identities. Additionally, people with TB are likely to be living with other stigmatised co-morbidities including HIV (67-69). The convergence of these marginalised identities can be explored through the intersectional lens. The intersectional lens is focused on the relational nature of power highlighting how it engenders both advantage and inequality and how this plays out in the everyday life experiences of individuals (70). In relation to TB, people who are at higher risk of TB often have less power to shape their worlds, they have a diminished degree of control over material, human, intellectual and financial resources that often translates into less access to quality housing, nutrition, health knowledge and quality health services. The convergence of stigmas faced by people with TB living with other stigmatised identities, including stigmatized comorbidities such as mental distress and HIV, and poverty result in a higher magnitude of stigma. For example, a 2009 study investigation of perceived stigma in 591 HIV patients in Ethiopia found that those with other stigmatised identities reported higher levels of stigma (71). More specifically participants who were co-infected with TB and HIV reported higher levels of perceived stigma compared to non-co-infected HIV participants, (OR = 1.4, 95% CI: 1.2, 2.0) (71). Additionally, those who were non-literate (OR = 1.9, 95% CI: 1.2, 3.0) and female (OR = 1.6, 95% CI: 1.2, 2.3) also reported higher perceived stigma (71). Intersectional stigma increases the barriers people face to accessing the necessary health and social support needed for improving their health and wellbeing (72, 73).

Stigma therefore both causes or exacerbates mental distress in people with TB while increasing barriers support. Both mental health and TB stigma delay health seeking and increase treatment noncompliance resulting in poor health outcomes particularly for individuals with comorbid presentation of both conditions.

This PhD acknowledges the importance of the intersectionality between TB and mental distress but is more narrowly focused on the syndemic nature of TB and mental distress, meaning it highlights how TB and mental distress reinforce each other and increase the general burden of disease in context of shared risk factors rather than focusing on the relative power dynamics reinforcing this relationship. It does so by reflecting on how poverty, stigma, and other social factors both contribute and exacerbate the mental health and TB comorbidity. Additionally, the PhD is only focused on people with TB and TB survivors rather than TB outcomes among people with mental distress.

Mental health services and tuberculosis care

General population mental health services in low to middle income countries

There is a significant scarcity in the mental health services in LMICs (74), despite more than 80% of the global mental health burden coming from these countries. As of 2009 mental health conditions and substance abuse disorders accounted for 8.8% and 16.6% of the total burden of disease in LMICs, respectively (75). A scoping review of 35 studies that aimed to summaries the key barriers to the provision and utilization of mental health services in LMICs concluded that the barriers that LMICs face in bridging the mental health service gap, include limited and unsustainable resources (financial and

skilled mental health personnel), the low priority of mental health when ranked against other diseases, and deficient stewardship (74).

Integration of mental health services into routine tuberculosis care

The high prevalence of mental distress in people with TB coupled with the negative health implications of this co-morbidity as described above provide compelling evidence for the need to integrate mental health services into TB care. Additionally, due to the syndemic nature of the TB epidemic in Zambia, mental health integration into TB services provides an opportunity for delivering mental health services to some of the most vulnerable members of society, such as the poor and those living with multi-morbidities including HIV. Moreover, data suggests that integration of mental health and TB services is cost effective (76) and thus an attractive opportunity in settings with limited mental health human and resource capacity such as Zambia (66).

There are several types of mental health interventions that have been integrated into primary health care in settings similar to Zambia (77). The primary health care setting provides health services at both individual and population level and caters for the bulk of the health care needs for most people (78). In this review I focus on interventions that aim to improve capacity of general health care teams to screen and treat mental distress because these interventions may be more applicable for people with TB who have more access to general health workers than trained mental health personnel, particularly in places like Zambia, which, in 2020 only had 10 psychiatrists and 425 mental health nurses in the public health sector to serve a population of over 18 million (79). More specifically, the review will focus on task sharing approaches where general health workers, including community health workers, are trained to deliver mental health services through task sharing approaches.

Examples of the integration of mental health services into primary care

Evidence suggests that given adequate training and support general health workers can effectively provide mental health services to their clients. A 2021 systematic review consisting of 95 trials compared the effectiveness of mental health treatments delivered by community health workers to services delivered via standard of care in LMICs (80). The standard of care was described as either encouraging patients to attend primary health care, continuation of primary health care, primary health care aided by depression guidelines, monthly symptom review, physical examination and general health education, or referral to mental health specialist (80). These standard of care components were compared with community health worker-led psychological interventions (80). The findings found that the use of community health workers in the delivery of mental health services resulted in lower prevalence of mental distress in intervention communities (243 per 1000 participants) compared to control communities that followed the standard of care (426 per 1000 participants) up to 6 months after the intervention (80).

There is currently limited evidence from TB and mental health integration. Below I focus on two examples of the integration of mental health services into primary care from which Zambia and TB care could learn, namely the WHO Mental Health Gap Action Programme (mhGAP) and the friendship bench.

WHO Mental Health Gap Action Programme (mhGAP)

The mhGAP is an example of a model that has been frequently used to integrate mental health services into primary health care in low resource settings. The mhGAP was developed through an intensive process of evidence generation, which was translated into interventions by a group of international experts, who collaborated closely with the WHO Secretariat (78). The mhGAP uses a task sharing

approach where non-mental health specialists in the primary health care setting, including primary care doctors, nurses and other members of the health-care workforce are trained to identify and treat mental distress using simple, evidence-based techniques for mild to moderate cases of mental, neurological and substance use disorders (81). People with severe mental health conditions are referred to specialised mental health workers (81). It was developed as a way of scaling up services for mental, neurological and substance use disorders, particularly in countries where the available mental health specialists cannot meet the mental health needs of the population. Based on the model, mental health specialists play an essential and substantial role in training, support and supervision of non-specialist health workers for delivery of mental health services (81).

Several studies in LMICs have evaluated the effectiveness of the task sharing approach proposed by the mhGAP model. Some studies have found the mhGAP model to be effective at training health workers to identify and treat mental distress. For example, a 2021 systematic review of 162 studies, mostly conducted in Africa (40%) and South-East Asia (25%) aimed to provide a summary of the use of the mhGAP in clinical practice highlighted positive outcomes at both facility and economy level (82). Health facility level findings were evaluated in (58/162) studies and these were focused on evaluation of the outcome of mhGAP training courses on non-specialised health care workers. The evaluations used by the studies included cross-sectional surveys, cohort studies, pre-test/post-test studies, retrospective medical records reviews and randomised control trials (82). Overall, health workers showed an increase in mental health knowledge and awareness, improved attitudes towards people with mental health conditions, more confidence in managing mental health conditions at health facility level, increased job satisfaction and interest in mental health training (82).

Seven studies conducted an economic evaluation of the mhGAP. These evaluated human resource requirements, based on the prevalence of mental health conditions in specific regions, and cost-benefit analyses of the scale-up of effective treatments for depression and anxiety (82). Findings suggest scaling up mental health services using the mhGAP model was cost effective. For example, a multi country study, included in the systematic review, was conducted in five countries, three from SSA and two from Asia, and assessed the expenditure of scaling up mental health services over a period of ten years in order to meet the estimated mental health needs in these countries over the period (82). The estimated population in need of mental health services was calculated by relating prevalence estimates for the different disorders to the total population in each country (82). The authors disaggregated the costs accounting for costs of training, supervision and management, and hospital-based services while accounting for inflation in different settings (82). The findings revealed that the additional costs per year to reach target service coverage were relatively low, averaging less than $0.10 per person in each country (82).

One of the limitations in the literature is the limited evidence regarding patient perspectives around satisfaction with the mhGAP, therefore more qualitative research needs to be done to understand how acceptable this model is for people with TB in this context.

The friendship bench

The friendship bench is an example of an intervention that has adapted the task sharing model to be better suited for the local context. The Friendship Bench trains community health workers to deliver a novel intervention consisting of cognitive behaviour therapy and problem-solving therapy for the treatment of mental distress. The friendship bench was originally developed as pilot intervention in a high-density community known as Mbare in Zimbabwe (83). A team of psychologists, a primary care

nurse and a psychiatrist trained 20 community health workers to deliver mental health services using a problem-solving approach (83). The community health workers (locally referred to as grandmother health providers) in the pilot worked at one of the four primary health facilities in Mbare, were female, literate, and had a mean age is 58 years (83). Prior to the pilot, their main roles were community health outreach, including providing practical, psychological, spiritual and adherence support for people living with HIV and TB (83). They also delivered community health education and promotion (83). The intervention was delivered on a bench placed in a discrete area of a clinic (83).

A 2016 cluster randomized clinical trial that evaluated the friendship bench in Zimbabwe consisted of 24 clinics, half receiving the intervention and the other half served as control communities (84). The primary outcome of the study was the score of the locally validated Shona Symptom Questionnaire (84). The trial followed 576 participants over six months (84). The finding revealed that participants in the intervention group had lower scores in the Shona Symptom Questionnaire (adjusted mean difference, −4.86) translating to fewer symptoms of mental health conditions than control group (84). Similarly, a 2021 study of 27 Zimbabwean women who received the friendship bench intervention found that the proportion of women with depression or suicidal ideation declined from 68% at baseline to 12% after the 6-week intervention (85). The authors also found a significant decline in symptoms of depression as evidenced by a drop in the mean score of the Shona Symptom Questionnaire from mean 7.2 at baseline to 1.6 post intervention (85).

The friendship bench has been piloted in both low income (Malawi, Zanzibar) and high-income countries (North America), showcasing a shift from the status quo in Global Mental Health practices as the friendship bench is an innovation developed in a low-income country and is now being applied to address health disparities in high income setting (86). Acceptability of the friendship bench has been

investigated using qualitative methods. For example, a study conducted in rural village in Zimbabwe adapted the friendship bench intervention to consist of nine village health workers conducting weekly home visits for 6 weeks, to 27 women who had symptoms of depression as established by a previous study (85). The village health workers used a structured approach to identify problems and generate solutions. They were also trained to identify signs of clinically significant depression or suicidal ideation (85). The study used FGDs with village health workers that were delivering the intervention, and IDIs with women receiving the intervention to assess how acceptable the intervention was to them (85). The findings showed that the women receiving the intervention responded well to the intervention, and several of the women hoped the intervention could continue beyond the duration of the study (85). Trust and familiarity between the women and the village health workers was integral to the acceptability of the intervention as the women feared being gossiped about and stigmatised if confidentiality was breached (85). A 2017 qualitative study also conducted in Zimbabwe assessed the perception of the friendship bench intervention by ten people living with HIV who had received the intervention (87). The authors found that participants perceptions of the intervention consisted of four main features: the first being feelings of relief that they were not being judged for their HIV status, the second was feelings of being supported in their efforts to resolve their problems, followed by a sense of empowerment that enabled them to overcome of their problem (87).

General health workers perception of mental health integration into routine care

Mental health integration has been evidenced to be something that general health workers are willing to do but feel they have limited knowledge and experience to implement (88-90). There is currently very scant literature specifically focused on exploring health workers perspectives of the TB and mental health nexus. Studies focused on provider perspectives around the integration of mental health services into HIV care highlight a positive attitude towards the integration of services. For example, a South

African study on HIV health worker attitudes and perception of mental health integration into routine HIV care found that 80% of the 197 health workers believed it is their responsibility to identify their clients with comorbid mental health conditions, and 87.5% believed they should intervene and help treat or manage mental health conditions in their clients. However, 72.5% expressed concern about the delivery of mental health services due to feelings of inadequacy with regards to screening and treating mental health conditions in their clients (91). Similar findings were highlighted from another South African study that conducted IDIs with 22 HIV health workers who agreed with the need to integrate mental health services into routine HIV care but did not feel confident enough to diagnose mental health conditions in their clients (92).

In addition to acceptability, it is also worth exploring how feasible health workers think these interventions are for them to deliver. The findings of a 2013 systematic review of 21 studies assessing the acceptability and feasibility of task-sharing among health workers had mixed results (93). For example, some studies in the review showed that community health workers and nurses had high levels of self-perceived competency to deliver the intervention, particularly those who had adequate training and multiple levels of supervision and support (93). Additionally, the review findings showed that some of the general health workers felt they were the right people to deliver interventions for mental distress in their communities because they were already well known and the rapport from their existing roles in providing health services to community members reduced concerns about confidentiality breaches (93). However, the review also highlighted that in some studies task sharing was demoralising due to the increase in workload that was not accompanied by adequate compensation or supervision by mental health specialist staff (93). Additionally, two studies in the review noted that community health workers often felt that they were not considered health workers or part of the team by nurses and doctors, who were not confident about the ability of community health workers to provide mental health care to

clients (93). In a separate 2019 qualitative systematic review of 10 studies, focused on the experiences of community health workers trained in task-sharing psychological interventions, the majority of studies indicated that community health workers felt that the training sessions were too short with insufficient information provided and participants often expressed a strong desire for adequate supervision and support (94). In both of the latter reviews, participants expressed feeling overburdened by the additional load of delivering the mental health interventions on top of their already existing roles and duties and how this led to both demotivation and burnout (93, 94).

The negative perceptions about implementation of mental health services highlighted by health workers reflect some of the barriers to mental health integration highlighted in the broader literature and should be considered during TB mental health integration. These barriers are structural, socio-cultural, and individual level barriers. Structural barriers include inadequate mental health training, and lack of the financial and human resources needed for successful intervention. A synthesis of stakeholder perceptions of factors acting as barriers and facilitators to the implementation of programmes for mental distress in primary health care in LMICs provides recommendations that could address the barriers confronted. The synthesis recommends that mental health integration in primary care should comprise of components that aim to strengthen health systems through improved financing, allowing for: adequate staff numbers to carry out the interventions; continuous capacity building for general staff who are delivering the intervention; and strengthening of specialist services and referral systems (95).

Other recommendations I draw on that I believe can be applied to TB and mental health integration in Zambia are based on two multi-country initiatives that aimed to provide concrete evidence to test and demonstrate the effectiveness of mental health interventions in primary care in low resource settings like Zambia. The first initiative was the Programme for Improving Mental Health Care (PRIME). PRIME is

a consortium of research institutions working together with Ministries of Health in five low resource countries in Africa and Asia with the aim of generating high-quality research evidence on the implementation and scaling up of treatment programmes for priority mental health conditions in primary and maternal health care. The treatment programmes were created through adaption, implementation, and evaluation of the mhGAP. The second initiative is the Africa Focus on Intervention Research for Mental health (AFRIM), which is a research and capacity building hub assessing the effectiveness of mental health task sharing by general health workers in low-income settings in Africa. Based on their experience, these initiatives highlight some essential steps worth considering when planning on integrating mental health services into routine care (96). The key lessons include:

1. Active stakeholder engagement through the planning and execution of the integration process. Stakeholders should include mental health specialists, researchers, policy makers, district level health planners and service providers, particularly nurses who are likely to be key players in the integration process (96).
2. Adequate ongoing, structed and supportive supervision (weekly if in groups, or bi-monthly or monthly if individualised) from trained mental health personnel or non-specialists in existing supervisory structures who have specifically been trained in mental health service provision (96).
3. The use of culturally appropriate tools that include locally identified cultural concepts of distress and manifestations of mental health problems that are commonly understandable, including the use vignettes rather than a checklist of symptoms (96).
4. The use of manual-based approaches such as mhGAP to deliver care through non-specialist health workers (96).
5. Adequately compensating health workers for the additional roles required by the mental health intervention (96).

With regards to this PhD, facilitators, and barriers to potential mental health integration into routine TB care will be considered at health facility and community level, focusing on health care workers and stakeholders' attitudes, knowledge, and current practices of mental distress management.

Summary

The relationship between TB and mental health is complex and goes beyond the biomedical definition of a comorbid relationship. Both conditions are fuelled by social factors, specifically poverty, and therefore often cluster in economically vulnerable populations. It is therefore worth exploring the convergence of these diseases through syndemic theory, which takes into account the biological realities of disease interactions and their health consequences in context of the social and economic conditions that create opportunities for such interactions to occur (97). To fully addresses the mental health needs of people with TB, policy makers also need to consider how to mitigate the social stressors attached to TB, particularly how to account for the threat of food and income insecurity posed by TB investigation and diagnosis in this setting. The prevalence of mental distress amongst people with TB is higher than that of the general population in the SSA region. Given the high need for mental health services by people with TB, it is vital to consider integration of mental health services into the routine TB treatment cascade. Such an integration needs to consider providers perspectives around the TB and mental health while also addressing any contextual barriers around mental health service integration that may exist.

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Chapter three: Methods

Reflections on Mixed Methods

In this PhD I used a mixed methods approach to critically reflect on the relationship between TB and mental health from TB investigation through to post TB treatment in Zambia. Before describing the methodology in detail, I first want to reflect on a mixed methods approach and why I conducted such for this research.

There are two broad approaches of data collection and interpretation in research: qualitative and quantitative methods. Qualitative research is descriptive and aims to understand phenomena that are not easily measured, such as human behaviour, particularly from the informant's perspective (1). Thus, the aim of qualitative research is to understand the social reality of participants as close to how they experience it as possible. Qualitative research emerged from different disciples in the social sciences leading to a variety of data collection methods, with the main approaches being observations (participant and structured), ethnography, interviews (for example, key informant, elite, in-depth interviews) group discussions, informal interactions (and resulting field notes) and document reviews (1). Qualitative methods provide rich contextual data, explaining the reasons behind specific phenomena (1). Qualitative findings are context specific, but they can be used in comparative analysis of one setting to another. In this thesis, two key qualitative methods (IDIs and FGDs) were used to investigate objectives one and three, focused on TB patients' and healthcare workers' understanding of mental distress and contextualised insights into experiences of mental health during TB investigation and treatment.

Quantitative methods on the other hand focuses on gathering numerical data. It is used to find patterns, make predictions, and test the relationship between factors of interest. Quantitative analysis in health research is designed to estimate population parameters and measure the relationship between biological, social, environmental, and behavioural factors (2). It is also used to estimate health conditions and outcomes (2). Quantitative findings in public health are often compared and/or generalised across different populations. There are several advantages with the use of quantitative methods including large volumes of data and reliability of results based on assessments of standardized tests, and generalizability of findings (2). The main downside to quantitative methods is that it does not determine the reason behind the phenomenon, providing less empirical data about this than qualitative research (2). Quantitative methods, in form of a cross sectional survey in one of the TREATS project study communities, was used in objective two of this PhD which investigated the prevalence of mental distress in TB survivors post TB treatment in a manner that is generalizable to similar settings.

Mixed methods make use of both quantitative and qualitative research methodology. In this thesis I employed an integration approach of mixing methods, whereby qualitative and quantitative data were collected and analysed separately and then integrated in the interpretation phase. The integration approach was one of the three approaches highlighted by a 2013 systematic review of 30 published health services research articles that aimed to describe how mixed methods researchers mix the qualitative and quantitative aspects of their studies (3). The review recommends an integration approach if the research aims to provide a better understanding of a phenomenon, as the approach provides the opportunity to triangulate conclusions reached through the different methods (3).

There was specific attention paid to the methodological needs of each objective. The approach of using a tailored method for each inquiry is highly recommended by a 2006 review of 232 social science articles focused on integrating quantitative and qualitative research methods, as it suggests there should be a clear relationship between the research topics and the overall design of the investigations (4). For example, objectives one and three were focused on exploring experiences and perceptions about mental distress by people with TB and those that treat them. Qualitative research was used for these objectives because it is well suited at unpacking human behaviour as it allows participants to explain how, why, or what they were thinking, feeling, and experiencing during an event of interest (5). Quantitative methods were better suited for objective two which aimed to investigate the burden of disease in a population group (6).

The mixed methods approach also provided the opportunity to corroborate findings across the different objectives; the detailed nature of qualitative data expands the depth of the research while the potential generalizability of quantitative methods offer a degree of breadth to the findings (7). For example, the qualitative inquiry in objective one is focused on understanding drivers of distress during TB investigation and treatment period while objective two aims to quantitatively assess if these drivers persist beyond the TB treatment period. The integrated methods approach from both objectives combines to provide a longitudinal conceptualisation of the relationship between TB and mental distress in Zambia. Additionally, the qualitative findings may provide deeper contextualised insight into the drivers of distress described in the quantitative analysis.

There are three notable challenges that come with utilising mixed methods that are presented in the literature and applicable to this thesis. The first is the possibility of collecting too much data that is not

sufficiently analysed or well-integrated (8, 9). For this research, all the data was collected to respond to a specific inquiry, for example, patient level qualitative data was collected to understand mental health experiences of people with TB while quantitative prevalence data was collected to understand the burden of distress in TB survivors. The different inquiries of the PhD were designed to speak to each other and provide a holistic understanding of TB and mental distress in the Zambian context by simultaneously addressing specific parts of this relationship. By being very specific about which research question each data component aimed to address, the research design avoided the pitfall of over collecting and under analysing data. For example, in the stakeholder FGDs I analysed all the mental health responses to answer objectives one and three, (see appendices 3f and 3h for FGD interview guides). The second challenge was the possibility of contradictory conclusions obtained from the qualitative and quantitative findings. In the case of this research, these contradictions could provide an opportunity for development of new research questions for clarification and exploration, which is an approach recommended by the literature (3). Additionally, these contradictions may reflect limitations in using certain methods or tools when measuring certain social phenomenon such as mental health or stigma. The last notable challenge is the increase and diversity in resources and skills required for data collection, management and analysis as compared to research that utilises one approach (9). The resource considerations were addressed in two ways: firstly, the PhD was embedded in a larger trial and all the data collection components were conducted as part of specific inquiries within TREATS, thus requiring minimal additional resources beyond those utilised in the larger inquiries. For example, the qualitative components of the thesis were part of the qualitative work package of the TREATS project with the mental health questions used in this PhD included in the broader qualitative interview and FGD guides. Similarly, the quantitative data was collected by being embedded in the TREATS prevalence survey. Secondly, the challenge of skills was mitigated by working collaboratively with a supervisory and advisory team that comprised of individuals with specialities in either or both methods (qualitative and

quantitative) and significant experience in conducting mixed methods research with interdisciplinary teams on field-based studies in Zambia and similar settings (for example, Malawi).

After carefully considering and mitigating the challenges posed by using mixed methods, I believe that combined they provide an opportunity to comprehensively explore the relationship between TB and mental health in Zambia. In the following section I detail the methods for each objective including the recruitment of participants, the training of RAs and the ethical considerations.

Qualitative Methods

Objectives 1 and 3

1. To critically examine how people with TB conceptualise and experience mental distress (common mental disorders and psychological distress) during TB investigation and treatment in the context of socio-economic factors contributing to the TB and mental distress in Zambia.
1. To explore TB health workers' and stakeholders' conceptualisation, management, and treatment of mental distress in people with TB in the Zambian context.

Background

These objectives one and three aimed to gain an overall understanding of the mental health experiences of TB patients in eight Zambian communities during their TB investigation and treatment period, investigating these experiences alongside those of TB health workers' and other stakeholders' conceptualisation and management of mental distress in TB patients during TB treatment. This qualitative inquiry of patient and provider experiences aimed to deliver a comprehensive overview of

mental health experiences, understanding and management approaches during TB investigation and treatment in Zambia, highlighting existing gaps and opportunities in mental health management during TB treatment. The findings will also aim to provide recommendations on how to better support people with TB in managing mental distress during TB while preparing and motivating health workers to provide more comprehensive care for people with TB.

Primary Qualitative Data Collection Activities.

Focus Group Discussion (FGD): This method of data collection was selected to explore the perspectives about mental health and TB from multiple stakeholders in the field of TB across eight communities. Each FGD consisted of approximately 7-15 participants. The sample size followed the rationale highlighted in the literature which states that the number of participants taking part in a FGD should be sufficiently large enough to create discussion and maximize viewpoints but small enough to create a controlled environment that enables all participants to be able to contribute (10-12). The literature points to the importance of selecting participants based on their ability to provide detailed insight and information about the research topic (11). Accordingly, each participant represented a different organisation or group that provided TB services, for example, community-based TB screening provided by non-governmental organisations (NGO), and schools providing TB literacy programmes, in each community. Each participant was knowledgeable about how people with TB manage having TB and potential drivers of distress associated with a TB diagnosis. FGDs were a convenient, time- and cost-efficient way of collecting data from multiple participants, which is one of the most commonly cited advantage of this methodology (13).

Additionally, FGDs are a good approach for exploring new phenomena (14); in the case of this research the new phenomenon is how the relationship between mental health and TB is understood by TB care providers in Zambia. The field of mental health is still in its nascent phase in Zambia, and little is known about how mental health interacts with chronic conditions such as TB in this setting. The open-ended questions used in the FGD guide allowed for broad range of responses, thus allowing more comprehensive exploration of the mental health and TB. For example, "*How has working in this community been*?". Furthermore, FGDs provided the ideal environment for stakeholders to voice their opinions while questioning and challenging other participants' views. For example, in the extract below two participants shared different viewpoints on how men and women are affected by mental health, with one participant believing women are more affected due to fear of stigmatising perceptions around TB infection, while the second participant did not believe mental health outcomes were tied to gender but rather to the information that people with TB had received and their personalities.

"I: …who gets more depressed between men and women

R1: women.

R1:… women cry saying that they are not prostitutes and don't sleep with men

I: Uhuh

R4: Okay on the issue of depression, I think it varies depending on information received. It varies, you will find that sometimes men will get more depressed, and a woman will take it lightly. Then sometimes a woman will get depressed, and a man will take it lightly. The same applies to children also you will find that a 10-year-old child will take it (their TB diagnosis) differently from a 12-year-old. So, what I can say is it is it depends on the person." (Z8, stakeholder FGD)

The different perspectives that emerged during the discussion also provided a space for reflection on participants' individual experiences with regards to mental health. For example, after discussion of how mental distress is expressed in different individuals the participant below used his nephews experience with mental distress to share a personal encounter of how he believes mental distress manifests in people with TB.

R3: As everyone has already said, mental health affects people in different ways, there are people who become short tempered, they become rude and can say anything. For example, my nephew who just passed away the other Sunday, he became short tempered and sometimes forgot the people he was talking to. (Z8, stakeholder FGD)

One of the strengths of FGDs is that the group interactions in FGDs enable participants to bounce ideas off each other and this often led to voiced opinions that may not have surfaced in individual interviews (13-16). The literature also points out that the group dynamic in FGDs may shift attention from the individual and allow participants to focus and share insights on what 'other' people do; this projection of an individual's perceptions onto others may reduce social desirability bias and may lead to richer data (15).

There were some drawbacks to consider with the use of FGDs for this research. Firstly, the logistics of organising FGDs, particularly finding appropriate spaces and times that were suitable for all participants, was at times challenging. Adequate preparation and planning were required, including sending out invitation letters and following up these invitations with phone call discussions with the aim of synchronizing appropriate times across participants. An additional organisational challenge was finding

an appropriate venue that was convenient for all participants. The process of finding a venue required planning and appropriate communication with local clinics and other community spaces for easily accessible locations such as an outside shaded space at the local clinic. Convenience for study participants is listed as a key consideration to promote participation during FGDs in the literature (17). RAs spent between one to two weeks to ensure all logistics were in place to successfully hold the meetings. Good planning and event organisation are integral components of conducting successful FGDs (18).

A further consideration is the potential power gradient that exists between researchers and participants and between individual participants. Participant to participant power relations can be managed through careful consideration of the composition of each FGD (19). For this research, we aimed for a spread based on age, sex, and occupation. Participants were chosen with the aim of encouraging varied viewpoints while keeping the atmosphere and power relations comfortable enough for everyone to contribute. For example, the stakeholder FGD conducted in Z8 consisted of 7 participants (five men and two women) aged between 27 and 55 years representing two health-based NGOs, a school, a theatre club, a clinic and faith-based organisation. The literature points out that there is no perfect composition a focus group and the composition should be tailored to the needs of the research question (14). Given the mix of participants, power dynamics in the groups were minimized with the use of a well-trained and skilled moderator. The moderators were trained to use covert and explicit strategies to minimize power dynamics, these included encouraging participation from all participants either overtly, or through selective eye contact or body language, or through polite interruption of a participant who was taking over the discussion. These strategies of minimizing unequal power dynamics between participants have been popularly employed and encouraged in the literature (11, 20). The moderator also played a key

role in reducing the potential power gradients between the researchers and participants by firstly producing an environment that enabled participants to take ownership of the discussion which shifted the control from the researcher to the participant. The literature points out that the strategy of empowering participants to discuss and interpret the questions, and ask their own questions not only reduces the perceived power held by the researcher but also results in richer data (21). Secondly, moderators came from the same residential towns as the participants, enhancing language and cultural understanding between the researcher and the participants.

FGD Recruitment and Participant Characteristics

In each of the communities, we conducted FGDs with NHC (n=96). The NHCs are community-based groups formed under the guidance of health personnel that play a key role in health planning and budgeting activities. They serve as a link between the community and the health facility, advocating for disease prevention and control in their communities. Purposive sampling was used to recruit members of the NHC. The eligibility criteria for the NHC participants included providing key TB services in the eight TREATS communities and clinics during the time of the PopART trial through data collection for the TREATS project. NHC participants were recruited through the help of trial community mobilisers and clinic-based TB treatment supporters.

FGDs were also conducted with stakeholders working in the field of TB (n=57). The TB stakeholders in each community were then identified through the NHC FGDs. TB stakeholders included government organizations (for example, schools and clinics) and NGOs (for example churches, public health institutions, home based care organizations). All stakeholders provided different types of TB services including screening, testing and follow up care for individuals with TB in their respective communities.

A total of nine NHC and Stakeholder FGDs were conducted, one in each community and two in a community that had two local clinics. Table 1 below summarises the FGD activities that contributed to this PhD

Table 1: FGD Table of participants

Activity	**Participant Type**	**Characteristic**	
Focus Group Discussion	NHC (N=96)	Number of activities	9
	Stakeholders (N=57)	Number of activities	9

In-depth interviews (IDIs): Semi structured IDIs were chosen due their ability to provide rich contextual evidence on mental health experiences of people with TB. Participants were health workers (n=9) and former TB patients (n=80) and were selected using Patton's maximum variation sampling strategy based on age and sex (22). A total of 89 IDIs were conducted. Like FGDs, the IDIs used open-ended questions, for example, "*Do you have any ideas what might reduce stress and worry for men and women with TB*?" (See health worker IDI guides in appendix 3a). These types of questions elicited a broad range of responses by giving participants the opportunity to respond in ways that made the most sense to them. The one-on-one interactions with participants allowed for deeper probing to encourage more meaningful elaboration of responses (23). Participants selected for IDIs usually have direct experience of the topic under review (24); in the case of this research, it was lived experiences with TB and potential

mental distress or, for health workers it was witnessing their clients with TB in mental distress and in some cases managing this through counselling or by referring them to available mental health services. One of the key advantages of IDIs is the depth of information obtained with regards to a participant's experiences and their interpretation and perceptions of the topic at hand. The literature highlights that IDIs provide the interviewer with access to the participant's world and allow participants to tell their own story often leading to a range of insights that are unattainable through other data collection techniques (24). For example, in IDI one from Z2 the participants relayed their story of TB diagnosis, starting with experiences of misdiagnosis during TB investigation, to his experiences of suicidal ideation after his TB diagnosis and how he managed to cope with the emotions resulting from his diagnosis. Furthermore, sensitive topics like mental health lend themselves well to IDIs because they afford the interviewer opportunity to establish a rapport with the interviewee before exploring personal information (25). For example, the former TB patient guide started by asking introductory questions, such as where the participant lives and who they live with, followed by their perceptions about TB transmission and then after ten questions focused on TB treatment seeking and taking TB medication, participants were asked about the impact of TB on their lives, including how TB affected their mental health. (See TB patient interview guide, appendix 3c).

Each interview was conducted by a graduate social scientist trained to administer the guide and trained in ethical conduct and the specific informed consent form process. I conducted two IDIs in two communities within Lusaka. Interviews lasted between 45 mins to 1.5 hours. Informed consent was obtained before the interview and took between 10 to 20 minutes. The consenting process included a brief introduction of the TREATS project including why the participant had been approached to take part in the study, what they can expect during the study activities, any potential benefits and risks for

participating in the study, how they can withdraw at any point of the study. Additionally, all consent forms contained a referral sheet that contained the and the contact details of the TREATS principal investigator and the and ethics committee chair in Zambia, which provided a channel for participant to share any concerns or questions that they might have about the study. Participants were provided with some time to read the information sheet attached to the consent form with RA staying close by to answer any questions. See (appendices 2 for consent forms) and the ethics reflection later in this chapter. Participants who agreed to take part in the study signed two consent forms, they kept one copy while the other copy was kept at in a locked cabinet at the site office. These were sent back to the head office by the Zambart district administrator either by vehicle or via a postal service. The consent forms were checked for quality assurance by the Zambart regulatory officer. If permission was obtained, audio-recordings of the interview were conducted to allow researchers to focus on the discussion during the interview. In addition to the recording, RAs also took brief notes which were used to create a summary soon after the interview was completed. The summaries were comprised of discussion points and information of interest that were shared by the participant during the interview. The summaries were reviewed by myself and a second social scientist (Melleh Gondwe) with the aim of assessing interviewing techniques and highlighting gaps or areas for improvement for subsequent interviews.

A potential shortfall with the use of IDIs in research pertaining to sensitive topics such as mental health and stigma is that participants might be unwilling to share their experiences. To mitigate against this, every effort was made to create a comfortable environment that would allow participants to share their experiences and thoughts in a neutral non-judgemental environment. For example, RAs received extensive training on mental health stigma and how to make participants feel comfortable when asking sensitive questions. For example, the guide highlights the following three key areas with making

participants comfortable during data collection 1.) active listening, RAs practiced how to listen to what respondent were saying while showing the participant that they were listening through gestures such as nodding 2.) Sitting position, RAs were encouraged to sit at a certain angle not directly opposite the participant as this may make them uncomfortable, 3.) RAs were trained to be comfortable with silence, as participants may need time to reflect on their emotions before responding to questions. See appendix 4a for further details of the mental health training package. Additionally, spaces were chosen to maximise participants' privacy in a bid to make sure participants were comfortable. Examples of spaces include participants living rooms, backyards, or rooms at the local clinic. Some of the practical draw backs of using IDIs in this research included the significant logistic and organisational effort required to set up each of the interviews, which included frequent calls with participants to set up a time to do the interview, finding a participant preferred location, and organisation of refreshments and transportation reimbursements for participants. RAs therefore spent a significant amount of time planning for each of the interviews. Additionally, transcriptions of the recordings were also a time-consuming venture. On average each recording took an average of two days to transcribe.

IDI Recruitment and Participant Characteristics

Purposive sampling was used to recruit health care workers. The eligibility criteria for health care workers included providing key TB services in the clinics from the eight TREATS communities during the time of the PopART trial. Eight of the health care workers recruited were nurses and one was a health technician; and they all worked predominantly with diagnosed TB patients by providing medication and follow up care. TB patient participants were recruited through the clinic TB registers with the help of TB treatment supporters from each clinic. The eligibility criteria for former TB patients included being 18 years and older, being diagnosed with TB between September 2016 and November 2017, and having a TB treatment outcome of 'complete' at the time of data collection. In each health facility we aimed to

recruit 14 participants in each of the intervention communities, seven of whom were diagnosed through passive case finding, while the other seven were diagnosed by CHiPs during the PopArt intervention. While in each of the control communities we aimed to recruit a total of 28 participants, 7 from each of the 4 communities. More details about the recruitment process for the IDIs with people with TB can be found in the methods section of chapter four. Table 2 below summaries participants characteristics.

Table 2: IDI Table of Participants

Activity	**Participant Type**	**Characteristic**	
In-depth Interviews	TB patient (N=80)	Male	47 (59%)
		Female	33 (41%)
		Age Range	19-75
		Self-Reported Living with HIV	37 (46%)
	TB Health Worker (N=9)	Male	2
		Female	7
		Age Range	25-58

Areas of Inquiry

Mental health questions were included in FGDs and IDIs as a distinct section and theme. Key questions included: the causes of mental distress during the TB diagnosis and treatment period; the implications of poor mental health for people with TBs' quality of life and TB treatment outcomes; availability and accessibility of mental health services for people with TB; and the understanding of mental health by TB health care providers and broader TB stakeholders. Areas of inquiry were guided by the literature and reviewed by the thesis supervisory team, which includes an expert in the field of mental health.

Data sources: TREATS qualitative dataset.

Training of qualitative research assistants

I facilitated training for the team of seven (four men and three women) TREATS social science RAs collecting qualitative data for the TREATS project with considerable assistance from a second social scientist. The RAs were development studies (5) and social work (3) graduates. Training took place over a 3-day period from August 15th -17th 2018. I trained the RAs on the relationship between TB and mental health. This component of the training provided a background on common mental health conditions including depression and anxiety and how these potentially interact with TB, both on a biological and social level in the Zambian context, and ways of making participants feel comfortable while asking sensitive questions. All the sessions were paired with practical sessions that included role play activities.

Training sessions on data collection was conducted by senior social scientist from the TREATS team. The sessions included theory on qualitative research methodology, namely FGDs, IDIs and observations. The theoretical sessions were paired with practical sessions for data collection in which RAs conducted mock IDIs and FGDs; this allowed them to practice techniques used in moderating FGDs and effective probing. Additional data collection training sessions included practicalities of organising FGDs and IDIs and building a rapport with participants. Data collection training also included a section on reflexivity which aimed to get RAs to reflect on how they influence participants interactions and participation. Reflexivity training also focused on identifying mental health and TB biases that RAs may have and the importance of being self-reflective during the research process.

Research ethics training was conducted by the TREATS regulatory officers; the training included lessons on principles of Good Clinical Practice (GCP) and Foundations of Research Ethics which included principles of beneficence and non-malfeasance. More specifically, RAs were trained on how to:

1. obtain informed consent from potential research participants
2. minimise the risk of harm to participants
3. protect participants' anonymity and confidentiality
4. avoid using deceptive practices
5. give participants the right to withdraw from the research.

Ethics training also covered principles on research integrity. These trainings were all based on workbooks that highlighted key moments in global ethics history with appropriate exercises to help facilitate learning.

I managed this team of RAs, with the assistance of a second social scientist, throughout the data collection period by accompanying them to the field, holding regular debriefing session through phone calls and face-to-face meetings where possible. I also regularly reviewed the data the team collected. It should be noted that, despite the comprehensive training on mental health and data collection, RAs still sometimes used stigmatizing terms about mental health during interviews, such as referring to people experiencing mental distress as crazy or mad. Additionally, RAs sometimes did not probe as comprehensively as needed. These shortcomings were addressed during the debriefing sessions between the RAs and myself or the second social scientist (MG).

Qualitative Data Analysis

IDIs and FGDs were recorded and transcribed verbatim. Verbatim transcription refers to the word-for-word transformation of recorded audio into a written form (26). The RAs were provided with transcription guidelines and were trained on the transcription process. Parts of the transcripts that were spoken in local languages were translated directly into English. In this research we aimed for naturalised verbatim where the content of the recording was transcribed as is (27). For example, local idioms such as "*thinking too much"* were not translated into depression but were translated directly as they were said during the interview. Preserving the content of the interviews and the FGDs provides material for deeper more contextualised analysis.

Data was analysed thematically. Thematic analysis is a method of analysis that includes identifying, organizing, and describing themes found within the data (28). Thematic analysis served practical advantages for this research, for example, the literature shows that thematic analysis is a useful method for highlighting similarities and differences while examining the perspectives of multiple participants (29). Additionally, the structured nature of thematic analysis is well suited for analysis of a large data set, as the structured approach guides the researcher into producing a clear and organized final report (29). Furthermore, thematic analysis allows for flexibility that leads to detailed, yet complex data (28, 29). For example, in our analysis we opted for a flexible approach to coding which included combination of a deductive and inductive coding approach. The literature indicates that a combination of the two approach provides a more comprehensive analysis (30). Deductive coding included the creation of a preliminary codebook or framework to help guide the analysis; this framework was created around the TB mental health literature, the WHO International Classification of Functional Disability and Health Framework (ICF) (31). Inductive coding involved identification of unexpected themes and patterns from

the data (32). Data was double coded by me and a graduate social scientist using ATLAS ti version 7 software. The process of double coding was done to increase the rigour of the analysis. Differences in output were discussed with my primary supervisor with guidance from my broader supervisory team.

Ethical Consideration

Informed consent was obtained from all participants prior to research activities. All participants who contributed data for this objective were 18 and above. Witnesses were present for all illiterate participants. There were two illiterate participants in the 80 IDIs conducted with people with TB. IDI and FGD participants were provided with refreshments, a packet of biscuits, and for participants that were interviewed outside their homes transport reimbursement of ZMW 50.00, which was equivalent to approximately $2.

The most common ethical challenge that was anticipated during field work was the incorrect consenting of illiterate participants. To mitigate against this, RAs were thoroughly trained on the how to determine the literacy levels of participants and the criteria of who can serve as an independent witness for illiterate participants. A potential risk to participants was unintentional disclosure of participants' TB or HIV diagnosis. To minimise this risk the following measures were taken:

1. Purpose of the data collection was kept between the participant and the data collector (either me and/or other RAs.)
2. All IDIs and FGDs occurred in private or at a participant-selected settings.
3. All personal data was stored securely as described in the *data management plan.*
4. Pseudonyms were used in published records of the data.

Qualitative Data Management Plan

Recruitment of participants was done with a recruitment document which had participants names and contact information. Each RA had a recruitment document pertaining to their data collection site. The hard copies of these documents were kept in locked cabinets (together with the consent forms) at the Zambart site offices. The Zambart district administrators and the RAs in each site had access to these cabinets. All data generated during research activities was managed based on data management practices taught to RAs during the training. These management practices ensured that all research notes were written up close to data collection by the RA who collected the data. Hard copies of the research notes and tools were kept with the RAs. All recordings were done on encrypted recorders, while soft copies of transcriptions were kept on a password-protected computer and all the participants names were replaced with pseudonyms in the transcripts. Transcripts were sent to the social science data manager via email in form of a password protected document. Audio recordings were deleted once the transcription process was complete. Pseudonyms were used in all research reports and publications.

I regularly reviewed the data in tandem with a graduate social scientist for quality assurance purposes. In events where there was irregularity in the data, the data would be sent back to RAs for necessary revisions.

Quantitative Methods

Objective 2

To investigate prevalence and risk factors of probable mental distress in TB survivors compared with individuals with no history of TB in an urban Zambian community.

Background

People with TB experience a high prevalence of mental distress during their TB investigation and treatment period (33). Mental distress during this period is driven by both by biological factors, such as morbidity, and social economic factors, including increased levels of poverty (34). These factors are likely to persist beyond TB treatment completion. Analysis from this inquiry aimed to establish if the burden of distress in adult TB survivors differs from that of people who have never had TB before. The findings would provide evidence on needs for long term mental distress management for people with TB.

Primary quantitative data collection activities

A cross sectional observational study design was used to investigate prevalence of probable mental distress in adult TB survivors compared with adults who had never had TB in an urban Zambian community. The hypothesis of the investigation was that TB survivors would have a higher prevalence of probable mental distress compared with adults who had never had TB. The literature shows that the cross-sectional study design is the most relevant design when assessing the prevalence of disease at a given time point (6). The study design is also credited for allowing comparison of prevalence of diseases between exposed and unexposed population (35); in the case of this PhD is allowed for the comparison of mental distress between individuals with a history of TB and those without, while also assessing the risk factors of distress in this population.

Quantitative outcome measure

Mental distress is a term that includes common mental disorders such as depression and anxiety as well as general psychological distress that does not reach criteria for formal psychiatric diagnosis.

Measuring Instrument

The measuring instrument for this work was nested within the *TREATS prevalence survey questionnaire (see appendix 3i)* that was conducted in one urban community in Zambia. In addition to the mental health screening tool, the questionnaire had several sections, including sections focused on TB symptom screening, TB history and health seeking, and TB stigma. The mental health screening tool was an abbreviated version of the Self Reporting Questionnaire (SRQ), which was used to screen for probable mental distress in TB survivors.

The SRQ was developed by the WHO primarily as a screening tool for CMDs in primary health settings in developing countries; it consists of 'yes' or 'no' questions that screen for depression, anxiety, and somatic manifestations of distress (36). A response of a 'yes' indicates the presence of the symptom in question and is given a score of 1, while a response of 'no' indicates the absence of that symptom and is given a score of 0. An abbreviated version of the SRQ (SRQ-5) was validated in Zambia. It includes 5 items from the SRQ-20; weighted scores on each item are summed to give a total score (37). The SRQ-5 was appropriate for screening for mental distress in this context as highlighted by the validation study (37), but the composition of the question that make up the SRQ-5 have a strong somatization inclination; we therefore included two mood related questions from the SRQ-20 which has also been validated in Zambia (36). The additional two questions were not part of the outcome variable as seen in

chapter 5 but were included in an exploratory sensitivity analysis to investigate whether their inclusion would affect the study outcome.

Justification of Choice of Measuring Instrument (SRQ 5)

The SRQ-5 is a valid tool for screening for mental distress in Zambia evidenced by its test characteristics from a 2013 validation study with 400 primary health care attendees conducted in Zambia (37). The SRQ-5 was validated using the Diagnostic and Statistical Manual of Mental Disorder 4th Edition as a gold standard criterion (37). In the validation study, the SRQ-5 had test characteristics similar to the SRQ-20 for detection of mental distress, with an area under the Receiver Operator Curve (ROC) of 0.925 (37). Due to resource constraints (time and personnel needed to administer the broader questionnaire) the TREATS project was only able to incorporate a very brief mental health measuring instrument (less than 10 items), that would require limited additional training, preferably with yes/no answers (rather than Likert scale) and didn't include a question on suicide as it obligates follow-on care that was beyond the capacity of the TREATS project. Other instruments considered included the PHQ-9 and the full SRQ-20, but both were incompatible with the requirements of the TREATS project. The SRQ-5 was appropriate as it was both brief and had been validated in Zambia (37). In the analysis we used the SRQ-5 scoring system (using weighted items) and a cut-off of 4/11 as determined by the validation study (37).

Disadvantages of Primary Outcome measuring Instrument

The SRQ is not a substitute for a clinical diagnosis but indicates probable cases of mental distress. Conventionally, SRQ item scores are summed, and a score above an optimum cut-off point chosen to define mental distress in the screened individual. However, there are significant limitations in measuring a continuous phenomenon such as mental distress using a categorical scale (38). Additionally, the point

analysis is unable to tease out specific patterns emerging from the data (39). To navigate these limitations, I conducted a sensitivity analysis that considered the SRQ scores as a continuous variable, in addition to the orthodox method of analysing the SRQ categorically. This methodology has been explored in the literature and allows potential mental distress symptom patterns unique to the populations under investigation to emerge while also being sensitive to fact that individual mental health exists on a continuous spectrum (40). The second limitation of using the SRQ-5 is that it was originally developed by professionals outside of the local context and therefore may not fully appreciate or capture the social and cultural context of mental illness in the Zambian setting, this limitation is discussed in further detail in the discussion of the thesis (chapter seven). The most appropriate screening tool would use ideologies of the local communities where the mental illness is being investigated and, in the absence of such a tool, qualitative methodology should play an integral role in the interpretation of data obtained from the screening tool. For example, local idioms of distress play an integral role in explaining how mental distress is understood in specific context. The literature has shown the importance of shifting away from total reliance on high resource setting conceptualizations of distress and adapting tools that screen for distress in each context with the appropriate idioms for distress (41). A 2016 literature review of the challenges associated with mental health measurement in low resource setting proposes the Design, Implementation, Monitoring and Evaluation (DIME) process which uses qualitative methods to build an assessment tool of mental distress from a qualitative understanding of target population (42). As part of the DIME process the qualitative work should aim to capture local terms, manifestations, understandings, and stigmas of mental health (42). The SRQ-5 was not adapted for the purpose of this study; however, I have recommended such adaptations for future research (see chapter seven).

Translation of Primary Outcome measuring Instrument

I facilitated a team of translators and RAs through the translation of the SRQ items used in this PhD. The SRQ was translated into Nyanja and Bemba, the predominantly spoken languages in the community where data for this objective was collected. The translations were carried out by experienced translators who have an extensive track record with translations of epidemiological questionnaires. A validated translated Chewa version was used for cross reference during the translation process of the Nyanja version as the two languages have strong similarities (43). After the first phase of the translation process, the translators facilitated a back-translation session with 15 study staff, including myself, all of whom are fluent in English and native speakers of either Nyanja or Bemba. None of the study staff, except me, had ever seen the SRQ tool and were consequently unbiased in their responses. Individuals were asked to independently translate each item back into English. These translations were then compared to the English version of the SRQ. Any discrepancies were discussed amongst the group and an independent native speaker who had not been exposed to the tool was asked to back-translate the agreed translation. The process of translation used in this research is termed 'back-translation and bilingual test' in a 2004 literature review of 47 studies on instrument translation (44). The review identified six types of translations process ranging from forward only translations (considered the least thorough translation process) to a back-translation with both monolingual and bilingual test (considered the most rigorous translation process) (44). According to the findings of the review back-translation and bilingual test is one of the most rigorous and complete instrument translation process (44). The review showed that this process allows for the detection and correction of discrepancies and requires a substantial effort to assure validity of the translation (44). Additionally, the use of the bilingual test provides a test for clarity and appropriate use within the context where the tool is being intended for use. The drawback of the back translation and bilingual test without the monolingual test is the

potential of recall bias (44), however, to rectify this the translation test process only used individuals who had never seen the SRQ before.

Training of study staff in Administering the Mental Health Screening Tool

A team of 18 RAs administered the TREATS prevalence questionnaire that contained the nested SRQ-5. Most of the RAs were trained psychosocial counsellors with previous experience administering epidemiological questions in the TREATS project study communities, specifically as part of the PopART intervention. The research teams were divided into two groups that were trained separately as part of the measures to prevent the spread of COVID-19 infection during the training. The training sessions occurred on the 10th and 17th of August 2020. Other measures taken to reduce the risk of COVID-19 infection included keeping training session short, exclusion of the piloting phase of the training, and strict adherence to the Zambart COVID-19 control measures, see appendix 5 for the Zambart COVID-19 protocol.

Most of the RAs were trained psychosocial counsellors with experience administering questionnaires from previous epidemiological studies, particularly PopART. However, they had no experience administering a mental health screening tool. I trained the team on administration of the SRQ and provided a brief conceptual background of mental health disorders with a focus on depression. The SRQ administration training was based on the *Training package for data collectors and monitors on the administration of Self Reporting Questionnaire (see appendix 4) adapted* from a similar context (45). The training included understanding of depression in TB patients, explanation, and discussions of the conceptual understanding of each item in the SRQ 5, strategies for making participants feel comfortable

when asking sensitive questions, and role-playing sessions (facilitated by study managers) which allowed RAs to gain familiarity with administering the tool.

Study setting and Participants

Data from this objective was obtained from an urban community where the TREATS project and the TREATS-COVID sub study were conducted. The community is in central Zambia with a population of approximately 28,000 individuals. The study community was divided into blocks, namely TREATS blocks and TREAT-COVID blocks. Data from this PhD was collected from the TREATS blocks only, therefore data from participants in the TREATS-COVID blocks were excluded from the analysis. The TREATS project and the TREATS-COVID study are described in further detail in chapter one and five of this thesis. A random sample of 9,533 were enumerated in the study community, of these 2,935 were excluded due to not meeting the eligibility criteria, leaving a total of 6,598 eligible participants. Of the eligible participants 3,013 did not consent and 192 were missing at least one of the mental health indicators used to comprise the mental health score and were therefore excluded. The total number of participants was 3393. See the methods section of chapter five for more details.

Statistical Analysis

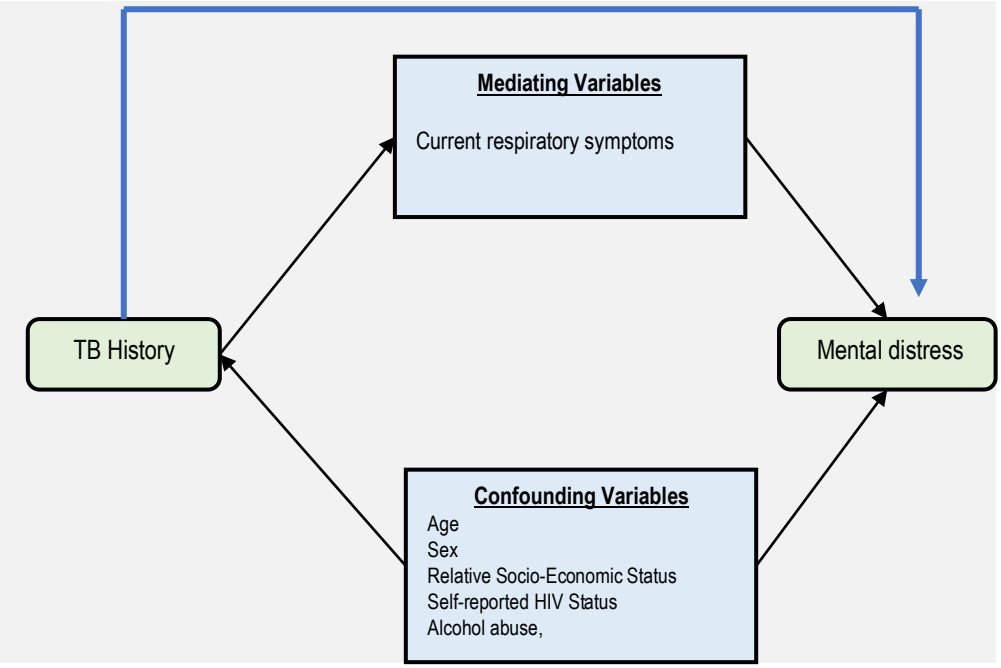
I defined the outcome as a binary variable in line with the traditional analysis of SRQ scores. The analysis categorised individuals with SRQ-5 scores of 4 or above as having probable mental distress. The main exposure variable was self-reported history of TB. Other exposure variables included socio-demographic characteristics including age, gender, education, employment status, and relative social economic status and health related variables for example HIV status and alcohol misuse. Associations were explored using (cross) tabulations and recoded if deemed necessary. Associations between the outcome

(probable mental distress yes/no) and primary exposure (TB history yes/no) and other co-variates were investigated using chi square test, and logistic regression.

Sensitivity Analysis.

Sensitivity analysis was conducted by exploring associations between the outcome and exposure variables at different cut-off values of the outcome variable, namely a cut-off 3 and 5, which were a value above and below the determined cut-off. Additional sensitivity analysis was conducted considering the outcome as a continuous variable, which included the additional 2 mood questions from the SRQ 20. This sensitivity analysis compared the distribution of the mean scores of the SRQ-5 (plus 2 mood items) in participants with and without a history of TB. Figure 6 below provides a summary of the analytical approach used in this analysis

Figure 6: Framework of analytical approach



Ethical considerations

Informed consent was obtained from all participants prior to research activities by the RAs. The information sheet and informed consent form were administered in the participants households during the TREATS prevalence survey enumeration process. Participants who were not found during the enumeration were consented when they came to the mobile field site at the reception in station. The consenting process took approximately 15 to 20 minutes. Participants that were did not wish to take part in the study were thanked for their time and were excused. Some of the benefits of taking part in the study included health education, and TB and HIV screening services provided at the MFS. Additionally, each participant was also given a t-shirt to change into during the chest-X-ray, and ZMW 20.00 (equivalent of ~USD 1.00) for transportation reimbursement.

All participants who contributed data for this objective were above 15 years of age. *An assent* form was used for participants aged below the age of 18 while those aged 18 and above provided their *informed consent*. Witnesses were required for all illiterate participants.

A potential risk to participants was unintentional disclosure of their TB or HIV diagnosis, however, to minimise this risk the following measures were taken:

5. All personal data was stored securely on the Zambart server.
6. All personal identifiers were stripped from the data.

As raised in the introduction, this data was collected during the COVID-19 pandemic, therefore unique ethical considerations pertaining to this objective had to be considered, these considerations included ethics around conducting research during a pandemic. This included an expeditated ethics review for the TREATS-COVID study from the National Health Research Authority (NHRA), and additional requirements on how TREATS would protect study participants and research teams during the pandemic. Safety of participants and research staff were of highest priority during data collection. These were detailed in the Zambart COVID-19 policy, (see appendix 5). The initiative adopted during the pandemic included provision of appropriate personal protective equipment for all study staff, individual risk assessment to tailor staff's work environments to minimize their risk of infection, frequent sanitation and cleaning of vehicles and surfaces and regular testing for COVID-19 infection in all field staff. All staff were tested using a self-test kit twice a week. If a staff member tested positive, then they had stay home for at least two weeks or longer if their symptoms persisted. Staff who tested positive and were not resident in the study site were asked to self-isolate in their hotel rooms. Managers supported staff through phone calls and referrals to local clinics if necessary.

Initiatives to protect participants included provision of two cloth face masks, temperature checks and enforced social distancing measures during data collection. Furthermore, the research team aimed to avoid placing any additional stress on participants and were therefore particularly sensitive to participants concerns especially with regards to their safety. For example, research staff provided participants with sanitizers, and all interviews were conducted outside. Data collectors also maintained more than 2 meters between themselves and participants during data collection activities. The research team also provided guidance on how to avoid getting infected with COVID. The COVID-19 pandemic affected my ability to be in the field during data collection as I was unable to travel to the community where data was being collected due to restriction that were in place at the time and my own health challenges during this period.

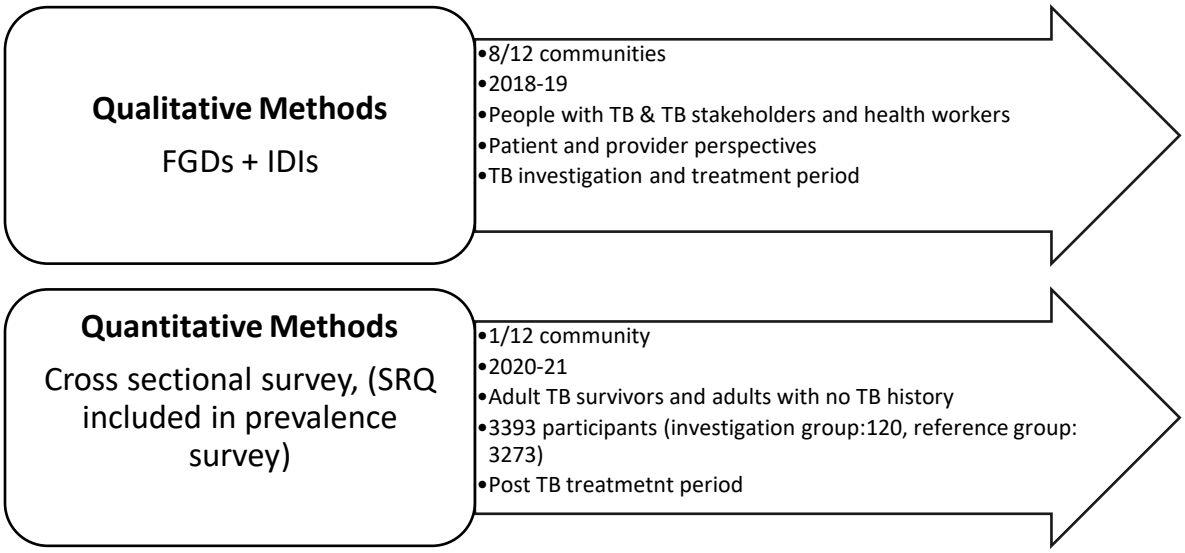
Quantitative Data Management Plan

Quantitative data for this PhD was collected from the TREATS prevalence questionnaire. The questionnaire was administered with the use of password protected electronic handheld device (tablet computer). The tablet computers were set up so that they cannot be used for any purpose other than data capture. All personal identifying information (including names, address, house number, telephone number, GPS-coordinates, and health care identifiers) were encrypted while all study consent forms, and any other research-related hard copies were stored in locked cabinets accessed only by authorised study staff (ethics and regulation officers and Principal Investigators) of the TREATS project. Data was synchronized daily to a central server at ZAMBART. All participant names were stripped and replaced with a unique study pin number to protect participants' confidentiality.

Summary of Research Methods

Figure 7 below provides a summary of the methods used in this thesis, detailing the number of communities, time period of data collection, and perspectives of interest.

Figure 7: Summary of research methods



Reflexivity

Mental health is a sensitive topic that requires introspection and solicits a degree of vulnerability from participants. Emotional vulnerability is not fully accepted in Zambia and the idea of openly discussing mental health challenges is still gaining traction. There are high levels of stigma towards mental health, which contributes to shame for people experiencing mental illness in this setting. The literature points out that understanding what constitutes shame in a particular culture should be part of the practice of doing no harm (46). Therefore, any research done on this topic in this setting should be conducted with a considerable amount of sensitivity particularly to the cultural understanding and navigation of mental health.

I walked between an insider and outsider identity through this research process. On one hand I had never had TB before or cared for someone with TB. In this way I was an outsider. However, my cultural background and lived mental health experience may have afforded me an insider perspective. As a Zambian social scientist, I feel I was well placed to conduct research on this topic as I had the skills and cultural understanding to do so. Both myself and the other researchers that collected the data were largely Zambian researchers conducting research on a Zambian participant base, and this allowed participants to identify with us and may have afforded us a degree of access and a willingness of participants to participate that may not otherwise have been the case. I had limited contact with participants due to my own health and later the COVID-19 pandemic and was only able to conduct two IDIs and co-facilitate two FGDs. However, my familiarity with the tools and contact with the RAs may have let to richer analysis through a better understanding of the data.

In some instances, my insider identity may have served as a weakness, most notable, is that my own preconceived ideas about how mental health is understood in this context may influence the research process and interpretation of the findings. This lack of objectivity and authenticity is cited in the literature as a strong argument against insider positioning (47-49). To mitigate against this, I constantly evaluated any potential biases I might have and continued to introspect on the influence of my identity through the data collection and analysis of this PhD. I did so by constantly collaborating with other researchers through all steps of the research. Some of the researchers had similar insider identities as my own while others had a stronger outsider identity with regards to this research sample. This is a common way of practicing reflexivity in qualitative studies as highlighted by a 2015 study with 34 scholars focused on methods, benefits and challenges of reflexivity in qualitative social work research (50). The study showed that speaking with others provided an opportunity to be less directly immersed

and allowed other people can provide an awareness of blind spots while providing alternative viewpoints and by so doing increasing the transparency and trustworthiness of the research (50).

Ethics

Ethical approval for all TREATS project procedures was obtained from the Bio-medical Ethics Committee of the University of Zambia (UNZABREC) (ref 005-02-18), National Health Research Authority and the institutional ethics review of the London School of Hygiene and Tropical Medicine (LSHTM 14985). Additional expeditated permission for the TREATS COVID study was also obtained from the NHRA, and the LSHTM ethic committee (22606).

Table 3: PhD timeline

Year		2018		2019				2020				2021				2022			
Quarter		Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Qualitative data collection		X	X																
Quantitative data collection											X	X							
COVID-19 PANDEMIC																			
Upgrading												X							
OBJECTIVE 1	Data analysis for objective 1					X	X	X											
	Write up of Objective 1 Manuscript									X	X	X	X						
OBJECTIVE 2	Data analysis for objective 2													X	X	X			
	Write up of objective 2 manuscript															X	X	X	
OBJECTIVE 3	Data analysis for objective 3					X	X	X											
	Write up of Objective 3 manuscript								X	X	X	X							
Report	Thesis preparation																X	X	
Viva																			X

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Results: Chapters four, five and six

People with Tuberculosis conceptualise and experience mental distress during TB investigation and treatment in the context of socio-economic factors contributing to the TB, and mental distress in Zambia.

Community engagement in a TREATS study community

"I used to feel like that (life was not making any sense) because I would be sleeping all the time, even when I was awake." (25-30-year-old woman Z7)

This chapter explores the mental health experiences of people with TB during TB investigation and treatment, focusing on the multi-layered drivers of distress, including individual, social economic and health facility level drivers. The chapter draws on data from 80 participants across 8 urban communities in Zambia. Data was collected in the form of IDIs. The chapter responds to objective one of this PhD, which is, *to critically examine how people with TB conceptualise and experience mental distress (common mental disorders and psychological distress) during TB investigation and treatment in the context of socio-economic factors contributing to the TB, and mental distress in Zambia*. It therefore addresses the gap in acknowledging and recognizing mental health experiences of people with TB **(Research Gap: 1)**.

This chapter was published in BMC Psychology on the 19th of July 2022. The published manuscript is included in full below. After the published manuscript, I include some additional findings about the coping mechanisms of former TB patients. These findings were excluded from the manuscript because they did not fully fit the theme of drivers of mental distress which were the focus of the manuscript. However, I believe it is vital to include these findings in the thesis as they give a more comprehensive understanding of mental health experiences of people with TB.

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RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A - Student Details

Student ID Number	1603214/RPHP	Title	Ms
First Name(s)	Tila Mwinde		
Surname/Family Name	Mainga		
Thesis Title	Critical assessment of the intersection between mental health and Tuberculosis (TB) during TB treatment and beyond in a Sub-Saharan context with a focus on Zambia		
Primary Supervisor	Professor Virginia Bond		

If the Research Paper has previously been published, please complete Section B, if not please move to Section C.

SECTION B - Paper already published

Where was the work published?	BMC Psychology
When was the work published?	19 July 2022

If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the .	Yes	Was the work subject to academic peer review/?	Yes

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SECTION C — Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	

Stage of publication	Choose an item*

SECTION D - Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	My role in the research includes selection of the mental health questions that were incorporated into the interview guide used to conduct in-depth interviews with the sample of 80 people with TB. These included questions pertaining to the causes of mental distress during the TB investigation and diagnosis and treatment period, the implications of poor mental health for people with TBs' quality of life and TB treatment outcomes, availability, and accessibility of mental health services for people with TB. I also trained and managed the 8 social science research assistants who collected these data. I conducted some of the in-depth interviews. I analysed the data using thematic analysis of the data. The data was double coded by me and a second social scientist. I drafted the manuscript and incorporated comments and suggestions from co-authors regarding the content of the manuscript. I then submitted the manuscript to the journal and addressed reviewers' comments with guidance from my supervisory team.

SECTION E

Student Signature	[redacted]
Date	06/09/2022
Supervisor Signature	[redacted]
Date	19/09/2022

Mainga et al. BMC Psychology (2022) 10:179

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BMC Psychology

RESEARCH ARTICLE Open Access

Qualitative study of patient experiences of mental distress during TB investigation and treatment in Zambia

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Abstract

Background: The mental health and TB syndemic is a topic that remains under-researched with a significant gap in acknowledging and recognizing patient experiences, particularly in the sub-Saharan African region. In this qualitative study conducted in Zambia, we aimed to explore the lived mental health experiences of TB patients focusing on their multi-layered drivers of distress, and by so doing highlighting contextual factors that influence mental distress in TB patients in this setting.

Methods: The study draws on qualitative data collected in 2018 as part of the Tuberculosis Reduction through Expanded Antiretroviral Treatment and Screening for active TB trial (TREATS) being conducted in Zambia. The data was collected through in-depth interviews with former TB patients (n = 80) from 8 urban communities participating in the TREATS trial. Thematic analysis was conducted. Additional quantitative exploratory analysis mapping mental distress symptoms on demographic, social, economic and TB characteristics of participants was conducted.

Results: Most participants (76%) shared that they had experienced some form of mental distress during their TB investigation and treatment period. The reported symptoms ranged in severity. Some participants reported mild distress that did not disrupt their daily lives or ability to adhere to their TB medication, while other participants reported more severe symptoms of distress, for example, 15% of participants shared that they had suicidal ideation and thoughts of self-harm during their time on treatment. Mental distress was driven by unique interactions between individual, social and health level factors most of which were inextricably linked to poverty. Mental distress caused by individual level drivers such as TB morbidity often abated once participants started feeling better, however social, economic and health system level drivers of distress persisted during and beyond TB treatment.

Conclusion: The findings illustrate that mental distress during TB is driven by multi-layered and intersecting stresses, with the economic stress of poverty often being the most powerful driver. Measures are urgently needed to support TB patients during the investigation and treatment phase, including increased availability of mental health services, better social security safety nets during TB treatment, and interventions targeting TB, HIV and mental health stigma.

Trial registration ClinicalTrials.gov NCT03 739736. Trial registration date: November 14, 2018.

Keywords: Tuberculosis, Mental distress, Contextual drivers, Poverty, Zambia, Patient experiences

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Background

There is growing global acknowledgment of the relationship

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between tuberculosis (TB) and mental distress [1–4] Mental (or psychological) distress refers to a state of emotional suffering characterized by symptoms of depression and anxiety" that can range from mild and transitory states to long-lasting and severe medically defined disorders [5]. Studies conducted in 2004 and 2009 indicate that the prevalence of common mental health disorders (CMD) in the general population in Zambia is between 20 and 14% respectively [6, 7]. Despite the potentially high prevalence of CMD, there is still a significant shortage of mental health services in country [8].

Prevalence rates of CMD amongst TB patients varies by country. A 2020 global systematic review and meta-analysis, that aimed to summarize the prevalence of depression among 4903 TB patients from seven countries, found a pooled prevalence estimate of 45% from 25 studies [9], which is significantly higher than the estimated global prevalence of depression of 3.8% [10]. The review highlighted a broad range of reported prevalence rates of depression from 80% in Pakistan to 16% in India [9]. Only two of the studies were conducted in countries (Turkey and China) that did not fit the criteria for the World Health Organization (WHO) 2016–2020 high TB burden [11], however the prevalence of depression among TB patients reported in the two studies also fell within the range reported from studies conducted in high burdened countries (China 17% and Turkey 61%) [9]. Further evidence, from a cross-sectional analysis of community based data from 48 low- and middle-income countries, found that TB patients were 3.5 (low-income) and 3.2 (middle-income) times more likely to be depressed than individuals without TB [12].

Zambia is among the top 20 highest TB burdened countries globally when measured by absolute number of incident TB cases [13]. Despite this considerable TB burden there has been little investigation of the mental health implications of a TB episode in the Zambian setting. Published studies conducted with regards to the intersection between TB and mental health in Zambia indicate a range in the prevalence of CMD in TB patients. One study found worryingly high rates of mental distress in their sample of 231 TB patients, with 30.9% expressing suicidality out of which 3.4% had attempted suicide at least once [14].

Mental distress in TB patients increases the likelihood of negative health outcomes by exacerbating poor health seeking behavior and ability to adhere to treatment [1, 3, 15]. The relationship between TB and mental distress is reciprocal and acts through complex channels [1]. People experiencing chronic mental distress are at higher risk of developing TB, while some biological and social drivers of TB increase the likelihood of mental distress in TB patients [1, 16]. Furthermore, high levels of mental distress have negative implications for TB treatment outcomes as highlighted by a multi-country study consisting of TB patients from Zambia, South Africa, Zimbabwe and Tanzania which showed that participants with higher levels of mental distress were more than two times more likely to be non-adherent than those with lower levels of distress [15].

TB, like many other life-threatening conditions can be considered an adverse life event due to how the disease can negatively alter an individual's physical and social state. In low and middle income (LMIC) settings like Zambia, individuals with TB may face an array of social economic adversities during the TB investigation and diagnosis period. For example, poverty can serve as a barrier to adequate TB investigation and treatment in this setting [17] and it is also a documented driver of mental distress [18]. Half of the Zambian population faces multi-dimensional poverty [19] and poverty is directly correlated with the TB epidemic, as documented by a 2013–2014 TB prevalence survey which highlighted higher TB prevalence rates in the lowest wealth category [20]. TB stigma is another social driver of mental distress in TB patients [21, 22]. The prevalence of TB stigma in Zambia is high. For example, 16.5% and 39.1% of the 115 patients in one urban community in Zambia reported experiencing high and moderate stigma, respectively [23]. Therefore, to both understand and address mental distress amongst TB patients, it is important to expand beyond a biomedical framework and examine the role that social context plays.

To our knowledge, the studies exploring the relationship between mental health and TB in the Zambian setting have mainly focused on investigating prevalence rates of CMD in TB patients [14, 24, 25]. This trend of quantifying mental distress levels in TB patients reflects other research in sub-Saharan Africa leaving a significant gap in acknowledging and recognizing patient experiences around the nexus of mental health and TB. Yet there is growing recognition of the importance of understanding patients experience of illness, including how illnesses intersect with patients' daily lives [26]. Furthermore, many TB patients in LMICs may be facing multiple health challenges and have complex health and social care needs that could undermine TB treatment outcomes if not adequately considered. Patient experiences therefore provide valuable knowledge that can be used to improve quality of health care, including mitigating the impact of contextual factors that may negatively impact the illness experience. This qualitative inquiry is the first study in the Zambian setting that aims to unpack the lived mental health experiences of TB patients focusing on their experienced social drivers of distress, and by so doing highlighting contextual factors that influence mental distress in TB patients in this setting.

Methods

The study draws on qualitative data collected in 2018 as part of the Tuberculosis Reduction through Expanded Antiretroviral Treatment and Screening for active TB trial (TREATS). TREATS is a follow-on study from the Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART) which was conducted in 21 communities, 12 in Zambia and 9 in South Africa. PopART was a randomized control trial that aimed to investigate the impact of combined community level TB/HIV interventions, including TB screening and counselling services, on HIV incidence. The intervention was delivered by approximately 400 community health workers known as Community HIV care Providers (CHiPs). A description of the full PopART intervention is detailed in a previous publication [27]. TREATS aimed to measure the impact of the PopART intervention on TB incidence and prevalence and is therefore being carried out in the same 12 PopART communities in Zambia.

Study setting

TREATS study communities were selected based on having TB notification rates greater than 400/100,000 per annum, a high HIV prevalence (ranging from 13 to 25%) and a proximity to a TB diagnostic Centre [28, 29]. All eight communities are urban and span across five provinces of Zambia. Common infrastructure includes a government health facility, schools, police stations, churches, market areas and transport depots [30]. Formal employment options are limited and most residents work in the informal sector as casual laborers or vendors trading in goods [30].

The government health facilities in all eight communities provide TB and HIV services. These services are provided in different departments and are coordinated by a by referral system [31]. HIV services are provided at the Antiretroviral Therapy (ART) department, where newly diagnosed HIV patients are enrolled in the national HIV program and also undergo clinical evaluations [31]. Newly diagnosed HIV patients are also tested for TB, most commonly though sputum smear microscopy, and are screened for TB symptoms at every ART visit [31]. All HIV positive patients who are diagnosed with TB are referred to the TB clinic to initiate TB treatment [31]. Individuals with presumptive TB are screened at the TB department for both TB and HIV. Those found to be HIV positive are referred to the ART department. The TB department is often staffed by one or two nurses and lay health workers known as TB treatment supports or peer educators [31]. All those diagnosed with drug susceptible TB are commenced on a six month anti- TB medication course as stipulated by national guidelines [31].

Data collection

Qualitative data was collected by a social science team consisting of seven field-based research assistants (three men and four women). The research assistants were graduates of development studies [5] and social work [2] and were guided by three experienced social scientists who provided training, de-briefing and field support (first, second and last authors). The social scientists were supported by the third author who is a psychiatrist with extensive experience in the region. The mental health training was conducted as component of a broader training around TB and TB stigma in Zambia and included components focused on: sensitivity to participants' emotional wellbeing; reflection of personal mental health biases; an understanding of emotional wellbeing; and a description of CMD in the region and how they are interlinked to TB in this context. The broader training included: an overview of qualitative data collection methods; research ethics; an overview of the TB and HIV epidemic in Zambia; and an overview of TB stigma in

Zambia. The training took place for 8 h a day over 5 consecutive days.

We conducted in-depth interviews (IDIs) with former TB patients across eight communities, four that received the PopART intervention and four that served as control communities during PopART. The eligibility criteria included: being 18 years and older; starting TB treatment between September 2016 and November 2017; having a TB diagnosis confirmed through sputum smear or gene expert; and a TB treatment outcome of 'complete' at the time of data collection.

We aimed to recruit 14 participants in each of the intervention communities who were divided into two groups. Seven were diagnosed through passive case finding and their diagnosis came about by participants going to the clinic without having been screened or referred to the clinic by a CHiP. Seven were diagnosed by CHiPs during the PopArt intervention and their diagnosis was a result of participants being screened by CHiPs as part of the CHiPS home visits during the PopART intervention. We therefore aimed to recruit a total of 56 participants from the intervention communities. In the control communities we aimed to recruit a total of 28 participants, 7 from each of the 4 communities. We believed this sample would provide an in-depth comparative perspective on TB diagnosis experiences between individuals diagnosed in the intervention and control communities. All participants from the control communities were diagnosed through passive case finding. TB patients diagnosed through passive case finding were recruited through the clinic TB registers while those diagnosed as part of the PopART intervention were recruited through the CHiPs PopART database. In each of the respective databases we selected the first two names from each month starting from September 2016 inclusive of December 2017 cumulating to 32 potential participants from each site. We used purposive sampling, based on Patton's maximum variation, to ensure a good distribution of age and sex [32]. Participants were invited to take part in the study through a phone using the cell phone numbers provided in the databases. If we were unable to reach the potential participant or if they declined to take part in the study, then we called the next potential participant who matched the demographic profile of the potential participant we initially tried to locate or invite. In total, 80 individuals agreed to take part in the study, of whom 52 and 28 were from the intervention control communities respectively. We were able to reach data saturation with this sample.

Interviews lasted between 45 min to 1.5 h. The time of the interview was determined by the participants depth of responses to the questions in the interview guide and any other additional information that they were willing to share. Areas of inquiry included an understanding of mental health, experiences and causes of mental distress during TB diagnosis and treatment, the implications of poor mental health for TB patients' quality of life and TB treatment outcomes, and availability and accessibility of mental health services for TB patients. A semi structured interview guide (see Additional file 1) was used, with probes where appropriate. Topic guides included: introductory questions; perceptions around TB transmission; treatment seeking pathways; TB treatment; impact of TB; TB stigma; support during TB investigation and treatment; TB treatment and food consumption; TB/ HIV co-infection; and closing remarks with an invitation for questions and comments from participant. The interview guide was adapted from the Converging Impact of Tuberculosis, HIV/AIDS, and Food Insecurity (RENEWAL) study, which was an anthropological study conducted in rural Zambia and peri-urban South Africa between 2006/7. The RENEWAL study documented the impact of TB and HIV co-infection in context of poverty and overstretched public health services and was conducted in 18 households affected by TB and in 17 comparative non-affected households. Findings from the RENEWAL study have been published previously [17, 32].

Research Assistants and participants agreed on the most convenient and private locations to conduct the interviews; these were often in participants homes (living rooms or an outside sitting area) or in a private location at a participating government clinic closest to the participant's home.

Ethical considerations

Ethical approval for all study procedures was obtained from the Observational Research Ethics Committee of the London School of Hygiene and Tropical Medicine (LSHTM) (#14985), and the Bio-medical Ethics Committee of the University of Zambia (005/02/18). Informed written consent was obtained from all participants prior to data collection activities. The emotional wellbeing of participants was central to the research process and participants were welcome to revoke participation at any point during the interview.

Data analysis

Interviews were conducted and recorded either in English or a local language that the participant was comfortable with. English transcripts were transcribed verbatim, while those conducted in local languages were translated into English during transcription. Data was analyzed thematically using a coding framework developed around the TB mental health literature, and the WHO International

Classification of Functional disability and health framework. Further codes were added during analysis. Data was double coded by the first and second authors using ATLAS ti software. Any discrepancies with themes emerging from the data were resolved by correspondence with the last author and securing common consent among the first, second and last authors. Additional exploratory analysis of how demographic, social, economic and TB characteristics (including TB history) mapped on mental distress symptoms of participants was conducted in excel by the first author and reviewed by the last.

For this analysis *TB stigma* is defined as a dynamic social process that is enacted through individuals, communities, organizations, and structures [33] resulting in the devaluation of people with TB [34]. It manifests as; experiences of exclusion and/or discrimination; perception, expectation and/or fear of being stigmatized; and feelings fear and/or shame and a loss self-esteem and dignity [35], due to confirmed or suspected TB disease. *Social isolation* is defined as the process of being separated from normal social networks due to TB. *Negative attitude* towards people with TB is defined as being rude, aggressive, and/or ignoring people with suspected of confirmed TB.

Results

The results firstly provide a summary of mental distress characteristics of participants that are then presented under three broad themes as identified by the analysis. The first theme examines individual level drivers of mental distress, while the second theme is focused on social and economic household level drivers of distress and the last theme examines health systems level drivers of mental distress as experienced by participants during TB investigation and treatment. Table 1 below, provides a description of participant characteristics. All the participants in the study had drug sensitive TB.

Table 1 Table of participants

Characteristics of participants	Distribution
Sex	
Male	47 (59%)
Female	33 (41%)
Age	
Age range	19–75
Self-reported severity of TB symptoms	
Non	3 (4%)
Mild	3 (4%)
Moderate	66 (82%)
Severe	8 (10%)
Number of TB episodes	
1	63 (79%)
2	15 (19%)
3	2 (2%)
Co-morbidity	
Self-Reported living with HIV	37 (46%)
Self-Reported symptoms of mental distress	61 (76%)
Employment	
Formal	17 (21%)
Informal	53 (66%)
Unemployed	10 (13%)

Summary of mental distress characteristics

Most participants (61/80) shared that they had experienced some form of mental distress during their TB investigation and treatment period. The reported symptoms included feelings of shame and guilt, reduced self-worth, hopelessness, and disengagement from activities that once provided pleasure. For some participants, these feelings were heightened during TB investigation and early on in treatment and subsided once morbidity from TB and side effects of the TB medication improved. The severity of these symptoms also varied. Some participants reported mild distress that did not disrupt their daily lives or ability to adhere to their TB medication. Other participants reported more severe symptoms of distress, for example, 12/80 participants shared that they had suicidal ideation and thoughts of self-harm during their time on treatment and some admitted that these feelings made it challenging to adhere to their medication. No patterns emerged by age. Women were more likely to report their inability to pursue their care giving roles as a cause of distress while men were more likely to be distressed by the disruptions to their role as financial providers for their families. Further analysis that quantitatively compared those with reported mental distress (n = 61) to those without (n = 29) did not reveal any clear pattern in the two groups. However, focusing on the 12/80 who shared suicidal ideation, it emerged that a combination of socio-economic stresses at individual, household and health system levels converge alongside having TB that could contribute to this extreme manifestation of mental distress. The following two case-studies illustrate these multi-layered and intersecting stresses, with the economic stress of poverty often being the most powerful driver.

Case Study 1, Z5 transcript 5: [Married man of unknown age, lived with his wife and parents during his TB treatment. He is HIV positive and had two episodes of TB, the first was in 2016, when he worked as a manual laborer at a cement factory, the second was in 2018 when he worked as a miner. In both incidents he was fired from his job due to his TB diagnosis. He incurred TB investigation costs (transport and Xray) and was evicted from his house

because he was unable to pay rent. He sold household items (stove) to try and meet his costs. His second TB diagnosis was delayed for 4 months due to poor medical investigation at the clinic, leading to severe TB morbidity (was hospitalized for one and a half months). He considered stopping his medication due to the side effects. He experienced TB stigma in form of being treated rudely by health personnel, friends avoiding him and being fired from his jobs. He struggled to cope with his wife's suffering which he attributed to him losing his job and house due to his diagnosis. His wife and mother provided emotional support through his treatment period. He did not receive financial support from family but did mention the doctor gave him money sometimes.]

Case Study 2, Z3 transcript 4: [30–35-year-old single woman, with 2 children. She works as a marketeer. She had recently cared for relatives who had TB. Her TB diagnosis was delayed due to poor medical investigation, and she subsequently developed severe TB symptoms (was hospitalized for one month). During her hospital stay it was also discovered that she was HIV positive. She stopped working and moved in with her sister. She thought she would die and worried about who would take care of her children if she did. She contemplated defaulting on her medication but was encouraged by nurses and her sister to continue. Her sister was very supportive, escorted her to collect her medication and nursed her through her illness. Neighbors and friends also provided financial and emotional support. She did not experience any stigma but was embarrassed by her diagnosis and worried that people were talking about her. She believed TB ran in the family or was acquired through acts that were deemed to be immoral].

Individual level drivers of mental distress At individual level, drivers of mental distress included morbidity and pain (77/80), bodily changes and accompanying involuntary disclosure (43/80), fear of death (10/80), HIV co-infection (37/80), and culpability (29/80).

Morbidity and pain

TB took a toll on patients' bodies. The symptoms of TB were a major source of mental distress to participants who described them as painful and immobilizing.

> *"I did not feel good. I used to sleep one side, I felt like water was boiling on the other side when I slept. I did not sleep without taking painkillers." (40–45-yearold woman, Z2)*

The majority (77/80) of the participants reported experiencing some level of physical morbidity from TB and 8/80 reported morbidity that was so severe that they were unable to walk or bathe themselves. All the participants who reported severe morbidity also reported mental distress symptoms. For some of these participants, their mental distress was so severe that they had suicidal ideation during their TB treatment period. On the other hand, six of the seven participants who reported little or mild morbidity resulting from TB reported no mental distress, with only one reporting very mild mental distress upon hearing their diagnosis.

Bodily changes and involuntary disclosure

Participants highlighted that TB symptoms caused visible changes to their bodies. The most notable changes were weight loss and changes in skin appearance which 43/80 participants described. These changes left patients feeling like *"they were not themselves"* because of how different they looked. Some participants reported feeling embarrassed by the way they looked when they had TB and some feared that these changes in their appearance led to unintended disclosure of their diagnosis. *".. I am light in complexion, but my skin became extremely dark which clearly showed that I was not well" (20–25-year-old woman, Z7)*

Fear of death

Participants' reflections of their TB diagnosis were poignantly linked to death. The severity of the TB symptoms that participants experienced led some to think they would die from the disease.

> *"When one has TB the only thing they think is that they are going to die." (40–45-year-old man, Z12)*

Other participants knew someone who had died from TB, and in some cases, this was someone close to them such as a spouse or sibling who they nursed through the illness. For 10/80 participants, the fear of death was accompanied by a deep and persistent sense of worry that their children would *"suffer"* if they died. There was also a sense of guilt and self-blame about bringing *"suffering"* to their children and family through *"exposing"* them to TB.

"… I would be sitting and look at the children and think, so just like that my children will begin to suffer, I have exposed my children to suffering because I have contracted TB…." (25-30-year-old man, Z7)

HIV co-infection

Many participants highlighted the assumption that being diagnosed with TB was an automatic indication of HIV diagnosis and this was very distressing for some participants mainly due to the stigma associated with HIV in this setting. An HIV diagnosis was sometimes described with moral undertones, exemplified by HIV negative participants' description themselves as being "*correct,"* or *"clean"* or *"never having indulged in bad activities*" when talking about their HIV status. The association between TB and HIV was source of discrimination for some participants, as illustrated by the following:

"My family segregated me because they thought that since I had TB, definitely I was also HIV positive." (25-30-year-old man, Z2)

For some of the 37/80 participants who shared that they were living with HIV, the co-infection added additional health and emotional challenges, 30/37 of them reported having mental distress symptoms with six reporting suicidal ideas. Many described the experience of the comorbidity with strong negative emotions, such as feelings of depression and hopelessness. However, half of the participants who reported being suicidal were HIV-negative, and it was thus other individual stresses that underlay their mental health distress. ***Daily medication regimes***

Participants mentioned that their TB symptoms abated after a couple of months of taking their TB medication except for, the challenges they faced with taking the medication that added an emotional burden for some participants. Reported challenges included large size of the tablets, long treatment regimen duration (usually a minimum of six months), debilitating side effects of the medication, and the frequent trips to the health Centre to collect medication. These challenges were even more pronounced for participants who were managing other co-morbidities, most commonly HIV. Some of the participants that reported being suicidal mentioned having challenges with adherence and needing to be encouraged by close family to continue. Indeed, one participant expressed that death was at some point a more attractive option than adhering to her medication. *"Yes, I thought it was better to die, so that I stop taking drugs." (20–25-year-old woman, Z12)*

Culpability

Popular community beliefs about TB that many participants shared were sometimes inaccurate and often a source of self-blame for their diagnosis. Participants mentioned beliefs that TB was contracted through excessive drinking or smoking, "promiscuous" 'sexual behavior (a colloquial expression implying moral judgement about multiple sexual partners or sexual contact with a woman who had had an abortion). These popular assumptions serve as a driver of TB stigma, increased feelings of shame, and reduced self-worth amongst participants. Furthermore, participants shared feelings of guilt for contracting TB, believing it was brought about by some morally unacceptable behavior. The participant below described self-perceived culpability of contracting TB because of their own "*careless"* smoking:

"I: But did you at some point think that maybe it is your fault for getting TB?
R: Yes, because of my carelessness.
I: Why did you think like that?
R: Because of my smoking of cigarettes"
(30–35-year-old man, Z8)

Social and economic household level drivers of mental distress

The socio-economic household circumstances of participants that contributed to mental distress include income loss (51/80), depending on others, isolation and/ or stigma (35/80).

Income loss

Morbidity associated with TB resulted in job or income loss for most working participants, as they became too ill to carry out their tasks. The majority of participants (53/80) worked in the informal sector, the men mainly worked as casual laborer's, illegal miners, mechanics or entrepreneurs, while women were more likely to be domestic workers, hairdressers or marketers. The nature of informal work meant their contribution to household living depended on them going out to work, and for these participants, this meant they could no longer make a living whilst they were ill.

A minority of participants (17/80) were in formal employment. Women were either employed as cashiers and office orderlies while men either worked in construction, artisans, the mines or as security guards. Only four of those in formal employment were granted sick leave during the time they were on treatment, and another four reported being fired on medical grounds. Some participants opted to hide their diagnosis from their employers all together. Participants often resumed income generating activities around three to four months after starting treatment, as they begun to feel better. One participant mentioned that he was unable to work as much as he did before having TB and another relayed how the days that he collected medication undermined his business. A smaller number did not manage to work at all during treatment, as detailed in the quote below. *"I was fired from work. I stayed for eight months without working and I no longer work…….I want to go back to work so that I can help my children go to school." (45–50-year-old man Z2)*

The quote above also highlights that TB can undermine educational attendance of children and TB patients; one young woman participant stopped attending school because of having TB and other participants spoke of children struggling to attend school.

Some participants reported that their households sold household items, borrowed food and used savings to get by during the period of having TB and financial support from close family (parents, spouse, siblings) was reported by 16 participants. A few participants also reported financial support from neighbors, friends and church members. No participant mentioned receiving financial assistance from the government. The economic stress of having TB is detailed below.

"TB worries mean there is no food at home because you can't provide for the family and there will be hunger, you will fail to pay school fees for the children as well as rentals." (40-45-year-old man Z10) This was particularly distressing for male participants who tied their ability to earn and take care of their dependents to their identity as a man and expressed that being unable to do this often led to feelings of reduced self-worth and shame.

"….the time I was ill I had worries because I was not able to work so that I earn. They used to bring food for me and that was not good for a married man with children."
(35–40-year-old man, Z2)

Isolation and stigma

Isolation was a common experience during TB treatment and was a concept strongly tied to mental distress during the treatment period. The isolation was either voluntary or forced. Voluntary isolation was practiced by some participants for two main reasons, the first being fear of infecting others with TB, as the participant below highlights.

"When I had TB I stopped going to school or playing with my friends so that I would not infect them…"
(20–25-year-old woman, Z5)

One man participant moved household to protect his children from TB, going to stay with his sister during TB treatment. Participants also isolated themselves to avoid being stigmatized. For example, the man below detailed how he avoided people when he went to church by sitting alone at the back bench, and further explained why being away from people was necessary for him.

"People used to laugh when you have TB, so it was very difficult to be found with friends." (40–45-yearold man, Z8)

However, a notable number of participants explained that isolation was imposed on them by others (often members of their households) through the use of separate cutlery, bedding and enforced social distancing. These experiences magnified aspects of mental distress as participants revealed feelings of shame and reduced self-worth and in some cases, feeling less than human, as is the example in the quote below where the use of separate cutlery made this participant feel *'like a dog'*.

"R: I felt ashamed of myself because when people know that you have TB they feel like you are something else I: Something else like what?
R: I don't know, like dog or I don't know…. The way some people decide to get a specific plate, spoon, and cup for a TB patient to use alone doesn't make a person feel free." (25–30-year-old-man, Z7)

Health system challenges

The health system challenges that that contributed to participants mental distress include poor health investigation (40/80), negative attitudes of health staff, and stock out of TB medication and consumables.

Health investigations at local clinics

There was often a significant delay in being diagnosed with TB, often at least two to three months in part due to

inefficiency in the health system. This was the case for close to half the participants who were misdiagnosed and or not adequately evaluated by medical staff at local clinics. In many cases participants were given antibiotics and painkillers without medical investigations being carried out. This delay could prolong morbidity and increase anxiety as health continued to deteriorate despite frequent visits to the health centres. This is illustrated by the following participant:

> *"I described how I was feeling to the health personnel at the clinic and I was then given medicine. They gave me Amoxil and Panadol. I went back to the clinic and they changed my medication to Anthramycin and Aspirin. I felt better for a while. I went there again and was given an injection with Anthramycin and Panadol. I stayed for a while yet the disease was becoming worse and pain inside were increasing until at last I started feeling eaten up and my voice became weak, my energy level reduced and my heart felt like it didn't have a place to stay,"*
> *(40-45-year-old woman, Z8)*

Many of these participants were only properly diagnosed after being referred to the nearest tertiary general hospitals. The following participant notes that she would have most likely died due to lack of proper investigation had she not moved from her local clinic to the general hospital in her area. *"R: I would have died at XX clinic I: Why do you say this?*

> *R: …the time I was ill, and I used to come here (clinic), and would tell them that the cough is not stopping, however, they would just give me Amoxil. They didn't check me to know what was causing the cough." (Unknown-age woman, Z8)*

Health workers attitudes

Negative attitude by health staff was also cited as a source of distress for participants. Some participants noted that some nurses would ignore them and were rude, when providing them with services. Altercations between health staff and patients sometimes resulted in withholding of care and medication as was the case for the participant below.

> *"They (nurses) have to learn to care for the patients. There is a nurse who used to shout at me and she even threw away my registration book. She told me to go back to XXX Clinic where I was getting treatment initially. I asked her why we were getting medication at 11:00 hours when we were getting at 07:00 hours at the other clinic. She told me to go back to XXX Clinic if I was not happy and she even refused to give me medication that day. Luckily, I was called by a certain doctor who told me that the nurse was not supposed to do that and he gave me the medication." (30-35-year-old woman, Z2)*

Stock out of TB medication and consumables Other distressing bottlenecks that participants noted included lack of equipment and consumables that hindered the TB investigation process. Additionally, one participant highlighted that sometimes the health facility she collected her medication from did not always have it available.

> *"I had worries because I felt I would die. The TB medicine would run out a lot (at the clinic)." (20–25-year-old woman, Z5).*

Discussion

TB patients experienced mental distress during their time on treatment. Mental distress expressed by participants was caused by individual, economic, social and health system level factors, highlighting the need for multilevel solutions to address mental health needs of TB patients during TB treatment and investigation. Symptoms of mental distress recalled by participants during their time on TB treatment were often synonymous with those of depression and anxiety disorders. This analysis highlights the patient experiences of social drivers of mental distress during TB investigation and treatment and therefore emphasises the role of social context in the mental health experiences of TB patients in this population.

Similar to findings from other settings, participants reported physical morbidity resulting from TB as one of the sources of their distress [36, 37]. Symptoms of TB, particularly pain, wasting, and other changes to participants' appearances were a major source of concern. Physical morbidity as a contributor to mental distress is not unique to TB: a recent meta-analysis focused on developing and emerging countries found a pooled prevalence of 36.6% of mental disorders in individuals with chronic physical illness [38]. Furthermore CMD such as depression increase the level of morbidity and pain experienced by individuals with chronic illnesses [39]. For some participants, TB presented a substatial threat to their lives and the morbidity they experienced brought them to a point of existential reflection. The potential finality of life was understandably

distressing for participants, particularly for those who had witnessed a loved one die from TB or those who feared for the wellbieng of their children. Fear is a natural response to a life threatening illness and it could aggrivate morbidity [40]. Fear of death, and fear of the social and economic consequences of TB was also reported in qualitative studies from other settings inclduing India [41], Vietnam [42], Parkistan [43] and China [44]. Furthermore, TB patients are likely to be experiencing an amalgamation of personal lossess resulting from their morbidity, some of these losses that came up in our findings included: a loss of independence, bodily image, physical functions, self worth, and potential loss of future. Similar algamation of losses have also been documented with other chronic illness [40].

Co-morbidity was another individual level driver of distress. In addition to TB, 46% of our participants also self-reported living with HIV, another chronic condition that could have debilitating implications on an individual's health if not well managed [45]. HIV is one of the leading drivers of the TB epidemic in Zambia. In 2019, Zambia had an estimated HIV prevalence of 11.5% amongst adults aged 15–49 [46]. Global indicators suggest that Zambia has one of the highest estimated numbers of incident TB cases among people living with HIV globally [13]. Similar to our sample, 47% of TB patients in Zambia were co-infected with HIV in 2019 and coinfected individuals accounted for 62% TB related deaths that occurred in that year [13]. The literature highlights that an HIV co-infection significantly increases the risk of experiencing mental distress during a TB episode [37]. A study conducted in Ethiopia comparing the mental health status of TB/HIV coinfected patients to non-co-infected patients found coinfected patients had a significantly higher prevalence of mental illness (63.7%) compared to non-co-infected patients (46.7%) [16]. These findings are echoed in our data, highlighting the urgency of mental health services for co-infected individuals.

At societal level stigma interfacing with TB that was cited as a source of distress for participants. There were some accounts of discrimination, such as gossip, job loss, and being treated rudely by health workers however, the most common forms of stigma reported were anticipated and internalised stigma. TB is a highly stigmatized condition in Zambia, and its implications have been thoroughly documented [35, 47, 48]. Studies from different setting highlight the link between TB stigma and poor mental health, for example a qualitative study from India found depression, anxiety and suicidal ideation were common outcomes of TB stigma [49]. In Lesotho participants who reported internalised, anticipated, and experienced stigma were 2.4, 1.7 and 2.9 times more likely to have moderate to server depressive symptoms than TB patients that did not report these stigma measures [50]. While a global systematic review consisting of 25 papers found TB patients with perceived TB stigma were 4 times more likely to develop depression than those without perceived stigma [51]. Participants in our study highlighted that TB symptoms often resulted in a different form of stigma, namely TB-HIV stigma. Bond and Nyblade [11] argue that this form of disease stigma is present in settings with high HIV prevalence such as Zambia due to the interconnectedness of TB and HIV in people's perceptions and understanding the conditions. Additionally, TB patients dealing with a mental health condition such as depression or anxiety could also experience mental health stigma which is also very prevalent in this setting [52, 53].

The economic implications of a TB episode were also highlighted as sources of distress by participants in the study. TB affected participants' ability to engage in income generating activities thereby often increasing the economic vulnerability of participants and their households. This increase in economic vulnerability is occurring in a setting with relatively high levels of poverty. The TB epidemic in Zambia is concentrated amongst lower socio-economic brackets particularly in urban settings which are exposed to the structural drivers of TB such as poor nutrition and overcrowded and lower quality housing which create a suitable environment for TB transmission and disease progression [54]. Independently of TB, poverty also serves as a driver of mental distress, according to a 2020 systematic review, within each given setting individuals in the lowest income brackets are 1.5 to 3 times more likely to experience CMD than those in the highest income brackets [55]. Therefore, in high TB burdened settings people living in poverty are at high risk of independently and jointly developing TB and mental ill health due to shared risk factors between two. Concurrently TB and mental ill health can both independently and jointly lead to impoverishment due to reduced productivity levels as a result of morbidity and the direct and indirect health related costs associated with both conditions [56]. For example, our data revealed that for 51/80 participants, TB illness resulted in income loss due to an inability to work and 48/80 reported indirect costs resulting from TB investigation and treatment.

Lastly participants also highlighted health system level drivers of distress similar to those documented in the literature from the region [57]. One of these health system failures included lack of adequate investigation at health facilities which was reported by half of our participants.

There is evidence from a 2013–2014 TB prevalence survey conducted in Zambia supporting our findings, 49.7% (80/161) of the symptomatic participants diagnosed with TB during the survey had previously sought care for their symptoms at a health facility and were not screened and subsequently not diagnosed for TB highlighting the magnitude of missed opportunity for TB diagnosis due to poor investigation in this setting [20]. In a 2022 global systematic review four studies indicated that symptom screening was not conducted for 33–96% of patients with TB symptoms while only a median of 38% of participants with TB symptoms were offered a diagnostic investigation [58]. This has implications for both the individual and the community. At individual level delayed diagnosis leads to increased severity of the disease, higher investigation and treatment costs, and poorer treatment outcomes which all ultimately contribute to mental distress in individuals with TB [37].

Recommendations

Based on our finding we propose the following multi-layered recommendations to improve mental health and TB treatment outcomes of TB patients in this setting.

Individual drivers of mental distress in TB patients, including morbidity and fear of death, need to be acknowledged by TB health care workers. Therefore, in addition to treating and educating patients on the curability of TB, health workers need to be sensitive to patients experiences of the illness, including the realities of the potential losses that patients have encountered due to morbidity from the illness. This calls for a more patient centered approach that transcends biomedical manifestation of TB by accounting for the multi-faceted ways in which TB affect patients lives. Patient centered care has taken on various models. A 2012 global systematic review of 32 studies focused on patient-centered care in chronic disease management highlights integral components of patient centered care including: acknowledging the patient's situation; legitimizing the illness experience; and offering realistic hope [59]. The acknowledgement of patient-centered care in TB treatment has resulted in it forming an integral part of the WHO first pillar of the post-2015 TB strategy [60]. As part of patient centered care the WHO recommends that all TB patients should receive educational, emotional, and economic support during TB investigation and treatment to prevent treatment default [60]. Patient centered care has in some cases been shown to improve patient wellbeing including mental health outcomes [61].

At societal level our findings reveal stigma as a major driver of distress for TB patients. It is therefore vital to tackle the multiple stigmas associated with mental ill health, TB and HIV at household, community, and health setting level in Zambia. More research is required to create context sensitive interventions that would account for the structural and contextual factors underlying the intersecting stigmas. Policy makers in Zambia can utilize the health-related stigma framework created by Stangl et al. (2019) as a guiding tool to creating research and intervention around intersecting health stigmas in the Zambian context. The benefit of this framework is that it acknowledges and addresses parallels in drivers and consequences of stigma across different conditions which is a shift from the existing stigma frameworks that typically take a siloed approach thus focusing on each health condition in isolation.

Economic drivers of distress include the income loss due to indirect costs during TB investigation and treatment, coupled with a significant reduction in productivity, often surmounting to catastrophic health costs for individuals with TB and their families. None of the participants in our study were in receipt of welfare state, highlighting the need for safeguards against job loss resulting from morbidity of TB, in addition to provision of social protection schemes for economically vulnerable TB patients. There are several laws in Zambia promoting these safeguards, but our findings indicate that these needs improve enforcement and accountability mechanisms. Economic stressors among TB patients are not new to this context. Previous research has highlighted the importance of transport and food aid for TB patients and people living with HIV on ART in Zambia [62]. Social Protection schemes could potentially alleviate one of the major drivers of mental distress in TB patients, as well as improve TB treatment outcomes for individuals, for example a 2018 global systematic review of five observational studies, with a total of 21,976 participants found that TB patients that were receiving socioeconomic support were 1.8 times more likely to have positive clinical outcomes that TB patients that did not receive socioeconomic support [63]. However, more research is required to guide the most appropriate form and implementation of social protection for this specific context.

At health systems level, our data revealed a dearth of mental health support services, despite the overwhelming need for them by our study participants. Mental health services are typically provided in centralised psychiatric hospitals located in the provisional headquarters across the country [8], with the exception of HIV counselling services,

which have proliferated in Zambia since the 1980s [64]. Originally these followed a home based care model, aimed to provide psychological support to AIDS patients and their families [64]. With the increased availability of ART, HIV counselling services have evolved to facility-based services with an emphasis on adherence counselling, and advice on sexual and reproductive behaviour of people living with HIV [64]. Similarly, TB treatment supporters also provide advice and encouragement to TB patients with a focus on adherence support to TB patients. To address the dearth of mental health support services for TB patients, it may be appropriate to train TB treatment supporters to screen, treat and/ or refer their patients with comorbid mental illness. The WHO Mental Health Gap Action Programme (mhGAP) provides guidance on how this can be achieved through a task shifting approach, where non-mental health specialists in the primary health care setting are trained to identify CMD and provide low-intensity intervention, using evidence-based techniques [65]. In this model, patients with severe symptoms (such as suicidal ideation) are referred to specialists for more intensive support. Government commitment in providing adequate and regular training, management and sufficient remuneration is essential for such a model to be successful [66, 67].

Strengths and limitations

This is the first study to explore patient perspectives on drivers of mental distress during TB investigation and treatment in this context. The major strength of the study was the sample size of participants which allowed for exploration of diverse experiences and perspectives from a sample with national level representation.

The weaknesses of the study include recall and selection bias. These limitations arise from this research being embedded in a larger TREATS study that aimed to explore experiences of TB patients who were diagnosed through standard of care, and those diagnosed through active case finding through the PopART study. The sample was therefore restricted to those who were diagnosed and completed treatment between September 2016 and November 2017 when the PopART intervention was still being conducted. Therefore, participants had to recall their time on TB treatment during data collection which occurred from October 2018 to February 2019. Additionally, our sample of participants had all completed TB treatment, and we are therefore unable to explore the mental health experiences of individuals who defaulted on their treatment. Furthermore, our analysis was unable to stratify based on time since TB treatment completion and mental health status prior to TB diagnosis. Finally, generalizability of our findings is limited to settings like Zambia, that is, high TB burdened and low to middle income countries.

Conclusion

Mental distress was pervasive among this group of TB patients from eight urban Zambian and geographically distinct communities and has implications on their treatment experience. Context plays a key role Mental distress experiences among TB patients in Zambia. The findings illustrate that mental distress during TB is driven by multi-layered and intersecting stresses, with the economic stress of poverty often being the most powerful driver. Measures are urgently needed to support TB patients during the investigation and treatment phase, including increased availability of mental health services, better social security safety nets during TB treatment, and interventions targeting TB, HIV and mental health stigma.

Abbreviations

CHiPs: Community HIV care Providers; CMD: Common mental health disorders; IDIs: In-depth interviews; HIV: Human Immunodeficiency Virus; LMIC: Low- and Middle-Income Countries; LSHTM: London School of Hygiene and Tropical Medicine; PopART : Population Effects of Antiretroviral Therapy to Reduce HIV Transmission; TB: Tuberculosis; TREATS: Tuberculosis Reduction through Expanded Antiretroviral Treatment and Screening for active TB trial; WHO: World Health Organization.

Supplementary Information

The online version contains supplementary material available at https:// doi. org/ 10. 1186/ s40359- 022- 00881-x.

Additional file 1. Tb Patient Individual Interview Guide. Qualitative data of TB patients TB investigation and treatment experiences in eight Zambian communities.

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Author contributions

TM, MG, VB, designed the study. MG managed data collection teams with oversight from TM and VB. TM, MG and VB collected some of the data. TM and MG coded the data, TM led the analysis with input from VB. TM drafted the manuscript which was edited by VB, IM, and RS. TM, VB, MG, IM, RS KS AND HA contributed to the interpretation

of the findings and commented on the drafted manuscript. All authors read and approved the final manuscript.

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Availability of data and materials
The data used or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
Ethical approval for all study procedures was obtained from the institutional review of the London School of Hygiene and Tropical Medicine (LSHTM) (#14985), and the Bio-medical Ethics Committee of the University of Zambia (005/02/18). Written consent was obtained from all participants prior to data collection activities.

Consent for publication
Written consent for publication of personal, clinical details and direct quotes was obtained from all participants and consent forms would be available on request.

Competing Interests
The authors declare no competing interests.

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Additional Findings: Coping mechanisms

Social Capital

Most participants relied on their social capital for emotional, financial and practical support. This social capital consisted mainly of family, friends, church members and other members of their communities. There was no participant who stayed alone during TB – they all stayed with close family who were their main source of support. For some participants this meant leaving their homes and moving into a family members house. Women emerge as particularly key for practical and emotional support – especially mothers, wives and sisters (sometimes daughters). Close family, including men (husbands, fathers, brothers), provided financial and emotional support. Neighbours, friends, and in some cases TB survivors close to participants, also provided emotional and practical support. No participant mentioned getting financial support from the government.

> *"I: Did you tell anyone in your family or health workers about the worries you had?*
>
> *R: I told my family everything and they helped me a lot. My brother, my sister and my uncle bought me food, paid school fees for my children, and helped me financially.*
>
> *I: Outside the household where did you get support when you had TB?*
>
> *R: My friends. They also helped me emotionally by encouraging me and telling me that I would be fine." (Unknown-aged man, Z3)*

Religion and Acceptance.

Acceptance of diagnosis appeared to be a contributing factor to participants' emotional outlook during their treatment period. Participants with a higher level of acceptance about their TB diagnosis were

more likely to report mild mental distress symptoms and often described their TB experiences through a less personal lens, highlighting that TB is a disease like any other disease that anybody can get. Subsequently, participants who reported difficulty in accepting their diagnosis were more likely to report higher levels of mental distress and sometimes described their diagnosis in more personal lines either as an attack or as punishment for something they did. This interpretation of their diagnosis inevitably affected their emotional outlook as illustrated in the following: "*I did not feel good because I thought it (TB diagnosis) was a punishment" (35-40-year-old man, Z7)*.

Acceptance also played a key role in willingness to start and adhere to medication. Some participants even cautioned that failure to accept ones' diagnosis could result in suicide as reflected below.

> *"You have to be free and proud of your diagnosis because those who fail to accept it (TB diagnosis) are the ones who end up committing suicide." (30-35-year-old man, Z8)*

However, for some participants, acceptance was characterised by undertones of disengagement from their situation. For example, one participant noted that it is better to "*ignore the diagnosis, not think about it too much", (30-35-year-old man, Z8).* In some cases this led to a kind of hopelessness or lack of agency in the outcome of their disease, as expressed by the following participant.

> *"I knew that over thinking would cause death so I accepted it (TB diagnosis) if I die I die, if I get cured I will be cured (Unknown-age, woman, Z5, female).*

In addition to acceptance, participants also used religion to cope with mental distress of TB and many felt that their fate is ultimately in God's hands. This religious belief positively impacted participants' mental health, and even helped with extreme bouts of mental distress as shown in the following participant.

"*Yes, I used to have (suicidal thoughts) but I prayed and put God first and even now I am putting God first." (43-year-old woman, Z4)*

Discussion

People with TB employed different coping mechanisms for their mental distress experiences, often relying on social networks and religion. The strategy of using religion to cope with chronic illness is not unique to this study population. The literature points out that religion is used in the reconstruction of traumatic events and provides a framework for understanding difficult situations, including chronic illness, and may positively influence health outcomes (1). For example, a study conducted in the USA examining the role that religion played with coping with chronic pain among 40 women with chronic illnesses, found that the 20% of participants who reported being highly religious had higher levels of coping and comfort compared to the 28% of participants who were not religious who described substantial difficulty in coping and accepting their chronic conditions (1). However, religious coping strategies can be both negative and positive, with negative strategies leading to detrimental health outcomes. This was highlighted by a 2020 global systematic review of 49 studies, on situation-specific religious coping methods, that conducted a meta-analysis (n=13,512) in order to determine the efficacy of positive and negative coping strategies for people dealing with stressful situations (2). Findings from the review suggest that a moderate positive relationship exists between positive religious coping strategies and positive outcomes to stressful events (2). Positive religious coping strategies include benevolent religious reappraisals, collaborative religious coping, and seeking spiritual support. Participants who employed these typically experienced more stress-related growth, spiritual growth, positive affect, and had higher self-esteem (2). While those with negative coping strategies (including spiritual discontent; passive religious deferral; and interpersonal religious discontent) experienced

negative psychological adjustment to stress including higher levels of depression, anxiety, and overall mental distress (2). Similarly, data from this research suggests that the negative coping strategies such as passive religious deferral led to disassociation from the situation that the participant was facing and a lack of agency over the outcomes of their conditions.

Social networks played a key role in providing support for participants either from family and friends or through organisations such as churches. In a setting, like Zambia, with a paucity of mental health services, and little governmental social security nets, social networks are shown to be integral in providing support during distressing periods. The findings showed that this support came in form of financial, practical, and emotional support and these made a positive contribution in participants ability to adhere to their treatment. There is a significant body of literature focused on the associations between social capital on health outcomes, with most highlighting a positive relationship. This association is summed up in a 2019 systematic review of 20 systematic reviews focused on social capital and health, which concluded that there is good evidence suggesting that social capital predicts better mental and physical health outcomes and is protective against mortality (3).

Conclusion

Both religion and social capital played a key role in providing emotional support for people with TB across the eight study communities. Zambia has no welfare state nor social protection so this social capital forms a very vital safety net in this setting. This practical support and encouragement may have contributed to better health outcomes by encouraging adherence during TB treatment.

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Chapter 5: Paper 2

Prevalence and risk factors of probable mental distress in Tuberculosis survivors compared with individuals with no history of TB in an urban Zambian community.

The TREATS mobile field site in one of the TREATS communities

This chapter explores the prevalence of mental distress in adults with and without a history of TB. The aim of this chapter is to examine if the mental distress experiences highlighted during the TB investigation and treatment period (Chapter 3) carry on beyond TB treatment completion (research gap 2). The chapter draws on data from 3,393 participants in one urban community in Zambia. Data was collected using a questionnaire with a mental health screening tool nested within it. The chapter responds to objective 2 of this PhD, which is*, to investigate prevalence and risk factors of probable mental distress in TB survivors compared with individuals with no history of TB in an urban Zambian community.*

The manuscript is ready for submission and is included in full below.

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Thesis Title	Critical assessment of the intersection between mental health and Tuberculosis (TB) during TB treatment and beyond in a Sub-Saharan context with a focus on Zambia		
Primary Supervisor	Professor Virginia Bond		

If the Research Paper has previously been published, please complete Section B, if not please move to Section C.

SECTION B - Paper already published

Where was the work published?	
When was the work published?	

If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
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SECTION C — Prepared for publication, but not yet published

Where is the work intended to be published?	PLOS One
Please list the paper's authors in the intended authorship order:	Tila Mainga, Ab Schaap, Nathaniel Scherer, Islay Mactaggart, Kwame Shanaube, Helen Ayles, Virginia Bond, and Robert Stewart
Stage of publication	Not yet submitted

SECTION D - Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	My role in the research includes selection of the mental health screening tool (SRQ-5) that was included in the survey that was administered to 3393 participants. I also trained the research assistants with regards to the relationship between mental health and TB and how to administer the mental health items to participants. I conducted the data analysis with support of the second author. I drafted the manuscript and incorporated comments and suggestions from co-authors regarding the content of the manuscript.

SECTION E

Student Signature	[redacted]		
Date	06/09/2022		
Supervisor Signature	[redacted]		
Date	19/09/2022		

Prevalence of mental distress in adults with and without a history of tuberculosis in an urban Zambian community

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Abstract

Introduction

People with Tuberculosis (TB) are susceptible to mental distress. During TB investigation and treatment, mental distress is driven by biological factors and social economic factors including deepening poverty. These factors can persist beyond TB treatment completion yet there is minimal evidence about the mental health of TB survivors compared to people who have never had TB before.

Methods

In 2020-21, during the COVID-19 pandemic, a cross-sectional TB prevalence survey of adults aged 15 years and above was conducted in an urban community in Zambia as part of the 'Tuberculosis Reduction through expanded ART and TB Screening' (TREATS) study. TREATS aimed to measure the impact of a HIV door-to-door intervention, including TB active case-finding, on TB incidence and prevalence. All TREATS TB prevalence survey participants were administered a brief screening measure of mental distress, the 5-item Self Reporting Questionnaire (SRQ-5), embedded in a questionnaire. Associations between primary exposure (history of TB) and other co-variates with mental distress were investigated using logistic regression and a random effects model, adjusting for clustering on sample area. The model also adjusted for other risk factors including sociodemographic and health related variables.

Results

Of 3393 study participants, 120 were TB survivors (3.5%). The overall prevalence of mental distress (SRQ-5 ≥4) in the whole study population was 16.9% (95% CI 15.6%- 18.1%). Previous TB history was not

associated with mental distress (OR 1.20, 95% CI 0.75-1.92, P value 1.66). Mental distress was associated with being female (OR 1.23 95% CI 1.00-1.51), older age (OR 1.71 95% CI 1.09-2.68) and alcohol abuse (OR 1.81 95% CI 1.19-2.76)

Conclusion

Our findings show no association between a previous TB history and mental distress. However, approximately one in six people in the study population screened positive for mental distress, indicating that this is a significant public health issue in Zambia that demands greater research and intervention attention.

Introduction

Although there is a growing acknowledgement of the relationship between pulmonary Tuberculosis (TB) and mental distress, there is limited longitudinal research on this relationship, despite the documented presence of persistent social (1) and biological (2) drivers of mental distress post-TB treatment. Mental distress is a broad concept encompassing common mental disorders including depression and anxiety as well as general psychological distress that does not reach criteria for formal psychiatric diagnosis. This paper aims to assess if TB survivors have a higher mental distress burden than people who have never had TB before.

An estimated 66 million people have been cured of TB since the year 2000 (3). According to the World Health Organization (WHO), a person is cured of bacteriologically confirmed TB if they are smear or culture negative in the last month of treatment and on at least one previous occasion (4). This definition does not necessarily account for the lasting structural and functional implications of TB on an individual's body (5). For example, people with TB may develop lung damage during the active or post-treatment phase of the disease (6), and individuals with a history of TB may have increased risk of respiratory complications including lung scarring, bronchiectasis, chronic pulmonary aspergillosis, airway stenosis and chronic obstructive pulmonary disease (5, 7, 8).

The health implications of TB can result in chronic conditions and functional limitations. As a result, when these functional limitations interact with environmental barriers and personal factors, many people with TB experience TB-related disability. A 2021 global systematic review and meta-analysis of 131 studies from 49 countries aimed to document the prevalence of TB-related disability (2), defining disability as "any participation restriction or impairment or activity limitation resulting from TB" (2).

Their findings showed that mental health conditions are the leading cause of disability post-TB, followed by respiratory impairment (2). The prevalence of respiratory impairment may decrease over time, as documented by findings from a Malawian cohort of 405 participants, where prevalence of respiratory impairment decreased from 60.7% at baseline to 30.7% after one year (9). The handful of studies investigating mental health in TB survivors are suggestive of significant mental distress in this population, particularly in individuals with respiratory symptoms. For example, a 2007 Indian study of 436 TB survivors found that participants who had persistent symptoms, including cough, chest pain and fever, had lower mental wellbeing scores than those who were symptom free (55 vs. 77 P value < 0.001) (10).

Furthermore, there is a growing body of literature that suggests that people who have been treated for TB have a higher general mortality rate than people who have never had TB before. For example, a 2018 systematic review of ten studies (n=40,781) found a pooled standard mortality rate of 3·76 (95% CI 3·04-4·66) among people who were cured of TB as compared to matched controls (11). According to this review, the leading causes of post-TB treatment mortality were cardiovascular disease, followed by cancer and infectious diseases (11).

In addition to lasting health complications, TB survivors also face lasting negative economic stressors. For example, a 2021 Malawian cohort study that followed up 405 people with TB over the course of 12 months, found that there was a 16.1% increase in the proportion of participants living in poverty one-year post-treatment completion (12). The study found that, post-TB treatment, the median income of participants were lower (US$44.13 vs US$72.20) and fewer participants were in paid employment (63% vs 72.4%, P value=0.006) (12).

TB and poverty exist in a vicious cycle, as poorer individuals are more likely to develop TB while TB often leads to further improvement of vulnerable households. For example, in Zambia, TB disease disproportionality affects the poor, as evidenced by the findings of a 2013-2014 TB prevalence survey (n=46,099), which found that individuals in the lowest social economic bracket had double the prevalence of TB (729 per 100 000) than those in the highest social economic bracket (359 per 100 000) (13). The economic stress of TB in Zambia is often compounded by a lack of social security support during TB treatment (14-17). TB disease can further lead to impoverishment due to reduced productivity levels as a result of morbidity and the direct and indirect health related costs (18).

Independent of TB, there is some evidence to suggest the burden of mental distress in the general Zambian population is high. For example, a 2009 study of 4,466 individuals aged 15-59 established the prevalence of mental distress in the general population in Zambia at 14% (19). Socio-economic stressors such as poor educational opportunities, food insecurity, poor quality housing, low socio-economic status and financial stress are strongly associated with mental distress in low-income countries such as Zambia (20). Approximately half of the Zambian population face multi-dimensional poverty, thereby experiencing multiple overlapping deprivations in health, education and standard of living (17).

To the best of our knowledge there are no published studies that have specifically looked at the prevalence of mental distress in TB survivors in the Southern African region, a region with one of the highest incidence of TB (3). Zambia is among the 20 highest TB burdened countries globally when measured by incidence of TB cases (21). For people with TB in the country, there is a high prevalence of documented social and economic drivers associated with mental distress (22, 23). People with a history of TB in Zambia are potentially at risk of mental distress, due to long-term health complications and

long-term socio-economic stressors (1, 2, 24). In this study, we aimed to compare the prevalence of mental distress in individuals with and without a history of TB in an urban community in Zambia.

Methods

Study Design:

Data for this cross-sectional study were collected from one of the 12 urban communities participating in the 'Tuberculosis Reduction through expanded ART and TB Screening' (TREATS) project where 4000 people were sampled. The main aim of TREATS was to measure the impact of a HIV intervention, that included active case finding for TB, on TB incidence and prevalence. The HIV intervention was part of a previous study known as the 'Population Effects of Antiretroviral Therapy to Reduce HIV Transmission' (HPTN 071, PopART), which was conducted in the same 12 communities in Zambia. A description of the full PopART intervention is detailed in a previous publication (25). TREATS study activities were conducted at a mobile field site (MFS). Study activities included TB screening and testing, and administration of a questionnaire that included a mental health screening tool. The study activities were conducted from 18th November 2020 to 24th of February 2021. This was during the COVID-19 pandemic and therefore all field activities followed strict COVID-19 standard operating procedures to protect researchers and participants.

Study Setting: The community in which the study was conducted is a middle to high density urban suburb in a district town located in the Central Province of Zambia with a total population of approximately 28,000 people. Infrastructure in the community include a government health facility, schools, police stations,

churches, market areas and transport depots (26). The majority of residents work in the informal sector as casual laborers or vendors trading in goods (26). The community has an estimated HIV prevalence of 21.9% (27) and an estimated TB prevalence of 0.5%-1% (28).

Participants: Participant recruitment began with community engagement activities focused on informing community members about the TREATS study. Community engagement activities predominantly comprised of meetings with key stakeholders including health facility staff, schools, churches, and community advisory boards. The community engagement activities were followed by enumeration, which entailed recording of demographic details of all individuals residing within each household in the eligible sample areas. Research enumerators then invited eligible participants to the MFS, according to specific geographical zones within the sample areas. The eligibility criteria included: being resident in the community; 15 years of age or older at time of enumeration; and ability to provide informed consent. Exclusion criteria included being a participant in a TB vaccine trial or any other TB prevention trial.

Variables: All variables are obtained from the TREATS data set. Mental distress was measured with a screening tool, the five-item Self-Reporting Questionnaire (SRQ-5), that was included in the TREATS questionnaire administered to all participants taking part in the study. The SRQ-5 is a shortened version of the 20-item Self-Reporting Questionnaire (SRQ-20) (29). The SRQ-20 was developed by the WHO as a screening tool for common mental disorders in primary health settings in developing countries. It consists of yes/no items that screen for symptoms of depression, anxiety, and somatic manifestations of distress (29). The SRQ-5 has been validated in Zambia using clinician diagnosis using the Diagnostic and Statistical Manual of Mental Disorder 4th Edition as a gold standard criterion (30). It includes 5 items

from the SRQ-20; weighted scores on each item are summed to give a total score. In the validation study, the SRQ-5 had test characteristics similar to the SRQ-20 for detection of mental distress, with an area under the Receiver Operator Curve (ROC) of 0.925 (30). The SRQ-5 was translated into Nyanja and Bemba, which are the two most spoken languages in the community. Translations were done by experienced translators who have an extensive track record with translations of epidemiological questionnaires. Additionally, a validated translated Chewa version was used for cross reference of the Nyanja version as the two languages have strong similarities (31). The final translation process included a back-translation stage consisting of 15 Nyanja and/or Bemba speakers who had never seen the SRQ tool before.

The main exposure variable was self-reported history of TB. This was ascertained by a yes/no question that asked if a participant had ever been treated for TB before. Other exposure variables in the questionnaire included in this analysis were socio-demographic characteristics including age, gender, education, employment status, and relative social economic status. Relative social economic status was measured using a set of social economic status questions. Health related characteristics included both self-reported HIV status and HIV testing data, and alcohol use. Alcohol use was measured using the Alcohol Use Disorders Identification Test (AUDIT), with scores of 8 and above suggesting harmful alcohol consumption.

Data Collection: The questionnaire was administered by a team of 18 research assistants (RAs). Most of the RAs were trained psychosocial counsellors with experience administering questionnaires from previous epidemiological studies. The RAs were trained by the first author on administration of the mental health items. The training was guided by 'a *package for data collectors and monitors on the*

administration of the SRQ', adapted from a similar context (32). The training included understanding of depression in people with TB, discussions around the conceptual understanding of each of the mental health items and strategies for making participants feel comfortable when asking sensitive questions. Role-playing sessions further allowed RAs to gain familiarity with administering the tool including translation.

Sample Size: A power calculation was conducted. Estimates from each group were based on prevalence survey participation rates from the nine Zambian communities in which the prevalence survey had previously been completed prior to data collection in this study community. We estimated that approximately 5% participants were likely to have a history of TB. We estimated the prevalence of mental distress in participants with a history of TB would be 27.9%, and in those without a history of TB to be 14%, based on the prevalence of mental distress in previous studies conducted in Zambia (19, 33). With a total expected sample size of 2,500 participants and assuming 5% of the participants have a history of TB (125 participants with history of TB and 2,375 with no history of TB) and using a significance level alpha of 0.05, we calculate a power of 81% to detect a difference of prevalence of mental distress of 25% in the group with a history of TB and 15% in the group with no history of TB.

Statistical Methods: Data was analysed using STATA version 16.0. Demographic, socioeconomic and health characteristics of the study population were described using descriptive statistics. Only respondents with no missing mental health data for the five questions that comprise the validated SRQ-5 tool were included in the analysis (N=3,393).

The outcome variable, mental distress, was analysed as a categorical variable. SRQ-5 total scores range from a minimum of 0 to a maximum of 11 points. The analysis categorised individuals with SRQ scores of 4 or above as screening positive for mental distress. The cut-off of 4 was determined by the previous Zambian validation study. In that study, at cut-off of 4, the SRQ-5 had sensitivity of 0.87 and specificity of 0.85 for detecting "overall mental distress" as defined by the authors based on DSM-IV diagnoses (30).

Associations between primary exposure (history of TB) and other co-variates with the outcome were investigated using chi square test and logistic regression using a random effects model, adjusting for clustering on sample area. In addition to adjusting for age and sex, the model also adjusted for other risk factors including education, employment status and relative social economic status. The health-related risk factors adjusted for in the model were HIV status and alcohol misuse.

Sensitivity analysis repeated the analyses with different cut-off values of SRQ-5, namely a cut-off value of 5 (sensitivity of 0.72 and specificity of 0.94 in the validation study) and a cut-off value of 3 (test characteristics not available) (30). Additional sensitivity analysis was conducted comparing total scores of the outcome variable as a continuous variable. The Wilcoxon Rank Sum Test was used to conduct this sensitivity analysis as the data were not normally distributed.

Note that one SRQ-5 item was mistakenly asked as a positive rather than negative question (*'Are you able to play a useful part in life?'* instead *of 'Are you unable to play a useful part in life?'*) so this item was reverse scored.

Ethics and Funders: Ethical approval for all study procedures was obtained from the institutional ethics committee at the London School of Hygiene and Tropical Medicine (REF:14985), and the Bio-medical Ethics Committee of the University of Zambia (REF:005/02/18). Unique ethical considerations pertaining to conducting research during a pandemic included fulfilment of additional requirements to ensure safety of study participants and research teams during the pandemic. In fulfilment of these requirements, the study had to ensure provision of appropriate personal protective equipment for all study staff, individual risk assessment to tailor staffs work environments to minimize their risk of infection, frequent sanitation and cleaning of vehicles and surfaces and regular testing for SARS-CoV-2 infection in all field staff. Initiatives to protect participants included provision of two cloth face masks, temperature checks and enforced social distancing measures during data collection. In addition to the health education and TB and HIV screening services provided at the MFS, each participant was also given a t-shirt to change into during the chest-X-ray, and ZMW 20.00 (equivalent of ~USD 1.00) for transportation reimbursement. Written informed consent was obtained from all participants prior to data collection activities. This research is funded by the EDCTP2 programme supported by the European Union (grant number RIA2016S-1632-TREATS). RS receives funding from the UK Medical Research Council/GCRF grant to the University of Edinburgh MR/S035818/1.

Results section

Participants: There were 9,533 enumerated individuals from the TREATS blocks, of whom 2,935 did not meet the eligibility criteria, leaving a total of 6,598 eligible participants invited to the MFS. Of the eligible

participants in the selected community, 3,585 attended the MFS and consented to the study (response rate of 54.3%). However, 192 were missing at least one of the items on the SRQ-5 and were therefore excluded from the analysis. In total, 3,393 participants were included in the analysis.

Socio-demographic characteristics: Two thousand and five (2,005) (59%) participants were female and 1,963 (57.4%) were below the age of 30. Over half of the participants (53.9%) had never been married with 2,690 (79.2%) having attained secondary level education or higher, 1,378 (40%) were unemployed and 392 (11%) were in formal employment.

History of TB and other health characteristics: One hundred and twenty (120) (3.5%) participants had a history of TB; 5 (1.3%) tested positive for HIV during the study HIV testing and counselling activity; and 94 (14.4%) self-reported to be living with HIV. One hundred and thirty-three (133) (3.9%) participants had an AUDIT score of 8 and above suggestive of alcohol misuse.

Prevalence of mental distress: The overall prevalence of mental distress (SRQ-5 ≥4) in the total study population was 16.9% (95% CI 15.6%- 18.1%). The prevalence of mental distress among people with a history of TB was 21.7% (95% CI 14.6%-30.1%) compared to 16.7% (95% CI 15.4%- 18.0%) in individuals with no history of TB. This difference was not significant in the unadjusted model (OR 1.38, 95% CI 0.87-2.15, P value 0.166).

In the univariate analysis, mental distress was associated with being female, older, widowed and alcohol misuse. Women had higher prevalence of mental distress (18.3%) compared to men (14.8%) (OR 1.28, 95% CI 1.06- 1.54, P value < 0.001). Individuals who had been widowed reported the highest prevalence of mental distress when compared to individuals who had never been married (26.5% vs 13.4%) (OR 2.34, 95% CI 1.69-3.23, P value < 0.001). Additionally, individuals with an AUDIT score of 8 and above had a higher prevalence of mental distress (26.3%) than those with a score of 7 and below (16.5%) (OR 1.81, 95% CI 1.22-2.69, P value < 0.005). The prevalence of mental distress of individuals lowest wealth quintile was higher (19.4%) than that of individuals in the highest wealth quantile (16.6%), however this difference was not statistically significant in the univariate analysis.

The multivariate model adjusted for age, sex and other risk factors including education, employment status, relative social economic status, HIV status and alcohol misuse. TB history was not associated with mental distress (OR 1.20, 95% CI 0.75-1.92, P value 1.66). Age was associated with mental distress with older individuals almost twice as likely to screen positive for mental distress than those in the youngest age category (15-19 years), for example individuals in the oldest age category (50+) had odds 1.71 (95% CI 1.09-2.68), while those aged 30-39 had odds 1.99 (95% CI 1.32-3.01) of being distressed as compared to 15–19-year-olds. HIV status was also associated with mental distress, specifically participants with unknown status had a lower likelihood being mentally distressed compared to those with a negative test (OR 0.62, 95% CI 0.47-0.80, P value 0.001). Being female, and alcohol misuse were also associated with mental distress in this model.

Sensitivity analysis using higher and lower cut-off scores on the SRQ-5 to define mental distress also showed no significant association between a previous history of TB and mental distress (adjusted for age

and sex): SRQ-5 cut-off ≥3 (OR 1.11, 95% CI 0.89-1.15, P value 0.82); SRQ ≥5 (OR 0.98, 95% CI 0.81-1.78, P value 0.80). Additional, sensitivity analysis using the Wilcoxon Rank Sum Test to compare the difference in means of the total SRQ-5 scores between individuals with a history of TB (mean 2.04 SD 2.3) and those without (mean 1.79 SD 2.2) also found no significant difference (P value 0.23).

Discussion

To our knowledge this is the first study in the Southern African region to examine if having a history of TB increases an individual's risk of mental distress. We investigated the prevalence and risk factors of mental distress using a brief validated measure (SRQ-5) and examined associations between mental distress and TB history in our study population. The proportion of participants with a history of TB in our sample was 3.5%, with a 21.7% (95% CI 14.6%-30.1%) prevalence of mental distress. While prevalence of mental distress in people without a history of TB was 16.7% (95% CI 15.4%- 18.0%), there was no statistically significant difference in the prevalence of mental distress between people with a history of TB and those without. Potential risk factors of mental distress included being female, older, widowed, and alcohol misuse.

Finding no difference in the prevalence of distress between people with a history of TB and those without is suggestive that mental distress does not persist beyond TB treatment completion. This finding is corroborated by cohort studies examining trends in the prevalence of mental distress in people with TB over the course of their TB treatment period. For example, a 2016 longitudinal study measuring the prevalence of mental distress in a cohort of 710 people with TB over the six-month course of their TB treatment found that 34.1% and 81.1% had severe and moderate symptoms of mental health conditions respectively at baseline compared to 21.8% and 56.2% after six months, representing a reduction of

12.3% and 24.9% in severe and moderate symptoms of mental health conditions (34). Similarly, a 2013 Ethiopian study that followed 124 TB/HIV co-infected patients over the course of their six months TB treatment found that 54.4% of the participants had mild to moderate depression at baseline as compared to 18.1% at the six months follow up, representing a 36.3% decline in depression (35). The observed decline in the prevalence of mental distress and depression observed in these studies could be attributed to reduction in both biological and social risk factors of mental distress during the TB treatment period. For example, while on TB treatment, people with TB start to experience less TB morbidity and potentially experience less stigma as they start to look healthier. The prevalence of mental distress after TB treatment completion was still relatively high in the above studies therefore work focused on understanding the mental distress in TB survivors should also consider the duration post TB treatment as such evidence would provide more comprehensive guidance for mental health and TB treatment.

Our findings suggest that the prevalence of mental distress (16.9%) in the general Zambian population is slightly higher than the global of estimates from WHO of approximately 13% (36). The results of this study highlight that mental distress prevalence has remained high since the 2009 study, despite there being a decade gap in which there has been significant funding and innovation in mental health within low-to-middle-income countries. For example, Zambia is among the WHO members that adopted the 2013-2030 WHO comprehensive mental health action plan and an accompanying commitment to meet ten global targets for improved mental health (36, 37). Other notable innovations include the development of the WHO Mental Health Gap Action Programme (mhGAP) which has been adopted widely as a means to bridge the mental health treatment gap in low resource settings (38), including in Zambia (39).

The high prevalence of mental distress in this research could be in part due to the fact this research was being conducted during one of the first waves of the COVID-19 pandemic as Zambia. The COVID-19 pandemic was associated with higher levels of distress globally, for example, according to the WHO the COVID-19 pandemic resulted in a 25% increase in prevalence of anxiety and depression globally (40). This study contributes to the body of literature regarding the impact of COVID-19 both on TB and mental distress.

The high rates of mental distress could also be attributed to an increase in socio-economic stressors over the last decade since the earlier study was conducted. Findings from a 2010 systematic review of 115 studies conducted in low- to-middle-income countries highlighted that poverty is both a cause of mental health problems and a consequence (20). Poverty causes poor mental health through social stresses, increased negative life events, stigma, and trauma (20). Similarly, mental health problems can lead to impoverishment due to loss of productivity and fragmentation of social relationships (20). Systematic economic stressors in Zambia over the last decade include electricity load shedding (blackouts) resulting in business failures, particularly for small to medium enterprises, droughts in 2016 and 2019, devaluation of the currency (negatively impacting on imports and availability of credit), and more recently the COVID-19 pandemic (41). Estimates suggest the growth rate of Zambia's Gross Domestic Product reduced by approximately 4.2% in 2020, and this reduction represented the lowest economic growth in the country since 1998 (42). It is worth noting that our finding suggests that mental distress was not associated with relative social economic position. This could in part be explained by the relative homogeneity in the income status of individuals in the surveyed community. Furthermore, descriptive statistics from our analysis indicate that poorer individuals had a higher prevalence of mental distress compared to those that were relatively wealthier off.

As with our findings, the literature also shows that women are more likely to experience a higher prevalence of mental distress as compared to men. For example, a global meta-analysis of 31 studies (n=19,639) found that men had a 37% decrease in the odds of developing depression than women (OR 0.63, 95% Cl 0.59-0.68) (43). This relationship holds for various reasons in settings such as Zambia. For example, in Zambia, women are more likely to experience a lack of autonomy and control over their lives resulting in lack of economic and empowerment opportunities, constraints in consumption choices and general lack of basic needs (44). Women-headed households make up a high proportion of chronically poor households in Zambia (41). Women living in poverty have high rates of depression as shown by a 2021 global systematic review and meta-analysis of 134 studies (n=218,035) which found a 37.4% prevalence of depression among poor women (45). According to a 2022 systematic review consisting of 14 randomised control trials psychosocial counselling including individual, manualized interventions, and cognitive behavioural therapy were shown to be effective at treating depression in poor women (46). Task sharing interventions, such as the Friendship Bench, that use psychosocial counselling and cognitive behavioural therapy delivered by non-specialist personnel have been effective in similar settings (47) and could be adapted for women experiencing distress in Zambia.

Alcohol misuse was associated with mental distress in our analysis. According to the literature alcohol misuse and mental health conditions, particularly depression, are often co-occurring. For example, a 2021 meta-analysis of 17 studies (n = 382,201) found that individuals with a mental health condition were twice as likely to report alcohol misuse (OR 2.02, 95% CI 1.72-2.36) (48). Similarly, in Zambia alcohol misuse often co-occurs with both mental and physical conditions. In a 2020 study among adults living with HIV, 94.2% of the 146 participants had unhealthy alcohol use and 72% of these had a mental

health condition (49). Alcohol misuse is a public health concern in Zambia; a population-based survey of 1,928 participants found the overall prevalence of alcohol consumption to be 26.3% (50). This was higher among men (43.5%) than women (17%), with close to half of participants who consumed alcohol reporting that they drunk an average of 5 or more standard alcoholic drinks a day (50). Some studies from this setting reveal that alcohol is used as a means of coping with life stressors including poverty and unemployment (51, 52).

The literature exploring treatment for mental distress and alcohol misuse provides inconclusive evidence about the best treatment practice. For example, a 2018 systematic review of seven studies that aimed to assess the evidence of interventions targeted at co-occurring depression and alcohol misuse concluded that there is a paucity of evidence on the best clinical practice for treating co-occurring depression and alcohol misuse (53). Similarly, a 2020 systematic review of 21 randomised control trials from 15 different low- to-middle-income countries assessing the effectiveness of psychosocial interventions targeting alcohol misuse found inconclusive results regarding the effectiveness of psychosocial interventions on alcohol misuse (53, 54). Therefore, more research needs to be done to understand and treat co-occurring mental distress and alcohol abuse in this context.

We argue that the burden of mental distress in Zambia needs urgent attention, with more investment and effort needed to scale up mental health promotion and treatment. The COVID-19 pandemic further highlighted the importance of mental health (40). A 2020 WHO estimate suggests the Zambian government spend 0.1% of its budget on mental health and 96.7% of this goes to mental health institutions (37). However, according to a 2022 WHO report on global mental health the majority of mental health needs can be met outside mental health hospitals (55). This statement is supported by a

growing body of evidence, including a 2021 Cochrane review that shows the effectiveness of task sharing models being implemented in primary health settings and communities, the review highlights that task sharing approach may increase the number of adults who recover from common mental health conditions in low-to-middle-income countries (56). A randomised control trial conducted in Zambia also found this approach to be effective in Zambia as well (39). In addition to treatment, the WHO also calls for mitigation of risk factors associated with development of mental health conditions, and this can be done by strengthening the understanding of social and structural determinants of mental health and intervening in ways that reduce risks of developing mental health conditions (55). In a Zambian context this would include increasing livelihood support to those in need of it.

Limitations of the study

The study had some limitations including the fact that the mental health data were collected during a global pandemic which may have resulted in a higher prevalence of mental distress than would have been the case if data were collected during more normal circumstances. A further significant limitation was missing data with regards to time since TB treatment completion, which did not allow us to explore the relationship between time since TB treatment completion and individuals' mental health profiles. Furthermore, we were unable to explore the mental health profiles of people with a TB and HIV comorbidity due to limitation in the number of people with the co-morbidity in the sample. An additional potential source of bias was the selection of the community included in the study. However, the selected urban community, located in the central province of Zambia, has a socio-economic and ethnic mix that allows for generalizability of results to other urban Zambian communities. Another potential source of bias is the administration and comprehension of the mental health screening tool that was originally written in English. To counter this bias, we undertook a rigorous process of

translation, training (in administration of the items) and piloting. However, it should be noted that participants sometimes still interpreted the questions in form of physical morbidity and did not always understand the underlying phenomenon the question was trying to ascertain. For example, when asked *"Is your daily life suffering?"* participants would respond, "*yes, when I am sick*." To mitigate this, RAs used carefully designed examples to guide participants thinking around the questions in the tool, for example with regards to the item above the example presented was: "*sometimes people find that their work in the home or garden is not successful because they are troubled by worries or sadness. Has that happened to you in the last 4 weeks?"*

Conclusion

Quantifying the prevalence of mental distress post-TB treatment provides valuable insight into comprehensive TB care, both during and post, TB treatment. Our findings show there is no significant statistical association between TB history and mental distress. The literature suggests that mental distress diminishes after the intensive phase of treatment, however every individual may have a different mental health experience during their TB treatment journey as some individuals may develop mental distress during the continuation phase of treatment while for others mental distress may persist beyond TB treatment completion resulting in post-TB disability. More research needs to be conducted with a larger investigation group allowing for stratification of the main exposure based on time since TB treatment completion, type of previous TB (multi-drug resistant versus drug sensitive TB), and number of times an individual had TB in the past. The results from this study indicate mental distress is a significant public health problem in Zambia, with approximately every one in six people screening positive for probable mental distress in the general population. Mental distress was associated with being older, female, widowed and misusing alcohol. It should be noted that the data was collected

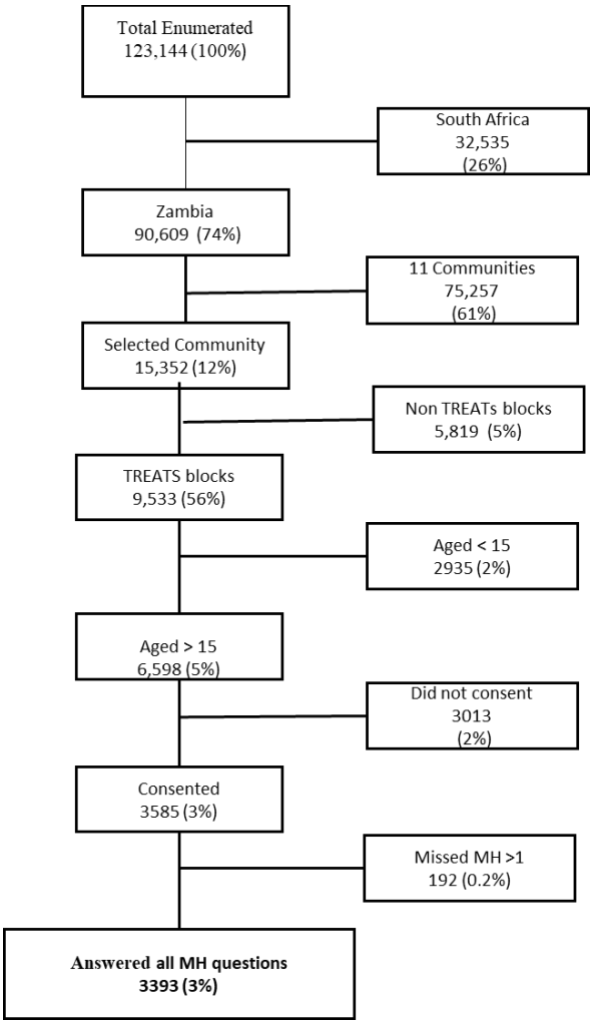
during the COVID-19 pandemic and therefore is also indicative of mental distress linked to the pandemic. Urgent measures are needed to understand and mitigate drivers of mental distress in this population.

Disclosure of interest

The authors declare that they have no competing interests.

Paper 2 Appendices

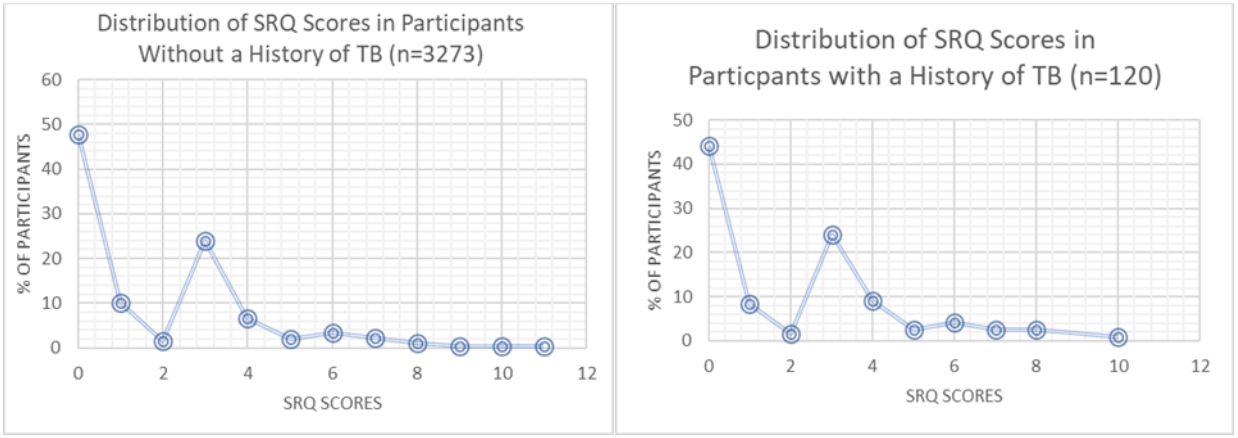
Appendix 1-Figure 8: Participants flow chart



Appendix 2-Table 4:Comparison of Distribution of SRQ Between Investigation and Control Groups

Question	N who reported yes	% In total sample	% In participants with No history of TB	% Participants with History of TB	% Difference (history of TB – no history of TB)
Do you sleep badly	318	9.37	9.4	10.0	0.7
Do you often have headaches?	693	20.0	19.9	24.2	4.3
Do you find it difficult to enjoy daily activities?	424	12.2	12.3	11.7	-0.6
Are you unable to play a useful part in life?	802	23.1	23.1	21.7	-1.4
Is your daily life suffering?	512	14.7	14.5	23.3	8.8

Appendix 3- Figure 9: Distribution of SRQ scores between TB survivors and adults with no medical history of TB



Appendix 4- Table 5: Univariate and multivariable analyses (p values based on likelihood ratio test)

Variable	Total cohort (N=3393) No.	Total cohort No. %	Mental distress (N= 572) No.	Mental distress No. %	**OR (95% CI)**	P value	**Adjusted OR (95% CI)**	P value
Primary exposure (History of TB)								
No TB history	3,273	96.46	546	16.7	1	0.166	1	0.166
TB history	120	3.54	26	21.7	1.38 (0.87-2.15)		1.20 (0.75-1.92)	
Social Demographics								
Sex						0.009		0.034
Male	1,388	40.9	206	14.8	1		1	
Female	2,005	59.1	366	18.3	1.28 (1.06-1.54)		1.23 (1.00- 1.51)	
Age group						<0.001		<0.001
15-19	872	25.55	98	11.30	1		1	
20-29	1091	32.01	164	15.10	1.39 (1.07-1.82)		1.41 (1.01-2.00)	
30-39	575	16.77	122	21.44	2.14 (1.60-2.86)		1.99 (1.32-3.01)	
40-49	356	10.49	78	21.91	2.20 (1.57-3.05)		1.96 (1.24-3.10)	
50+	519	15.18	110	21.36	2.13 (1.58-2.87)		1.71 (1.09-2.68)	
Marital status						<0.001		0.123
Never married	1828	53.9	244	13.4	1		1	
Currently married or living as married	1,139	33.6	228	20.0	1.62 (1.33-1.98)		1.26 (0.97-1.64)	
Divorced or separated	196	5.8	39	19.9	1.61 (1.11-2.35)		1.13 (0.73-1.74)	
Widowed	230	6.8	61	26.5	2.34 (1.69-3.23)		1.72 (1.12-2.64)	
Highest level of education completed						0.132		0.762
None	100	3.0	24	24.0	1		1	
Primary school	603	17.8	112	18.6	0.72 (0.46-1.19)		0.89 (0.63-1.07)	
Secondary school	2,376	70.0	382	16.1	0.61 (0.38-0.97)		0.81 (0.72-1.36)	
Higher education	314	9.2	54	17.2	0.66 (0.38-1.13)		0.78 (0.75-1.49)	

Type of employment						0.003		0.635
Unemployed	1,378	40.7	247	17.9	1		1	
Informal employment	640	18.9	111	17.3	0.96 (0.75-1.23)		0.82 (0.63-1.07)	
Formal employment	392	11.6	76	19.4	1.01 (0.82-1.47)		1.00 (0.72-1.36)	
Student	739	21.8	91	12.3	0.64 (0.49-0.83)		1.06 (0.75-1.49)	
Other	237	7.0	47	19.8	1.13 (0.80-1.60)		0.89 (0.60-1.28)	
Socio- economic position						0.219		0.408
1st wealth quantile (poorest)	670	19.8	130	19.4	1		1	
2nd wealth quantile	716	21.1	123	17.2	0.86 (0.66-1.13)		0.89 (0.67-1.17)	
3rd wealth quantile	795	23.5	117	14.7	0.72 (0.54-0.94)		0.76 (0.58-1.01)	
4th wealth quantile	584	17.2	98	16.8	0.84 (0.63-1.12)		0.87 (0.64-1.17)	
5th wealth quantile	625	18.4	104	16.6	0.83 (0.62-1.10)		0.89 (0.67-1.20)	
Health Related Characteristics								
HIV status						0.005		0.001
Negative test	2,195	64.7	393	17.9	1		1	
Positive test	43	1.3	5	11.6	0.60 (0.24-1.56)		0.51 (0.20-1.32)	
Self-reported positive	490	14.4	94	19.2	1.09(0.85-1.40)		0.77 (0.58-1.02)	
Unknown & did not wish to disclose	665	19.6	80	12.0	0.63(0.48-0.81)		0.62 (0.47-0.80)	
Alcohol use						0.005		0.031
AUDIT score <7	3,260	96.1	537	16.5	1		1	
AUDIT Score ≥ 8	133	3.9	35	26.3	1.81(1.22-2.69)		1.81 (1.19-2.76)	

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Additional analysis

Sensitivity Analysis with SRQ 5+2

Additional sensitivity analysis was conducted using the SRQ 5 with 2 additional questions from the SRQ 20. This analysis explored the outcome as a continuous variable. The outcome variable was not continuously distributed therefore the Wilcoxon Rank Sum Test was used to investigate the distribution of the mean SRQ scores in individuals with a history of TB and those without. Findings from this analysis show the difference

in means between individuals with a history of TB (mean 3.61) and those without (mean 3.01) was not significant difference (P value 0.14).

Table 6 below provides descriptive statistics on the distribution of responses to the two additional mood questions in the total sample. The table also highlights the percentage of those with a response of yes in those with and without a history of TB, with the last column showing the percentage difference in the yes responses.

Table 6: Distribution of responses to the 2 additional questions

Question	Number who reported yes in total sample	% In total sample	% In participants with No history of TB	% Participants with History of TB	% Difference (history of TB – no history of TB)
Do you feel nervous tense or worried?	754	21.6	21.8	30.0	8.3
Do you feel unhappy?	647	18.7	18.7	23.7	5.0

Chapter 6: Paper 3

TB health workers' and stakeholders' conceptualisation, management, and treatment of mental distress in people with TB in the Zambian context.

A health facility worker and volunteer in one of the communities taking part in the TREATS study

*"**I**: ... So, the last question we wanted to ask is about emotional difficulties that people with TB face…. So in your experience do they-do they suffer from depression or anxiety or other worries? What's your experience with that?*

***R2**: They suffer-they suffer from depression, and anxiety… it can even lead them to paralysis where the person is refusing even to get up, they will say things like I can't do this..**I:** Yah..**R2**: But I think that is one of*

the areas where we have recorded success. Where we have been able to get the depressed person to come out of that lying down... Umm.. …to walking and working and doing any other activity.."

(Z12_TB_Stakeholder_FGD)

This chapter explores how the intersection between mental health and TB is understood by TB health workers, and stakeholders. The chapter also highlights how TB health workers currently manage mental distress in their clients with TB. This provides a holistic overview of the mental health and TB landscape in Zambia when examined against the mental health burden and experiences of people with TB during TB investigation, treatment and beyond in this context (chapters 3 and 4). This chapter responds to the third objective of this PhD which is, *to explore TB health workers' and stakeholders' conceptualisation, management, and treatment of mental distress in people with TB in the Zambian context* and thereby addressing the gap in the literature, in understanding TB health workers and stakeholders' perspectives and current practices regarding the relationship between TB and mental health (gap 3). The chapter draws on data from 8 urban communities in Zambia. Data was collected through IDIs with health workers (n=9) and 17 FGDs with local health committee members (n=96) and TB stakeholders (n=57)

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Student ID Number	1603214/RPHP	Title	Ms
First Name(s)	Tila Mwinde		
Surname/Family Name	Mainga		
Thesis Title	Critical assessment of the intersection between mental health and Tuberculosis (TB) during TB treatment and beyond in a Sub-Saharan context with a focus on Zambia		
Primary Supervisor	Professor Virginia Bond		

If the Research Paper has previously been published, please complete Section B, if not please move to Section C.

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SECTION D - Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	My role in the research includes creation/selection of the mental health questions that were incorporated into the focus group discussion and interview guides used for data collection. These included questions pertaining to the causes of mental distress during the TB diagnosis and treatment period, the implications of poor mental health for TB patients' quality of life and TB treatment outcomes, availability, and accessibility of mental health services for TB patient and the understanding of mental health by TB health care providers and broader TB stake holders. I also trained and managed the 8 social science research assistants who collected these data. I conducted some of the in-depth interviews with TB health workers and moderated some of the focus group discussions with TB stakeholders. I conducted thematic analysis of the data. The data was double coded by me and a second social scientist. I drafted the manuscript and incorporated comments and suggestions from co-authors regarding the content of the manuscript. I then submitted the manuscript to the journal and addressed reviewers' comments with guidance from my supervisory team.

SECTION E

Student Signature	[redacted]
Date	06/09/2022
Supervisor Signature	[redacted]
Date	19/09/20

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Mental Health Systems

RESEARCH Open Access

Conceptualization, detection, and management of psychological distress and mental health conditions among people with tuberculosis in Zambia: a qualitative study with stakeholders' and TB health workers

T. Mainga[1,2*], M. Gondwe[1], R. C. Stewart[4,5], I. Mactaggart[3], K. Shanaube[1], H. Ayles[1,3] and V. Bond[1,2]

Abstract

Background: In recent years, there has been increased recognition of the need to integrate mental health services into routine tuberculosis (TB) care. For successful integration, policymakers need to first understand the practices of TB health workers in the management of mental health conditions, including depression, anxiety, and psychological distress, and use this to decide how best mental health services could be delivered in tandem with TB services. In this qualitative study we aimed to understand how TB health workers and other stakeholders viewed mental health conditions linked to TB and how they screened and treated these in their patients.

Methods: The study draws on qualitative data collected in 2018 as part of the Tuberculosis Reduction through Expanded Antiretroviral Treatment and Screening for active TB trial (TREATS), conducted in eight urban communities in Zambia. Data were collected through 17 focus group discussions with local health committee members (n = 96) and TB stakeholders (n = 57) present in the communities. Further in-depth interviews were held with key TB health workers (n = 9). Thematic analysis was conducted.

Results: TB stakeholders and health workers had an inadequate understanding of mental health and commonly described mental health conditions among TB patients by using stigmatizing terminology and overtones, for example *"madness"*, which often implied a characterological flaw rather an actual illness. Psychological distress was also described as "*overthinking"*, which participants attributed to psychosocial stressors, and was not perceived as a condition that would benefit from mental health intervention. There were no standard screening and treatment options for mental health conditions in TB patients and most TB health workers had no mental health training. TB

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Stakeholders and health workers understood the negative implications of mental health conditions on TB treatment adherence and overall wellbeing for TB patients.

Conclusions: TB stakeholders and health workers in Zambia have a complex conceptualisation of mental health and illness, that does not support the mental health needs of TB patients. The integration of mental health training in TB.

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services could be beneficial and shift negative attitudes about mental health. Further, TB patients should be screened for mental health conditions and offered treatment.

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Introduction

Zambia has a long-standing history with tuberculosis (TB) and efforts to eradicate it date back to the 1960s [1]. Despite major progress in TB treatment and eradication, Zambia is still ranked among the thirty countries with the highest burden of TB globally [2]. This is due, in part, to the high prevalence of Human Immunodeficiency Virus (HIV) in the country. TB continues is one of the most significant co-infections for people living with HIV (PLWH) in Zambia, and accounts for a third of all deaths in this population [2]. Zambia has an estimated HIV prevalence of 11.3% amongst adults aged 15–49 and an approximate HIV/TB co-infection rate of 23.8% [3, 4].

Mental health conditions affecting people with TB include general psychological distress (which may itself be overwhelming and disabling) and conditions that can be diagnosed according to established classificatory systems (e.g. International Classification of Disease (ICD)), for example, depression and anxiety disorders. In general, mental health conditions that cause significant distress and functional and/or social impairment are regarded as mental illness (although individual, professional and cultural factors may affect the application of this label). Mental health conditions can act as a risk factor for TB, and amongst TB patients act as a barrier to TB management and eradication, by negatively impacting health behaviours such as diet, health care seeking, medication adherence, and/or treatment completion [5]. TB can in turn act as a risk factor for mental health conditions including psychological distress, depression and anxiety [6], as a result of morbidity and reduced quality of life [7, 8], duration and side effects of treatment [6, 9], social stigma attached to the illness [5, 8, 10, 11], fear of transmitting TB disease to others [6], and other potential comorbidities (especially HIV) that are associated with TB [12]. In this way, TB and mental ill-health share a syndemic relationship; each increases risk and exacerbates morbidity in the other. This creates a vicious cycle for those with co-morbid presentation of both, negatively impacting health and wellbeing [5].

As seen in other settings with high burden of TB, efforts to eradicate the disease in Zambia have not focused on the complex relationship between TB and mental health [13, 14]. The lack of attention given to mental health in TB care could be attributed to nascent mental health landscape in Zambia, which experiences several service provision gaps, including services being highly centralized, with few trained mental health personnel [15, 16].

Although the figure varies from one study to the other, the prevalence of mental health conditions was found to be high amongst TB patients. A 2020 global metaanalysis estimated a pooled prevalence of depression of 49.2% from 25 studies [17]. A significant proportion of the studies (8/25) in the meta-analysis were from subSaharan Africa, specifically three were from Nigeria with prevalence of depression ranging from 27.7 to 45.5%, one from Cameroon with a prevalence of 61%, and four from Ethiopia with a range of 31.1% to 54%. Similar to Zambia, the represented countries all have a high TB burden. The few studies looking at mental health and TB in the Zambian context also highlight potentially high levels of distress in TB patients. For example, a 2013 study conducted across 16 primary health centres in Zambia found 30.9% of 231 TB patients expressed suicidality, with 3.4% having attempted suicide at least once [18].

The 2015–2035 World Health Organization (WHO) End TB Strategy strongly advocates for the integration of

mental health and TB treatment [19], however low- and middle-income countries (LMICs) often lack the trained mental health personnel needed to deliver such services [20]. Sweetland et al. [20] discuss how a task shifting model established within TB care in many LMICs, is well placed for the detection and treatment of mental health conditions, like depression, in TB patients. They emphasise that the bulk of TB care in LMICs, including TB screening and follow-up of patients, is conducted by community health workers, and training this cadre of health workers on how to detect and manage mental health conditions among TB patients would be an efficient way of integrating mental health service into the current TB infrastructure [20].

Health workers and other TB stakeholders, such as home-based care providers and public health institutions, are at the core of TB service provision, and their perspectives and understanding of mental health and TB, and the delivery of care, are integral to implementing an integrated model. Literature from the region highlights, for example, how negative attitudes of health workers serve as a barrier towards treatment for both TB and mental health conditions among patients [21–23]. To the best of our knowledge, there has been no work done to understand how TB stakeholders and health workers in Zambia understand the possible causes and implications of mental health conditions among TB patients, and how they currently navigate mental health screening and treatment in TB patients. We define TB stakeholders as individuals or organisations that work directly with TB control or management. This study sets out to explore: the conceptualization of mental health and TB amongst TB health workers and stakeholders; the causes of mental health conditions in TB patients as understood by health workers and stakeholders; and mental health screening and treatment practices delivered by TB health workers in Zambia.

Methods

The study draws on qualitative data collected in 2018 as part of the Tuberculosis Reduction through Expanded Antiretroviral Treatment and Screening for active TB trial (TREATS). TREATS is a follow-on study from the Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART) Trial, a randomised control trial that aimed to investigate the impact of combined community level TB/HIV interventions on HIV incidence [24]. PopART was conducted in 21 communities—12 in Zambia and 9 in South Africa.

The aim of TREATS is to measure the impact of the PopART intervention on TB incidence and prevalence. TREATS is being carried out in the same 12 communities as PopART in Zambia. The TREATS qualitative inquiry, where this data was collected, was conducted in four intervention and four control communities. The qualitative work aimed to comparatively describe how TB patients experienced the PopART intervention and document popular understanding of TB and TB stigma in these communities. Data was collected by a social science team consisting of seven field-based research assistants. The research assistants were development studies [5] and social work [3] graduates [4 males and 3 females], who were guided by three experienced social scientists who provided training, de-briefing and field support (first, second and last authors). The social scientists are from different disciplines (economics, education, and anthropology) and were guided by the third author who is a psychiatrist with extensive experience in the region. Due to the sensitive nature of the data being collected, researcher assistants were trained to be sensitive to participants and reflective of their own biases around mental health conditions, how their identity impacts participants and the resulting implications on the data collected.

In each of the eight communities, we conducted Focus Group Discussions (FGDs) with local Neighbourhood Health Committees (NHCs) working in the field of TB.
The NHCs are community-based groups formed under the guidance of health personnel that play a key role in health planning and budgeting activities. They serve as a link between the community and the health facility, advocating for disease prevention and control in their communities. We also conducted FGDs with TB stakeholders directly delivering TB services, including screening, testing and follow-up care for TB patients in our eight study communities. TB stakeholders included government organizations such as schools and clinics, and non-government organizations such as churches, public health institutions, and home-based care organizations.

FGDs were selected to explore the perspectives of various stakeholders in the field of TB. Locations most convenient for participants were organised prior to the discussions, and venues were chosen to maximise the privacy of participants. Open-ended questions were guided by a semi-structured interview guide to encourage wide-ranging perspectives. Each FGD was facilitated by a moderator who guided the discussion and an assistant moderator who assisted with facilitation and note taking. Each FGD was approximately 1.5 to 2 h long.

Data were also collected via in-depth interviews (IDIs) with TB health workers, exploring mental health conceptualisation and the experiences of mental health treatment and management of TB patients. The majority (8/9) of the health workers recruited were nurses and one was a health technician. All worked predominantly with diagnosed TB patients, providing medication and follow-up care in their respective clinics. Interviews lasted between 45 min to 1.5 h. Interviews were conducted in a private and comfortable location for the participants.

FGDs and IDIs interview guides included questions on mental health guided by the literature. Areas of inquiry included the understanding of mental health in the Zambian context, the drivers of mental health conditions during TB diagnosis and treatment, the implications of mental health conditions for TB patients' quality of life and TB treatment outcomes, and availability and accessibility of mental health services for TB patients.

Recruitment

The FGDs were conducted with a maximum of 10 to 12 participants. Maximum variation sampling was employed, with a spread based on age, sex, and occupation. Participants were chosen with the aim of encouraging varied viewpoints while keeping the atmosphere and power relations comfortable enough for everyone to contribute. Purposive sampling was used to recruit health workers for the IDIs. The eligibility criteria for health workers and the NHC participants included providing key TB services in the clinics from the eight TREATS communities during the time of the PopART trial through data collection for this study. NHC members were recruited through the help of community mobilisers, who serve as the link between the TREATS study and the community members. Clinic-based TB treatment supporters were also used to help identify members of the NHC. Subsequently, the TB stakeholders in each community were identified through FGDs with the NHC.

Table 1 provides a summary of data collection activities and description of participants.

Data analysis

IDIs and FGDs were recorded and transcribed verbatim. Data was analysed thematically using a coding framework developed from the TB and mental health literature. Further codes were iteratively added during the analysis. Data was double-coded by the first and second authors using ATLAS.ti software. Any discrepancies with themes emerging from the data were resolved with correspondence with the last author and securing common consent among the first, second and last authors.

Results

The results are presented under three broad themes. The first explores TB stakeholders' and health workers' conceptualization of mental health and the impact of mental health conditions on TB patients experiences and overall wellbeing. The second explores causes of mental health conditions in TB patients, as understood by TB stakeholders and health workers. Thirdly, the results explore how TB health workers screen and treat mental health conditions in TB patients.

Conceptualisation of mental health and implications of mental health conditions for TB patients by TB health workers and stakeholders

There were two overarching definitions of mental health conditions presented by health worker and other stakeholder participants; *"Ku funta"* and *"Ku ganiza maningi"*, loosely translated to "*madness*" and "*thinking too much*". "*Madness"* was more equivalent to psychotic symptoms of mental illness while "*thinking too much*" was similar to symptoms of depression and anxiety. Participants also identified implications of mental health conditions on TB patients, namely suicide, poor adherence, and disruption to family dynamics.

Table 1 Table of participants

Activity	Participant type	Characteristic	
In-depth interviews	TB health worker (N = 9)	Male	2
		Female	7
		Age range	25–58
Focus group discussion	NHC (N = 96)	Number of activities	9
	Stakeholders (N = 57)	Number of activities	9

Conceptualisation of mental health and mental health conditions

"Madness" ("Ku funta") When initially asked about mental health and mental health conditions, most participants were momentarily discontented and often broke out into nervous laughter before responding. The terms "mental health conditions and mental illness" did not illicit definitions from health workers and TB stakeholders that were equivalent to a biomedical definition of the terms. Rather, *"Madness" (Ku funta)* was often the initial definition of mental illness stated by stakeholders. In the

local context the word more often implies a characterological challenge or personality flaw rather than an illness. Taken further, a "*mad*" person in this context can also be called "*Chi Silu"*, which loosely translates into "a foolish or useless person". Such conceptualisations of mental illness significantly devalue those experiencing symptoms and when used in dialogue, these definitions have strong stigmatizing undertones towards people with mental health conditions. For example, when asked to define mental health, one NHC FGD (Z3) said it was *"madness of the mind".*

The symptoms of "*madness"* provided by stakeholders included: patients behaving irrationally, being short tempered and aggressive, hoarding items such as stones and animal skins, refusing to take their medication, "*delusional behaviour*", extreme sex drive (particularly in men) or no sex drive at all, and memory loss.

"Overthinking or thinking too much" ("Ku ganiza maningi") When asked specifically about depression and anxiety disorders in TB patients, stakeholders and health workers had different ways of expressing these conditions. Some of the definitions included TB patients being the term "*emotional*" (sometimes with emphasis, for example, "*over emotional", "emotionally stressed"),* but most commonly they were described as *"Ku ganiza maningi" ("overthinking* or *thinking too much")* by most of the participants. Participants described TB patients who were "*over thinking* or *thinking too much"* as being overly sad and incessantly worried, with a tendency of isolating themselves.

Implications of mental health conditions

Suicide Participants acknowledged the negative implications that mental health conditions had on the lives of TB patients; pinpointing an amalgamation of personal and social losses, including loss of self-worth and standing within their communities, which in some cases reportedly resulted in suicide.

> *"They (TB patients) start seeing that they are nothing in the community, that there is nothing that they can even do. Because people have looked down on them, that is what now becomes of the person. Others end up killing themselves because of such thinking." (FGD, NHC, Z3)*

Poor adherence Participants further detailed how mental health conditions such as depression, anxiety and alcohol addiction sometimes led to poor adherence in their patients, particularly for those with poor social support systems.

> *"I: In your opinion, do emotional and mental health problems affect the ability of TB patients to adhere to treatment? R: Yes because they will end up thinking about things that are not even in existence. As a result, they will not even trust the same medication that they are taking and, in the end, they will fail to adhere to TB treatment and later on they will become defaulters." (IDI, Health worker, Female, Z7)*

In some cases, recalled by participants, mental health conditions were present before their patient's TB diagnosis and served as a barrier to engagement with TB treatment, which unfortunately resulted in death for some TB patients, as seen in the example below: *"R: According to the information we got from his parents, he was already depressed ever since his wife left him after he got fired from his Job, so when he was even found with TB he refused to start treatment even when his parents escorted him here to the clinic. We educated him, explained to him, he still refused to start treatment. I: Ok what about the other person who died? R: The other person who died, we used to talk to him, but he didn't accept that he had TB and he loved drinking alcohol too much. He would come and collect drugs on time but would just go and pack the medicine at home and would not drink it." (FGD, Stakeholders, Z4)*

Despite acknowledging that TB patients sometimes defaulted because of a mental health condition, participants still felt a sense of responsibility for their patient's challenges in adhering to their treatment. For example, there was a sense of frustration in a stakeholder who described feeling ignored and like a failure when their patients defaulted and died.

> *"We have seen them (TB patients) dying because of poor adherence. You find that when you advise them not to drink, they are found drinking all sorts of beer. That is one thing that I have seen where we have failed on our side as helpers to these people in the community. It's like they are ignoring us. Sometimes they come to a point where, I don't know whether it's stigma or self-denial, where they reach a point of let it (death) come, I die. We really feel our work is not being heard because the people that you have been informing for some time will die and when you look*

back, you ask yourself: 'we have been working with that person, we have been going to that person, but how has that person defaulted?'" (FGD, Stakeholder Z8)

Disruption of household dynamics Participants noted that psychological distress and mental health conditions in TB patients also negatively affected relationships within the household. They described distressed TB patients, particularly men, as aggressive and short tempered and, in some cases, suspicious of their spouses. These feelings sometimes resulted in violence towards women and was destabilising for the household.

"Like what they have said, men are the most difficult, because they feel life has ceased and it will not be the same again. So, they are short tempered such that most of the times women don't stay well. That's why you see women leaving, it's because of the behavior the man begins to portray when they are sick. They refuse medicine, sometimes they become very upset, and they do not want to take medicine. So, when their wife tries to force them to take the medicine, they would even want to beat their wives, so this causes the women to want to run away from what is happening with their husbands." (FGD, Stakeholders, Z7)

Participants highlighted both personal and social implications of psychological distress and mental health conditions in TB patients, including death through suicide and poor TB treatment adherence. In some cases, stakeholders and health workers reflected on the death of TB patients as personal failings in their duty despite acknowledging the role that mental health conditions play

Causes of psychological distress and mental health conditions in TB patients as understood by stakeholders and health workers

According to TB stakeholders and health workers, psychological distress and mental health conditions in TB patients was either caused by physiological factors or social and economic factors. Physiological drivers were more associated with "madness", while social and economic factors were associated with depressive symptoms. Stated physiological factors included location of TB in the body and side effects of TB medication. Social and economic drivers included loss of income resulting from TB morbidity, TB stigma, and misinformation or lack of adequate information about TB transmission and treatment, compounded by a fear of death.

Physiological factors

Locations of TB in the body There was a belief among some stakeholders that TB causes *"madness"* due to physiological factors, such as "*TB bacteria entering the brain"* of the patient.

"It depends on the area that the TB germ goes to live in the body. If its TB of the brain, it can make the person mad. They would be looking mad." (FGD, NHC, Z3)

Anti-TB medication A minority of participants attributed mental health conditions in TB patients to TB medication, either as a direct side effect of the medication or because of the other side effects resulting from TB medication.

"The side effects of the medication make them (TB patients) experience mental health challenges." (FGD, NHC, Z10)

Social and economic factors

Loss of ability to earn a living Participants discussed the significant economic implications of TB, as a source of psychological distress for many TB patients who mostly work in the informal sector meaning their ability to earn was dependant on their ability to work. Participants stressed that few of their patients had the liberty of paid sick leave. Below, a member of a NHC describes the negative impact of TB on their patients' income and the ripple effect this has on a patient's family and mental health:

"He (TB patient) is the one who goes for work, right, then he is diagnosed with TB, and he is told that he can't go for work. You see, these jobs that they (TB patients) do, unless they report for work, they will not get paid, if they don't report for work they won't be paid. So, this adult will be thinking a lot… 'how I am going to feed my children'. If it means going to the fields to farm, he is not able to because of the disease, so he will have a lot of thoughts about how to look after the family while he is sick. So, they have double problems, planning for the family and looking after themselves while they have the disease…... that's where I see agony to be biggest." (FGD, NHC, Z12)

Stigma and discrimination Most stakeholders and health workers believed that TB stigma was a major driver of psychological distress and mental health condition in TB patients. One stakeholder described stigmatization as

"mental torture" (FGD, NHC, Z3) that would eventually result in "*madness"* in TB patients. Another FGD participant went as far as to state that in the absence of stigma, TB patients would not develop depression. *"If they (TB patient) are not being stigmatized they can't go through depression." (FGD, NHC, Z4)*

The stigma, that sometimes resulted in discrimination, that most participants alluded to was experienced most commonly at household level, from family members or close friends living with TB patients. Forced isolation was a commonly discussed form of discrimination; for example, participants described how some caregivers make TB patients use their own eating utensils and bedding or force them to sleep in separate rooms. *"Another thing that contributes (to psychological distress) is how those (family members) with TB patients behave. They avoid sitting near them (TB patients) ... Even eating with TB patients, they refuse saying, 'you might contract TB'." (FGD, NHC, Z7)*

Another participant in the same FGD went on to share a personal experience of how such behaviours led to their brother contemplating suicide whilst receiving TB treatment.

> *"I have a younger sibling, his name is X, he had TB. When he had TB I used to stay with him and my in-laws… my aunt used to treat my brother in a way similar to what we discussed, where she would give him his own cup, plate and his own room... he used to have worries because of this treatment. He reached an extent of saying I would rather hang myself instead of me staying alone, there is no one close to me, no one even chats with me."(FGD, NHC, Z7)*

As well as stigma from household members, participants told us that TB patients experience stigma in health care settings, particularly from health workers providing non-TB services. The negative attitudes of health workers towards TB patients were attributed to the fear of contracting TB and inadequate training about TB in general. Stigmatizing behaviours towards TB patients by health workers included talking to TB patients rudely and denying them health services.

> *"R: The pharmacist said, 'no no no, he (TB patient) is infectious, he will infect others so you should not be allowing him to come here, he should just stay at the TB corner. The peers should come and collect his drugs on his behalf…'. That is what happened.*
> **I:** *So, do health workers stigmatise TB patients?*
> **R***: They stigmatised that one.*
> **I***: *Nervous Laugh* So they do.*
> **I2***: Why do you think other health workers would stigmatise them?*
> **R***: They are scared of contracting TB." (IDI, Health Worker, Z7)*

Misinformation about TB Limited understanding of TB transmission was discussed as another common driver of psychological distress and mental health conditions amongst TB patients.

> *"I think it (psychological distress) all goes back to lack of knowledge and understanding of the TB infection. To some people, once they are diagnosed with TB, they will feel emotionally defeated and challenged. They will feel that what they have is something that will never be cured." (IDI, Health Worker, Female, Z2)*

Participants also highlighted how some TB patients believe that TB is incurable and how this misinformation often contributed to psychological distress and mental health conditions.

> *"The reason why they (TB patients) think too much when they have TB, is that they think that they won't get well and they will die." (FGD, TB Stakeholder, Z3)*

This lack of understanding about TB treatment was underlined by the misunderstanding of many TB patients as to the cause of the disease, informed by popular assumptions and beliefs. According to participants, patients mentioned that TB was contracted through excessive drinking or smoking, "promiscuous" behaviour (having sex with multiple partners) or sexual contact with a woman who had had an abortion. These popular assumptions and beliefs served as drivers of TB stigma, increasing feelings of shame and reducing perceptions of self-worth amongst TB patients. Participants stressed how these beliefs made it harder for TB patients to understand how they were infected with TB, illustrated by the stakeholder's experience below:

> *"After seeing her TB results in red pen stating smear positive and being told that she was found with TB and had to start drugs, she started crying saying, 'I don't sleep with men, am not a prostitute, how can I be found with TB…'" (FGD, TB Stakeholder, Z8)*

Additionally, participants noted that TB patients often associated TB with HIV, with many of their TB patients

automatically assuming that their TB diagnosis meant that they were also HIV positive. This association between the two conditions was often emotionally distressing for TB patients.

> *"Others had beliefs to say when you have TB, and definitely when you start TB drugs, then you will have HIV; those were the misconceptions that they had…TB patients think that when they start taking TB drugs people will know that they are HIV positive." (FGD, TB Stakeholder, Z8)*

Participants did note, however, that a genuine experience of TB and HIV co-morbidity did present an extra emotional burden on TB patients. TB health workers bore witness to how emotionally challenging it was for patients to accept and cope with having both TB and HIV. For some of their patients, the co-morbidity, underscored feelings of denial and depression and could lead to death.

> *"They (two TB patients) were depressed because they were told that they had TB and HIV. The one who was from area X was very much in denial. He refused to believe he could have TB or HIV because he claimed he never had sex with women. That is how he died. Then the other one had a wife who was pregnant. He also refused to accept that he had TB. A lot of them believe when you have TB then you automatically have HIV. He refused to accept it. We tried by all means to help and counsel him. When you are around, he would accept to come (to the clinic) but when you leave his home, he would change his mind. That is how he died." (FGD, NHC, Z2)*

TB health workers and stakeholders provided a detailed understanding of the causes of psychological distress and mental health conditions among TB patients during TB investigation and treatment. Participants placed more emphasis on the interactions between social and economic level drivers as compared physiological causes of psychological distress and mental health conditions.

Identification and treatment of mental health conditions in TB patients

Participants told us that they did not receive any indepth training with regards to mental health and they do not have a standard method for identifying mental health conditions in TB patients during routine TB care. Treatment options in cases where participants suspected a mental health condition in their TB patients included adherence support, encouragement and referral to the main psychiatric hospital.

Screening and training

Mental health screening TB health workers and stakeholders told us that mental health screening is not part of routine TB treatment in Zambia. Both diagnosis and treatment of mental health conditions were reliant on the health workers' interpretation of patients' emotional state. For example, some health workers said that they would raise mental health issues with specific patients if the patient looked visibly upset by the news of their TB diagnosis or appeared to be isolating themselves from others.

> *"***I:** *Do you regularly provide emotional support to TB patients in your work?"*
> *R: Not so often, but once there is a new client, we give ample time to that client to express themselves and ask questions where they are not sure. We then explain to them according to the questions they are asking. We give them time to talk and ask questions." (IDI, Health Worker, Female, Z8)*

Training Most health workers interviewed stated that they had not received any in-depth training regarding mental health and illness. Some had undergone short psychosocial counselling courses, but such courses were not targeted towards supporting chronically ill patients with depression and anxiety. For those that had received mental health training, they had rarely received regular refresher training or support.

> *"Eh… I wanted to say that we do not have health workers who are professionally trained in dealing with depression. They are trained in general counselling, where they talk on the surface and try to calm the person (distressed patient). We don't have someone who's trained specifically for depression or organizations that have come in to help on matters of depression." (FGD, TB stakeholder, Z3)*

Treatment of mental health conditions in TB patients

TB knowledge and adherence support Treatment offered by health workers for psychological distress and mental health conditions is often focused on a discussion around TB treatment, with the belief that distressed patients just need encouragement and knowledge about their condition. Most of these discussions are provided by the nurses in charge of TB treatment and by TB treatment supporters (community volunteers). TB treatment supporters also provide

education on TB, informing patients and the community about TB causes, transmission, and how to take care of themselves when diagnosed. This health education places emphasis on the importance of adherence to medication to cure TB and often try to dispel misconceptions about TB.

> *"Every time they (TB patients) take their drugs, we make them sit here and then we ask, 'what is your problem?' Then we try to explain what TB is and give them information about TB. We ask the patient, 'do you really understand this disease you have?', 'where you contracted it?', 'how do you feel?', 'where do you feel you got it?', and they will try to explain to us and then we chip in and give the information if there are any myths and misconceptions." (IDI, Health Worker, Female, Z8)*

Referral to psychiatric hospital Some health workers acknowledged that they were not equipped to deal with mental health conditions. For example, when asked about psychological distress or mental health conditions in her patients, one nurse (IDI, Health Worker, Z7) simply stated, "*Hmm, I am not a mental nurse… I don't have a psychiatric paper (degree).*" As a result, some health workers and stakeholders opted to refer emotionally distressed patients to the country's main psychiatric hospital.

> *".....at times we refer those people (TB patients), in case it becomes complicated, like when they start becoming mentally ill…." (FGD, TB stakeholders, Z7)*

TB health workers acknowledged that they were not well equipped to handle the mental health needs of TB patients dealing with psychological distress or mental health conditions.

Discussion

This research has explored conceptualisation, implications, and drivers of psychological distress and mental health conditions among TB patients in Zambia as understood by TB stakeholders and health workers. Insights into current mental health screening and treatment practices have also been highlighted by participants. It is clear from our findings that TB stakeholders and health workers are mindful of the drivers and implications of psychological distress and mental health conditions among TB patients. There are limitations in participants conceptualisation of mental health and mental health conditions, which in part are due to inadequate training and guidance on mental-ill health management in comorbid TB patients. Integrating mental health training and support into TB clinics may offer a solution.

The TB stakeholders and health workers we spoke to in our study conceptualised mental health conditions into two distinct categories: madness and overthinking. "*Madness" (Ku funta)* was often the initial way in which TB stakeholders and health workers described potential mental health conditions in TB patients and was more equivalent to psychotic symptoms caused by physiological factors, such as TB entering the brain or TB medication. Although there is some literature that suggests TB infection [5] and TB medication can lead to neuropsychiatric complications in TB patients, these complications are rare; a global meta-analysis calculated a pooled estimate of 1.1% (95% CI 0.2–2.1) for central nervous system related adverse drug reactions in TB patients [25]. Our findings reveal that this conceptualisation of mental health conditions was inundated with stigmatizing undertones affirming the work of other studies exploring the attitudes towards mental health conditions in Zambia [16, 21, 26, 27].

Our researchers were not impervious to these attitudes. Despite comprehensive training in mental health conditions and stigma prior to data collection, research assistants still used stigmatizing language such as *"(ku funta) madness, and sickness of the mind"* in reference to mental health conditions, when conducting interviews. This highlights how deep-rooted mental health conditions biases are in this context and the potential challenges that may arise in attitudinal shifts towards mental health conditions. More research around the understanding of mental health and illness in this context would provide guidance of how to talk about mental health conditions in a sensitive and context appropriate manner. Stigmatizing attitudes towards mental health conditions are not unique to Zambia and are prevalent throughout the region [28–30]. They are, in part, driven by traditional beliefs in supernatural causes of mental health conditions, such as witchcraft [26, 30]. In our findings however, TB occupied a parallel space to witchcraft, providing another explanation as to the cause of "*madness*" in TB patients.

There are profound negative implications of these stigmatizing attitudes for TB patients dealing with mental health conditions on both their quality of life and health seeking behaviours [6]. TB alone is a highly stigmatized condition in Zambia [31] and TB is strongly associated with HIV, again heavily stigmatised in this context [32]. Thus, TB patients dealing with mental health conditions could experience a convergence of multiple stigmas. It is vital that

the government and service providers tackle the multiple stigmas associated with mental health conditions, TB and other stigmatized conditions. The health-related stigma framework, developed by Stangl et al. [33] offers guidance in tackling stigma brought about by mental health conditions and TB. It acknowledges and addresses parallels in drivers and consequences of stigma across different conditions and recommends a cross-cutting approach to addressing stigma. Research focused on this framework and the creation of context sensitive interventions addressing intersectional stigma would be highly beneficial in this context.

The attitudes towards mental health conditions in Zambia are present not only among community members, but also at policy level, as evidenced by the 1951– 2019 Mental Disorders Act use of archaic terms such as *"idiots, imbeciles*, and *invalids"* in reference to patients with mental health conditions [15]. Stigma towards mental health conditions could be partly addressed by the new Mental Health Act passed in April 2019. Among other things, the Act aims to increase awareness of mental health and tackle mental health stigma [34]. Implementation of this act will require government commitment, funding and coordination of community awareness activities and comprehensive changes throughout public administration, if understanding is to be improved and stigmatising attitudes reduced.

Aside from "*madness*", TB health workers and stakeholders also described TB patients in psychological distress as "*overthinking* or *thinking too much",* a description similar to other countries in the region [35–38]. Our participants' conceptualization of "*overthinking* or *thinking too much"* has overlaps with depression; for example, both are characterised by sadness/low mood, isolation, and suicidal ideation. However, there are significant differences between the two, namely, *"overthinking* or *thinking too much",* unlike depression, was not considered to be an actual illness by participants and was thought to be alleviated through provision of adequate information about TB and rendering encouragement to TB patients who appear distressed. The conceptualisation of "*overthinking* or *thinking too much"* as a social problem, which consequently requires a social solution, is echoed in work from the region. For example, in work with HIV positive women in South Africa, HIV infection was not considered to be the cause of their psychological distress but rather social factors such as stigma, poverty, and stressful life events resulting from their condition were to blame [39]. Accordingly, social support emerged from participants as the most appropriate intervention for psychological distress or mental health conditions [39]. Psychosocial interventions offer non-pharmacological solutions and are instead focused on psychological or social factors of psychological distress and mental health conditions. They are well-evidenced to be effective for people with mental health conditions and co-morbid physical conditions, especially in low-resource settings [40]. Mental health integration into TB care would benefit from research exploring psychosocial interventions among TB patients in this context, given our findings of limited support options for people with mental health conditions in Zambia and limited training of health care staff.

As well as limited mental health support for people with mental health conditions in Zambia, our findings also indicate a dearth of standard screening and diagnosing mechanisms for TB patients suspected to be dealing with mental health conditions. Both diagnosis and the consequent treatment options were reliant on health workers' perceptions of the patient. When thinking on the need for better diagnosis and intervention, it is important to recognise that Zambia is extremely under resourced in relation to trained mental health personnel [15]. As Sweetland et al. [20] argue, a context such as Zambia could lend itself well to the WHO Mental Health Gap Action Programme (mhGAP) model. mhGAP utilises a task-shifting model, training non-mental health specialists in detection and management of ten priority disorders including psychosis, alcohol and drug use, depression, and suicide [41]. This model places emphasis on pharmacological treatments, while providing some brief structured psychotherapies that can be delivered by non-specialists [41]. In Zambia, such training could be provided to both clinic-based health workers and community health workers, who are at the helm of TB management. Community health workers provide services such as community TB screening, contact tracing, and follow-up and monitoring of TB patients in the community. Their established position within local communities and the primary care structure would allow for a more contextually sensitive understanding and delivery of mental health services and can alleviate the need for specialist mental health personnel.

This model of training non-specialised health workers in detection and treatment of mental health conditions has proved to be somewhat effective in the region. Evidence on task-shifting models has demonstrated improved knowledge about mental health conditions and improve confidence in identifying mental health conditions among

clinic based [42–44] and community based [45] health workers, as well as significant reductions in symptoms of mental health conditions among patients in primary care [46]. Evidence has shown the benefits of similar interventions for non-TB groups in Zambia, and it may prove appropriate for TB patients [47]. There are possible concerns with this approach, including a potential over use of pharmacological solutions to address psychosocial challenges, resource constraints affecting adequate supervision of non-specialised mental health staff [48] and the need to appropriately motivate and compensate community health workers without relegating their dedication and constantly evolving roles and responsibilities to bouts of altruism [49]. That said, evidence suggests such a model may be appropriate for mental health in TB patients in a Zambian context, especially when integrated into the TB care system, where health workers are given very little support and training on mental health, despite the number of people they meet needing support. Future research should focus adoption and evaluation of mhGAP or similar task-shifting models, following well-evidenced adaptation processes, feasibility studies and pilot evaluations, to inform a culturally and contextually appropriate intervention [50]. Any intervention developed for TB patients should incorporate improved information on TB cause and transmission, having seen our participants describe widespread assumptions that have an impact on psychological distress and selfstigma. Developing an intervention that addresses both the underlying causes of mental health conditions in TB patients, as well as alleviation of prevailing symptoms, will be needed to reduce the burden among this population in Zambia.

The findings of this study come at a timely juncture, as the world of TB contemplates ways of integrating mental health screening and treatment into the TB care cascade. The work provides insight into how health workers and stakeholders working in the field of TB understand the intersection between mental health conditions and TB in the Zambian setting, highlighting baseline knowledge and gaps. Recommendations for further research based on our findings include: contextual understanding of mental health conditions; stigma interventions tacking intersectional mental health, TB and HIV stigma; training for health facility and community-based health workers on mental health screening and treatment; and an exploration and evaluation of psychosocial interventions with TB patients screened for mental health conditions in the Zambian context. Furthermore, in context of these findings, it is worth addressing the social underlying causes of mental health conditions in TB patients including improving social security nets for economically vulnerable TB patients.

Limitations

Despite training, some research assistants in the study maintained stigmatising attitudes towards people with mental health conditions, which were evident in their interpretation/communication of the mental health questions to participants. The major strengths of the study were the large sample size and geographical reach of participants which spanned across eight urban communities in Zambia. This allowed for exploration of diverse experiences and views around mental health and TB from a sample with national level representation.

Conclusion

TB stakeholders and health workers are cognisant of the increased risk of psychological distress and mental health conditions among TB patients, although their understanding of mental health conditions often comes through stigmatizing. Health workers generally lack the toolkit to adequately detect and treat mental health conditions in their patients and could benefit from mental health training. The mental health training and sensitization for health workers should aim to increase knowledge about mental health and chronic illness, while shifting negative attitudes around mental health conditions. Task-shifting models may represent an appropriate method to integrate a standardised pathway of care for TB patients with mental health conditions in TB clinics. Interventions must include contextually appropriate identification and treatment methods, and efforts must be made to address the social drivers of psychological distress and mental health conditions, including TB stigma and economic vulnerability.

Abbreviations

FGDs: Focus group discussions; ICD: International classification of disease; IDIs: In-depth interviews; HIV: Human immunodeficiency virus; LMIC: Low- and middle-income countries; LSHTM: London School of Hygiene and Tropical Medicine; MhGAP: Mental health gap action programme; NHCs: Neighbourhood health committees; PLWH: People living with HIV; PopART : Population effects of antiretroviral therapy to reduce HIV transmission; TB: Tuberculosis; TREATS: Tuberculosis reduction through expanded antiretroviral treatment and screening for active TB trial; WHO: World Health Organization.

Supplementary Information

The online version contains supplementary material available at https:// doi. org/ 10. 1186/ s13033- 022- 00542-x.

Additional file 1. Stakeholder analysis interview guide.

Additional file 2. TB health worker in-depth interview guide.

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Author contributions

TM, MG,VB, designed the study. MG managed data collection teams with oversight from TM and VB. TM, MG and VB collected some of the data. TM and MG coded the data, TM led the analysis with input from VB. TM wrote the first draft of the manuscript which was edited by VB. TM, VB, IM,RS, MG KS AND HA, contributed to the interpretation of the findings and commented on the drafted manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The data used or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Ethical approval for all study procedures was obtained from the institutional review of the London School of Hygiene and Tropical Medicine (LSHTM) (#14985), and the Bio-medical Ethics Committee of the University of Zambia (005/02/18). Written consent was obtained from all participants prior to data collection activities.

Consent for publication

Consent for publication was obtained from all participants, and consent forms would be available on request.

Competing interests

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ed in these deaths.

Chapter Seven: Discussion

This chapter summarises and critically examines the findings across the three objectives and reflects on the methodology, including limitations of the methods and the influence of my experience of mental health on data collection and interpretation. The chapter then focuses on the drivers of mental distress and potential mitigation strategies, drawing on three key areas – livelihood support, TB and mental health stigma reduction and health system strengthening. These strategies are used to help make recommendations for improving care and support for people with TB. The chapter ends by highlighting future areas of research.

Holistic reflections across the findings

The aim of this PhD is to understand how mental health intersects with TB in the Zambian setting focusing on three main areas of inquiry the first is mental health experiences of people with TB, the second investigates the burden of mental distress in TB survivors and the last area explores TB health workers and stakeholders' conceptualisation of the relationship between mental health and TB and how they manage mental distress in their clients.

Most people with TB experienced mental distress during their time on treatment. The severity of distress ranged from mild distress that did not interfere with participants ability to engage in day-to-day activities, to severe distress which included suicidal ideation and led to disruption of TB treatment. For some participants, these feelings were heightened during TB investigation and early on in treatment and subsided once morbidity from TB and side effects of the TB medication improved. This is corroborated by findings from the quantitative inquiry which showed that TB survivors did not have a

disproportionate burden of mental distress when compared to people with no medical history of TB. The fact that TB survivors did not have a disproportionate burden of distress could speak to a level of resilience and ability to bounce back despite challenging experiences. Social capital and religion played a key role in supporting and mitigating mental distress in people with TB during their investigation and treatment periods and demonstrates some sources of resilience. These findings may also highlight the fact that alongside TB, people in this setting face other distresses, such as poverty, which may override the distress associated with a medical history of TB. Indeed, the quantitative data revealed that independent of TB, the prevalence of mental distress in Zambia is high (16.7%), as every one in six people interviewed screened positive for mental distress with women, older people and people who misuse alcohol being at higher risk of being mentally distressed.

Mental distress experienced by people with TB during TB investigation and treatment was caused by individual, economic, social and health system level factors. The findings show that TB and mental distress were both linked to poverty in the Zambian context. For example, qualitative findings revealed that most people with TB who contributed data to this thesis were disproportionately poor and the additional economic stress of TB increased their mental distress burden. Further, the quantitative findings suggest that poorer individuals had higher prevalence of mental distress than those with more wealth, highlighting the potential role poverty plays in development of mental distress independent of TB. Other social factors that contributed to mental distress included stigma that was experienced at health facility, community, and family level. People with TB used resilience and adaptation as positive coping mechanisms to manage their distress during their TB investigation and treatment period. Resilience often took the form of emphasis on self-care practices such as eating the correct foods when they were available, resting and adhering to their medication. Resilience also presented as having a

positive outlook and believing that if one is adherent to their medication then they will be cured. Religion often served as the lens through which positivity and acceptance was expressed to cope with distress during TB investigation and treatment. Many participants found solace in putting their fate in a higher power and accepting that their diagnosis and healing was part of Gods plan. Adaption was often seen in how participants shifted their living situations to be better able to absorb the stress associated with their diagnosis. For example, several participants moved in with relatives who could nurse them through their illness or sent their children to live with other family members to help balance the financial and caring needs of the home during their TB treatment.

The findings from objective one show that mental distress increased the overall disease burden for people with TB. For example, for some participants their experiences of mental distress made it challenging for them to adhere to their TB medication, which has the potential to increase TB morbidity and mortality. Therefore, in addition to mental distress sharing risk factors with TB such as poverty, TB in this context also served as risk factors for developing mental distress and the two conditions collectively increased the burden of illness for individuals who were experiencing both. These findings thus add credence to the syndemic nature of mental health and TB in this context.

Health workers and stakeholders had two distinct conceptualisations of mental health. The first was "K*u funta"* which loosely translated to madness. According to health workers *"madness"* was more equivalent to psychotic symptoms of mental illness and was caused by physiological factors including the location of TB in the body and side effects of TB medication. This conceptualisation of mental illness often had strong stigmatizing undertones towards people with mental health conditions and significantly devalued those experiencing symptoms in this setting. The second way in which health

workers and stakeholders described mental distress was *"Ku ganiza maningi,"* which *means "thinking too much."* According to TB health workers and stakeholders *"thinking too much"* has similar symptomology with both depression and anxiety and was caused by social and economic factors. In their experience, the health implications of *"thinking too much"* included increased risk of mortality due to poor TB treatment outcomes and suicide. The social implications included disruption to the social and family dynamics of TB clients. The data revealed that health workers did not receive any in-depth training with regards to mental health and they do not have a standard method for screening and managing mental distress in their clients. Treatment options for mental distress included adherence support, encouragement, and referral to the main psychiatric hospital.

Overall, the findings show that people with TB experience an elevated level of mental distress during TB investigation and treatment. Drivers of distress included biological factors such as TB morbidity, and socioeconomic drivers including stigma and poverty. Although the severity and duration of the distress varied from person to person, findings from objectives one and two suggest that the severity of distress reduces over time. Individual and social level drivers of distress experienced by people with TB were well understood by health workers and stakeholders. However, there was a general lack of acknowledgement of the health system level drivers of distress by health workers and stakeholders. Further, health workers lacked the skills to support their clients with TB who were experiencing mental distress.

Using the ICCC framework, the PhD identified meso level gaps in management of mental distress among people with TB and thus highlights both community and health facility level opportunities for providing mental health care and support for people with TB. The community level meso analysis calls attention to

community level support services that will help people with TB prevent and or manage mental distress during their time on TB treatment. The community level inquiry therefore feeds into the provision of complementary services in the ICCC community building blocks. By focusing on health worker perceptions and attitudes with regards to mental health and their current practices in managing mental distress in their clients, the health worker ICCC meso level analysis establishes the lack of preparedness in health workers providing care for clients with TB who are experiencing mental distress. Therefore, health facility level recommendations are centered around how TB health workers can be trained to screen, treat, and refer mentally distressed clients with TB, while also reducing health facility level drivers of distress, thereby creating a conducive environment that allows people with TB to seek care for mental distress at the health facility.

This PhD used both qualitative and quantitative methods to assess the relationship between TB and mental health in Zambia. The qualitative methods were used to draw out experiences and perspectives around this relationship while the quantitative methods aimed to assess the burden of mental distress in TB survivors post TB treatment completion. Qualitative methods in form of IDIs and FGDs were used in objectives one and three of this PhD, while quantitative methods in form of a cross sectional survey was used to respond to objective two. This mixed method methodological approach enriched the findings of the thesis; quantitative methods established the burden of mental distress in TB survivors and provided generalizable findings for similar settings, while the qualitative methods provided in-depth contextual data providing a better understanding of how mental health is understood and experienced by the study population. The mixed methods approach provided an opportunity to explore the relationship between mental health and TB through varied perspectives while providing an opportunity for triangulation of findings. Findings from my work have also shown me that it is important to leverage

the contextualised knowledge generated from qualitative findings to adapt screening tools that are not developed from the context of the study population. My reflections on mixed methods methodology pertaining to this thesis are discussed in detail below.

Summary of Findings

Table 7 provides a summary of research gaps, objectives, methods of inquiry and findings.

Table 7: Summary of Findings

Aim: To identify ways of providing holistic care for people with TB in Zambia by critically assessing the intersection between mental health and TB during TB investigation, treatment and beyond in this context.			
Research Gap	**Objective**	**Methods**	**Main findings**
Lack of acknowledgment and recognition of mental health experiences of people with TB in sub-Saharan Africa.	1. To critically examine how people with TB conceptualise and experience mental distress (common mental disorders and psychological distress) during TB investigation and treatment in the context of socio-economic factors contributing to the TB, and mental distress in Zambia.	Qualitative Analysis In-depth interviews with former TB patients (n=80) from 8 urban communities' Data was analysed thematically. Additional quantitative exploratory analysis mapping mental distress symptoms onto demographic, social, economic and TB characteristics of participants was conducted.	Most participants (76%) had experienced some form of mental distress during their TB investigation and treatment period. The reported symptoms ranged in severity. Some participants reported mild distress that did not disrupt their daily lives or ability to adhere to their TB medication, while other participants reported more severe symptoms of distress, for example, 15% of participants shared that they had suicidal ideation and thoughts of self-harm during their time on treatment. The drivers of distress were categorised into individual, social and health system drivers of distress
No empirical evidence for the prevalence of mental distress in TB survivors in Zambia.	2. To investigate prevalence and risk factors of probable mental distress in TB survivors compared with individuals with no history of TB in an urban Zambian community.	Quantitative Analysis Cross-sectional study conducted in one urban Zambian community amongst TB prevalence survey participants (n=3393). A screening measure of mental distress (SRQ-5) was included in the TREATS questionnaire. Associations between history of TB, and other co-variates, with mental distress were investigated using logistic regression.	There was a total of 3393 participants in the study, 120 of whom were TB survivors (3.5%). The overall prevalence of mental distress (SRQ-5 ≥4) in the whole study population was 16.9%. TB history was not associated with mental distress (OR 1.09, 95% CI 0.67-1.77, P value 0.166). Mental distress was associated with being female, older age and alcohol abuse. Further, the data was collected during the COVID-19 pandemic (late 2020 to early 2021).

Lack of understanding TB health workers and stakeholders' perspectives regarding the relationship between TB and mental health.	3. To explore TB health workers' and stakeholders' conceptualisation, management, and treatment of mental distress in people with TB in the Zambian context.	Qualitative Analysis 17 focus group discussions with local health committee members (n=96) and TB stakeholders (n=57) in eight communities. In-depth interviews were held with key TB health workers (n=9). Thematic analysis was conducted.	Health workers and stakeholders understanding of mental health and TB included: • "*Madness,"* which often implied a characterological flaw rather an actual illness. • Psychological distress was also described as "*overthinking*," which participants attributed to psychosocial stressors, and was not perceived as a condition that would benefit from mental health intervention. Health workers had no standard practices for screening, managing, or treating mental distress in their clients.

Reflection on methods.

Quantitative Methods

For the quantitative analysis, I used the SRQ-5 mental distress screening instrument that was validated in Zambia using the Diagnostic and Statistical Manual of Mental Disorder 4th Edition as a gold standard criterion (4). Results from the validation study show that the SRQ-5 had good test characteristics for detection of mental distress, with an ROC of 0.925 (4). The SRQ was developed by the WHO to measure mental distress primarily in developing countries (5). The SRQ 5 is originally written in English but was translated into Nyanja and Bemba for the purpose of this research. However, despite translations and validation, in the piloting, some concepts were understood by RAs and participants, as referring to physical causation rather than related to mental distress. For example, the items *"Do you have headaches often?"* and *"Do you sleep badly?"* were interpreted in context of morbidity, so participants would report that they slept badly when they were physically ill rather than poor sleep that was a result of anxiety. Similarly, the item "*Is your daily work suffering?"* was interpreted with regards to physical morbidity rather than pertaining to depression. Similar observations were noted in a 2010 study that validated the SRQ-10 with 400 participants in a primary health setting in Lusaka (6). According to the study, the differences in understanding could have been due to literacy levels of those whom the scale was being administered. I argue that this interpretation of the mental health items could potentially lead to underestimation of the burden of mental distress in participants who were not experiencing any form of physical morbidity, and an overestimation of distress for participants who were experiencing some form of physical morbidity. To mitigate against this, I conducted sensitivity analysis that checked if the significance of the difference in mental distress scores between the investigation and treatment groups changed at a higher or lower cut off value. Secondly, I conducted further analysis which included

an additional two mood related questions from the SRQ 20, namely "*do you feel nervous tense or worried*" and "*do you feel unhappy*?" These mood related questions aimed to balance the somatic symptoms that dominate the SRQ 5. Further sensitivity analysis was conducted which considered the SRQ as a continuous variable. This analysis aimed to tease out symptom patterns unique to the populations under investigation, this method of analysing the SRQ has been explored in the literature and allows potential patterns of mental distress to emerge while also being sensitive to fact that individual mental health exists on a continuous spectrum (7). Findings from all the sensitivity analysis conducted corroborated the main findings of no significant difference between people with a history of TB and those without.

The discrepancies in the understanding of the screening tool may go beyond language translation, and literacy aspects highlighted above. They may speak to differences in conceptualisation of mental health between the western settings where the tool was designed to the African context where it was applied. For example, mental health screening tools often focus on detecting mental health conditions (e.g., anxiety, depression) as defined in western-developed classificatory systems such a DSM and ICD. I argue that this definition of mental health too narrow and overlooks other aspects of mental health such as wellbeing. In the case of the SRQ-5, it was validated against Diagnostic and Statistical Manual of Mental Disorder 4th Edition. This strengthens comparability with studies using the same classificatory systems across different settings but does not overcome the concern that people in psychological distress may present in fundamentally different ways across cultures. Culture can influence how people express their symptoms, for example somatization is possibly more common among Asian (8) and African populations (9) than it is in western cultures. Additionally, conceptualisation of symptoms of mental health conditions also differs by region. For example, a 2017 qualitative systematic review of 138 articles, aimed at understanding how depression is experienced around the world, found that populations in

sub-Saharan Africa used the idiom "*thinking too much"* (52.6% of the time) to express depression more frequently than western populations (9.1% of the time) (10). The qualitative findings from this work corroborate this as, *"thinking too much"* was the most common way of describing depression used by most participants. Despite these differences, the literature highlights some commonalities in ways in which mental health is understood and experienced around the world. For example, symptoms such as low mood are common to most cultures providing evidence that scales such as the SRQ are indeed measuring and providing meaningful information regarding mental distress in African contexts (10). A 2014 systematic review of 65 studies from 16 countries, assessing the validity of screening instruments for depression and anxiety in sub-Saharan Africa, found that there was enough overlap in symptoms of depression and anxiety across African and Western cultures to be able to effectively use instruments designed in the west to screen for depression and anxiety in African populations. However, the review called for minor adaptations that incorporate local understandings and idioms of mental health in order to enhance validity of these measures (5).

A potentially superior approach to the adaptation of western-derived measures is to generate mental health measures from "the bottom up" through in-depth qualitative research. Qualitative research plays a vital role in filling these knowledge gaps by creating rich contextualised data. For example, findings from the qualitative work in this study framed the phenomenology of mental distress expressed by participants in its context as participants highlighted that the cause of their mental distress stemmed from the biological, social, and economic implications of their TB diagnosis rather than the mental distress being an actual pathology. This finding may suggest that the mental distress reported by people with TB might be a normal reaction to adverse physical, social, and economic circumstances that they were in. Indeed, this was the view of mental distress that was emphasised by health worker and stakeholders in this research. Some authors argue that assessing symptoms of mental distress without

adequately considering the context in which they occur may lead to incorrect diagnosis of mental illness, overmedicalization and reduced access non-medical and non-Western healing spaces (11).Although mental health screening tools such as the SRQ have been validated and thus shown to be able to screen for mental distress, like the literature, I argue that more qualitative specifically anthropological work needs to be done to understand how mental health and illness are conceptualised in Zambia to ensure that measures of mental health and wellbeing are valid in this context.

The quantitative data for this PhD was collected from 18th November 2020 to 24th of February 2021, corresponding to the second wave of the COVID pandemic in Zambia (12). The second wave of the pandemic was caused higher mortality than the first, and unlike the first wave, the second wave increasingly infected younger people (12). Despite not having a national lock down, there were restrictions aimed to curb the spread of virus. These public health measures included restrictions on movement and gatherings. These measures, coupled with my own illness at the time, prevented me from being present during quantitative data collection for this objective. I would have ideally liked to have been in the field more during the TB prevalence survey administration. My absence meant that I was unable to provide support to the RAs during data collection. However, I was able to monitor the data weekly to check for any potential inconsistencies in the data. Additionally, I had provided comprehensive training to the RAs on how to administer the mental health questions with role play exercises used to solidify the learnings from the training. Furthermore, RAs were provided with carefully constructed examples to help them explain the mental health questions to participants.

An additional limitation to the quantitative analysis is the lack of investigation of the mental health, TB and HIV multi-morbidity given the shared risk factors that all three conditions share. Like people with TB, there is evidence that PLHIV may have a higher prevalence of mental distress and are more likely to

develop mental health conditions such as depression, anxiety, and severe mental illness when compared to HIV negative individuals (13). In addition, an HIV infection is an established risk factor to developing TB disease (14). People experiencing a TB and HIV co-morbidity are at increased risk of mental distress due to social factors including living with two stigmatized conditions(15), and the biological implications of living with both conditions (16). Findings from chapter four highlight some of these drivers of distress for participants who were living with a TB and HIV co-morbidity.

Qualitative methods

The data was collected by a team of eight social science graduates from different social science disciplines. None of the graduates had any prior mental health training before being engaged in this data collection activity. The social scientist RAs were trained in data collection methods and on how to talk to participants about mental health. Further details of the training are described in the methods section of this thesis. Despite this training and frequent debriefs during fieldwork, there were still evident gaps in RAs' abilities to talk about mental health with participants, including the use of stigmatizing language (such as *"craziness"* and *"madness"*) when asking the mental health questions. Additionally, RAs did not often probe when it came to the mental health questions. For example, RAs often did not ask participants why they felt a certain way or did not elicit detailed information about how participants managed their feelings when distressed. As a result, some nuanced opportunities were missed. Learnings from this experience include more detailed training on sensitive and non-stigmatising language with regards to mental health and more roleplaying activities focused on asking mental health questions. Additionally, this experience has highlighted the importance of lead researchers being more

present during field work which would allow them to collect more of their own data and provide better support and debriefing to RAs.

Limitations

While this thesis provided new insight into each of the research gaps that it set out to fill, there were some notable methodological limitations. The first being that the qualitative work did not ascertain the mental health status of participants prior to TB diagnosis. Therefore, it is possible to overestimate the mental health implication of TB particularly in individuals who were experiencing mental distress prior to their TB investigation and treatment journey. Additionally, the qualitative data was collected post TB treatment to fit into the qualitative TREATs objectives. This therefore required participants taking part in the qualitative inquiry to think back to their mental health state when they had TB, which potentially introduced recall bias. Other limitations with the qualitative work include a possibility of selection bias because of limitations in the type of participants who were interviewed. This selection bias could result in a restricted perspective on experiences of TB and mental health, for example, the sample did not include people with MDR TB, or people who had defaulted on their treatment. Further limitations included inadequate training for RAs in relation to the appropriate language to use when asking about mental health and how to probe effectively around the mental health information. In future research more time spent on training, particularly role play with mental health questions would be integral for qualitative RAs, particularly those that do not have a mental health background. Additionally, increased presence of lead researchers in the field which would allow them to collect more of their own data while providing support to RAs which would greatly improve the quality of the data. Limitations in the quantitative data collected for this thesis include a relatively small sample of participants with a history of TB leading to failure to stratify mental health status based on key variables of interest such as time

since TB treatment completion, type of previous TB (MDR versus drug sensitive TB), and number of times an individual had TB in the past.

Reflexivity

As a researcher, it is important that I reflect on my positionality in relation to my study, including my experiences, assumptions, and beliefs, which may impact on my research focus and findings. My interest in doing a PhD focused on mental health was sparked by my own experiences and responses to a diagnosis of depression during my undergraduate training, the lack of research on this topic in Zambia, and the wish to highlight the importance of addressing how poor mental health has the potential to negatively impact health outcomes. I therefore brought the value of this lived experience which has played a role in the choice of questions included in the qualitative inquiry and, I feel, provided a more meaningful understanding and interpretation of the data.

In this paragraph I provide my historical perspectives on mental health and how it could potentially influence my interpretations of the findings of this PhD. I had been curious about mental health as a young adult, but I did not give it much thought until I was diagnosed with depression in in 2010 during the second year of my undergraduate degree, which I was undertaking at a liberal arts college in the North America. Looking back at this experience what I found interesting was my inability to accept my diagnosis as something serious even though it hindered me from being a functional college student. The college medical staff strongly insisted that I start counselling. I went for two sessions before being prescribed anti-depressants. I stopped the counselling sessions and never took the anti-depressants, mainly because I did not believe depression was a real disease. I attribute this denial of my diagnosis to

my upbringing in Zambia where social norms discourage people from talking about their feelings. Additionally, depression was never really acknowledged as a disease in Zambia during my childhood and teenage years, and therefore did not require any medical intervention.

I have now come to accept that depression is real. This happened through life experiences and educating myself more about mental health. My previous lack of belief that depression as an illness was mirrored in many of the people who took part in this Zambian based research. I noticed that mental health questions were often received with an uncomfortable laugh, or quickly interpreted as an inquiry about psychosis. I believe my experience allowed me to be more understanding of participants responses and to think more openly about how to talk about mental health in this context.

Reflecting on my experience as a Zambian who had been educated and diagnosed with a mental illness in the west, I wondered if this might influence the way I interpreted data about mental health experiences from participants in this study. My experiences and desire for the needs of people with poor mental health to be taken seriously may have skewed my interpretation of health workers pragmatic approach to the mental distress burden of their clients. For example, I regard their approach as too dismissive. In addition, I may also have misinterpreted normal reactions to emotional distress following difficult life events, as more significant indicators of mental illness during the coding of the qualitative data. To mitigate this potential for personal bias, the qualitative data was double blind coded by myself and a second social scientist and differences in our output were discussed with my primary supervisor with guidance from my broader supervisory team that includes a practicing psychiatrist.

Reducing drivers of mental distress

The community and health care level strategies of reducing mental distress for people with TB that have or could be applied to both TB and mental health encompass three fundamental areas, namely i) livelihood support; ii) reducing TB-related stigma and mental health stigma and discrimination; iii) addressing structural health system drivers of distress.

1.) **Livelihood support**

Qualitative evidence generated in objectives one and three revealed that the social and economic challenges that people with TB experienced during TB investigation and treatment were one of the leading drivers of distress. The patient level data showed that most participants worked in the informal sector and for most of them morbidity associated with TB resulted in job or income loss as they became too ill to carry out their tasks. Additionally, the financial strain associated with seeking care and treatment created an extra challenge for participants to adhere to their treatment. This economic stress was compounded by the fact that there was limited income security even for the few participants in the formal sector; only four of the 17 participants in the formal sector were granted sick leave during their time on TB treatment, while another four were fired due to their illness. These findings firstly highlight the urgent need for protection of labour rights of people with TB, and secondly point out the need for social protection initiatives for people with TB and their households while they seek care and treatment. Social protection against the cost of illness is a central policy objective in the WHO Global Strategy to end TB (17). The strategy aims to mitigate the crippling economic impact of TB in a bid to end the global TB epidemic by 2035 through a 95% reduction in TB morbidity and a 90% drop in TB incidence (17). It does so by calling for a decrease in out-of-pocket expenditure and mitigation or compensation for income loss and other indirect cost for people with TB. However, the strategy requires sufficient political will and commitment (18).

Social protection initiatives should not be contingent on formal employment as this mostly excludes workers in the informal economy (19) who, in the case of TB, have a disproportionate burden of the disease and are vulnerable to the health economic shocks associated with TB in this setting. Social support initiatives should be both formal and informal programmes designed to reduce poverty and vulnerability by improving people's capacity to manage economic risks (20). These initiatives include health insurance, food assistance, travel vouchers and cash transfers among others (20).

There is a general consensus in the literature both from Zambia (21) and globally that people with TB need to be supported financially in order to allow them to prioritise their; health, access to care, and completion of treatment. For example, findings from a 2018 systematic review, aimed at assessing the effects of social protection on TB treatment outcomes in low-to-middle-income countries with high TB burden, conducted a meta-analysis of nine randomized controlled trials with a total of 1,687 participants, showed that social protection strategies were associated with a TB treatment success risk ratio of 1.09 (95%CI: 1.03-1.14) and a reduction of 0.37 risk of TB treatment default (0.63; 95%CI: 0.45-0.89) (22).

Currently in Zambia there are no nationwide social protection schemes for people with TB, but evidence suggests that there are some fragmented bottom-up schemes (23) that are not well documented in the literature. Historically HBC organisations played a key role in support people with TB during treatment. For example, results from a 1999 study with 142 people with TB and eight HBC organizations estimated that approximately 50% of people with TB patients in Lusaka were receiving care and support from HBC

organizations during that year (24). The care included provision of food aid, practical and emotional support and medical advice and treatment (24). The majority of people with TB in the study highlighted an improvement in their situation based on the support they received from these HBC organisations (24). More recent work based on HIV social protection schemes conducted in Zambia also provide evidence that these schemes could improve economic outcomes for people with TB in this context, as HIV is the primary risk factors for developing TB in Zambia (25, 26). For example, a social support intervention conducted in the Eastern province of Zambia in 2018 also found positive effects of social support for vulnerable households affected by HIV. The intervention included the provision of cash transfers to purchase income-generating assets, access to a savings account, and life-skills training on food security for PLWH (27). Findings from the trial showed that participants who received the intervention (n = 50) had lower food insecurity scores when as compared to the control group (n = 51) (adjusted mean difference −3.77, P value < 0.05)(27).

Community involvement in provision social protection for people with Tuberculosis

Patient level data revealed that there was minimal financial and material support available for people with TB, but some participants mentioned receiving financial support from family members and faith-based organisations such as churches, while stakeholders mentioned the availability of some HBC organisation that provide both psychological and financial support. I argue that the community could provide an opportunity for distribution of social protection for people with TB as a complimentary TB support service. Community Based Organisations (CBOs) know the communities that they work in and may be better placed to reach and help those in need of support. South Africa provides state distributed social protection grants for people with TB in the form of a disability grant that is applied for through the South African Social Security Agency (28). There are some documented challenges with accessing these

grants including documentation, and approval processes, however, it does in principle provide a buffer the economic implication of TB for people with TB in South Africa (28).

NGOs and other Civil Society Organisations (CSOs) working with TB in Zambia could use their reach and spread to provide complimentary support to vulnerable people with TB and their households through coordination and support of the NTLP. The extensive history of HBC in Zambia, described below, coupled with the potential challenges of distribution of social protection though the state, illustrated in South Africa, provides a basis for arguing that the community is best placed to offer social protection to economically disadvantaged people with TB. The strength of HBC organisations lies in their close contact with the communities they work with, including the more vulnerable groups (widows, orphans, the very poor)(24).

History of community-based care in Zambia

NGOs and other CSOs in Zambia consist of a broad spectrum of entities including community-based organisations, faith-based organisations, patient-based organisations and professional associations (29). Zambia has a rich history of provision of complimentary health services through CSOs and NGOs. They played a critical role in caring for people with HIV and AIDS through their HBC initiatives during the onset of the HIV pandemic in Zambia starting around 1985. These organisations actively engaged patients, families, and community members. Their initiatives included basic nursing care, bathing patients, doing household chores, encouraging patients to eat and take their medication and mobilising broader support including food and financial support, particularly prior to the availability of ART (30). Christian organisations provided care and support mostly with their own resources and via congregation

members (30), and CSOs increasingly garnered financial support from international NGOs, especially after formalising their training and care manuals in line with those of the Ministry of Health (30). CSOs also drew on broader support mechanisms such as farmer support groups to help provide food for economically disadvantaged PLWH and their households (30). Post the introduction of free ART for PLWH in Zambia, CSOs begun to integrate more into primary health care services (30). Many of the NGOs and CSOs that provide HIV services have also historically provided TB services (24).

How CSOs and NGOs can provide social protection for people with TB.

CSOs and NGOs can use their own initiatives to raise resources for social protection for people with TB, (30). However, relying solely on this approach can lead to unreliable and uncoordinated outcomes. For example, the literature highlights that some of the shortcomings of NGO and CSO involvement in TB include, fragmentation, isolation, and distrust of each other (24, 31, 32). A study of HBC organisations conducted in Zambia found that HBC organisations struggled with collaborating with each other and health facilities due to suspicion and competition with each other (24).

Resource generation would require political commitment and would need to be coordinated though the NTLP. The WHO, through the ENGAGE-TB approach, which advocates for a shift in the global perspective of TB from a medical illness to a more comprehensive socioeconomic and community problem, emphasises the importance of the role that the NTLP plays in providing operational guidance and creating collaborative partnerships with NGOs and other CSOs in implementing, monitoring and evaluating community-based TB activities, including those that involve providing material and financial support to people with TB (29). The ENGAGE-TB guide highlights six areas to facilitate the engagement

of NGOs and other CSOs in community-based activities that apply to social protection for people with TB, these are: a situational analysis; creation of guidelines and tools; task identification aimed at increasing synergy and effectiveness of all the NGOs, CSOs, and the NTLP; regular monitoring and evaluation; and lastly capacity-building aimed at strengthening and sustaining the engagement of NTLPs, NGOs and other CSOs in implementing and scaling-up community-based TB activities (33). Zambia is making some progress in relation to some of these six areas. For example, findings from the 4th survey of national TB policies conducted by the Stop TB Partnership and Médecins Sans Frontières in 2020 assessing the extent to which national policies pertaining to TB diagnosis, treatment, and prevention align with international best practices based on WHO guidelines found that Zambia has implemented 10 of the 14 internationally recommended key policies (34). However, monitoring and evaluation of current TB programmes and coordination of the various TB players working in Zambia remains a significant weaknesses (35). To address these weaknesses one of the strategic interventions of the 2017-2021 national health plan is to improve and strengthen the managerial and technical capacities of the NTLP which includes strengthen coordination between the NTLP and collaborating partners including CSOs and NGOs.

Provided improved coordination between NTLP and local partners coupled with sustained political will I argue that the community, through NGOs and CSOs can provide social support for vulnerable people with TB and their households. Their reach and understanding of their communities make them well placed to provide this kind of support. Using the community to distribute social protection would build into the provision of complementary services ICCC building block.

2.) Reducing Tuberculosis-related stigma and mental health stigma and discrimination

Stigma as a driver of distress was also jointly acknowledged by health workers, stakeholders, and people with TB. This included both TB and mental health stigma albeit recognition of TB stigma was more prevalent than mental health stigma among participants. Experiences of mental health and TB stigma were reported at health facility and community level. Stigma is a social process that includes labelling, stereotyping, and separation (36). It can result in discrimination, which includes unfair and unjust action towards an individual or group based on the stigmatized attribute (36). Within the health system, stigma undermines access to diagnosis, treatment, and successful health outcomes (36). TB stigma and mental health stigma share cross cutting drivers which include negative attitudes, a degree of culpability for the condition, myths and institutional policies, procedures, and practices (36). Our data highlighted that TB stigma and discrimination within health facilities was driven by negative attitudes held by health workers towards people with TB. The literature points out that negative attitudes play a key role in patients' decision to disengage with care. For example, a study in Nigeria consisting of FGDs with 76 health workers noted that the attitudes of health workers are a key determinant in TB patients decision to adhere to their medication (37). This is corroborated by a case control study conducted in Madagascar that found that poor health worker attitudes were one of the key reasons why 38 TB patients defaulted on their treatment when compared with 111 controls who had completed treatment under comparable conditions (38). Our data highlighted that TB discrimination within health facilities towards people with TB took the form of people with TB being treated rudely and ignored by health workers when seeking services. Discrimination by health workers towards people with TB has been reported in other studies conducted in Zambia. For example, a 2008 mixed methods study conducted in Lusaka with 300 people with TB reported that people with TB were treated rudely by nurses when attempting to receive treatment at the clinic (39). Despite not directly addressing mental health stigma, findings from this thesis show that health workers and TB stakeholders also held negative attitudes about mental distress, which was apparent in the way they described people who were experiencing

mental illness. Mental health stigma at health facility level has been reported in other studies conducted in Zambia (40, 41). In a 2011 study of 111 health workers that aimed to explore health care providers' attitudes towards people with mental illness within two districts in Zambia found that a high proportion of health workers held stigmatising attitudes towards people with mental illness, for example, 74.7% of respondents believed that people with a mental illness should not be allowed to have children or work, while 55.8% of the respondents agreed with the idea that the political and individual rights of people with mental illness should be suspended while they are on treatment (40).

Health facility level stigma reduction interventions

Negative health worker attitudes are incompatible with the people-centred care highlighted in the WHO end TB strategy (18). People-centered care calls for compassionate care and effective communication, which situates the people being treated at the centre of their care and focuses on the impact of TB on their everyday lives (18). Stigma reduction initiatives are not a part of the routine way in which health services are delivered or evaluated in Zambia despite the presence stigma in the health care setting in Zambia (39, 40, 41). I argue that including stigma reduction initiative would improve the quality of care provided for people with TB, mental illness, and other stigmatised conditions. According to a global 2019 review of 42 interventions aimed at reducing health facility stigma, of seven stigmatised conditions (including TB and mental illness), there are six stigma reduction approaches that have been documented in the literature (36). These are: provision of information about the condition and/or stigma associated with that condition; skills-building activities that enable healthcare workers to work directly with the stigmatized group; participatory learning approaches that require health care workers and/or clients to actively engage in the intervention; contact with the stigmatized group with the aim of humanizing the stigmatized group; an empowerment approach focused on improving clients coping mechanisms to

overcome stigma at the health facility level; and structural or policy change approaches (36). The approaches were often used together with the most common approaches being contact with the stigmatized group (n = 30), and provision of information (n = 29) (36). The review noted that interventions that focused on interactions between the groups being stigmatised, and health workers often yielded the best response, particularly when the stigmatised group get involved with the intervention as trainers or speakers (36). Additionally, interventions that target the different ecological levels of the health facility also offer more promising results (36).

There are a growing number of TB stigma interventions that have been developed to tackle different ecological levels of stigma. A good example is the TB Stigma Module developed in 2009 in Zambia with people with TB, health workers and community TB support staff (42). The module is designed to be used with a variety of audiences to help tackle TB stigma including community leaders, medical staff, family members of people with TB, and TB support groups (42). Other stigma toolkits include the those developed by the KNCV Tuberculosis Foundation in 2018, the first, was the Inside Out toolkit which aims to help people with TB address self-stigma and shame associated with TB (43), and the second is the Allies approach that aims to change the attitudes and workplace conditions of health care workers to enable them to provide empathic, non-stigmatizing care to people with TB (44). Despite the availability of TB stigma reduction interventions, very few have been implemented, as evidenced by the conclusion of a global systematic review aimed at assessing the effectiveness of TB stigma interventions which concluded that there is a noticeable dearth in implemented TB stigma related interventions (45).

Similar to the growing body of literature supporting a move away from the siloed approach of addressing TB stigma (36, 46, 47), I argue that TB and mental health stigma should be tackled through a

more health-related stigma approach as both conditions share similarities in the drivers and manifestations of stigma as several other stigmatised conditions (36). I propose the use of approaches such as the Total Health Policy Approach which is a coordinated package of *"best practice*" tools for health facilities aimed at reducing health facility level HIV stigma (48, 49). It was created by a group of international experts who reviewed, prioritized, adapted, and synthesized existing measures and programmatic tools for stigma reduction (48). These best practices were drawn from work done in nine countries across Africa, the Caribbean, and South and Southeast Asia (48). Zambia was one of the countries that contributed field experience to the project (48). The main objective of the package is to support health workers in recognizing and challenging stigma and discrimination within health facilities and create an accommodating and enabling environment for all staff and patients (48). The Health Policy Project toolkit consists of three main steps; the first is to assess or measure the extent of the stigma or discrimination within the health facility using a standard questionnaire. The second step involves participatory training aimed at increasing health workers' awareness about stigma and discrimination in the health facility to facilitate changes in their attitudes and behaviours toward the stigmatized populations. Increasing awareness could include a mix of strategies highlighted above including contact with people with TB and mental distress and information giving about both conditions. The third step includes sustaining a stigma free environment through development of policies and procedures that support staff in providing stigma free services (48).

Additionally, this broader approach to tackling TB stigma would fit in with the concept of economies of scope, which aims at managing conditions alongside each other to pool resources. Implementing stigma reduction initiatives within health facilities would create an enabling environment for health workers to

care for clients with the comorbid presentation of TB and mental distress, which relates to the *"organise and equip health care teams*" ICCC building block.

Community level stigma interventions

People with TB also experienced stigma at community level, mainly from family and social networks. Despite limited literature on TB interventions at community level, there are a few studies that suggest that it may be possible to reduce stigma, particularly internalised and anticipated stigma, at community level. For example, a 1999 study done in two similar communities in northern Bangladesh conducted an intervention where they provided health talks in one of these communities while the other community served as a control (50). The health education programme ran for a period of two years and included flipcharts, a bullhorn speaker, and a slide series of TB survivors TB experiences. Information giving was also targeted at all schools in the district (50). Findings from this intervention revealed lower levels of community stigma in the intervention community when compared to the control community (50). In a 2003 mixed methods study assessing the impact of TB clubs (small support groups composed of people with TB living in a similar location) on internalised stigma and societal attitudes associated with TB was conducted in two rural districts of Northern Ethiopia (51). The study involved 128 people with TB followed over the course of their TB treatment, half of whom were assigned to a TB club and the other half served as the comparison groups (51). Findings from the study suggest that TB clubs led to better TB treatment outcomes while reducing internalised stigma in people with TB by improving their understanding of their condition (51). Interventions such as these fall withing the ICCC framework in that they empower people with TB to be better informed about their condition while motivating them to better manage their treatment. An adaptation of this approach could include mental health

education and possible management techniques that would increase the applicability of such interventions for people with TB who are experiencing mental distress.

3.) Addressing structural health system level driver of distress

Findings from patient level data showed that health system failures were a significant source of distress for people with TB during their TB investigation period. Half of the participants had delayed diagnosis due to inadequate quality medical investigations that resulted in heightened distress resulting from additional money and time spent on TB investigations and the development of more severe TB symptoms, which often resulted in hospitalization for participants with TB. The WHO highlights that delays in TB diagnosis can result in poor health outcomes for people with TB, lead to catastrophic costs for their families and continued transmission of TB to others in their communities (52). According to a 2014 TB prevalence survey conducted in Zambia, close to half of people with TB are not diagnosed with TB due to poor medical investigations at the health facility (53). In LMICs poor quality investigations are not unique to TB and result in avoidable deaths. For example, findings from a 2018 systematic analysis, which aimed to assess the number of amenable deaths due to low quality health services in 137 LMICs using data from the 2016 Global Burden of Disease, found that 56.3% of the 152,119 deaths amenable to health care in the southern African region were due poor-quality health services (54). The geographical stratification analysis revealed that Zambia fell into the category with the highest deaths due to poor quality health services; the mortality ranged from 119 to 202 per 100 000 population. Countries in the lowest categories had deaths ranging from 7 to 52 per 100 000 population (54). The

study concluded that half of the TB related deaths in LMICs were attributed to poor quality of health services (54).

In our data we didn't collect reflections of the impact of poor-quality services on people with TB from health workers and stakeholders, so we are unable to gauge how aware health workers and stakeholder are about the quality of TB investigations and the resulting implications on the mental health of their clients. The end TB strategy asserts that quality TB care is a human right for all people with TB (18). Data in this thesis suggests that more needs to be done to improve the quality of TB investigation and treatment in the country. The current standard of quality assurance is the WHO standard to diagnose at least 70% of people with sputum smear-positive TB and cure at least 85% of these. Based on our data and findings from the 2014 prevalence survey, the use of these indicators' alone positions Zambia as operating an unsatisfactory TB programme with poor health worker performance.

To counter missing case detection the WHO recommended systematic screening of all suspected active TB patients who come to the health facility in all LMICs (52). Systematic screening of those at high risk for TB is a key component of the 2016-2035 end TB strategy, and it involves the identification of people with TB symptoms being screened and tested for TB using tests, examinations, or other rapid procedures (52). Systematic screening also includes targeting screening for high-risk groups including household contacts of people with TB (52). Although Zambia implemented systematic screening in the early 2000s, there are notable challenges with implementing it. According to a 2022 qualitative study, assessing the integration of systematic screening for tuberculosis in outpatient departments of urban primary healthcare facilities in Zambia, outpatient department nurses perceived TB screening as an additional task that was not compatible with the pre-service training and work schedules (55).

Additionally, health staff faced challenges with adapting to learning new concepts such as TB medications and their side effects, treatment algorithms, follow-up of patients, reporting systems and templates (55). The study concluded that health care workers lack ownership of the TB program and question the legitimacy of TB screening (55). The inadequate knowledge of TB symptoms and lack of TB training was also highlighted in a qualitative study in Ghana, investigating poor TB case detection at health facility level. Both studies concluded that non-TB health workers needed routine training and sensitization on standard operating procedure for TB case detection (55, 56).

I therefore argue that both TB health workers and other front-line workers need routine TB training in detection of TB. According to a 2008 study focused on lessons from training front-line health workers for TB, it is also important to monitor the quality of TB training at different levels, including participant learning, job behaviour and organizational levels (57). Quality of training at participant level can be done through health worker participant feedback, and pre and post training performance tests (57). At job behaviour level, the tools for assessing the quality of training include questionnaires administered to health workers on how the training is impacting on job performance, coupled with formal site visits by trainers to observe health workers in the clinic settings (57). At organizational level, the quality of training may be indirectly assessed by its impact on TB detection and treatment outcomes (57). Such training would fall in line with the ICCC building block aimed at organising and equipping health care teams. Training health workers to provide quality TB investigation services would have a positive impact on mental distress of participants as it would reduce time and money spent on TB investigations and allow people with TB to receive treatment while they have milder TB symptoms.

Patient level data also revealed that people with TB were not always adequately informed about their condition. Knowledge gaps about TB were often centred around TB transmission and duration of infectiousness after commencement of TB treatment. The misinformation regarding TB transmission was linked to behaviours that are deemed to be improper in the Zambian context, such as excessive drinking, smoking and /or having many sexual partners, which often led to feelings of shame in people with TB. Health workers data showed that although health workers and TB treatment supporters aimed to dispel this misinformation, the health education being provided may not be adequate or effectively understood due to several factors including inadequate time afforded to health talks, and poor patient and health worker relations.

I therefore suggest that part of the comprehensive TB control training mentioned above should include how to provide neutral information regarding TB transmission and treatment. This information should aim to dispel prevailing misconceptions about TB in this context. The education should include information about other risk factors of TB for example, social risk factors (such as poverty, overcrowding, homelessness, and inadequate health care) and other biological factors that lead to reduced immune function, apart from HIV. Such information would help manage the concern that that a TB diagnosis automatically infers an HIV positive diagnosis. However, people with TB need to be supported with accessing HIV services and be made aware that HIV can be well managed as a chronic condition. The training should also address poor health worker attitudes when providing care to people with TB.

Mental health services for people with Tuberculosis

TB health workers, stakeholders and people with TB agreed that there are not enough mental health services available for people with TB. At health facility level the most common form of psychosocial support was provided by TB treatment supporters and often in form of counselling centered around adherence support. TB treatment supporters have been shown to be beneficial in various stages of the TB treatment cascade, including improved: case detection; linkage to care; treatment support and treatment success (58). For example, a CHW initiative conducted in Ethiopia between 2010 and 2015 found that TB treatment supporters increased treatment success rates from 76% to 95% within five years and also reduced patients lost to follow-up from 21% to 3% (59). However, the data from objective one revealed that the type of psychosocial support offered by TB treatment supporters is not always enough to address their psychological needs as it was often too focused on TB treatment adherence and overlooked, and in some cases dismissed, patients fears and feelings about their diagnosis. This finding is corroborated by the fact that existing global guidance available for health workers largely focuses on systematic screening and on treatment adherence, with less attention paid to the psychosocial needs of people with TB (60). This gap in the type of psychosocial counselling offered to people with TB has been acknowledged in the TB treatment world and prompted the creation of a technical guide for psychosocial counselling and treatment adherence support for people affected by TB. This technical guide was created by the International Union Against Tuberculosis and Lung Disease, in collaboration with TB Alert, WHO and the Stop TB Partnership (60). The guide aims to be comprehensive in its scope covering different ways to assist people with TB overcome different drivers of distress including stigma, discrimination, barriers to diagnosis and barriers to treatment, and handling the common co-morbidities (including mental health conditions that are associated with TB) (60).

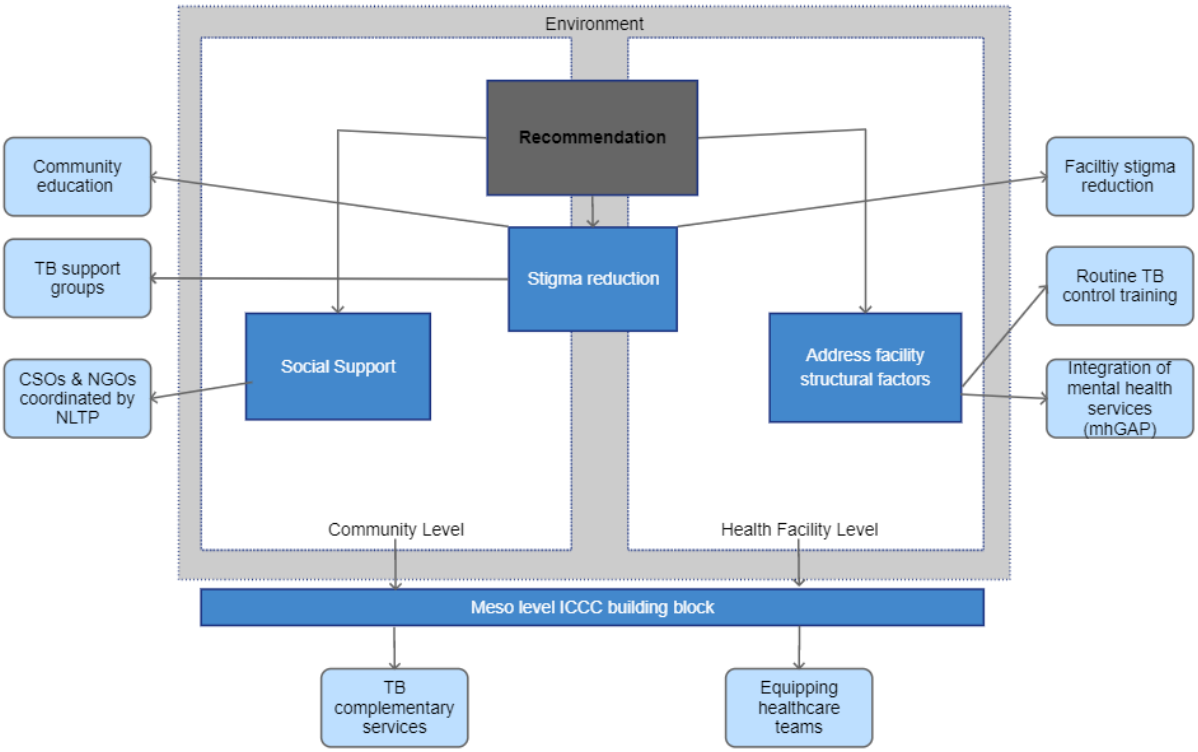
The task sharing approach, described in chapters one and two of this thesis, is also a way in which people with TB can receive help for their mental health needs at both facility and community level. At facility level, task sharing would result in a degree of mental health and TB service integration as both services will be provided by the same health workers. However as highlighted in chapter six, there are possible concerns with the task sharing approach, including a potential over use of medicalization to address psychosocial challenges such as income insecurity and stigma linked to TB, resource constraints affecting adequate supervision of non-specialised mental health staff which could potentially lead to low quality health services and the lack of appropriate compensation and recognition for the additional tasks assigned to these health workers. Despite these potential challenges with task sharing, it still holds promise as evidence suggests task sharing models may be appropriate for mental health screening and treatment in TB patients in low resource contexts like Zambia, particularly when integrated into the TB care system. A limitation in the literature is the lack of evidence regarding patient perspectives around their satisfaction with the mental health services received within the task sharing approach, therefore more qualitative research needs to be done to understand how acceptable this model is for people with TB in this context. This study could constitute part of the situational analysis required for mental health service integration into routine TB care as recommended the 2013–2030 comprehensive global mental health action plan, that calls for conducting a preliminary situational analysis on treatment and care of mental health conditions at different levels of care (61). Our findings revealed significant knowledge gaps that need to be addressed if mental health services were to be integrated into routine TB care. These gaps and their potential solutions, discussed in detail in earlier chapters (see four and six), demonstrated how both facility and community-based TB health workers in Zambia need more comprehensive training around understanding what mental health is, the symptoms of common mental health conditions (including depression and anxiety disorders) and how to screen for them. Health workers also need training on how to treat mild cases of mental health conditions and understand

referral process for more severe cases. The training can be based on manuals that follow evidence based practices such as the WHO mhGAP (62). When adapting these training manuals, it is integral they are tailored to suit local cultural context. For example, in relation to mental health in Zambia, cultural considerations would include local idioms such as *thinking too much*. Additionally, similarly with the training on TB control mentioned above, the quality of the mental health training needs to be evaluated at the different ecological levels (57). These training would aim to motivate and empower health workers to address the mental health needs of their clients and thus be part of the equipping health workers ICCC building block.

Summary of Discussion points

In this discussion, I highlight integral components that need to be addressed to better support the mental health needs of people with TB, which include steps that are aimed at reducing drivers of mental distress, (for example, stigma reduction at health facility and community level) and steps towards managing and treating mental distress in people with TB (for example, integration of mental health services). These steps are at both community and health facility levels and are compatible with the WHO meso level block of the ICCC framework for managing chronic conditions such as TB and mental health conditions. Figure 10 below summarises these steps and the corresponding ICCC building blocks.

Figure 10: Health facility and community level steps for improving the mental health of people with TB in Zambia



Recommendations

The recommendations provided below are framed around the ICCC framework, building on the preceding discussion, they consist of health facility and community level recommendations with some overlap across both levels. The recommendations can be feasibly attained with adequate financial and political will.

Health facility level recommendations

The recommendations provided below aim to prepare and motivate health workers to support self-management and prevention of mental distress in people with TB as per ICCC building block. These recommendations will prepare health workers to empower people with TB with accurate knowledge about TB and mental distress. The recommendations can feasibly be achieved through adapting training manuals for health workers that primarily provide services to people with TB and other front line health workers. Recommendations listed are related to the organising and equipping health care teams ICCC building block. They include:

1. Routine comprehensive training on TB control for health workers, particularly those that provide TB services and key frontline workers.
2. Anti-stigma training based on the total health facility approach.
3. Incorporation mental health screening and treatment into routine TB care guided by evidence-based programs such as the mhGAP-Intervention guide.
4. Inclusion of trained mental health personnel in TB services to provide supervisory support to the non-mental health specialists.

Community level recommendations

The recommendations listed aim to raise awareness and provide complimentary community level service as advocated by the ICCC framework. They include:

1. Provision of capacity for community-based organisations to provide social and economic assistance to meet livelihood needs of people with TB as a TB complimentary service.
2. Provision of stigma reduction initiatives.
3. Sensitisation of TB stakeholders about the relationship between mental health and TB.

4. Provision mental health training guided by the mhGAP-Intervention guide to community health workers and health-based organisation affiliated with the primary health service system.

Recommendations for future research

The recommendations for future research are based on the methodological limitations identified in the thesis findings and include:

1. Qualitative research focused on mental health experiences of people who have defaulted on their TB medication. This research is important because poor mental health has been linked to adverse TB treatment outcomes, including treatment default, and qualitative research will provide deeper insight into how poor mental health contributed to these outcomes. Additionally, it will allow for a comparison of experiences that will help establish what the comparative driving factors distinguishing people with TB who default on their medication and those that do not.

2. The second recommendation for future research is quantitative research aimed at exploring how both persistent TB symptoms and time since TB treatment completion affect prevalence of mental distress in TB survivors. Although, the literature base of mental health of TB survivors is still scant, there is a growing body of evidence about TB-associated disabilities among people who have completed treatment for TB, including impairment in lung function, and neurological disorders resulting from the TB disease and its treatment. It is worth establishing how these disabilities affect the mental health of TB survivors who are experiencing them.

3. The last recommendation for future research is ethnographic work aimed at understanding how mental health is conceptualised in Zambia. This work would provide the needed guidance of how to adapt current mental distress screening tools to increase their accuracy in this population. This piece of work could also assess the appropriateness of tools developed in similar contexts, such as the Shona Symptom Questionnaire that was developed to screen for common mental disorders in Zimbabwe (63), for screening mental distress in Zambia.

Steps to disseminate findings to aid adoption of recommendations

A 2022 workshop presentation conducted by the Zambian NHRA reflects that there has been a positive shift in the research environment in the country since the Zambian 2021 elections (64). The NHRA has made various steps towards both co-ordinating research within Zambia and facilitating the application of research so that it impacts the lives of people in Zambia (64). The NHRA has employed two strategies 1) to harmonise research through a shared platform (a research observatory platform) where all research being conducted will be listed and detailed; 2) a knowledge-translation action plan for all research (64). The latter includes a knowledge focal point persons in each province and institutionalising knowledge translation through drawing up guidelines and providing support (64).

I will therefore aim for the research findings from this thesis to be included in the research observatory platform which would allow the findings to have a broader reach within Zambia decision makers at health facility, district, and policy level. I would also advocate that these findings are included in the knowledge translation action plan. Other initiatives to aid dissemination of the findings include presenting these findings to the NHRA and NTPL stakeholders including the Lusaka Province Focal point person. Health facility and community level initiatives would include working with Zambart to

disseminate the findings to TB stakeholders within Lusaka by linking with their current work with TB stakeholders. In future I intend to contribute more to research in improving mental health and TB health outcomes in Zambia and other similar settings.

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Conclusion

In this thesis I set out to identify ways of providing holistic care for people with TB in Zambia by critically assessing the intersection between mental health and TB during TB investigation, treatment and beyond in this context. I used a mixed methods approach to address this aim and framed the recommendations around the WHO ICCC framework. I used qualitative methods in the form of IDIs and FGDs to explore the mental health experiences of people with TB and triangulated these experiences with TB health workers and stakeholders' conceptualisation and management of mental distress in their clients with TB. I then used quantitative methods to investigate if TB survivors have a disproportionate mental health burden when compared with people who had never had TB before.

The findings showed that the mental distress is prevalent among people with TB and is heightened after diagnosis and early on in treatment but does not persist after TB treatment completion. Mental distress is driven by interlacing stressors often compounded with the stress of poverty. Health workers and stakeholders had limited understanding of mental health and were inadequately skilled and equipped to manage, treat, or refer their mentally distressed clients. Recommendations drawn from this data include training health facility and community-based health workers in the detection and management of mental distress in their clients. Recommendations also include mitigating drivers of mental distress at health facility and community level, including stigma reduction initiatives, community level social support schemes and health system strengthening through addressing health facility structural drivers of distress.

These findings contribute to a limited but growing body of work around mental health and TB in the Sub-Saharan African region. The findings lay out the landscape of the relationship between mental health and TB in Zambia by providing patient level perspectives on drivers of mental distress during the investigation and treatment period and current mental health management and treatment practices in routine TB care. Additionally, this body of work contributes the first investigation into the burden of mental distress in TB survivors in an African context, while providing a recent, during pandemic estimate of mental distress in the Zambian urban population.

People with TB in Zambia could benefit from mental health support at both community and health facility level in form of managing and treating mental distress and reducing the prevalent drivers of distress such as stigma, and the economic stressors associated with TB in this context.

Appendices

Appendix 1 Consent forms

Appendix 1a. TREATS UNZABREC Approval

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm
Assurance No. FWA00000338
IRB00001131 of IORG0000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

14th February, 2018.

Your Ref: 005-02-18

ZAMBART,
University of Zambia, Ridgeway
Campus, Lusaka.

Dear Dr. Shanaube,

RE: "TUBERCULOSIS REDUCTION THROUGH EXPANDED ANTI-RETROVIRAL TREATMENT AND SCREENING (TREATS) PROJECT" (Ref. No. 005-02-18)

The above-mentioned research proposal was submitted to the Biomedical Research Ethics Committee on 2nd February, 2018. The proposal is approved.

CONDITIONS:

1. This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.

□ If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.

2. Any serious adverse events must be reported at once to this Committee.
3. Please note that when your approval expires you will need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).

4. Where appropriate, apply in writing to National Health Research Authority for permission before you embark on the study.
5. Ensure that a final copy of the results is submitted to this Committee.

Yours sincerely,

Appendix 1b: TREATS NHRA Approval

Dr. S. H Nzala
VICE-CHAIRPERSON
Date of approval: February 2018.
Date of expiry: 13th February 2019.

April 2018
Dr. Kwame Shananube
Principal Investigator
ZAMBART
LUSAKA

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled "Tuberculosis Reduction through Expanded Anti-Retroviral Treatment and Screening (TREATS) Project ."

I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been approved on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, University leadership, and all key respondents.

Yours sincerely,

Dr. Godfrey Biemba

Director/CEO

National Health Research Authority

All correspondences should be addressed to the Director/CEO National Health Research Authority

Appendix 1c: TREATS LSHTM ETHICS Approval letter

Observational / Interventions Research Ethics Committee

Dr Helen Ayles
Professor of Infectious Diseases and International Health
Department of Clinical Research (CRD)
Infectious and Tropical Diseases (ITD)
LSHTM

31 May 2018

Dear Helen

Study Title: Tuberculosis Reduction through Expanded Anti-retroviral therapy and TB Screening (TREATS)

LSHTM Ethics Ref: 14905

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received,

where relevant. **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Investigator CV	Musonda_biosketch_TREATS	31/01/2018	1
Investigator CV	Modupe Amofa-Sekyi_CV_ JAN2018	31/01/2018	1
Investigator CV	PDFsam_EDCTP_CVsRIA2016S-1632-Primary-Application-Form	01/02/2018	1
Protocol / Proposal	TREATS protocol V1 FINAL SUBITTTED UNZA BREC 20180202	02/02/2018	1
Protocol / Proposal	TBPSquestionnaire v1 20180202	02/02/2018	1
Protocol / Proposal	Infection Cohort Baseline Questionnaire V1	02/02/2018	1
Information Sheet	TREATS SAMPEL ICF-QUALITATIVE PARTICIPANTS	02/02/2018	1
Information Sheet	TREATS SAMPLE ICF-INFECTION COHORT ICF 15-17 yrs	02/02/2018	1
Information Sheet	TREATS SAMPLE ICF-INFECTION COHORT ICF 18-24 yrs	02/02/2018	1

Information Sheet	TREATS SAMPLE ICF-INFECTION COHORT ICF Assent 15-17 yrs	02/02/2018	1
Information Sheet	TREATS SAMPLE ICF-PREVALENCE SURVEY	02/02/2018	1
Protocol / Proposal	TREATS protocol V1.1 FINAL SUBMITTED LEO_21052018	21/05/2018	V1.1
Information Sheet	TREATS INFECTION COHORT (18-24yrs)_ICF_ General Template_ V1.1_21052018	21/05/2018	V1.1
Information Sheet	TREATS INFECTION COHORT (15-17yrs)_Parent ICF_General Template_V1.1_21052018	21/05/2018	V1.1
Information Sheet	TREATS INFECTION COHORT (15-17yrs)_Assent Form_General Template_V1.1_21052018	21/05/2018	V1.1
Information Sheet	TREAT PREVALENCE SURVEY_ICF_General Template_V1.1_21052018	21/05/2018	V1.1
Information Sheet	TREAT PREVALENCE SURVEY (15-17yrs)_Parent ICF_General Template_V1.1_21052018	21/05/2018	V1.1
Information Sheet	TREAT PREVALENCE SURVEY (15-17yrs)_Assent Form_General Template_V1.1_21052018	21/05/2018	V1.1
Information Sheet	TREATS _IDI_ICF_General Template_V1.1_ 21052018	21/05/2018	V1.1
Information Sheet	TREATS_FGD_ICF_General Template_ V1.1_21052018	21/05/2018	V1.1
Local Approval	Ethics Approval_SA_Pharmaethics	21/05/2018	1
Local Approval	Ethics Approval_Zambia_NHR	21/05/2018	1
Local Approval	Ethics Approval_Zambia_U.BREC	21/05/2018	1
Protocol / Proposal	IDI_HW_TREATS_21052018	21/05/2018	1
Protocol / Proposal	TB_OptionsChart_TREATS_21052018	21/05/2018	1
Protocol / Proposal	Infection Cohort Baseline Questionnaire _V1.1_21052018	21/05/2018	V1.1
Protocol / Proposal	Prevalence Survey Questionnaire_V1.1_21052018	21/05/2018	V1.1
Covering Letter	Cover Letter	22/05/2018	V1

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

Professor John DH Porter
Chair

ethics@lshtm.ac.uk
http://www.lshtm.ac.uk/ethics/

Appendix 1d: TREATS-COVID NHRA approval

Ref No:…….
Date: 31st July, 2020

The Principal Investigator
Dr. Kwame Shanaube
ZAMBART
University of Zambia,
Ridgeway Campus,
Lusaka.

Dear Dr. Shanaube,

Re: Request for Authority to Conduct Research

The National Health Research Ethics Board (NHREB) is in receipt of your request for authority to conduct research titled **"Understanding the Epidemiology of SARS-COV-2 and the Inter Relation of COVID-19 with TB and HIV in Zambia (TREATS-COVID) Study."**
I wish to inform you that following submission of your request to the Board, its review of the same and in view of the ethical clearance, this study has been **approved** on condition that:

1. **A Material Transfer Agreement is obtained and cleared by the National Health Research Ethics Board should there be any need for samples to be sent outside the country for analysis.**
2. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
3. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
4. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
5. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, and all key respondents.

All correspondences should be addressed to the Director/CEO National Health Research Authority

Yours sincerely,

Prof. Patrick Musonda
Chairperson
National Health Research Ethics Board

Appendix 1e: TREATS COVID LSHTM ETHICS Approval Letter

Observational / Interventions Research Ethics Committee

Prof Helen Ayles
LSHTM

17 August 2020

Dear Helen

Study Title: UNDERSTANDING THE EPIDEMIOLOGY OF SARS-COV-2 AND THE INTER RELATION OF COVID-19 WITH TB AND HIV IN ZAMBIA (TREATS-COVID) STUDY

LSHTM Ethics Ref: 22606

Thank you for responding to the CaRR Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received,

where relevant. **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Information Sheet	ICF_nonTREATS _V1.0 Final draft	21/07/2020	v1.0
Information Sheet	ICF_TREATS TBPS ARM C-TREATS COVID V1.0 Final draft	21/07/2020	v1.0
Information Sheet	ICF_TREATS COVID-CONTACT TRACING_V1.0 Final draft	21/07/2020	v1.0
Information Sheet	Parental consent form_nonTREATS_V1.0 Final draft	21/07/2020	v1.0
Information Sheet	Parental consent form_TREATS COVID-CONTACT TRACING_V1.0 Final draft	21/07/2020	v1.0
Information Sheet	Parental consent form_TREATS TBPS ARM C-TREATS COVID_V1.0 Final draft	21/07/2020	v1.0
Information Sheet	Assent form_nonTREATS_V1.0 Final draft	21/07/2020	v1.0
Information Sheet	Assent form_TREATS COVID-CONTACT TRACING_V1.0 Final draft	21/07/2020	v1.0
Information Sheet	Assent form_TREATS TBPS ARM C-TREATS COVID_V1.0 Final draft	21/07/2020	v1.0
Protocol / Proposal	TREATS-COVID PROTOCOL_Version1 0_Final_submitted 20200721	21/07/2020	v1.0
Investigator CV	Dr Kwame Shanaube CV	24/07/2020	v1
Investigator CV	Prof Helen Ayles CV	24/07/2020	v1

Investigator CV	Prof Christophe Fraser CV	24/07/2020	v1
Investigator CV	Barry Kosloff CV	24/07/2020	v1
Investigator CV	Sian Floyd CV	24/07/2020	v1
Investigator CV	Dr David Bonsall CV	24/07/2020	v1
Investigator CV	Dr Sarah Fidler CV	24/07/2020	v1
Investigator CV	Prof Richard Hayes CV (1)	24/07/2020	v1
Investigator CV	CV_Dr. Maria Rupérez_18072020	24/07/2020	v1
Investigator CV	Musonda_biosketch_TREATS	24/07/2020	v1
Investigator CV	KlinkenbergCV_Jan2020	24/07/2020	v1.0
Investigator CV	CV Nico Kalisvaart KNCV	24/07/2020	v1.0
Investigator CV	CV Petra de haas july2020	24/07/2020	v1.0
Investigator CV	VirginiaBond_ShortCV_20200617	24/07/2020	v1.0
Investigator CV	Alwyn Mwinga resume 2020	24/07/2020	v1.0
Investigator CV	Ab_Schaap_CV_2020	24/07/2020	v1.0
Covering Letter	response letter to LSHTM ethics_12082020	12/08/2020	V.1
Protocol / Proposal	TREATS-COVID PROTOCOL_Version1.1_track changes_12082020	12/08/2020	v1.1
Protocol / Proposal	TREATS-COVID PROTOCOL_Version1.1_clean_12082020	12/08/2020	v1.1

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

Professor Jimmy Whitworth
Chair

ethics@lshtm.ac.uk
http://www.lshtm.ac.uk/ethics/

Appendix 2: Consent forms

Appendix 2a: TREATS WP5 In-depth interview Information and Consent Form

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)
In-depth Interview (IDI) Information and Consent Form

Participant Information Sheet
Please ask the study investigator or the study staff to explain any words or procedures that you do not clearly understand.

This form gives you information about the research study you are being asked to join. The form describes the purpose, procedures, benefits, and risks of the research study. Please read this Information and Consent Form and ask as many questions as needed. You should not sign this form if you have any questions that have not been answered to your satisfaction. If you choose to sign this form you are giving permission to be included in this research study.

This study is being funded by the European and Developing Countries Clinical Trials Partnership (EDCTP)

Purpose of the Study
The TREATS study is made up of 4 studies that will look whether the PopART intervention that has been carried out in some communities, reduced the chance of getting TB infection or developing TB disease. The PopART intervention involved HIV testing and treatment as well as screening for the symptoms that suggest you might have TB. In total fourteen (14) communities are included in this research, 8 in Zambia and 6 in South Africa.

You are being asked to participate in the **qualitative research activities which aim to understand how TB is experienced and managed by community members and local stakeholders.**

Description of the study
This research is being carried out in your community because your community participated in the PopART study. Some members of the community – like yourself - will be asked to participate and be interviewed by the study social science's team.

Your involvement
You are being asked to participate in one of the qualitative studies as someone who can contribute to our understanding of TB in the community. You are being approached because you are either a TB stakeholder, a TB health facility staff member, or a TB patient diagnosed either through community HIV care providers (CHiPs) or through the local health facilities.

You are being asked to participate in an interview with a study staff member who will ask you questions about your life and your own experience of TB in this community. Each interview is expected to last about 60-90 minutes. The staff member will take notes, and, with your permission, the interview will be recorded. We really value the information and time you share with us.

Confidentiality
We will do everything possible to protect your confidentiality if you join this study. We do this by giving you a study number (for example, 1234782) and any information will be labelled with this number. Your name and any other information that may identify you or your household will be kept confidential and only the research staff will be able to link this number to your name. Although we will record with your permission the interview, information will not be linked or traced back to you. When the interview is fully transcribed (written up), the transcription will not bear actual names of informants. The results of this research may be published and full quotes from individuals may be used, but your identity and confidentiality will be protected because the quotes will not be linked to named individuals. However, if we identify any serious health or welfare problems during the course of this research, we are obligated to refer to others who can help.

You have the right to control the use and disclosure of your personal information. People who may review your records include the University of Zambia Biomedical Ethics Committee and National Health Research Authority**.** All personnel accessing your records are required to respect your confidentiality at all times. All records identifying you will be kept confidential, and to the extent permitted by applicable laws and regulations, will not be made publicly available. No personal information will be included in the study data that will be forwarded to the sponsor or sponsor representatives. You will be identified by a coded number in any reports of publications produced from this study (study data). By signing this document, you are authorizing such access.

To protect your privacy, you will meet with the researcher in a private area.

Data Protection
What kind of information will be collected from you?
No one will be able be to recognise you in all of the data that will be collected. A barcode ID with your study number will be allocated to you and will be used instead of your name.

Data protection for this study will be conducted in accordance with the Electronic Communications and Transactions Act 2009 of Zambia, Part VII (Protection of personal Information) and Section 42. This act generally discusses how the data that is collected from you will be collected and used. This Act can be found on internet using this link https://www.zicta.zm/Downloads/The%20Acts%20and%20SIs/ect_act_2009.pdf. If you do not have access to the internet, this Act can be gotten from Government printers.

How will data be recorded?
Some of the information that you give us will be recorded on paper, for example the assent form that you will sign. All this information will be assigned a barcode ID so that your confidentiality is maintained. We will record the IDI and we will take notes on it. Notes and recordings will be then uploaded into a centrally managed system at head office and into a data protected folder which is password protected and has limited access. Recordings will be transcribed and destroyed afterwards. The transcription will be cleaned of any identifiers. We will then upload these transcriptions into a qualitative data software for analysis and coding.

How will it be stored?
All paper copies that will have your information will be kept securely in a locked cabinet in a locked room that will only be accessed by assigned study staff. All electronic data will be stored on a server and will be encrypted and password protected and will only be accessible by the data manager.

All the information collected will be stored for approximately 7 years after the study has ended after which, data will be destroyed.

Who will the information be shared with?
We may share it with people who check that the study is done properly (like the independent ethics committee or review boards). The data that we collect, but not your name or anything else that can identify you will be shared with other researchers working on the TREATS study. These include researchers working at Zambart in Zambia, Health Systems Trust in South Africa, the London School of Hygiene and Tropical Medicine, Imperial College and the University of Sheffield in the UK and KNCV in the Netherlands. We will publish study results in medical journals, for meetings and on the internet for other researchers to use. Your name or personal information will not appear in any publication.

After the study is complete, copies of the data, without any details that could identify you, will be made publicly available via the internet for other researchers to use. To make sure you can never be identified we will remove information such as your name, where you live, your date of birth, the name of your community and any other data that may lead to someone being able to identify you.

Voluntary participation and withdrawal
Your participation in the research is voluntary. If you feel uncomfortable about any questions we ask, please feel free not to answer them. If you no longer wish to participate in this interview, you may do so with no penalty.

Alternatives to participation
The alternative to participating in the interview is not to participate, which, as noted, will not result in any penalty or loss of benefits you normally receive.

Risks and benefits
There is a chance that some of our questions may cause discomfort or emotional stress. If so, you are not obligated to answer them. There are no direct benefits associated with participation in these individual interviews, but there may be indirect benefits for your community in the future. The information gained in this study may help organizations design future HIV prevention interventions.

Compensation
You will be interviewed at a time and location convenient to you because we know your time is valuable. This could be at your home or place of work (lunch time). All qualitative activities will last about one hour and thirty minutes.During this time, we will provide a snack refreshment.

Reasons for stopping participation
You may be withdrawn from the study if the research study, or this part of the study, is stopped or cancelled. You may also be withdrawn if the study if staff feels that completing the study or this part of the study would be harmful to you or others.

Contacts for questions
If you have any questions about your participation in this research study, your rights as a research subject, or if you feel that you have experienced a research-related injury, contact:

Principle investigator's Name: *Dr Kwame Shanaube*

Research Site Address (es): *Zambart, Ridgeway Main Campus, P.O. Box 50697 Lusaka Zambia,*

Daytime telephone number (s): *+260-211-254710*

If you have any other questions or concerns about your rights as a research participant or want to discuss a problem, get information or offer input, you may contact:

Independent Review Board/Ethics Committee: *University of Zambia Biomedical Ethics Committee, Ridgeway Main Campus, Lusaka Zambia*

Address of Independent Review Board: *School of Medicine Ridgeway Main Campus, P.O. Box 50110, Lusaka.*

Daytime Telephone Number: *+260-211-256067*

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)
In-depth Interview
STATEMENT OF CONSENT

1. I have been given sufficient time to consider whether to take part in this study.
2. I have read the Information Sheet carefully, and has been explained to me to my satisfaction.
3. I understand my role in the interview and why the discussion is being recorded on a voice recorder.
4. I understand that my participation in this research is entirely voluntary, i.e. I do not have to participate if I do not wish to.
5. I have been informed that refusal to take part will involve no penalty or loss of services to which I am otherwise entitled.
6. I understand that if I decide to take part, I am free to withdraw at any time without penalty or loss of services and without giving a reason for my withdrawal.
7. I have been informed that I may choose not to answer particular questions that are asked in the study and that if there is anything that I would prefer not to discuss, I am free to say so
8. I have been told that the information collected in this interview will be kept strictly confidential.
9. I understand that what I tell in the interview can be written up word for word (directly quoted) in any publications or reports, but that these quotations will NOT be linked to me personally.
10. I understand that if I choose to participate in this interview the signed consent is required below before I proceed with the interviews.

VOLUNTARY CONSENT

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

I now consent voluntarily to be a participant in this study and understand that I have the right to withdraw at any time, and to choose not to answer particular questions that are asked in the course of the interviews.

I voluntarily agree to take part in this research study.

_____ _____

Participant's Name (print) **Participant's Signature/Thumbprint**

Date: _____

I certify that the information provided was given in a language that was understandable to the participant.

_____ _____

Name of Study Staff Conducting Consent Discussion (print) **Study Staff Signature**

Date: _____

_____ _____

Witness' Name (print) (As appropriate) Date **Witness' Signature/Thumbprint**

Date: _____

FIX BARCODE HERE

STUDY COMMUNITY: _____

Appendix 2b: TREATS WP5 Focus Group Discussion Information and Consent Form.

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)
Focus Group Discussion (FGD) Information and Consent Form

Participant Information Sheet
Please ask the study investigator or the study staff to explain any words or procedures that you do not clearly understand.

This form gives you information about the research study you are being asked to join. The form describes the purpose, procedures, benefits, and risks of the research study. Please read this Information and Consent Form and ask as many questions as needed. You should not sign this form if you have any questions that have not been answered to your satisfaction. If you choose to sign this form you are giving permission to be included in this research study.

This study is being funded by the European and Developing Countries Clinical Trials Partnership (EDCTP)

Purpose of the Study
The TREATS study is made up of 4 studies that will look whether the PopART intervention that has been carried out in some communities, reduced the chance of getting TB infection or developing TB disease. The PopART intervention involved HIV testing and treatment as well as screening for the symptoms that suggest you might have TB. In total fourteen (14) communities are included in this research, 8 in Zambia and 6 in South Africa.

You are being asked to participate in the **qualitative research activities which aim to understand how TB is experienced and managed by community members and local stakeholders.**

Description of the study
This research is being carried out in your community because was a community participating in the PopART study. Some members of the community – like yourself - will be asked to participate and be interviewed by the study social science's team.

Your involvement
You are being asked to participate in one of the qualitative studies as someone who can contribute to our understanding of TB in the community. You are being approached because you are a community HIV care provider (CHiP) from the PopART study who carried out TB screening and testing in households.

You are being asked to participate in a focus group discussion with other CHiPs and a study staff member who will ask you questions about your job as a CHiP and your own experience of TB in this community. Each focus group discussion is expected to last about 60-90 minutes. The staff member will take notes, and, with your permission, the interview will be recorded. We really value the information and time you share with us.

Confidentiality

We will do everything possible to protect your confidentiality if you join this study. We do this by giving you a study number (for example, 1234782) and any information will be labelled with this number. Your name and any other information that may identify you or your household will be kept confidential and only the research staff will be able to link this number to your name. Although we will record with your permission the interview, information will not be linked or traced back to you. When the interview is fully transcribed (written up), the transcription will not bear actual names of informants. The results of this research may be published and full quotes from individuals may be used, but your identity and confidentiality will be protected because the quotes will not be linked to named individuals. However, if we identify any serious health or welfare problems during the course of this research, we are obligated to refer to others who can help.

You have the right to control the use and disclosure of your personal information. People who may review your records include the University of Zambia Biomedical Ethics Committee and the National Health Research Authority**.** All personnel accessing your records are required to respect your confidentiality at all times. All records identifying you will be kept confidential, and to the extent permitted by applicable laws and regulations, will not be made publicly available. No personal information will be included in the study data that will be forwarded to the sponsor or sponsor representatives. You will be identified by a coded number in any reports of publications produced from this study (study data). By signing this document, you are authorizing such access. To protect your privacy, you will meet with the researcher in a private area.

Data Protection

What kind of information will be collected from you?

No one will be able be to recognise you in all of the data that will be collected. A barcode ID with your study number will be allocated to you and will be used instead of your name.

Data protection for this study will be conducted in accordance with the Electronic Communications and Transactions Act 2009 of Zambia, Part VII (Protection of personal Information) and Section 42. This act generally discusses how the data that is collected from you will be collected and used. This Act can be found on internet using this link https://www.zicta.zm/Downloads/The%20Acts%20and%20SIs/ect_act_2009.pdf. If you do not have access to the internet, this Act can be gotten from Government printers.

How will data be recorded?

Some of the information that you give us will be recorded on paper, for example the assent form that you will sign. All this information will be assigned a barcode ID so that your confidentiality is maintained. We will record the FGD and we will take notes on it. Notes and recordings will be

then uploaded into a centrally managed system at head office and into a data protected folder which is password protected and has limited access. Recordings will be transcribed and destroyed afterwards. The transcription will be cleaned of any identifiers. We will then upload these transcriptions into a qualitative data software for analysis and coding.

How will it be stored?

All paper copies that will have your information will be kept securely in a locked cabinet in a locked room that will only be accessed by assigned study staff. All electronic data will stored on a server and will be encrypted and password protected and will only be accessible by the data manager.

All the information collected will be stored for approximately 7 years after the study has ended after which, data will be destroyed.

Who will the information be shared with?

We may share it with people who check that the study is done properly (like the independent ethics committee or review boards). The data that we collect, but not your name or anything else that can identify you, will be shared with other researchers working on the TREATS study. These include researchers working at Zambart in Zambia, Health Systems Trust in South Africa, the London School of Hygiene and Tropical Medicine, Imperial College and the University of Sheffield in the UK and KNCV in the Netherlands. We will publish study results in medical journals, for meetings and on the internet for other researchers to use. Your name or personal information will not appear in any publication.

After the study is complete copies of the data, without any details that could identify you, will be made publicly available via the internet for other researchers to use. To make sure you can never be identified we will remove information such as your name, where you live, your date of birth, the name of your community and any other data that may lead to someone being able to identify you.

Voluntary participation and withdrawal

Your participation in the research is voluntary. If you feel uncomfortable about any questions we ask, please feel free not to answer them. If you no longer wish to participate in this interview, you may do so with no penalty.

Alternatives to participation

The alternative to participating in the interview is not to participate, which, as noted, will not result in any penalty or loss of benefits you normally receive.

Risks and benefits

There is a chance that some of our questions may cause discomfort or emotional stress. If so, you are not obligated to answer them. There are no direct benefits associated with participation in these individual interviews, but there may be indirect benefits for your community in the future. The information gained in this study may help organizations design future HIV prevention interventions.

Compensation
You will be interviewed at a time and location convenient to you because we know your time is valuable. If you have to travel to meet us, we will give you a ZMK50 to cover your transportation cost. This could be at your home or place of work (lunch time). All qualitative activities will last about one hour and thirty minutes. During this time, we will provide a snack refreshment.

Reasons for stopping participation
You may be withdrawn from the study if the research study, or this part of the study, is stopped or cancelled. You may also be withdrawn if the study staff feels that completing the study or this part of the study would be harmful to you or others.

Contacts for questions
If you have any questions about your participation in this research study, your rights as a research subject, or if you feel that you have experienced a research-related injury, contact:

Principle investigator's Name: *Dr Kwame Shanaube*

Research Site Address (es): *Zambart, Ridgeway Main Campus, P.O. Box 50697 Lusaka Zambia,*

Daytime telephone number (s): *+260-211-254710*

If you have any other questions or concerns about your rights as a research participant or want to discuss a problem, get information or offer input, you may contact:

Independent Review Board/Ethics Committee: *University of Zambia Biomedical Ethics Committee, Ridgeway Main Campus, Lusaka Zambia*

Address of Independent Review Board: *School of Medicine Ridgeway Main Campus, P.O. Box 50110, Lusaka.*

Daytime Telephone Number: *+260-211-256067*

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)
Focus Group Discussion
STATEMENT OF CONSENT

1. I have been given sufficient time to consider whether to take part in this study.

2. I have read the Information Sheet carefully and it has been explained to me to my satisfaction.
3. I understand why I have been approached for a focus group discussion.

4. I understand that my participation in this research is entirely voluntary, i.e. I do not have to participate if I do not wish to.

5. I have been informed that refusal to take part will involve no penalty or loss of services to which I am otherwise entitled.

6. I understand that if I decide to take part, I am still free to withdraw at any time without penalty or loss of services and without giving a reason for my withdrawal.

7. I have been informed that I may choose not to answer particular questions that are asked in the study, and that if there is anything that I would prefer not to discuss, I am free to say so.

8. I understand that the information collected in this discussion will be kept strictly confidential.

9. I understand that what I tell in the interview can be written up word for word (directly quoted) in any publications or reports, but that these quotations will NOT be linked to you personally.

10. I understand that if I choose to participate in this discussion, my signed consent is required below before I proceed with the discussion.

VOLUNTARY CONSENT

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

I now consent voluntarily to be a participant in this study and understand that I have the right to withdraw at any time, and to choose not to answer particular questions that are asked in the course of the interviews.

I voluntarily agree to take part in this research study.

_____	_____
Participant's Name (print)	**Participant's Signature/Thumbprint**

Date: _____

I certify that the information provided was given in a language that was understandable to the participant.

_____	_____
Name of Study Staff Conducting Consent Discussion (print)	**Study Staff Signature**

Date: _____

_____	_____
Witness' Name (print) (As appropriate) Date	**Witness' Signature/Thumbprint**

Date: _____

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STUDY COMMUNITY: _____

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)
Prevalence Survey (≥18years old)-Information and Consent Form

Participant Information Sheet
Please ask the study staff to explain any words or procedures that you do not clearly understand.

This form gives you information about the research study you are being asked to join. The form describes the purpose, procedures, benefits, and risks of the research study. Please read this Information and Consent Form and ask as many questions as needed. You should not sign this form if you have any questions that have not been answered to your satisfaction. If you choose to sign this form you are giving permission to be included in this research study.

This study is being funded by the European and Developing Countries Clinical Trials Partnership (EDCTP)

Your participation is voluntary
You do not have to take part in this study if you do not want to. Access to health care from the health centres in your community will not be affected if you choose not to participate in the study. You are also free to withdraw from the study at any stage, without consequences to you or your family.

What is tuberculosis (TB)?
TB is an infectious airborne disease caused by bacteria (germs) which are spread through droplets from coughing or sneezing which are inhaled in into the lungs. The TB germ mainly affects the lungs but it can also affect other parts of the body. When the TB germ enters your lungs, we say you have **TB infection.** When you have TB infection, you are usually healthy and do not feel sick at all. You may have TB infection for some time which can be for some weeks up to years. Some people may have TB infection and may never feel unwell. If you start to feel unwell because of the TB germs in your lungs, we say you have **TB disease.**

Purpose of this study
The TREATS study is made up of 4 studies that will look whether the PopART study that has been carried out in 21 communities, 12 in Zambia and 9 in South Africa, reduced the chance of getting TB infection or developing TB disease. The PopART intervention involved HIV testing and treatment as well as screening for the symptoms that suggest you might have TB.

This particular study is called the "Prevalence Survey". In ***Zambia*** this study aims to recruit ***approximately 4000*** people 15 years and older from this community to measure how much TB disease there is in this community. You have been selected to be one of the people from your community who we are asking to take part in this study.

What will happen during this study?

If you take part in this study, we will ask you some questions about you, your family and your health, as well as about risk factors for TB disease. We will then ask you to have a chest X-ray taken at our mobile X-ray machine. This is a very simple procedure and it is very quick, it takes around 5-10 minutes and you will not be charged. The chest X-ray picture of your lungs will be seen on a computer and this can tell us if there might be a chance you have TB disease.

If you have signs and symptoms of TB or your chest X-ray does not look normal we will ask you to produce ***two (2)*** sputum sample (s) to test for TB. Your sputum sample (s) will be tested on the spot for TB and the result will be available in 1 or 2 days. In addition we may ask for additional sputum samples to be sent to the laboratory for additional testing for TB. This test can take up to 8 weeks and so if this is the case we will tell you and will come to find you or contact you over the telephone to give you the results when they are ready.
If you are found to have TB, we will contact you and notify your local health facility and refer you there for treatment. If you do not have TB but your chest X-ray shows that you could have other disease we will ask a clinician to discuss this with you and provide you with a referral to a health facility for further investigation or treatment.

We may also request a blood sample of up to 10mls of blood (2 teaspoons) from some individuals to use for new tests to detect TB.
If you agree, we will perform an on-the-spot HIV test. We will provide counselling before and after being tested by qualified counsellors.

If you know that you have HIV, or we test you and find that you have HIV, we will ask for a small sample of blood to be taken using a finger-prick so that we can look at the HIV virus to see if any treatment you are taking has reduced the amount of virus in your blood.We will look at the different types of virus found in blood samples of different people in the community who are living with HIV. In science we call this Phylogenetics. This kind of research will help the PopART research team to understand better how the trial affected the spread of HIV and other viruses in your community.

If you are found to have TB or HIV we will provide counselling by qualified counsellors and medical staff and refer you to the clinic for further assessment and care.

What are the possible risks or discomforts?
You may become embarrassed, worried or anxious when learning your HIV or TB infection status. A trained staff member will help you deal with any feelings or questions you have.

Risks associated with chest X-ray are minimal as the radiation exposure from these new machines is very low, and the x-rays are directed at the chest. However, if you are pregnant or have any concerns about the effects that the X-ray may have on your health or on that of your unborn baby please discuss it in detail with the radiographer and make sure all your questions are answered. You can still continue to take part in the study even if you choose not to have the chest X-ray.

Risks associated with blood sampling may be that you will have a small bruise on the site of the blood draw. Occasionally some people may feel a bit faint when blood is drawn but we will try to avoid this by drawing blood when you are sitting comfortably.

What are the potential benefits?
During the study you will learn whether you have TB disease and if so will be linked to care to cure the TB disease. Also you will learn more about the signs and symptoms of TB disease and have an X-ray of your lungs taken free of charge. You will have the opportunity to learn your HIV status and be provided with information on where to receive treatment and care services if needed. You will also be able to ask questions about your health. In addition, the results will help design better programs to control TB and HIV and promote better health for you and your family as well as helping with acceptance of TB as a community-wide health problem.

Are there any alternatives to participation?
If you decide not to take part in this study, we will refer you to other places where you can be screened for TB disease or receive an HIV test.

How will my confidentiality and privacy be protected?
We will do everything possible to protect your confidentiality if you join this study.
To protect your privacy, you will meet with the researcher in a private area.

What kind of information will be collected from you?
During this study we will collect general information such as your gender, age, home address and employment status. You will also be asked to provide information about the type of house you live in, tobacco and alcohol intake. You will also be asked questions about TB and HIV. No one will be able to recognise you in all of the data that will be collected. A barcode ID with your study number will be allocated to you and will be used instead of your name.

Data protection for this study will be conducted in accordance with the Electronic Communications and Transactions Act 2009 of Zambia, Part VII (Protection of personal Information) and Section 42. This act generally discusses how the data that is collected from you will be collected and used. This Act can be found on internet using this link https://www.zicta.zm/Downloads/The%20Acts%20and%20SIs/ect_act_2009.pdf. If you do not have access to the internet, this Act can be gotten from Government printers.

How will data be recorded?
Some of the information that you give us will be recorded on paper for example the consent form that you will sign, and test results. Other information like the questionnaire will be recorded electronically and will be recorded on a hand-held device. The hand-held device is securely protected by a password only known by the Research Assistant. All this information will be assigned a barcode ID so that your confidentiality is maintained.

How will it be stored?
All paper copies that will have your information will be kept securely in a locked cabinet in a locked room that will only be accessed by assigned study staff. All information that is recorded in hand-held devices is accessed only by the Research Assistant. All electronic data will be stored on a server and will be encrypted and password protected and will only be accessible by the data manager.

All the information collected will be stored for approximately 7 years after the study has ended after which, data will be destroyed.

Who will the information be shared with?
We may share it with people who check that the study is done properly (like the independent ethics committee or review boards). The data that we collect, but not your name or anything else that can identify you will be shared with other researchers working on the TREATS study. These include researchers working at Zambart in Zambia, health Systems Trust in South Africa, the London School of Hygiene and Tropical Medicine, Imperial College and the University of Sheffield in the UK and KNCV in the Netherlands. We will publish study results in medical journals, for meetings and on the internet for other researchers to use. Your name or personal information will not appear in any publication.

After the study is complete copies of the data, without any details that could identify you, will be made publicly available via the internet for other researchers to use. To make sure you can never be identified we will remove information such as your name, where you live, your date of birth, the name of your community and any other data that may lead to someone being able to identify you. Some members of the study team may revisit you in the future to ask some follow up questions about the results of the tests you had, the treatment that you received or about other information provided to us in the course of this study.

What happens if I am injured by participating in this study?
It is very unlikely that you could be injured because of taking part in this study. However, if you are injured while taking part in this study, you will be given immediate treatment for your injuries and referred to the health facility. You will be compensated if an injury occurs during any of the study procedures. You will not be giving up any of your legal rights by signing this Information and Consent Form.

All principal investigators and sites are covered by the LSHTM sponsorship insurance and have Medical Malpractice Insurance to cover claims.

Will I receive any payment?
If you take part in this study, you will be refunded your transport costs to the value of **ZMW20** for each regular study visit.

What are some reasons why I may be withdrawn from this study without my consent?
You may be withdrawn from the study without your consent for the following reasons:

1. The research study, or this part of the study is stopped or cancelled
2. The study staff feels that completing the study or this part of the study would be harmful to you or others

Persons to Contact for Problems or Questions
If you have any questions about taking part in this research study, your rights as a research participant, or if you feel that you have experienced a research-related injury, contact:

Principle investigator's Name: *Dr Kwame Shanaube*

Research Site Address (es): *Zambart, Ridgeway Main Campus, P.O. Box 50697 Lusaka Zambia.*
Daytime telephone number (s): +260-211-254710

If you have any other questions or concerns about your rights as a research participant or want to discuss a problem, get information or offer input, you may contact:

Independent Review Board/Ethics Committee: *School of Medicine Ridgeway Main Campus, P.O. Box 50110, Lusaka*

Address of Independent Review Board: *University of Zambia Biomedical Ethics, Committee, Ridgeway Main Campus, Lusaka, Zambia*

Daytime Telephone Number: *+260-211-254710*

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)

Prevalence Survey (≥18years old)-

STATEMENT OF CONSENT

1. I have been given sufficient time to consider whether to take part in this study.
2. My taking part in this research study is voluntary. I understand that I may decide not to take part or can withdraw at any time from the study without penalty or loss of benefits or treatment to which I am entitled.
3. I understand the research study may be stopped at any time without my consent.
4. I have been informed of the procedures and tests that may be performed during the research study, as well as of the possible risks and benefits. I have had an opportunity to ask questions about this research study and my questions have been answered to my satisfaction.
5. I understand that the information I have given will be published in reports and papers, but that confidentiality will be maintained and it will not be possible to identify me from any publications.
6. I have been informed that my data will be shared with the partners and organisations that are working with Zambart on this study.
7. I understand that I do not give up my legal rights by signing this form.
8. I understand that I will receive a signed and dated copy of this Participant Information and Consent Form.

If you have either read or have heard the information in this Participant Information and Consent Form, if all your questions have been answered, and if you agree to take part in the study, please print and sign your name and write the date on the line below.

I voluntarily agree to take part in this research study

Participant's Name (print)	**Participant's Signature/Thumbprint**

Date _____

I certify that the information provided was given in a language that was understandable to the participant.

Name of Study Staff Conducting Consent Discussion (print)	**Study Staff Signature**

Date _____

Witness' Name (print) (As appropriate) Date	**Witness' Signature**

Date _____

FIX BARCODE HERE

Study Community _____

Appendix 2d: TREATS Prevalence Survey Parental/Guardian Information and Consent Form

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)
Prevalence Survey (15-17years old)-Parent/Guardian Information and Consent Form

Participant Information Sheet
Please ask the study staff to explain any words or procedures that you do not clearly understand.

This form gives you information about the research study that the adolescent in your care is being asked to join. If you sign this form, you will be giving your permission for the adolescent in your care to take part in the study. The form describes the purpose, procedures, benefits, and risks of the research study. Please read this Information and Consent Form and ask as many questions as needed. You should not sign this form if you have any questions that have not been answered to your satisfaction. If you choose to sign this form you are giving permission for the adolescent in your care to be included in this research study.

This study is being funded by the European and Developing Countries Clinical Trials Partnership (EDCTP)

Participation is voluntary
Taking part in this study is completely voluntary. Your adolescent does not have to take part in this study if you do not want to. Access to health care from the health centres in your community will not be affected if your adolescent chooses not to participate in the study. You are also free to withdraw your adolescent from the study at any stage, without consequences to you or your family.

What is tuberculosis (TB)?
TB is an infectious airborne disease caused by bacteria (germs) which are spread through droplets from coughing or sneezing which are inhaled in into the lungs. The TB germ mainly affects the lungs but it can also affect other parts of the body. When the TB germ enters your lungs, we say you have **TB infection.** When you have TB infection, you are usually healthy and do not feel sick at all. You may have TB infection for some time which can be for some weeks up to years. Some people may have TB infection and may never feel unwell. If you start to feel unwell because of the TB germs in your lungs, we say you have **TB disease.**

Purpose of this study
The TREATS study is made up of 4 studies that will look whether the PopART study that has been carried out in 21 communities, 12 in Zambia and 9 in South Africa, reduced the chance of getting TB infection or developing TB disease. The PopART intervention involved HIV testing and treatment as well as screening for the symptoms that suggest your adolescent might have TB.

This particular study is called the "Prevalence Survey". In ***Zambia*** this study aims to recruit ***approximately 2000*** people 15 years and older from this community to measure how much TB

disease there is in this community. Your adolescent has been selected to be one of the people from your community who we are asking to take part in this study.

What will happen during this study?
If your adolescent takes part in this study, we will ask them some questions about them, your family and their health, as well as about risk factors for TB disease. We will then ask your adolescent to have a chest X-ray taken at our mobile X-ray machine. This is a very simple procedure and it is very quick, it takes around 5-10 minutes and they will not be charged. The chest X-ray picture of your adolescent's lungs will be seen on a computer and this can tell us if there might be a chance they have TB disease. If your adolescent has signs and symptoms of TB or their chest X-ray does not look normal we will ask your adolescent to produce ***two (2)*** sputum sample (s) to test for TB. Your adolescent's sputum sample (s) will be tested on the spot for TB and the result will be available in 1 or 2 days. In addition we may ask your adolescent for additional sputum samples to be sent to the laboratory for additional testing for TB. This test can take up to 8 weeks and so if this is the case we will tell your adolescent and will come to find them or contact them over the telephone to give them the results when they are ready.
If your adolescent is found to have TB, we will contact them and notify your local health facility and refer them there for treatment. If your adolescent does not have TB but their chest X-ray shows that they could have other disease we will ask a clinician to discuss this with you and your adolescent and provide your adolescent with a referral to a health facility for further investigation or treatment.

We may also request a blood sample of up to 10mls of blood (2 teaspoons) from some individuals to use for new tests to detect TB.
If you agree your adolescent to take part in the study, we will perform an on-the-spot HIV test, we will provide counselling before and after being tested by qualified counsellors.

If your adolescent knows that they have HIV, or we test them and find that they have HIV, we will ask them for a small sample of blood to be taken using a finger-prick so that we can look at the HIV virus to see if any treatment they are taking has reduced the amount of virus in their blood.We will look at the different types of virus found in blood samples of different people in the community who are living with HIV. In science we call this Phylogenetics. This kind of research will help the PopART research team to understand better how the trial affected the spread of HIV and other viruses in the community.

If your adolescent is found to have TB or HIV we will provide counselling by qualified and medical staff and refer your adolescent to the clinic for further assessment and care

What are the possible risks or discomforts?
Your adolescent may become embarrassed, worried or anxious when learning their HIV or TB infection status. A trained staff member will help them deal with any feelings or questions they have.

Risks associated with chest X-ray are minimal as the radiation exposure from these new machines is very low, and the x-rays are directed at the chest. However, if your adolescent is pregnant or have any concerns about the effects that the X-ray may have on their health or on that of their

unborn baby please discuss it in detail with the radiographer and make sure all your questions are answered. Your adolescent can still continue to take part in the study even if they choose not to have the chest X-ray.

Risks associated with blood sampling may be that your adolescent will have a small bruise on the site of the blood draw. Occasionally some people may feel a bit faint when blood is drawn but we will try to avoid this by drawing blood when someone is sitting comfortably.

What are the potential benefits?
During the study your adolescent will learn whether they have TB disease and if so they will be linked to care to cure the TB disease. Also your adolescent will learn more about the signs and symptoms of TB disease and have an X-ray of their lungs taken free of charge. Your adolescent will have the opportunity to learn their HIV status and be provided with information on where to receive treatment and care services if needed. They will also be able to ask questions about their health.

In addition, the results will help design better programs to control TB and HIV and promote better health for your adolescent and your family as well as helping with acceptance of TB as a community-wide health problem.

Are there any alternatives to participation?
If your adolescent decides not to take part in this study, we will refer them to other places where they can be screened for TB disease or receive an HIV test.

How will my confidentiality and privacy be protected?
We will do everything possible to protect your adolescent's confidentiality if they join this study. To protect their privacy, your adolescent will meet with the researcher in a private area.

<u>What kind of information will be collected from your adolescent?</u>
During this study we will collect general information such as your adolescent's gender, age, home address and employment status. Your adolescent will also be asked to provide information about the type of house they live in, tobacco and alcohol intake. Your adolescent will also be asked questions about TB and HIV. No one will be able to recognise your adolescent in all of the data that will be collected. A barcode ID with your study number will be allocated to your adolescent and will be used instead of their name.

Data protection for this study will be conducted in accordance with the Electronic Communications and Transactions Act 2009 of Zambia, Part VII (Protection of personal Information) and Section 42. This act generally discusses how the data that is collected from you will be collected and used. This Act can be found on internet using this link https://www.zicta.zm/Downloads/The%20Acts%20and%20SIs/ect_act_2009.pdf. If you do not have access to the internet, this Act can be gotten from Government printers.

<u>How will data be recorded?</u>
Some of the information that your adolescent give us will be recorded on paper for example the assent form that you and your adolescent will sign, and test results. Other information like the

questionnaire will be recorded electronically and will be recorded on a hand-held device. The hand-held device is securely protected by a password only known by the Research Assistant. All this information will be assigned a barcode ID so that your adolescent's confidentiality is maintained.

How will it be stored?

All paper copies that will have your adolescent's information will be kept securely in a locked cabinet in a locked room that will only be accessed by assigned study staff. All information that is recorded in hand-held devices is accessed only by the Research Assistant. All electronic data will be stored on a server and will be encrypted and password protected and will only be accessible by the data manager.

All the information collected will be stored for approximately 7 years after the study has ended after which, data will be destroyed.

Who will the information be shared with?

We may share it with people who check that the study is done properly (like the independent ethics committee or review boards). The data that we collect, but not your adolescent's name or anything else that can identify them will be shared with other researchers working on the TREATS study. These include researchers working at Zambart in Zambia, health Systems Trust in South Africa, the London School of Hygiene and Tropical Medicine, London School of Economics, University of Oxford, Imperial College and the University of Sheffield in the UK and KNCV in the Netherlands. We will publish study results in medical journals, for meetings and on the internet for other researchers to use. Your adolescent's name or personal information will not appear in any publication.

After the study is complete copies of the data, without any details that could identify your adolescent, will be made publicly available via the internet for other researchers to use. To make sure your adolescent can never be identified we will remove information such as their name, where they live, their date of birth, the name of their community and any other data that may lead to someone being able to identify them.

Some members of the study team may revisit your adolescent in the future to ask some follow up questions about the results of the tests they had, the treatment that they received or about other information provided to us in the course of this study

What happens if your adolescent is injured by participating in this study?

It is very unlikely that anyone could be injured because of taking part in this study. However, if your adolescent is injured while taking part in this study, they will be given immediate treatment for your injuries and referred to the health facility. Your adolescent will be compensated if an injury occurs during any of the study procedures. You and your adolescent will not be giving up any of your legal rights by signing this Information and Consent Form.

All principal investigators and sites are covered by LSHTM sponsorship insurance and have Medical Malpractice Insurance to cover claims.

Will I receive any payment?
If you take part in this study, you will be refunded your transport costs to the value of ZMW20 for the first study visit at the mobile field site.

What are some reasons why I may be withdrawn from this study without my consent?
Your adolescent may be withdrawn from the study without your consent for the following reasons:
1. The research study, or this part of the study is stopped or cancelled
2. The study staff feels that completing the study or this part of the study would be harmful to your adolescent or others

Persons to Contact for Problems or Questions
If you have any questions about taking part in this research study, your rights as a research participant, or if you feel that you have experienced a research-related injury, contact:

Principle investigator's Name: *Dr Kwame Shanaube*

Research Site Address (es): *Zambart, Ridgeway Main Campus, P.O. Box 50697 Lusaka, Zambia.*

Daytime telephone number (s): +260-211-254710

If you have any other questions or concerns about your rights as a research participant or want to discuss a problem, get information or offer input, you may contact:

Independent Review Board/Ethics Committee: *School of Medicine Ridgeway Main Campus, P.O. Box 50110, Lusaka*

Address of Independent Review Board: University of Zambia Biomedical Ethics, Committee, Ridgeway Main Campus, Lusaka, Zambia

Daytime Telephone Number: *+260-211-254710*

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)
Prevalence Survey (15-17yrs) - Parent/Guardian Information and Consent Form
STATEMENT OF CONSENT

1. I confirm that I am the parent or legal guardian of this adolescent
2. I have been given sufficient time to consider whether to allow my adolescent to take part in this study.
3. I understand that my adolescent taking part in this research study is voluntary. I understand that they may decide not to take part or can withdraw at any time from the study without penalty or loss of benefits or treatment to which they are entitled.
4. I understand the research study may be stopped at any time without my or my adolescent's consent.
5. I have been informed of the procedures and tests that may be performed during the research study, as well as of the possible risks and benefits. I have had an opportunity to ask questions about this research study and my questions have been answered to my satisfaction.
6. I understand that the information my adolescent has given will be published in reports and papers, but that confidentiality will be maintained and it will not be possible to identify them from any publications.
7. I have been informed that my adolescent's data will be shared with the partners and organisations that are working with ***Zambart*** on this study.
8. I understand that I do not give up my legal rights or those of my adolescent by signing this form.
9. I understand that I will receive a signed and dated copy of this Participant Information and Consent Form.

If you have either read or have heard the information in this Participant Information and Consent Form, if all your questions have been answered, and if you agree that your adolescent takes part in the study, please print and sign your name and write the date on the line below.

_____

Adolescent's Name (print)

_____ _____

Parent/Guardian Name (print) **Parent/Guardian signature/Thumbprint**

Date _____

I certify that the information provided was given in a language that was understandable to the participant.

_____ _____

Name of Study Staff **Study Staff Signature**
Conducting Consent Discussion (print)

Date_____

_____ _____

Witness' Name (print) **Witness' Signature/Thumbprint**
(As appropriate) Date

Date _____

FIX BARCODE HERE

Study Community _____

Appendix 2d: TREATS Prevalence Survey Information and Ascent Form

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)
Prevalence Survey (15-17years old)-Information and Assent Form

Participant Information Sheet
Please ask the study staff to explain any words or procedures that you do not clearly understand.

This form gives you information about the research study you are being asked to join. The form describes the purpose, procedures, benefits, and risks of the research study. Please read this Information and Consent Form and ask as many questions as needed. You should not sign this form if you have any questions that have not been answered to your satisfaction. If you choose to sign this form you are giving permission to be included in this research study.

This study is being funded by the European and Developing Countries Clinical Trials Partnership (EDCTP)

Your participation is voluntary
You do not have to take part in this study if you do not want to. Access to health care from the health centres in your community will not be affected if you choose not to participate in the study. You are also free to withdraw from the study at any stage, without consequences to you or your family.

What is tuberculosis (TB)?
TB is an infectious airborne disease caused by bacteria (germs) which are spread through droplets from coughing or sneezing which are inhaled in into the lungs. The TB germ mainly affects the lungs but it can also affect other parts of the body. When the TB germ enters your lungs, we say you have **TB infection.** When you have TB infection, you are usually healthy and do not feel sick at all. You may have TB infection for some time which can be for some weeks up to years. Some people may have TB infection and may never feel unwell. If you start to feel unwell because of the TB germs in your lungs, we say you have **TB disease.**

Purpose of this study
The TREATS study is made up of 4 studies that will look whether the PopART study that has been carried out in 21 communities, 12 in Zambia and 9 in South Africa, reduced the chance of getting TB infection or developing TB disease. The PopART intervention involved HIV testing and treatment as well as screening for the symptoms that suggest you might have TB.

This particular study is called the "Prevalence Survey". In ***Zambia*** this study aims to recruit ***approximately 2000*** people 15 years and older from this community to measure how much TB disease there is in this community. You have been selected to be one of the people from your community who we are asking to take part in this study.

What will happen during this study?
If you take part in this study, we will ask you some questions about you, your family and your health, as well as about risk factors for TB disease. We will then ask you to have a chest X-ray taken at our mobile X-ray machine. This is a very simple procedure and it is very quick, it takes around 5-10 minutes and you will not be charged. The chest X-ray picture of your lungs will be seen on a computer and this can tell us if there might be a chance you have TB disease. If you have signs and symptoms of TB or your chest X-ray does not look normal we will ask you to produce ***two (2)*** sputum sample (s) to test for TB. Your sputum sample (s) will be tested on the spot for TB and the result will be available in 1 or 2 days. In addition we may ask for additional sputum samples to be sent to the laboratory for additional testing for TB. This test can take up to 8 weeks and so if this is the case we will tell you and will come to find you or contact you over the telephone to give you the results when they are ready.
If you are found to have TB, we will contact you and notify your local health facility and refer you there for treatment. If you do not have TB but your chest X-ray shows that you could have other disease we will ask a clinician to discuss this with you and provide you with a referral to a health facility for further investigation or treatment.

We may also request a blood sample of up to 10mls of blood (2 teaspoons) from some individuals to use for new tests to detect TB.
If you agree, we will perform an on-the-spot HIV test. We will provide counselling before and after being tested by qualified counsellors.

If you know that you have HIV, or we test you and find that you have HIV, we will ask for a small sample of blood to be taken using a finger-prick so that we can look at the HIV virus to see if any treatment you are taking has reduced the amount of virus in your blood.We will look at the different types of virus found in blood samples of different people in the community who are living with HIV. In science we call this Phylogenetics. This kind of research will help the PopART research team to understand better how the trial affected the spread of HIV and other viruses in your community.

If you are found to have TB or HIV we will provide counselling by qualified counsellors and medical staff and refer you to the clinic for further assessment and care.

What are the possible risks or discomforts?
You may become embarrassed, worried or anxious when learning your HIV or TB infection status. A trained staff member will help you deal with any feelings or questions you have.

Risks associated to the chest X-ray are minimal as the radiation exposure from these new machines is very low, and the x-rays are directed at the chest. However, if you are pregnant or have any concerns about the effects that the X-ray may have on your health or on that of your unborn baby please discuss it in detail with the radiographer and make sure all your questions are answered. You can still continue to take part in the study even if you choose not to have the chest X-ray.

Risks associated with blood sampling may be that you will have a small bruise on the site of the blood draw. Occasionally some people may feel a bit faint when blood is drawn but we will try to avoid this by drawing blood when you are sitting comfortably.

What are the potential benefits?
During the study you will learn whether you have TB disease and if so you will be linked to care to cure the TB disease. Also you will learn more about the signs and symptoms of TB disease and have an any possible events that may have occurred will be discussed. X-ray of your lungs taken free of charge. You will have the opportunity to learn your HIV status and be provided with information on where to receive treatment and care services if needed. You will also be able to ask questions about your health.
In addition, the results will help design better programs to control TB and HIV and promote better health for you and your family as well as helping with acceptance of TB as a community-wide health problem.

Are there any alternatives to participation?
If you decide not to take part in this study, we will refer you to other places where you can be screened for TB disease or receive an HIV test.

How will my confidentiality and privacy be protected?
We will do everything possible to protect your confidentiality if you join this study. To protect your privacy, you will meet with the researcher in a private area.

What kind of information will be collected from you?
During this study we will collect general information such as your gender, age, home address and employment status. You will also be asked to provide information about the type of house you live in, tobacco and alcohol intake. You will also be asked questions about TB and HIV. No one will be able to recognise you in all of the data that will be collected. A barcode ID with your study number will be allocated to you and will be used instead of your name.
Data protection for this study will be conducted in accordance with the Electronic Communications and Transactions Act 2009 of Zambia, Part VII (Protection of personal Information) and Section 42. This act generally discusses how the data that is collected from you will be collected and used. This Act can be found on internet using this link https://www.zicta.zm/Downloads/The%20Acts%20and%20SIs/ect_act_2009.pdf. If you do not have access to the internet, this Act can be gotten from Government printers.

How will data be recorded?
Some of the information that you give us will be recorded on paper for example the consent form that you will sign, and test results. Other information like the questionnaire will be recorded electronically and will be recorded on a hand-held device. The hand-held device is securely protected by a password only known by the Research Assistant. All this information will be assigned a barcode ID so that your confidentiality is maintained.

How will it be stored?
All paper copies that will have your information will be kept securely in a locked cabinet in a locked room that will only be accessed by assigned study staff. All information that is recorded hand-held devices is accessed only by the Research Assistant. All electronic data will stored on a server and will be encrypted and password protected and will only be accessible by the data manager.

All the information collected will be stored for approximately 7 years after the study has ended after which, data will be destroyed.

Who will the information be shared with?
We may share it with people who check that the study is done properly (like the independent ethics committee or review boards). The data that we collect, but not your name or anything else that can identify you will be shared with other researchers working on the TREATS study. These include researchers working at Zambart in Zambia, health Systems Trust in South Africa, the London School of Hygiene and Tropical Medicine, London School of Economics, University of Oxford, Imperial College and the University of Sheffield in the UK and KNCV in the Netherlands. We will publish study results in medical journals, for meetings and on the internet for other researchers to use. Your name or personal information will not appear in any publication.

After the study is complete copies of the data, without any details that could identify you, will be made publicly available via the internet for other researchers to use. To make sure you can never be identified we will remove information such as your name, where you live, your date of birth, the name of your community and any other data that may lead to someone being able to identify you.
Some members of the study team may revisit you in the future to ask some follow up questions about the results of the tests you had, the treatment that you received or about other information provided to us in the course of this study

What happens if I am injured by participating in this study?
It is very unlikely that you could be injured because of taking part in this study. However, if you are injured while taking part in this study, you will be given immediate treatment for your injuries and referred to the health facility. You will be compensated if an injury occurs during any of the study procedures. You will not be giving up any of your legal rights by signing this Information and Consent Form.

All principal investigators and sites are covered by the LSHTM sponsorship insurance and have specific Medical Malpractice Insurance to cover claims.

Will I receive any payment?
If you take part in this study, you will be refunded your transport costs to the value of ZMW20 for the first study visit at the mobile field site.

What are some reasons why I may be withdrawn from this study without my consent?
You may be withdrawn from the study without your consent for the following reasons:
1. The research study, or this part of the study is stopped or cancelled
2. The study staff feels that completing the study or this part of the study would be harmful to you or others

Persons to Contact for Problems or Questions
If you have any questions about taking part in this research study, your rights as a research participant, or if you feel that you have experienced a research-related injury, contact:

Principle investigator's Name: *Dr Kwame Shanaube*

Research Site Address (es): *Zambart, Ridgeway Main Campus, P.O. Box 50697 Lusaka* Zambia.

Daytime telephone number (s): +260-211-254710

If you have any other questions or concerns about your rights as a research participant or want to discuss a problem, get information or offer input, you may contact:

Independent Review Board/Ethics Committee: School of Medicine Ridgeway Main Campus, P.O. Box 50110, Lusaka.

Address of Independent Review Board: University of Zambia Biomedical Ethics, Committee, Ridgeway Main Campus, Lusaka, Zambia

Daytime Telephone Number: *+260-211-254710*

Tuberculosis Reduction through expanded antiretroviral therapy and TB screening (TREATS)

Prevalence Survey (15-17years old) - Information and Assent Form

STATEMENT OF CONSENT

1. I have been given sufficient time to consider whether to take part in this study.
2. My taking part in this research study is voluntary. I understand that I may decide not to take part or can withdraw at any time from the study without penalty or loss of benefits or treatment to which I am entitled.
3. I understand the research study may be stopped at any time without my consent.
4. I have been informed of the procedures and tests that may be performed during the research study, as well as of the possible risks and benefits. I have had an opportunity to ask questions about this research study and my questions have been answered to my satisfaction.
5. I understand that the information I have given will be published in reports and papers, but that confidentiality will be maintained and it will not be possible to identify me from any publications.
6. I have been informed that my data will be shared with the partners and organisations that are working ***Zambart*** on this study.
7. I understand that I do not give up my legal rights by signing this form.
8. I understand that I will receive a signed and dated copy of this Participant Information and Consent Form.

If you have either read or have heard the information in this Participant Information and Consent Form, if all your questions have been answered, and if you agree to take part in the study, please print and sign your name and write the date on the line below.

I voluntarily agree to take part in this research study

Adolescent's Name (print)	**Adolescent's Signature/Thumbprint**

Date: _____

Remember to obtain signed consent from parent/guardian

I certify that the information provided was given in a language that was understandable to the participant.

Name of Study Staff Conducting Consent Discussion (print)	**Study Staff Signature**

Date: _____

Witness' Name (print) (As appropriate) Date	**Witness' Signature/Thumbprint**

Date: _____

FIX BARCODE HERE

Study Community _____

Appendix 3: Tools

Appendix 3a: TB Health Worker In-depth Interview Guide

TUBERCULOSIS (TB)-Tuberculosis Reduction through Expanded Anti-retroviral and Screening for Active TB (TREATS)

TB Health Worker In-depth Interview Guide

Purpose: To describe the impact of PopART on the provision of health services for people living with TB.

Objectives:

1. *To describe popular understandings of TB among health workers at PopART facilities*
2. *To describe the strategies and processes supporting implementation of TB-related services at health facilities*
3. *To explore perceptions TB treatment and care from a health workers' perspectives*
4. *To describe the influence of TB-stigma on the uptake and adherence to TB treatment from a health workers' perspective*
5. *To explore perceptions and experiences on the role of the CHiPs/ PopART in TB service provision*

Materials needed: Map of community, map of clinic, coloured card cut into circles/ovals, marker pen, large white paper, informed consent forms, note book, pen, pencil, audio-recorder

Form of data recording: (1) Audio-recording of all talk from "Preamble" to "Closing". (2) Notes of key points per topic area handwritten by the facilitator into a printed copy of this document

Expected time needed: Not more than an hour.

Date activity conducted: _____

Place conducted: _____

Time period: _____

Administer Informed Consent – once/if completed continue.

Preamble (to be read by facilitator): Today is the (insert date [day xxth Xx xxxx]) and it is (insert time XX:XX). This is a discussion with a health staff working with TB at (XXXX) Clinic as part of the social science work of TREATS. Thank you for your time. All information collected here will be reported anonymously. If permissible, I would like to audio-record this discussion and I will also take some notes. We will also look at some maps together and discuss them. Do you have any questions before we begin?

Our particular interest is during the PopART intervention period, so we are going to be asking you to think back to the period that PopART was being carried out from 2014-2017.

(Facilitator to read bolded text below and elaborate with prompts at their discretion)

Topic Area 1 – Clinic and Community

1. What is your position in the clinic?

1. What are some of your roles?

2. How long have you been working with TB?

1. How do you feel about working specifically with TB?
2. Who else do you work with at this clinic when supporting TB patients?
3. Do TB staff rotate through other departments?
4. Have you ever done any specific training for TB? Please explain what kind of training.
5. Please describe what you did yesterday at this TB clinic/corner?
    1. *Probe: Starting from when you arrived at work to when you left, can you share with me what happens?*

3. How long have you worked at this clinic?

1. What has changed since you started working here?

2. What have been some of the biggest challenges while working here?

4. What community/ies does this clinic serve?

1. What are some of the biggest challenges in this community?

2. What health problems are found in this community, which are not a problem in other communities? How do they affect the clinic?

5. Do you live in this community?

1. If no, where are you from?

2. If yes, when did you move to this community? Why did you move to this community?

3. Do any of your family members also live in this community?

4. What is it like to work in the same community as where you live?

5. Looking at this map of the community [*use map of community],* are there any places in the community that you consider more at risk of TB, like a 'TB hot-spot'? Probe for: particular housing/houses, particular areas, particular ethnicities in community, transport depots, bars/taverns/shebeens, video/gaming places, clinics, markets, schools. What makes a place risky for TB? Probe for cooking stoves, alcohol habits, smoking habits, ventilation, crowding/congestion, darkness, dampness, sexual behaviour?

Topic Area 2 – Tell us about you

6. **Can you tell us more about your family?**

1. Household composition: Who lives with you? Are you married? Cohabitating? Single? Widowed? Divorced? Do you have any children? How old?
2. Household hierarchy: Who makes most of the decisions for the family? Who takes care of the home?

3. **Do you have any family members who have had TB before?**

1. When was that? Would you mind telling me a bit about this experience (who? Age? Gender? TB treatment? Outcome?)
2. Are you concerned about anyone in your family developing TB in the future? Why?

Topic area 3 – Knowledge, Training and Experience

3. **For ARM A sites only (2014-2017):** How have PopART activities (i.e. anything to do with PopART) affected TB activities (i.e. anything to do with TB treatment and care) in the clinic?

1. Do you know about the CHiPs? (Explain if not clear). What did they do in the households with TB when they went door to door? Do you personally know anyone diagnosed with TB through CHiPs?
2. Do you think that PopART TB screening in the households increased the number of people diagnosed and treated for TB at the clinic?
3. Since CHiPs stopped going door to door, has there been any change in the number of TB patients being diagnosed?
4. Now that they have introduced the hubs, do people go there to access TB services? If not, where do they go?

5. For ALL sites: Here is a list of other people/organisations involved in the implementation of HIV and adolescent service provision?

1. Could we go through this list together and confirm if any of these stakeholders (including the health facility where you work) were working with TB during the PopART intervention (2014-2017)? Is there anyone missing from this list that we should add?

2. Explain their relationship with this clinic, what they do and how they contribute to TB services in the clinic and community?

3. Since the beginning of this year (2018), are there any new TB programmes that are happening in this community and/or health facility? If so, please could you share details with us.

4. *For ARM C sites only:* In some other communities where we did PopART (explain if necessary what PopART is), we had CHWs going door to door doing HIV testing and counselling, and screening for TB. Have you ever had this type of initiative in this community? Please explain if you have. Do you think it is a good idea?

5. Looking at the map of this clinic, can we discuss which departments you interact with when based at the TB corner/clinic?

1. Do you interact with: OPD, MCH, HIV, laboratory services, the pharmacy, the mortuary, the wards (Zambia only), any other departments?

2. At the laboratory, how are they testing for TB? Probe: sputum, microscope, Gene expert, culture.

3. In relation to TB drugs, what regimens do you give? What if someone has relapse TB? What if someone has multi-drug resistant TB?

4. Please explain in some detail how you liaise with HIV services? Do all TB patients test for HIV? Do you test them here or refer them?

5. Overall, what has your experience of providing TB services at this health facility been like?

6. Have you experienced any challenges in delivering TB services? **Probe: Delay in results?** Shortage of medication? Shortage of staff? Long lines? Waiting periods at clinic? Lack of privacy? Congestion? Patients defaulting? Being asked for a transfer letter?

7. Are there any things you would like to change about the way TB services are provided here?

8. Are there any support systems for TB patients? Are there any food items given to TB patients?

9. **What has your experiences of delivering TB services in this community been like?**

1. Are there any particular challenges to providing TB services in this community?

2. **Are there any efforts to promote facility-based TB screening amongst staff and patients?**

3. **Were there any efforts that focused on particular groups of people?**

1. How did you prioritise who to screen for TB? (prompt: Specific services access? Ages? Gender?)

Topic area 4 – TB and Stigma

2. Looking at this map of the clinic*[show map of clinic]*:

3. Where do TB patients feel comfortable?

4. Where do TB patients feel uncomfortable?

5. Has the way that people talk about TB in the community/clinic changed over the years?

1. What did they used to say about TB? What do they say now?

2. Are TB patients more or less stigmatised now than they were in the past? What do you think has contributed to the change?

3. From what you know/ have seen, does the fear of being stigmatised stop people with TB symptoms from seeking treatment/ care?

1. Can this also delay diagnosis of TB?

2. If TB was not stigmatized, would people get treatment sooner? Why?

3. Does stigma affect adherence to TB drugs?

4. Does stigma ever cause death in your opinion?

5. Do you know of TB patients who are afraid to ask their friends and family for help? Can you give an example of this?

6. Do you think that people feel nervous about TB patients?

7. Do you think that people feel pity for TB patients?

8. Do you think that developing TB is a person's own fault?

9. Do you feel angry towards TB patients ever?

10. Do you think TB patients should ever be isolated?

11. Do you think TB patients should be forced to take treatment if necessary?

12. From what you know, do health workers stigmatise TB patients?

1. Do some health workers stigmatise people living with TB?

2. How does it make you feel when TB patients cough while at the clinic?

3. Are you concerned about developing TB?

4. How do you manage that?

5. If a health worker is also living with HIV, are they advised to take IPT to protect them against TB?

6. In your experience, are health workers that provide TB services stigmatized?

1. Has this ever happened to you or someone you know? Could you tell us about it?

2. In your experience, what is it like for TB patients who also have HIV?

3. Do you think it is hard to take two different sets of pills?

4. Do TB patients face stigma?

5. Is this stigma linked to HIV?

6. Has ART reduced HIV stigma?

7. Has ART reduced TB stigma?

8. Do you think they face stigma for having both diseases?

9. What could be done about stigma towards TB patients?

10. Finally, we would like to ask you some questions about TB and mental health.

1. What implications do you think TB has on the emotional wellbeing of your patients?

2. In your opinion, do emotional and mental health problems affect the ability of TB patients to adhere to treatment?

3. Do you regularly provide emotional support to TB patients in your work? How does this affect your emotional well-being?

4. Have you ever received training on how to best emotionally support your patients? Was any of this training specifically about mental health issues such as depression or anxiety?

5. Are there organisations that you are aware of that are tailored to assist the emotional needs of TB patients?

Thank you so much for all your time. We really value you sharing your experience and opinions. Are there any questions you would now like to ask me?

Appendix 3b: TREATS Health worker IDI Activity Report Form

ACTIVITY REPORT FORM – IDI Health Worker

Research Assistant & Community Mobiliser:

Name of activity:

Place conducted (community, venue):

Date:

Materials and tools used:

Process:

Key findings: [Provide a detailed summary before transcribing]

1. How did the interview go? Was the respondent open or cautious with their answers? Was this the right person to interview about TB at the health facility?

2. What has been learnt about TB stakeholders, including the role of the local clinic and PopART? What was their opinion of PopART?

3. What has been learnt about TB stigma?

4. What has been learnt about TB mental health?

5. Is there anything else you would like to add?

Appendix 3c: TB PATIENT INDIVIDUAL INTERVIEW GUIDE

TB PATIENT INDIVIDUAL INTERVIEW GUIDE

Objective: To understand the experiences of TB patients and any influence of PopART on these experiences, including the influence of CHiPs.

Expected time needed: 1 – 2 Hours

Date activity conducted: _____

Place conducted: _____

Time period: _____

Materials Needed: map of the community, map of the clinic, coloured crayons (red, blue, green), informed consent forms, audio-recorder, notebook, pen, pencil

Form of data recording: (1) Audio-recording of all talk from "Preamble" to "Closing" depending on the tool used. (2) Notes of key points per topic area handwritten by the facilitator into a printed copy of this document. Preamble (to be read by facilitator): Today is the (insert date [day xxth Xxx xxxx]) and it is (insert time XX: XX). This is a discussion with a TB patient (community member). Thank you for your time. As we have explained, we are conducting this interview as part of the social science research of the TREATS study. For this interaction we would like to find out more about your life. All information collected here will be reported anonymously. I remind you that we are audio recording this discussion and ask that you speak loudly and clearly. As the facilitator I will also be taking some notes. Do you have any questions before we begin?

INTRODUCTORY QUESTIONS

1. I understand you have/had TB. Could you tell me how long you have been on TB treatment? Was this your first time to have TB? Could you kindly confirm when you were diagnosed with TB? Where? How long were you on treatment?

2. How long have you lived in _____?

3. Where did you live before you moved to _____?

4. What was your main reason for coming to_____?

1. Had family here
2. Had friends here
3. Work
4. Displaced
5. Married here
6. Had family/friends in area
7. Studies/education
8. Seeking treatment for current illness
9. Housing
10. Other…….

11. Before you developed TB, what did/do you do to contribute to household living?

12. When you had TB, who did you live with? Are you living with the same people? If not, would you mind telling me why you moved? *Collect details of household members and relationship to patient, using a diagram*

PERCEPTIONS AND TRANSMISSION

13. Did you consider yourself at risk of getting TB?

14. Where do you think you got your TB? Within this community or outside?

15. Looking at the map of this community *[map of the community]*, could you let us know firstly where you spend time on a regular/daily basis (and with whom)?

16. In your opinion, would any of these places (and/or people) have exposed you to TB?

1. Probe: Places: Bars/shebeens/taverns, clinic, churches, video/games clubs, hair salons, schools, houses (which kind), minibuses/buses/taxis
2. Probe: What is it about these places? E.g. poor ventilation, small/blocked/no windows, overcrowding, small rooms, other TB patients, sexual behaviour, smoking, charcoal stoves inside houses, sharing utensils, prolonged time in that space.

3. How did you feel when you were diagnosed with TB?

4. Did you fear that you might transmit TB to others in your family? [Probe on how long they thought they would remain infectious to others]

5. Would you kindly tell us the precautions you took as a TB patient to prevent transmission of TB to others?

6.What precautions did your family members take to cut down transmission of TB in the house?

TREATMENT SEEKING

We would now like to talk about where you looked for treatment for your TB in this community. Could you think back to the time that you first had symptoms and talk about everything that happened until you finally got diagnosed with TB? *It is critical to allow any contact with CHiPs to emerge in this sequence of health seeking, alongside other treatment options. If it doesn't emerge, but TB patients were selected on basis of being diagnosed through CHiPs, then probe for it once you have allowed the participant to discuss all the options and decides they wish to.*

USING CHART, LEAD PARTICIPANT WITH THE FOLLOWING QUESTIONS:

1. When you first knew you were sick, what did you do to treat your symptoms?

USING NETWORK CHART

FOR EACH TREATMENT SOURCE MENTIONED ASK:

2. How did you know about it?

3. What happened there?

4. What treatment were you given?

5. How long was the course of treatment?

6. How much did it cost?

7. Did they refer you elsewhere?

8. Of these places/people, are there any that you feel uneasy about?

9. If contacted by CHiPs ask them to recall in some detail what happened during the interaction with CHiPs. Probes include:

1. initial contact with the household,
2. TB screening questions,
3. producing sputum and giving sputum to the CHiPs,
4. going to the health facility with sputum,
5. waiting and receiving results,
6. any follow up and support from CHiPs
7. ask about differences between CHiPs and other volunteers, including TB treatment supporters.

8. How long did it take you to get diagnosed with TB?

9. Did you decide on your own or a household member advised you to seek treatment for your symptoms

1. **If seeking treatment was delayed for more than two weeks, probe reasons for delay** (PROBE: fear of diagnosis, treatment course or completion, stigmatisation, affordability, accessibility of health centre)

2. Where did you receive your treatment from (clinic, DOTS in the community, hospital?).

   1. How did you get there?

   2. How long did it take you to get there?

   3. How often did you go there?

   4. When were you last there?

   5. The last time you went, how long did you take there? How much did it cost to get there?

6. Looking at the map of the clinic you are attending as a TB patient *[map of the clinic]*, could you explain:

1. Where you went in the clinic when you first went there with TB symptoms? *Probe for role of CHiPs in navigating the clinic.*
2. How were you treated?
3. Where did you go within the clinic once you were diagnosed with TB symptoms?
4. Using these three colours, could you colour places within the clinic thinking about:
   1. Places that make you feel comfortable (blue)
   2. Places that make you feel uncomfortable (green)
   3. Places where people talk badly about TB patients (red)

1.
2. Did you worry about going to the place where you got your treatment? What worried you?

3. What is your opinion of the treatment that you received at the health centre/clinic, both in the TB clinic and outside of it?

TB TREATMENT

4. Can I ask what medication you were taking?
5. Probe for details about medication – collection (how, where, who), what medication, side effects, other problems, number of pills or injections a day, supervision of treatment.

6. Did you ever hide the fact that you were on TB treatment?

7. Whilst taking TB treatment, was there any period when you stopped taking medication?
8. Was there any period when you considered stopping medication?

9. Did you take any other therapy? For example, immune boosters, herbs, faith healing, witchfinding?

10. When you were first diagnosed with TB, did you think you would get cured? Do you believe you are cured now?

IMPACT OF TB

11. Were you admitted at the hospital because of TB? If so for how long? Or when you had TB, were you just cared for at home?

12. How did TB affect your:
    - Body?
    - Daily activities? (Perform daily tasks, personal care)
    - Participation in life? (Probe for ability to work and earn, provide)

13. Did TB stop you doing what you should be doing as a man/woman? Does this worry you? (probe for self-criticism from self or others)

14. Do you have any ideas what might reduce stress and worry for men and women with TB?

15. If having TB worried you, how did it compare with other worries? Can you name any of the other worries?

16. Were you able to talk about your worries to anyone in your family or health care workers or others?

17. Are there any organisations that you know of that TB patients can seek emotional support from?

18. Are you able to say what has helped reduce your worries? (If that is the case) or made your worries worse?

19. Thinking back, when you were diagnosed with TB, did you experience less interest or pleasure in doing things?

20. When you had TB, did you feel down or hopeless? If so, did these feelings get in the way of your ability to complete your TB treatment or perform you normal daily activities?

21. Thinking back to when you had TB, did you have any thoughts that you would be better off dead, or did you hurt yourself in some way?
22. When you had TB, did you feel bad about yourself - or feel that you are a failure or that you had let yourself or your family down?
23. How has TB affected your relations with your friends, relatives not living with you, neighbours and other people in the community?

24. How has having TB affected your relations with household members?

TB STIGMA

25. Did you feel that people acted nervously around you when you had TB? Probe: Who? Why? An example of this?

26. Did you think that people felt pity for you when you had TB? Probe: in what way (how did you recognise this?)? Who? Why? Example?

27. Did people try to stay away from you when you had TB? Probe: in what way (how did you recognise this?)? Who? Why? Example?

28. Did you feel isolated when you had TB? Probe for physical isolation (with examples) and social isolation (with examples) and emotional isolation (with examples)

29. Did people think it was your own fault that you developed TB?

30. Did you think it was your own fault that you developed TB?

31. Did you feel ashamed about having TB?

32. Did people feel angry towards you when you had TB? Probe: Who? Why? An example of this?

33. Did people gossip about you when you had TB? Please give examples.

34. Did people talk badly about you to your face when you had TB? Please give examples.

35. Since falling ill with TB, have you experienced any direct discrimination because of your TB? For example, losing a job, being thrown out of a house, being excluded from church/market/school/social events, divorce/separation

36. In your opinion, is TB stigmatised? What can you and others do about reducing TB stigma?

SUPPORT

37. Who did you shared your TB diagnosis with:
1. Inside the household?
2. Outside the household?

3. What kind of support did you get from your family (*Probe: emotional, financial, practical*)?

4. When you had TB, was there a time when you felt very sick and unable to take care of yourself?

5. Who in the household helped you when you had TB – accompanied to the health centre, household member fetch medication for you, and preparation of food, personal hygiene? *Probe for identity of primary caregiver.*

6. Outside the household where did you get support when you had TB?

TB TREATMENT AND FOOD CONSUMPTION

7. Did you have any problems taking your TB medication?

8. Is it true that TB medication makes you hungry?

9. How is the hunger linked to TB medication different from the hunger you had felt before you had TB?

10. Were you able to get food every time you felt hungry whilst on TB medication? Please explain how you managed to get food.

1. Use cash savings to buy food
2. Defer payment for other household needs (what)
3. Sell household assets
4. Borrow money to buy food (from whom)
5. Borrow food from the local shop (credit)
6. Receive remittances (in cash or kind – from whom. If in kind what was received)
7. Sustain hunger

8. What kinds of food were you told to eat or not to eat because of your TB illness? By whom?

9. When you had TB, if you asked for special foods, how did others in the household react?

10.
11. **TB/HIV CO-INFECTION**
12.
13. Have you been tested for HIV?
14. Would you mind telling me your result?
15. If HIV-negative, did you worry that you might have HIV when you were diagnosed with TB?
16. If HIV-positive, would you mind telling me about having HIV and TB at the same time?
17. *Probe: If co-infected with HIV, how does TB compare to HIV? How long have you known you had HIV? Are you on ART? If on ART, how did it feel taking two types of medication at once?*
18.
19. Do people in the community link TB to HIV?
20.
21. Which is worse in your experience – TB stigma or HIV stigma? Has this changed over time?
22.
23.
24. **CLOSING QUESTIONS**
25.
26. How do you feel about your own future at the moment?
27.

28. Thinking back to 2014 and thinking about this community and TB in this community, do you think TB is now better or worse than it used to be in 2014?
29.
30. If you had to improve the situation of people like you (who have had TB before), what would you do? *Probe: food security, clinic services, stigma reduction*, *emotional support, housing type*

31. Finally, what do you think is the role of volunteers (like CHiPs or TB treatment supporters) for TB patients? Do you think we need them to do this work on TB?

We have now finished our discussion. Now, are there any questions you would like to ask us? Thank you very much for participating. We really value your time and the information and experiences you have shared with us.

Appendix 3d: TB patient IDI -Activity Report Form

ACTIVITY REPORT FORM – IDI TB Patient

Research Assistant & Community Mobiliser:

Name of activity:

Place conducted (community, venue):

TB Patient Profile (CHiPs identified/clinic identified, gender, age):

Date:

Materials and tools used:

Process:

Key findings: [Provide a detailed summary before transcribing]

1. How did the interview go? Was the respondent open or cautious with their answers? Did they mind talking about their experience of having TB?

2. What did you learn from them about transmission of TB?

3. What did you learn from them about TB treatment seeking?

4. What did you learn from them about TB treatment?

5. What did you learn from them about the impact of TB on their lives? This should include mental health issues.

6. What was their experience of TB stigma?

7. What did you learn about food consumption during TB treatment?

8. Did you think, from what they told you, that they were well supported during TB treatment?

9. What ideas did they have about support for TB patients?

10. Is there anything else you would like to add?

Appendix 3e: Stakeholder invitation letter

P. O. Box 50697
Lusaka, ZAMBIA
Tel/Fax: +260 211 254 710
Email: info@zambart.org.zm

18 September 2018.

Dear TB Stakeholder,

REF: Invitation to a stakeholder meeting-TREATS STUDY ZAMBART

Zambart is conducting a study called TREATS which is looking at the impact of the PopART intervention on TB incidence. The stakeholder meeting is one of the qualitative activities being conducted under TREATS. The aim of this meeting is to broaden our understanding of how PopART affected the provision and management of health services for people living with TB in this community.

In this regard, we would like to request for your participation to the Stakeholder meeting (Focus Group Discussion) together with other stakeholders dealing with TB in this community.

The objectives of this discussion include;

1. Describing the popular understandings of TB among stakeholders in PopART communities,
2. Exploring perceptions of TB treatment and care from stakeholders' perspectives,
3. Understanding the interaction between the stakeholders involved in TB treatment in this community and the potential interactions between stakeholders and the TREATS study.

The meeting will be held at the local health facility on the 19th of September, 2018, at 14:00. Transport refund of ZMK50 and refreshments will be provided.
We are very appreciative of your support as your participation in this study will contribute to our understanding of TB in the community.

Yours sincerely,

Tila Mainga (TREATS Social Scientist)

For any questions please contact, Gracious Witola (Social Science Research Assistant)

Cell: 0976 604711

Appendix 3f: Stakeholder Focus Discussion Guide

Tuberculosis (TB) reduction through expanding antiretroviral therapy for Tuberculosis screening (TREATS)

Stakeholder Focus Discussion Guide

Purpose: To describe the impact of PopART on the provision of health services for people living with TB. (Please note that this guide can also be used as interview guide for stakeholders who missed the discussion. This discussion should build on the NHC discussion.)

Objectives:

4. To describe popular understandings of TB among stakeholders in PopART communities.
5. To describe the strategies and processes supporting implementation of TB-related services in the communities.
6. To explore perceptions of TB treatment and care from stakeholders' perspectives.
7. To describe the influence of TB-stigma on the uptake and adherence to TB treatment from a stakeholders 'perspective.
8. To explore the interaction between the stakeholders and the potential interactions between stakeholder and the TREATS study.

Materials needed: Flip chart paper, crayons, markers, pencils, note book, audio recorder, informed consent forms, community map, list of stakeholders, audio-recorder, activity report form, participant detail sheet, and participant numbers

Logistical requirements:
1. Arrange meeting time and venue.
2. Invite all the stakeholders through contacting them directly.
3. Purchase snacks and drinks beforehand.

Data recording, entry and storage:
4. Field notes kept by community mobiliser and summary of the meeting transferred to an ACTIVITY REPORT FORM by social science RA.
5. Photo (on phone, downloaded) of timeline of TB and organisations
6. All cards and flipchart paper and marked maps
7. Recording of main discussion to be transcribed and entered into MS word.
8. Maps, recordings and flipchart data to be stored in a secure place in Zambart office.

Outcomes:
9. An up-to-date overview of the recent history of TB stakeholders
10. An overview of TB hotspots, and opinions about TB stigma and mental health linked to TB

The social science research assistant facilitates the meeting while the community mobiliser makes notes of the conversation.

Introduction:

1. The RA welcomes and thanks everyone for attending.
2. Explains the purpose of the meeting
3. Clarifies that attendance at the meeting is voluntary. Drinks and snacks will be provided.
4. The meeting should last between one and two hours depending on the discussion.
5. Fill in participant details and demographics (Include the names of the organisations but not the names of the people representing the organisations)
6. Each Stakeholder to take note of the number they are assigned.
7. Administer the FGD informed consent from – continue once complete.

May I remind you that we are audio recording this discussion and ask that you speak loudly and clearly. We will also be taking some notes. Do you have any questions before we begin?

INTRODUCTION

We have selected all of you to represent your community because of the role you play related to provision of TB services. We ask you to be free to share as much as you can during the discussion/ meeting.

Activity: Stakeholder Profile

Open the meeting with a short 'presentation' on what TREATS is and allow for time to respond to questions the stakeholders may have.

Variable	Task	Objective
Name	1. Distribute plain coloured cards (half of A4 size) to each stakeholder participant.	Identify stakeholders
	2. Ask them to write the name of the organization they are representing on top of the paper.	
	3. Below it ask them to write the year they started working in the PopART community.	
	4. Ask them to write the number they have been assigned in the 'participant details and demographics table' on the top right corner of the paper. Tell them they will have to write this number on every paper going forward.	

Period	1.	Collect the papers from the participants and stick them on a wall according to the year they started working in the community.	Period service delivery
Involvement	2.	Give them A4 size paper to write/list the activities or services they provide in bullet form. (All activities)	Whether TB service delivery is primary objective
	3.	Collect the papers and stick them below the earlier paper with the name of stakeholder and the year	
Interest	1.	Ask them to list TB activities or services they provide in the community, or what they do to assist their clients/patients' concern on TB (TB activities/services only).	Whether TB service delivery is secondary/tertiary objective
	2.	After they list down, collect the papers and place them under the organisations' names on the wall.	
	3.	Ask them how it is to work in this community. Challenges? Rewards?	
	4.	In their opinion, what activities for TB patients worked well? What did not work well?	
Influence	1.	Ask them if they work together with other organizations in any way on TB related activities (should write this on separate A4 papers. Let your co-facilitator stick the papers on the wall so that you, 1) continue with facilitation 2) remain audible for the recording).	Influence of stakeholder on TB service delivery in the community.
	2.	Ask them if they at all worked or collaborated with the CHiPs on TB activities. (Arm A only).	
	3.	If any of the stakeholders did, ask them to list the role they played with the CHiPs (should write this on separate paper). (Arm A only).	
	4.	Looking at the timeline of TB activities that has been built together, is anything missing?	
	5.	What happened with TB before 2014?	
	6.	What has happened with TB since the beginning of 2018?	

	7.	Reflecting on what we have built together about the history of TB, is the management of TB now better or worse than in 2014?	
	8.	In all communities, ask if PopART activities increased the number of people diagnosed and treated for TB at the local health facility?	
	9.	In their opinion, what initiatives at the health facility have improved TB services?	
	10.	Ask them to write about how they think TREATS will influence their work; positive/negative?	
	11.	List other stakeholders not present. (Review list)	
Alignment	1.	Ask them to explain the groups, age, gender, and areas they work with/ from in the community.	Groups targeted and not targeted
	2.	How do you prioritise which groups to work with and target for TB?	
	3.	What do people say when they don't want to screen for TB?	
TB Stigma	4.	Has the way that people talk about TB in the community/ organization changed over the years? What did they used to say about TB? What do they say now? Are people living with TB more or less stigmatised now than they were in the past? What do you think has contributed to the change?	TB stigma
	5.	From what you know/ have seen, does the fear of being stigmatised stop people living with TB from seeking treatment/ care? Can this also delay diagnosis of TB? If TB was not stigmatized, would people get treatment sooner? Why? Do you know of people living with TB who are afraid to ask their friends and family for help? Can you give an example of this?	

Mental Health	1.	When people have TB, do they suffer from emotional difficulties? If so what kinds of emotional difficulties? For example, depression, anxiety, feelings of fear about the future, loss of self-esteem or other emotional difficulties. Does it differ for men or women? If younger or older? Can you tell a story of someone you know or saw had this problem?
	2.	Are there any forms of support for emotional difficulties related to TB? What are they? Who provides this support?

If it is not possible to gather all the required information for all the stakeholders, schedule specific meetings with the affected stakeholders as well as those that were not present that are important for TB. Adapt this guide for an in-depth interview.

We have now finished our discussion. Are there any questions you would like to ask us? Thank you very much for participating. We really value your time and the information and experiences you have shared with us.

Appendix 3g: Activity Report Form-Stakeholder Meeting

ACTIVITY REPORT FORM – Stakeholder MEETING

Research Assistant & Community Mobiliser:

Name of activity:

Place conducted (community, venue):

Date:

Materials and tools used:

Process:

Key findings: [Provide a detailed write up]

1. What has been learnt about TB and TB activities that the stakeholders provide in the community? How, why and where is TB thought to be spread? Where do people go for TB treatment? What treatment options are available for people with TB (both bio-medically and through other alternative therapies)? What is the history of TB in this place?

2. What has been learnt about TB stakeholders and how they work together, including the role of the local clinic and PopART?

3. What has been learnt about TB stigma?

4. What has been learnt about TB mental health?

5. Is there anything else you would like to add?

Appendix 3h: Neighbourhood Health Committee (NHC) MEETING

Neighbourhood Health Committee (NHC) MEETING

Purpose: To obtain **Neighbourhood Health Committee** (NHC) input on a map of the community and places of relevance to TB transmission and treatment within the community, and on a list of stakeholders involved in TB services.

Objective:

6. To draw an up-to-date map of the community
7. To identify places of relevance to TB transmission (TB hotspots)
8. To identify places of relevance to TB treatment and management
9. To review a list of TB stakeholders

Materials needed: Flip chart paper, crayons, markers, pencils, note book, audio recorder, informed consent forms, audio-recorder, activity report form, participant detail sheet, and participant numbers

Logistical requirements:

10. Arrange meeting time and venue. Members of the NHC may only be able to meet in the afternoon after work. The schedule is then to be adapted and transport arrangements made.
11. Purchase snacks and drinks beforehand.

Data recording, entry and storage:

12. Field notes kept by community mobiliser and summary of the meeting transferred to an ACTIVITY REPORT FORM by social science RA.
13. 3 Sheets of flipchart paper – list of places, list of treatment options, sketch map.
14. Recording of main discussion to be transcribed and entered into MS word.
15. Maps, recordings and free-lists stored in a secure place in Zambart office.

Outcomes:

16. An up-to-date map of the community to be photocopied onto A4 paper to share in other interviews and activities with participants
17. An overview of TB hotspots drawn on the map and TB treatment options, and opinions about TB stigma and mental health linked to TB
18. An updated list of TB stakeholders to use when inviting stakeholders for a stakeholder FGD.

The social science research assistant facilitates the meeting while the community mobiliser makes notes of the conversation.

Introduction:

19. The RA welcomes and thanks everyone for attending.
20. Explain the purpose of the meeting

21. Clarify that attendance at the meeting is voluntary. Drinks and snacks will be provided.
22. The meeting should last between one and two hours depending on the discussion.
23. Fill in participant details and demographics
24. Administer the FGD informed consent from – continue once complete.

Map of the community:

1. Ask the NHC to help draw up a map of their community (refer to a copy of an older map if helpful)
2. Either ask the committee to make a sketch map of the area on flipchart paper, providing a number of marker pens and encouraging all to participate. Make it clear that the map does not have to be perfect. If necessary, suggest that they begin with the main roads and boundaries. Encourage them to use whatever symbols and words they choose. Or, if a formal map exists, this can be taken along and the map sketched onto it once all have recognised and comprehended the existing map. It may be necessary to make corrections.
3. Ask the committee to indicate any significant socio-economic sub-divisions and boundaries within the community.

Gathering Places and TB hot-spots [through this discussion, refer to their map but do not mark on the map which is needed for future discussions]:

1. Asks the Committee to list or name the places in the community where people gather in groups and writes these down on flipchart paper.
2. Ask them to indicate in which of these places they believe that TB is commonly spread. Mark these with an asterisk.
3. Which places outside the community do they believe TB is coming from?
4. Ask them to list or name places or people that can be consulted for treatment of TB or its symptoms. Write this on a separate flipchart page.
5. Ask which are the most common or popular. Note next to each option.

TB Timeline:

1. Using a flipchart paper, with 2014, 2015, 2016, 2017, 2018 listed on a long line, ask them what TB activities have occurred during this period in the community and who was taking a lead in these activities. Probes: Activities should include health education, TB screening (sputum testing), TB treatment.
2. Ask them to think about the period BEFORE 2014. Were there any TB activities then? What were they? Who was implementing these activities? Probe for ZAMSTAR.
3. As them to think about this year. Are there any new TB activities since January 2018? What are they? Who was implementing them, where are they implemented
4. Ask them to reflect on whether the management of TB has improved or worsened over the years and in what way.

TB stakeholders:

1. Share with the NHC a printed list of HIV and adolescent stakeholders compiled for their community. Explain to them that we got this information from previous PopART social science work.

2. Ask them if we left out any stakeholders?
3. Ask them to identify which stakeholders are also involved in TB and note what they do.
4. Ask them to identify any stakeholders not on the list who work with TB and list these down.
5. Ask them what PopART did in their community with TB, and what their opinion is of the work PopART did. Probe about the role of CHiPs and how this compared to the role of TB treatment supporters in Arm A communities. Ask them if they think PopART would have reduced TB in their communities (ask in both Arms).
6. Ask them if any other organisations were providing TB screening in households in the community since 2014.

TB stigma:

1. Do you think TB is stigmatised as a disease? Could they explain how and why?
2. Since ARVs, has this TB stigma got worse or better?
3. Are there any specific places in the community that are stigmatising to people with TB?
4. Have there been any specific TB stigma reduction activities in the community? What were they? Who is implementing these activities

TB and mental health:

1. When people have TB, do they suffer from mental health problems? What kinds of problems? For example, depression or other emotional difficulties. Does it differ for men or women? If younger or older? Can you tell a story of someone you know or saw had this problem?
2. Are there any forms of support for mental health problems related to TB? What are they? Who provides this support?

Thank the committee for their time and contributions.

Appendix 3i: TREATS TB Prevalence Survey Questionnaire

Household Enumeration (TBPS Census) Register

Registration of all individuals who are member of the visited household in the blocks selected and enumerated for the TB prevalence survey

Date: ____ / ____ / _____ (dd/mm/yyyy)

Community Code: ☐☐ Household ID: ☐☐☐

Census zone nr: __ ☐☐ ☐☐ _____Block nr __ ☐☐ ☐☐ _____Plot / House No. _____ ☐☐ ☐☐ _____

GPS location _____(longitude)_____(latitude)

Household consent obtained for interview (from head of HH or his/her representative) yes/no

Results first visit Completed(1), No household members present (2), no competent respondent at home at time of visit (3), Entire household absent for extended period of time (4), Refused (5), Dwelling vacant (6); Other (96)

(if first visit not completed add result for 2nd and 3rd visit)

		DATA COLLECTED DURING CENSUS (List all members of the household – all ages)												
Subject ID	First name	Surname	Age	Sex	Head of Household	Marital statues	Occupation	Highest level of Education completed	resident	Length residency	Present at visit number.	Eligible for TBPS (≥ 15 yrs & resident)	Consent provided	Remarks (reasons for non-consent etc.)
			(In Years)	M/F	Y/N	(Category code) Select 1-4	(Category code) Select 1-9	(Category code) Select 1-6	Y/N	1: <=1 yrs 2: 1-5n yrs 3: 5-10 yrs 4: >10 yrs	indicate visit nr (1st or follow up)	Y/N	Y/N	(e.g. reasons non-consent and other remarks

Marital status

1. Never married
2. Currently married or living as married
3. Divorced or separated
4. Widowed

Main Occupation

1. Unemployed
2. Occasional/seasonal employment
3. Employed by government
4. Employed in private sector
5. Self-employed
6. Pupil / student
7. Housewife / homemaker
8. Working on own land
9. Other (Specify – Max. 25 characters) _____

Highest level of Education completed

1. None
2. Primary school grade – if ticked, fill actual grade
3. Secondary school grade – if ticked, fill actual grade
4. Higher education - if ticked, fill details, i.e. Masters, Diploma, College, University, Trades, other (specify) etc.

Household assessment of SE status

This section is asked once per HH, to be administered to the head of the HH or his her representative at the time of visit (i.e. responsible adult member)

1. Which of the following best describes the <u>main type of building</u> that this household occupies?
Variable: **ECBUILD**

- ☐ **Single unit/brick structure on its own plot = 1**
- ☐ **Cluster/multi-unit/'mudadada" – living in a single/multiple room(s) that is/are part of a larger structure / 2**
- ☐ **Traditional hut/structure made from traditional material = 3**
- ☐ **Flat in block of flats = 4**
- ☐ **Servant quarters = 5**
- ☐ **Caravan/tent = 6**
- ☐ **hostel = 7 (Worker's/college/school/nurses)**
- ☐ **Shack (SA for backyard dwellers) = 8**
- ☐ **Other = 9, specify……**
- ☐ **No Answer = 99**

2. What is the main type of flooring for this household?
Variable: **ECFLOOR)**

- ☐ **Dirt/earth = 1**
- ☐ **Wood/plank = 2**
- ☐ **Parquet = 3**
- ☐ **Lino = 4**
- ☐ **Cement = 5**
- ☐ **Tile = 6**
- ☐ **Other = 7, specify……**
- ☐ **No Answer = 99**

3. A How many rooms does this housing unit have?(living and sleeping rooms)
(*Variable:* ECROOM)

- ☐ The picture can't be displayed. **rooms**
- ☐ **No Answer = 99**

3 B In how many rooms are people sleeping?

(*Variable:* ECROOMSLEEP)

 **rooms**

No Answer = 99

Notes for DD:

Display Edit Message when ECROOM < 1: Value must be between 1 and 20.

Display Edit Message when ECROOM > 20: Value must be between 1 and 20.

Display Edit Message when ECROOM is not Numeric: Value entered must be numeric.

4. What is the main source of drinking water for this household?

***Variable:* ECWATER**

Piped indoors = 1

Stand pipe/tap within plot = 2

Communal tap = 3

Borehole = 4

Protected well = 5

Unprotected/shallow well river/dam/lake/pan = 6

Bowser/tanker = 7

Other = 8, specify……

No Answer = 99

5. What is the main source of energy used for cooking?

***Variable:* ECENERGY**

No cooking done in household = 1

Electricity (mains) = 2

Electricity (individual solar) = 3

Gas = 4

Paraffin = 5

Charcoal = 6

Wood = 7

Other = 8, specify……

No Answer = 99

6. What is the main toilet facility used in your household?

***Variable:* ECTOILET**

Own flush toilet = 1

Shared flush toilet = 2

Own pit latrine = 3

Shared pit latrine = 4

☐ **Own VIP latrine = 5**
☐ **Shared VIP latrine = 6**
☐ **Pail/bucket = 7**
☐ **Communal chemical latrine = 8**
☐ **Bush = 9**
☐ **Other = 10, specify……**
☐ **No Answer = 99**

Read to Participant: I will now ask you some questions about the source of your household's income, household spending and food. Do you have any questions before we begin?

7. Does any member of your household have access to the following items in good working order?
Variable: **ECITEM0 - (*check all that apply*)**
None (*Variable:* ECITEM0) **If "None," other responses can't be checked**

1. Working Cellphone (*Variable:* ECITEM1)
2. Bicycle (*Variable:* ECITEM2)
3. Motorcycle or scooter (*Variable:* ECITEM3)
4. Car/bakkie (*Variable:* ECITEM4)
5. Electricity to house (*Variable:* ECITEM5)
6. TV (*Variable:* ECITEM6)
7. Fridge/freezer (*Variable:* ECITEM7)
8. Radio (*Variable:* ECITEM8)
9. Computer/Laptop (*Variable:* ECITEM9)
10. CD or MP3 player (*Variable:* ECITEM10)
11. Stereo/cassette /other music player (*Variable:* ECITEM11)
12. Working internet (*Variable:* ECITEM12)
13. No Answer = 99 (*Variable:* ECITEMNR)

14. What is the main source of income for this household?
Variable: **ECINCOME**
☐ **Regular employment (salary) = 1**
☐ **Farming = 2**
☐ **Trading = 3**
☐ **Fishing = 4**
☐ **Commercial sex work = 5**
☐ **Transportation = 6**
☐ **Artisan = 7**

☐ **Government grant = 8**
☐ **Casual work ("piecework") = 10**
☐ **Other = 9, specify……**
☐ **No Answer = 99**

15. Do you or anyone in your household receive any government grants?
Variable: **ECGRANT**

☐ **Yes = 1** **go to ECCHILDNUM (question 10)**
☐ **No = 2** **go to ECFSMON (question 11)**
☐ **No Answer = 99**

SHOW IF ECGRANT = 1

16. **Which type of grants are being received by your HH (or a member thereof)**

Note: tick all the apply, Coding: 1 for yes (thick) and 0 for no (not thick)

For South Africa:

1. **Child support (*variable* ECCHILDNUM): yes/no**
2. **Old age pension (*variable* ECPENSNUM) : yes/no**
3. **Foster care(*variable* ECFOSTNUM) : yes/no**
4. **Disability (disability dependency) (*variable* ECDISNUM) : yes/no**
5. **Other, specify…… (*variable* ECOTHNUM) : yes/no**
6. **No Answer (*variable ECNoAnsw)***

For Zambia

7. **social cash transfer grant /social welfare grant (government) (*variable ECCTFSWGNU)* : yes/no**
8. **Other , specify…… (variable ECOTHNUM) : yes/no**
9. **No Answer (variable ECNoAnsw)**

10. **During the last 12 months, how many months were there when your household did not have enough food to eat?**

Variable: **ECFSMON**

The picture can't be displayed. **months**

No Answer = 99

Display Edit Message when ECFSMON is not Numeric: Value entered must be numeric.

Display Edit Message when ECFSMON > 12: Value must be between 0 and 12.

11. **In the last 12 months, did your household receive relief food or free food (food packages) from government or other groups?**

Variable: **ECRELIEF**

Yes = 1

No = 2

Don't Know = 98

No Answer = 99

12. **Over the last 12 months, did your household have to reduce the number of meals or food intake, because you did not have enough food? *Variable:* ECMEALS**

1

2

3

1. Don't Know = 98

2. No Answer = 99

3. In the last 12 months, did your household have to eat food you would not ordinarily eat for meals, because of food shortage or lack of money?

Variable: ECSHORT

- ☐ **Yes = 1**
- ☐ **No = 2**
- ☐ **Don't Know = 98**
- ☐ **No Answer = 99**

4. In the last 12 months, did your household have to reduce spending on other household items (e.g. soap, tissues), because of lack of money?

***Variable:* ECHHITEM**

- ☐ **Yes = 1**
- ☐ **No = 2**
- ☐ **Don't Know = 98**
- ☐ **No Answer = 99**

5. In the last 12 months, did your household have to borrow cash (kaloba, borrowing from friends) because of lack of money?

***Variable:* ECBOR**

- ☐ **Yes = 1**
- ☐ **No = 2**
- ☐ **Don't Know = 98**
- ☐ **No Answer = 99**

6. In the last 12 months, did your household have to sell belongings, because of lack of money?

***Variable:* ECBELONG**

- ☐ **Yes = 1**
- ☐ **No = 2**
- ☐ **Don't Know = 98**
- ☐ **No Answer = 99**

7. In the last 12 months, did your household have to send household members away because you were short of money?

***Variable:* ECAWAY**

- ☐ **Yes = 1**
- ☐ **No = 2**

Don't Know = 98

1. **No Answer = 99**

Individual questionnaire - screening, health seeking behavior and risk factors

Note: Asked to all participants at the survey site (station screening)

BARCODE ☐☐-☐☐☐-☐☐

Date: ____ / ____ / _____

I would like to ask about any health problems you may be experiencing.

1a. Do you have a cough?

1 . ☐ Yes (Go to 1b)

2 . ☐ No (Go to 2)

1b. If yes, for how many weeks did you have this cough? _____weeks

2a. Do you have fever?

1. ☐ Yes (Go to 2b)

2. ☐ No (Go to 3)

2b. If yes, for how many weeks did you have this fever? _____weeks

3a. Do you have chest pain?

1. ☐ Yes (Go to 3b)

2. ☐ No (Go to 4)

3b If yes, for how many weeks have you had chest pains? _____weeks

4a. Do you have night sweats?

1. ☐ Yes (Go to 4b)

2. ☐ No (Go to 5)

4b. If yes, for how many weeks did you have these night sweats? _____weeks

5a. Do you have weight loss (unexplained)?

1. ☐ Yes (Go to 5b)
2. ☐ No (Go to 6)

5b. For how many weeks did you have this weight loss? _____weeks

6. Do you currently have any other symptoms besides those just asked? IF YES, for how long?

Symptom	**Duration (weeks)`**	**remarks**

Individual questionnaire - health seeking behavior section

Note: Questions (7-9) are to be asked to participants that report any symptoms as per questions 1-5 (cough, fever, chest pain, night sweats, weight loss) irrespective of duration. I should be noted that any other symptoms reported in Q6 are not to be taken into account….

1. **Thinking about the symptoms you are currently having (cough/fever,/chest pain/night sweats/weight loss) as just indicated :, Did you consult with someone for help?**

Yes No no answer/unknown

(If yes continue to question 8, if no(not sought help) go to question 10)

2. **Thinking back to when you first fell ill/had symptoms, could you please share with us where you went for help at first, and then after that where you went, until you reached the point you are at now? (one or more answers)**

First ask in general than probe for all other options (tick in the right column where person went first, second and thereafter to seek care (visualize the care seeking pathway), Once ticked the system should prompt to fill the actual number of weeks ago the person visited this provider

	Care provider	*First*	*Second*	*Third*	*Fourth*	*Fifth*	*Sixth*
1.	Family/Friends						
2.	Local shop/market stall/Ntemba						
3.	Traditional Healer						
4.	Community Health Worker/CHiPs						
5.	Pharmacy						
6.	Clinic or Community Health Centre (i.e. nearest government health facility)						
7.	Private medical doctor						
8.	Hospital (central, provincial etc)						
9.	Private clinic/hospital						
10.	Other, please specify						

9.1 Did someone ask you to give a sputum sample?

(If Yes, continue. If No or Unknown go to Q9.6) Yes No Unknown

1. If yes, who asked you to provide a sputum sample?

1 CHW/CHiPs
2 Pharmacy
3 Clinic or Community Health Centre (i.e. nearest government health facility)
4 Private medical doctor
5 Hospital (central, provincial etc)
6 Private clinic/hospital
7 Other, please specify

2. Did you provide a sputum sample? Yes No Unknown

(If Yes, continue. If No go to Q9.5, If Unknown go toQ9.6)

3. Did you get the results and if yes are you willing to tell us? (after go to 9.6)

1 No did not get results
2 Yes got results not willing to disclose
3 Yes, it was Positive for TB
4 Yes, it was Negative for TB
5 Awaiting result
6 Unknown

4. If you did not give a sputum sample, why not?

1 Could not produce sputum
2 No money for transport to health centre/clinic
3 Did not consider it important
4 No sputum container
5 No time to go
6 Other, specify

5. Did someone ask you to go for a chest x-ray?

Yes No Unknown

(If Yes, continue. If No or Unknown, go to Q9.9)

6. If yes, did you have a chest x-ray?
(If No, continue. If Yes/Unknown go to Q 9.9)

7. If you did not have a chest x-ray, why not? (give the main reason, only 1 answer!)

1 No money for transport to hospital
2 Did not consider it important
3 No money for chest x-ray
4 No time to go
5 Other, specify

8. Were you given any medicine?
(Hereafter go the Q11)
Yes No Unknown

10. If you did not seek help for your current symptoms why not? ***(Note: this question is answered when the answer to question 7 is No).***

1 No money for transport to health centre/hospital
2 Did not consider it important
3 Already on treatment
4 Other, specify

Go to next section

Individual questionnaire – Previous & Current TB treatment section

Note: Asked to all participants at the survey site (station screening)

Q 11. Read to Participant:
I will now ask you some questions about tuberculosis testing and treatment. Do you have any questions before we begin?

Q11.1 **Have you EVER been treated for Tuberculosis/TB?** *Variable:* **TBTOLD**

☐ Yes (1) (***continue to TBCURRENT***)
☐ No (2) (***continue to TBCURRENT***)
☐ Don't know (3)

Q11.2a **Are you CURRENTLY on TB treatment?** *Variable:* **TBCURRENT**

☐ Yes (1)

☐ No (2) (go to TBIPT (qstn 11.7))

☐ Don't know (3)

Q11.2.b **Was any of the treatment (current or past) for drug resistant TB?** *Variable:* **TBMDR**

☐ Yes (1)

☐ No (2)

☐ Don't know (3)

Q11.3 In which health care facility are/were you treated for TB? (please ask to provide details for the most recent episode of TB -if more than one occurred); Variable: **TBHF**

Name and type (i.e. hospital/health facility etc):

_____

Area/Region (different list to be added for SA and Zambia):

Q11.4 **When was your TB treatment?** *Variable:* **TBtiming**

☐ ≤ 12m ago (1)

☐ >12 months ago but ≤ 2 years ago (2)

☐ > 2 years ago (3)

☐ Don't know (98)

1. No answer (99)

Q11.5 Do you recall the exact dates from which you have you received TB treatment? Yes/ no

If yes please fill details on dates:

Date start treatment: _____ *(day/month/year) Variable:* **TBSTART**

*End date treatment:*_____ *(day/month/year)*

or tick box ☐ *if still on treatment Variable:* **TBEND**

Q11.6 Do you have your TB number? *Yes/ no (Variable:* **TBNUM)**

If yes please fill details on dates:

Record Number from card = 1 
TB Card Number not available = 2
Did not agree to provide TB number = 3
No Answer = 99
Display Edit Message when TBNUM is 1(Record number preferably from card): Check Record Number before entering value.

Q11.7 Have you ever/are you currently taking isoniazid preventive treatment to prevent TB?
***Variable:* TBIPT**
Yes, current= 1
Yes, completed= 2 (ASK HOW LONG AGO… MONTH/YEAR)
No = 3
Don't Know = 98
No Answer = 99

Q11.8 Has anybody in your household been treated for TB in the past or is currently on TB treatment? Variable: **TBHH**

☐ Yes, current (1)

☐ Yes, in the past (2)

☐ No (3), go to Q12

☐ Do not know (98), go to HFtransport (Q12)

☐ No Answer = 99, go to HFtransport (Q12)

Q11.9 How long ago has the most recent TB patient in your household started TB treatment?

(Variable: **TBHHtime)**

_____*(months), tick box* ☐ *if >12 months and fill as number of years…*

(note for data dictionary: add options

Don't Know = 98
No Answer = 99)

Q12 What type of transport do you mainly use to visit the nearest health facility?

(*Variable:* **HFtransport)**

☐ walk (1)

☐ bicycle (2)

☐ motorbike (3)

☐ private car/taxi (4)

☐ tractor / truck (5)

☐ cattle cart (6)

☐ bus (7)

☐ other, specify_____ (8)

Q13 How long would it take to reach the nearest health facility using this means?

(*Variable:* **HFtime)**

☐ <30min (1)

☐ 30-60min (2)

☐ 1-2hrs (3)

☐ >2 hrs (4)

Q14 When waiting at the health facility to be seen, how long do you mostly have to wait before being seen? *Variable:* **HFwait** ☐ Less than 1 hour (1)

☐ 1 to 2 hours (2)

☐ 3- 4 hours (3)

☐ >5 hours / full day (4)

Section Experience with POPART intervention –

Questions 15 & 16 to be asked for ARM A communities only, Question 17 for both Arm A and C communities

1. Did a CHiPs Team ever visit your household? (*Note: describe CHiPs uniform or show picture*)

***Variable:* HHCHIPS**

Yes = 1
No= 2
Don't Know = 3
Not Sure = 4
No Answer = 99

2. Did you ever participate in the PopART intervention (*e.g. explain as received health counselling from CHiPs*)

Yes = 1
No= 2
Don't Know = 3
Not Sure = 4
No Answer = 99

3. **Did you participate in the PopART Population Cohort study.**

Yes = 1
No= 2
Don't Know = 3
Not Sure = 4
No Answer = 99

Section RISK FACTORs

Note: To be asked to all participants at the survey site (station screening)

I would like to ask you some question about habits and other characteristics

1. Do you belong to any of the following groups (multiple answers can be given): (variable: RISKGROUP)

1. Miner ☐
2. Ex-miner ☐
3. Current HCW ☐
4. Former HCW ☐
5. Living in a congregate setting
   1. Ex-Prisoner ☐
   2. Factory worker ☐
   3. Migrant worker ☐
   4. *Seasonal worker* ☐

Smoking (Please tick one response only)

2. Do you currently smoke tobacco (cigarettes, others?) :

   4.1. Daily ☐ 4.2. Less than daily ☐ 4.3. Not at all ☐

   (if not at all continue to Q 28, if daily or less than daily go to Q29)

3. Have you smoked tobacco in the past? (**if yes continue if no go to question RFQ6**)

   yes ☐ no ☐

4. In the past, have you smoked tobacco on a daily basis, less than daily? *Note: If respondent has done both "daily" and "less than daily" in the past then respond 'Daily'*.

1. Daily 2. Less than daily

2. How long has it been since you last smoked **daily**? (mention in years)

3. How old were you when you first started smoking tobacco? (mention in years)

4. Do you currently use smokeless tobacco (including, for example, spit or chewing tobacco) on a daily basis, less than daily, or not at all?

   1. Daily 2. Less than daily 3. Not at all

Alcohol use (Please tick one response only)

Read questions as written. Record answers carefully. Begin the AUDIT by saying "Now I am going to ask
you some questions about your use of alcoholic beverages during this past year." Explain what is meant
by "alcoholic beverages" by using local examples of beer, wine, vodka, etc. Code answers in terms of
"standard drinks". Place the correct answer number in the box at the right.

Read to Participant:
I will now ask you questions about drinking alcohol and drug use. I know these questions are sensitive and want to remind you that your answers are completely confidential. This means that they will not be shared with anyone outside of the study team. No one will know what particular answers you give. If we should come to any questions that you don't want to answer, just let me know and we will go on to the next one. Do you have any questions before we begin?"

5. How often do you have a drink containing alcohol?
Row 312 (*SASname*: ACFREQ), AUDIT Q1
If value is null or ='No Answer' assign value as '.M' (Missing)

☐ **Never = 0**	**go to ACINJURE (q52)**
☐ **Monthly or less = 1**	**go to ACNUM (q45), ACMORE (q46)**
☐ **2 to 4 times a month = 2**	**go to ACNUM (q45), ACMORE (q46)**
☐ **2 to 3 times a week = 3**	**go to ACNUM (q45), ACMORE (q46)**
☐ **4 or more times a week = 4**	**go to ACNUM (q45), ACMORE (q46)**
☐ **No Answer**	**go to ACNUM (q45), ACMORE (q46)**

6. How many drinks containing alcohol do you have on a typical day when you are drinking?
Row 313 (*SASname*: ACNUM), AUDIT Q2
If ACFREQ<>'Never' and value is null or ='No Answer' assign value as '.M' (Missing)
If ACFREQ='Never' assign value as '.S' (Skipped)

☐ **1 or 2 = 0**	**go to ACMORE (q46)**
☐ **3 or 4 = 1**	**go to ACSTOP (q47) – ACFORGET (q51)**
☐ **5 or 6 = 2**	**go to ACSTOP (q47) – ACFORGET (q51)**
☐ **7, 8, or 9 = 3**	**go to ACSTOP (q47) – ACFORGET (q51)**
☐ **10 or more = 4**	**go to ACSTOP (q47) – ACFORGET (q51)**
☐ **No Answer**	**go to ACSTOP (q47) – ACFORGET (q51)**

7. How often do you have six or more drinks on one occasion?
Row 314 (*SASname*: ACMORE), AUDIT Q3
If ACFREQ<>'Never' and value is null or ='No Answer' assign value as '.M' (Missing)
If ACFREQ='Never' assign value as '.S' (Skipped)

☐ **Never = 0**	**go to ACINJURE (q52)**
☐ **Less than monthly = 1**	**go to ACSTOP (q47) – ACFORGET (q51)**
☐ **Monthly = 2**	**go to ACSTOP (q47) – ACFORGET (q51)**
☐ **Weekly = 3**	**go to ACSTOP (q47) – ACFORGET (q51)**
☐ **Daily or almost daily = 4**	**go to ACSTOP (q47) – ACFORGET (q51)**

☐ **No Answer** **go to ACSTOP (q47) – ACFORGET (q51)**

8. **How often during the last 12 months have you found that you were not able to stop drinking once you had started?**

Row 315 (*SASname*: ACSTOP), AUDIT Q4

If ACFREQ<>'Never', ACNUM<>'1' or '2', and ACMORE<>'Never', and value is null or ='No Answer' assign value as '.M' (Missing)
If ACNUM='1' or '2' assign value as '.S' (Skipped)
If ACMORE='Never' assign value as '.S' (Skipped)
If ACFREQ='Never' assign value as '.S (Skipped)

☐ **Never = 0**
☐ **Less than monthly = 1**
☐ **Monthly = 2**
☐ **Weekly = 3**
☐ **Daily or almost daily = 4**
☐ **No Answer**

9. **How often during the last 12 months have you failed to do what was normally expected from you because of drinking?**

Row 316 (*SASname*: ACFAIL), AUDIT Q5

If ACFREQ<>'Never', ACNUM<>'1' or '2', and ACMORE<>'Never', and value is null or ='No Answer' assign value as '.M' (Missing)
If ACNUM='1' or '2' assign value as '.S' (Skipped)
If ACMORE='Never' assign value as '.S' (Skipped)
If ACFREQ='Never' assign value as '.S' (Skipped)

☐ **Never = 0**
☐ **Less than monthly = 1**
☐ **Monthly = 2**
☐ **Weekly = 3**
☐ **Daily or almost daily = 4**
☐ **No Answer**

10. **How often during the last 12 months have you needed a first drink in the morning to get yourself going after a heavy drinking session?**

Row 317 (*SASname*: ACMORN), AUDIT Q6

If ACFREQ<>'Never', ACNUM<>'1' or '2', and ACMORE<>'Never', and value is null or ='No Answer' assign value as '.M' (Missing)
If ACNUM='1' or '2' assign value as '.S' (Skipped)
If ACMORE='Never' assign value as '.S' (Skipped)
If ACFREQ='Never' assign value as '.S' (Skipped)

☐ **Never = 0**
☐ **Less than monthly = 1**
☐ **Monthly = 2**
☐ **Weekly = 3**
☐ **Daily or almost daily = 4**
☐ **No Answer**

How often during the last 12 months have you had a feeling of guilt or remorse after drinking?

Row 318 (*SASname*: ACREMORS), AUDIT Q7
If ACFREQ<>'Never', ACNUM<>'1' or '2', and ACMORE<>'Never', and value is null or ='No Answer' assign value as '.M' (Missing)
If ACNUM='1' or '2' assign value as '.S' (Skipped)
If ACMORE='Never' assign value as '.S' (Skipped)
If ACFREQ='Never' assign value as '.S' (Skipped)

 **Never = 0**
 **Less than monthly = 1**
 **Monthly = 2**
 **Weekly = 3**
 **Daily or almost daily = 4**
 **No Answer**

11. **How often during the last 12 months have you been unable to remember what happened the night before because you had been drinking?**

Row 319 (*SASname*: ACFORGET), AUDIT Q8
If ACFREQ<>'Never', ACNUM<>'1' or '2', and ACMORE<>'Never', and value is null or ='No Answer' assign value as '.M' (Missing)
If ACNUM='1' or '2' assign value as '.S' (Skipped)
If ACMORE='Never' assign value as '.S' (Skipped)
If ACFREQ='Never' assign value as '.S' (Skipped)

 **Never = 0**
 **Less than monthly = 1**
 **Monthly = 2**
 **Weekly = 3**
 **Daily or almost daily = 4**
 **No Answer**

12. **Have you or someone else been injured as a result of your drinking?**

Row 320 (*SASname*: ACINJURE), AUDIT Q9
If value is null or ='No Answer' assign value as '.M' (Missing)

 **No = 0**
 **Yes, but not in the last year = 2**
 **Yes, during the last year = 4**
 **No Answer**

13. **Has a relative or friend or a doctor or another health worker been concerned about your drinking or suggested you cut down?**

Row 321 (*SASname*: ACCONC), AUDIT Q10
If value is null or ='No Answer' assign value as '.M' (Missing)

 **No = 0**
 **Yes, but not in the last year = 2**
 **Yes, during the last year = 4**
 **No Answer**

THE FOLLOWING QUESTIONS (section H-I) are to be asked to a random subset of 10% of the participants – this part can be integrated in the individual questionnaire at the screening station)

Section TB STIGMA

Note: Asked to all participants at the survey site (station screening)

1. Community perspectives toward TB

Now we would like you to think about the community where you live. I will read you 9 different statements. Could you for each of them judge how much you agree or disagree with these statement, i..e whether you strongly disagree, disagree, agree or strongly agree for each of the statements I will read. Do you have any questions before we start?

Statements/Response categories:	Strongly disagree /Not at all	Disagree/Not much	Agree/quite a bit	Strongly agree/ a lot
1. How nervous are you around TB patients?	Never	Occasionally	Usually	All the time
2. How much pity do you feel for TB patients?	Never	Occasionally	Usually	All the time
3. How likely are you to help a TB patient?	Never	Occasionally	Usually	All the time
4. I would try to stay away from a TB patient	Strongly disagree	Disagree	Agree	Strongly agree
5. I think developing TB is a person's own fault.	Strongly disagree	Disagree	Agree	Strongly agree
6. How angry do you feel towards TB patients?	Not at all	Not much	Quite a bit	A lot
7. I think it would be best for TB patients to be isolated	Strongly disagree	Disagree	Agree	Strongly agree
8. TB patients are dangerous?	Strongly disagree	Disagree	Agree	Strongly agree
9. I think taking TB treatment should be forced if necessary	Strongly disagree	Disagree	Agree	Strongly agree

Source: Corigan scale

Section ON VMCC and SEXUAL BEHAVIOR

Note: Asked to a random subset of 10% of all participants at the survey site (station screening)

Section on Circumcision

First section on circumcision (qstn 55 – 59) to be administered to all male participants determined by DEMSEX (in the 10% random subset)

Read to Participant: Now I would like to ask you about male circumcision. As a reminder, by male circumcision, I mean removal of the foreskin of the penis. Before we begin, do you have any questions?

1. ***Are you circumcised? By this we mean by anyone, not necessarily at a clinic. In other words, do you consider yourself to have undergone circumcision?***
   Variable: CSSTAT
   - ***Yes = 1*** — ***go to CSdate qstn 37 (when circumcised)***
   - ***No = 2*** — ***section ends***
   - ***Not Sure/don't know = 98*** — ***section ends***
   - ***No Answer = 99*** — ***section ends***

2. ***When were you circumcised (mm/year) Variable CSdate***
   ENTER MONTH: MM
   ENTER YEAR: YYYY
   ****Edit Check: Must be before today and after their DOB***

1. ***Not Sure/don't know = 98***
   If date not known ask for age at which they were circumcised)
   At what age where you circumcised:  ***years***

2. ***Who circumcised you? (check all that apply)***
   Variable: CSWHO0—CSWHONR)
   Government health worker (Variable: CSWHO0)
1. ***Private practitioner (Variable: CSWHO1)***
2. ***NGO/FBO health worker (Variable: CSWHO2)***
3. ***Traditional practitioner (Variable: CSWHO3)***
4. ***Other (Variable: CSWHO4), Specify……***
5. ***Don't know (code 98 - Variable: CSWHO5)***
6. ***No Answer (code 99 - Variable: CSWHONR)*** ***If not null assign value as '99'***

7. ***What were the main reasons why you were circumcised?***
   Variable: CSREAS
   - ***Tradition or religious = 1*** — ***go to CSOREA0***
   - ***To protect myself against HIV = 2*** — ***go to CSOREA0***
   - ***Hygiene = 3*** — ***go to CSOREA0***
   - ***Other medical reason = 4*** — ***go to CSOREA0***
   - ***Other = 5*** — ***go to CSOREA0***

☐ *Don't know = 98* *section ends*
☐ *No Answer = 99* *section ends*

8. *Were there any other reasons? (check all that apply) (Variable: CSOREA0—CSOREA5)*
1. *No other reason (Variable: CSOREA0)*
2. *Tradition or religious (Variable: CSOREA1)*
3. *To protect myself against HIV (Variable: CSOREA2)*
4. *Hygiene (Variable: CSOREA3)*
5. *Other medical reason (Variable: CSOREA4)*
6. *Other (Variable: CSOREA5)*
7. *No Answer = 99 (Variable: CSOREANR)* *If not null assign value as '99'*

Section on Sexual behavior

To be asked to all in the random 10% subset (males & females)

8. **Have you ever had sex?**
(*variable* SBEVER)
If value=null or 'No Answer' and SBFAGENR <> 'No Answer' assign value as '.M' (Missing)
☐ **Yes = 1** **go to SBFAGE—SBFAGENR (q105), SBALLNUM—SBALLNUMNR (q106), SBYR (q107)**
☐ **No = 2** **go to Alcohol Use (Section P)**
☐ **No Answer** **go to Alcohol Use (Section P)**

9. **How old were you when you had sex for the first time? If you can't recall the exact age, please give a best guess.**
***Row 211* (*SASname:* SBFAGE—SBFAGENR)**
If value is null, SBFAGENR is null, and SBEVER is 'Yes' assign value as '.M' (Missing)
If SBEVER is not 'Yes' assign value as '.S'" (Skipped)

☐ The picture can't be displayed. **(*SASname:* SBFAGE)**
years old (*SASname:* SBFAGEU) **Assign value as null if SBFAGE is null**
☐ **No Answer (*SASname:* SBFAGENR)** **If not null assign value as '99'**

Display Edit Message when SBFAGE is not Numeric: Value entered must be numeric.
Display Edit Message when SBFAGE ≤ 10: Age entered is less than 10. Please confirm.
Display Edit Message when SBFAGE > ELIGIBILITY.DEMAGE: Age entered is greater than participant's current age. Please re-enter.

10. **In your lifetime how many different people have you had sex with (including your husband/wife)? If you can't recall the exact number, please give a best guess.**
***Row 212* (*SASname:* SBALLNUM—SBALLNUMNR)**

If value is null, SBFAGENR is null, and SBEVER is 'Yes' assign value as '.M' (Missing)
If SBEVER is not 'Yes' assign value as '.S'" (Skipped)

 **(*SASname:* SBALLNUM)**
sexual partners (*SASname:* SBALLNUMU) **Assign value as null if SBALLNUM is null**
 **No Answer (*SASname:* SBALLNUMNR)** **If not null assign value as '99'**

Display Edit Message when SBALLNUM is not Numeric: Value entered must be numeric.
Display Edit Message when SBALLNUM < 1 or >999: Value entered must between 1 and 999.

11. Have you had sex in the past 12 months?
***Row 213* (*SASname:* SBYR)**

If value=null or 'No Answer' and SBFAGENR <> 'No Answer' assign value as '.M' (Missing)

☐ **Yes = 1** & if SBEVER is Yes, go to SBYRNUM—SBYRNUMNR (q108), SBYRSP—SBYRSPNR (q109), SBYRFR—SBYRFRNR (q110), SBYRCAS—SBYRCASNR (q111), SBYRONE—SBYRONENR (q112), SBYROTH—SBYROTHNR (q113), SBYROUT (q114), SBLCOND (q115)

☐ **No = 2** go to Alcohol Use (Section P)

☐ **No Answer** go to Alcohol Use (Section P)

12. In the past 12 months, how many different people have you had sex with (including your husband/wife)? If you can't recall the exact number, please give a best guess.
***Row 214* (*SASname:* SBYRNUM—SBYRNUMNR)**

If SBYR is 'Yes', SBYRNUMNR is null, and value is null assign value as '.M' (Missing)
If SBYR is not 'Yes' assign value as '.S' (Skipped)

☐ (*SASname:* SBYRNUM)
people (*SASname:* SBYRNUMU) Assign value as null if SBYRNUM is null
☐ **No Answer (*SASname:* SBYRNUMNR)** If not null assign value as '99'

Display Edit Message when SBYRNUM is not Numeric: **Value entered must be numeric.**
Display Edit Message when SBYRNUM < 1 or >999: **Value entered must between 1 and 999.**
Display Edit Message when SBYRNUM > SBALLNUM: **Total in past 12 months cannot be more than total in lifetime.**

13. Of the [Display PCQ_SEX.SBYRNUM] partners you had in the last 12 months, how many were your husband/wives?
***Row 215* (*SASname:* SBYRSP—SBYRSPNR)**

If SBYR is 'Yes', SBYRSPNR is null, and value is null assign value as '.M' (Missing)
If SBYR is not 'Yes' assign value as '.S' (Skipped)

☐ (*SASname:* SBYRSP)
husband/wives (*SASname:* SBYRSPU) Assign value as null if SBYRSP is null
☐ **No Answer (*SASname:* SBYRSPNR)** If not null assign value as '99'

Display Edit Message when SBYRSP is not Numeric: **Value entered must be numeric.**
Display Edit Message when SBYRSP > 10: **Value must be 10 or less.**
Display Edit Message when the sum of [SBYRSP + SBYRFR + SBYRCAS +

SBYRONE + SBYROTH] is not SBYRNUM: The number of partners entered does not add up to the number of people the participant had sex with in the past 12 months.

14. Of the [Display PCQ_SEX.SBYRNUM] partners you had in the last 12 months, how many were boyfriends/girlfriends?
***Row 216* (*SASname:* SBYRFR—SBYRFRNR)**

If SBYR is 'Yes', SBYRFRNR is null, and value is null assign value as '.M' (Missing)
If SBYR is not 'Yes' assign value as '.S' (Skipped)

The picture can't be displayed. **(*SASname:* SBYRFR)**
boyfriends/girlfriends (*SASname:* SBYRFRU) **Assign value as null if SBYRFR is null**
No Answer (*SASname:* SBYRFRNR) **If not null assign value as '99'**

Display Edit Message when SBYRFR is not Numeric: Value entered must be numeric.
Display Edit Message when the sum of [SBYRSP + SBYRFR + SBYRCAS + SBYRONE + SBYROTH] is not SBYRNUM: The number of partners entered does not add up to the number of people the participant had sex with in the past 12 months.

15. Of the [Display PCQ_SEX.SBYRNUM] partners you had in the last 12 months, how many were casual partners you knew before having sex?
***Row 217* (*SASname:* SBYRCAS—SBYRCASNR)**

If SBYR is 'Yes', SBYRCASNR is null, and value is null assign value as '.M' (Missing)
If SBYR is not 'Yes' assign value as '.S' (Skipped)

The picture can't be displayed. **(*SASname:* SBYRCAS)**
casual partners (*SASname:* SBYRCASU) **Assign value as null if SBYRCAS is null**
No Answer (*SASname:* SBYRCASNR) **If not null assign value as '99'**

Display Edit Message when SBYRCAS is not Numeric: Value entered must be numeric.
Display Edit Message when the sum of [SBYRSP + SBYRFR + SBYRCAS + SBYRONE + SBYROTH] is not SBYRNUM: The number of partners entered does not add up to the number of people the participant had sex with in the past 12 months.

16. Of the [Display PCQ_SEX.SBYRNUM] partners you had in the last 12 months, how many were a one-time partner you did not know before having sex?
***Row 218* (*SASname:* SBYRONE—SBYRONENR)**

If SBYR is 'Yes', SBYRONENR is null, and value is null assign value as '.M' (Missing)
If SBYR is not 'Yes' assign value as '.S' (Skipped)
The picture can't be displayed. **(*SASname:* SBYRONE)**
one-time unknown partners (*SASname:* SBYRONEU) **Assign value as null if SBYRONE is null**
No Answer (*SASname:* SBYRONENR) **If not null assign value as '99'**

Display Edit Message when SBYRONE is not Numeric: Value entered must

be numeric.
Display Edit Message when the sum of [SBYRSP + SBYRFR + SBYRCAS + SBYRONE + SBYROTH] is not SBYRNUM: The number of partners entered does not add up to the number of people the participant had sex with in the past 12 months.

17. **Of the [Display PCQ_SEX.SBYRNUM] partners you had in the last 12 months, how many were other types of partners we have not counted yet?**
Row 219 (*SASname:* SBYROTH—SBYROTHNR)
If SBYR is 'Yes', SBYROTHNR is null, and value is null assign value as '.M' (Missing)
If SBYR is not 'Yes' assign value as '.S' (Skipped)
☐ (*SASname:* SBYROTH)
other type of sexual partners (*SASname:* SBYROTHU) Assign value as null if SBYROTH is null
☐ No Answer (*SASname:* SBYROTHNR) If not null assign value as '99'

Display Edit Message when SBYROTH is not Numeric: Value entered must be numeric.
Display Edit Message when the sum of [SBYRSP + SBYRFR + SBYRCAS + SBYRONE + SBYROTH] is not SBYRNUM: The number of partners entered does not add up to the number of people the participant had sex with in the past 12 months.

18. **Of the [Display PCQ_SEX.SBYRNUM] partners you had in the last 12 months, do any live outside of [Display HH.DEMCOM]?**
Row 220 (*SASname:* SBYROUT)
If SBYR is 'Yes' and value is null or 'No Answer' assign value as '.M' (Missing)
If SBYR is not 'Yes' assign value as '.S' (Skipped)
☐ Yes = 1
☐ No = 2
☐ Don't Know = 3
☐ No Answer

19. **The last time you had sex did you/your partner use a male or female condom?**
Row 221 (*SASname:* SBLCOND)
☐ Yes = 1
☐ No = 2
☐ No Answer

HIV Section - HIV Testing and ART Uptake – Disclosure of HIV Status (PCQ_HIV)

Note: all questions in section are to be asked as part of pre-counselling as part of the HIV work station

Read to Participant:
Now I would like to ask you some questions about HIV testing. *Some of these questions may have been asked to you before by a study team. We are required to ask the same questions again as we do not have access to the information you provided last time. This is so your responses are kept confidential*. Your answers will be kept completely confidential. Before we begin, do you have any questions?

1. Have you ever been tested for HIV?
***Variable:* HIVEVER12**

- ☐ **Yes = 1** — **go to 17 - HIVNUM**
- ☐ **No = 2** — **go to RISK FACTOR SECTION**
- ☐ **Don't Know = 3**
- ☐ **No Answer = 99**

2. When was the last time you were tested for HIV? If you don't know the exact date, give a best guess. Please give month and year.
***Variable:* HIVTSTMMYY**

☐ **MM** ☐ **YYYY**
☐ **No Answer = 99**

***Display Edit Message when HIVTSTMM is not Numeric:* Month entered must be numeric.**
***Display Edit Message when HIVTSTMM < 1:* Month must be between 1 and 12. You may enter 99 if month is unknown.**
***Display Edit Message when HIVTSTMM > 12 and < 99:* Month must be between 1 and 12. You may enter 99 if month is unknown.**
***Display Edit Message when HIVTSTYY is not Numeric:* Year entered must be numeric.**
***Display Edit Message when HIVTSTYY < 1990:* Year must be between 1990 and [TODAY]. You may enter 9999 if year is unknown.**
***Display Edit Message when HIVTSTYY > current year and < 9999:* Year must be between 1990 and [TODAY]. You may enter 9999 if year is unknown.**

3. Have you been tested for HIV in the last 12 months? HIVLASTYEAR

- ☐ ***Yes = 1***
- ☐ ***No = 2***
- ☐ ***Don't Know = 98***

1. No Answer = 99

2. The last time you were tested for HIV, where were you tested?

Variable: **HIVLOC**

Government hospital or clinic (includes ANC, TB, etc.) = 1

Private/church/mission hospital or clinic = 2

Stand-alone HIV testing centre = 3

1. Mobile testing site (caravan, tent, etc.) = 4

Work place = 5

1. Home = 6

Other = 7, specify…….

1. Don't know = 98

2. No Answer = 99

3. **The last time you were tested for HIV, do you know what type of test was used?**

Fingerprick blood sample

Oral self-test,

Oral self-test followed by fingerprick test?

4. Other, specify

5. Do not know = 98

6. No Answer = 99

7. Have you ever tested with either PopART CHiPs or the PC Study Nurse? (note describe their uniform/show picture)

New variable: HIVPOPART

Yes = 1

8. by ☐ PopART CHiPs only ☐ PC Study Nurse only ☐ both

9. In which year did you last test for HIV with PopART? YYYY

No = 2

Don't Know = 98

No Answer = 99

***10.* If you feel comfortable, would you mind telling me what the result of your last HIV test was?**

Variable: HIVRESLT

HIV-negative = 1

HIV-positive = 2

HIV-indeterminate = 3

***Not comfortable/Don't know = 98 go to* RISK FACTOR SECTION**

***No Answer = 99 go to* RISK FACTOR SECTION**

11. Have you disclosed your HIV status to anyone, except to me for the purpose of this study?

Variable: **HIVDISC**

Yes = 1 go to qstn 27 (to whom disclosed)

No = 2 (end of section)

No Answer = 99

12. To whom did you disclose your HIV status? (*check all that apply*)
(*Variable:* HIVWHOM0 – HIVWHOM5)

13. Husband/wife (*Variable:* HIVWHOM0)
14. Sexual partner other than married partner (*Variable:* HIVWHOM1)
15. Family member (*Variable:* HIVWHOM2)
16. Friend/neighbor/colleague (*Variable:* HIVWHOM3)
17. Religious leader/someone from church/mosque (*Variable:* HIVWHOM4)
18. Health care worker (*Variable:* HIVWHOM5)
19. CHiPs (*Variable:* HIVWHOM6)
20. Other (*Variable:* HIVWHOM7)
21. No Answer (*Variable:* HIVWHOMNR)

Note the next question (27-35) are to be asked to all those who report being HIV positives [HIVRESLT=2]

22. When was your first positive HIV test result? *Variable:* HIVTESTPOS
☐**MM** ☐**YYYY**

23. Have you ever registered for any HIV related medical care? (if yes go to 27, if not go to RISK FACTOR SECTION)
***Variable:* HIVCARE**
☐ **Yes = 1**
☐ **No = 2**
☐ **No Answer = 99**

24. If yes , when did you last attend the clinic for HIV care?
☐**MM** ☐**YYYY**

25. Which clinic did you attend? [*Drop down list names with nearby clinics, add options other*]

26. Have you ever taken ART?
☐ **Yes = 1**
☐ **No = 2**
☐ **No Answer = 99**
27. When did you first start taking ART?
☐**MM** ☐**YYYY**

28. Are you currently taking ART (taken ART in the last 1 month)?
☐ **Yes = 1**
☐ **No = 2**
☐ **No Answer = 99**

29. In the last 7 days, did you miss taking any of your ART pills?

Yes = 1

No = 2

1. No Answer = 99

2. In the past 12 months, have you ever stopped taking your ART? [not essential, but could be helpful to know].

Yes = 1 if yes specify duration of treatment interruption (in weeks/months).

No = 2 go to NEXT SECTION

No Answer = 99 go to NEXT SECTION

Mental Health Tool - Self Reporting Questionnaire (SRQ-5+2) – Modified English version

Instructions : *Now I am going to ask you some questions about the thoughts and feelings that you have* ***experienced over the last 4 weeks****. You should answer yes or no to each question. If you are not sure, give the answer that is closest to how you have been feeling. If you do not understand a question, please ask and I can give you an example of what the question means.*

1	Do you often have headaches?	Yes	No
2	Do you sleep badly?	Yes	No
3	Do you find it difficult to enjoy your daily activities?	Yes	No
4	Are you unable to play a useful part in life?	Yes	No
5	Is your daily work suffering?	Yes	No
6	Do you feel nervous tense or worried?	Yes	No
7	Do you feel unhappy?	Yes	No

Appendix 4: Training Manual

Appendix 4a: SRQ Training Manual

Training package for data collectors and monitors on the administration of Self-Reporting Questionnaire *(Adapted)*

CONTENT OF TRAINING PACKAGE

1. Introduction
2. Depression and TB.
3. How to make the study participants feel comfortable when you are administering the questionnaires.
4. SRQ
    1. Introduction to the form
    2. When it is to be administered
    3. What you will need to administer the form
    4. How to administer the form
    5. What to do if the person doesn't understand
    6. Special questions to ask if the participant says that she have thought about suicide
    7. What to do if you are very worried about the participant
5. Role Play
6. Revision and conclusion

1. Introduction

Today you are going to learn how to administer the SRQ. The SRQ asks about feelings of sadness and worries that some TB patients may have experienced after diagnoses and/or during and post TB treatment.

Please feel free to ask questions at any point during the day if you do not understand anything or want to add anything to the discussion.

The programme for the training is as follows:

1. Introduction to depression.
2. How to make the study participants feel comfortable when you are administering the questionnaires.
3. SRQ
    1. What you will need to administer the form
    2. When it is to be administered
    3. How to administer the form
    4. What to do if the person doesn't understand
    5. Special questions to ask if the participant says that they have thought about suicide
    6. What to do if you are very worried about the participant
4. Role Play

2. Depression and TB

There are several reasons why TB patients may be worried, including feeling too ill, duration and side effects of medication etc. For some people these troubles can lead to sadness, worry and minor physical symptoms that may last for a long time and may make it hard for him/her to enjoy life or to carry out their normal activities. We call this *depression*.

Certain things make life harder for TB patients and increase the likelihood that they will experience depression. Other things make life easier for TB patients and reduce the likelihood that they will experience depression.

EXERCISE 1

Can you suggest things that may cause depression?

Can you suggest things that may prevent depression?

Things that can cause depression:

1. Feeling ill
2. TB medication- duration
3. TB medication – side effects
4. Sigma- being treated badly because of having TB
5. Being too ill to make money
6. Not having enough money to buy food or go to the hospital
7. Seeing loved ones suffer because you are unable to provide for them
8. Other health problems

Things that can prevent depression:

1. Good relationships with family and friends
2. Getting help with responsibilities
3. Having sufficient food, good housing etc
4. Having time to do pleasurable things e.g. singing in choir.

The symptoms of depression

When a person is experiencing lots of the negative things and not enough of the positive things she/he may experience depression. When a person is depressed:

1. She/he may feel sad most of the time
2. She/he may not be able to enjoy things that they used to enjoy.

EXERCISE 2

What else might they experience in terms of thoughts, feeling and physical changes?

Other symptoms of depression

1. Not being able to sleep well (or sleeping too much)
2. Loss of appetite
3. Feeling tired all the time
4. Loss if interest in sex
5. Not able to concentrate
6. Feeling worthless or useless
7. Thinking about death or even suicide
8. “Thinking too much” – thinking all the time about the problems or worries in their life.
9. Feeling anxious, tense or “jumpy”
10. Having lots of minor physical symptoms including:
    1. Headache
    2. Stomach pains and digestion problems
    3. Other aches and pains.

3. How to make the study participants feel comfortable when you are administering the questionnaires.

Some of the participants to whom you will be administering the questionnaires may be ashamed about how they are feeling or believe that you will be judging them. There are certain things that you can do that will help the participant feel comfortable and to trust you.

1. you need to listen to what the respondent is saying and show that you are listening
2. sit at a certain angle not opposite
3. comments like eh, uh and nodding might make the respondent know that you are listening
4. be comfortable with silence: give them time to answer.

4. Self Reporting Questionnaire

First, let's look at the Nyanja version of the form. You will see there is an introductory paragraph and then 20 questions each with a choice of 2 answers YES or NO.

Each of the questions asks about a symptom of depression that the person may have had over the last **4 weeks**. If a participant answers YES to a question it indicates that they have that symptom of depression. The more YES answers they give the more likely it is that they have depression. The number of YES answers is added up and scored out of 20.

You should read out the introductory paragraph to the participant and check that they understand what you want them to do.

Next you should read out each question EXACTLY AS IT IS WRITTEN and record the answer given by the participant (Yes or No) by marking the appropriate box.

If the woman doesn't understand a question or is not sure whether to answer yes or no, you should refer to the **"List of Examples"** in the same language as the form you are using. The **"List of Examples"** sheet gives simple explanations of what the questions mean and encourages the woman to choose the answer that best applies to her over the last 4 weeks.

You should read out the example corresponding to the question EXACTLY AS IT IS WRITTEN and then read the question again. You should then record the answer given by the participant (Yes or No) by marking the appropriate box.

You should not enter into a long discussion about the participants answers. The questionnaire should not take more than 7-8 minutes.

You should try to ensure all questions have been answered by the participant.

Lets go through each question in turn.

Q1. Most of the participants will understand what this means so there is no example on the examples sheet. If they answer YES it means that they ARE bothered by headaches.

Q2. ***IMPORTANT***: Be sure that you and the participant understand this question. The question asks:

Is your appetite poor?

So what does it mean if they answer “YES”?

Remember that “YES” answers indicate that the participant may have depression. So answering YES to this question means that he/she has a PROBLEM with their appetite. Please check that you have recorded this correctly. Use the example if you need to help her understand.

[Go through Q3 – 20 ensuring that the data collectors understand the question and have looked at the corresponding example]

IMPORTANT - When you have finished the questionnaire you must check back to see if the participant has answered YES to question 18 which asks about thoughts of suicide.

If the participant answers yes to this question, at the end of the interview, ask them again about these thoughts.

You should ask him/her the following questions as shown in the Examples Sheet:

1. *Do you have the thought of suicide all the time?*
2. *Have you thought of a method of committing suicide?*
3. *Have you actually tried to commit suicide?*

If they answers yes to any of these questions, you should refer her urgently to the mental health clinic at xxx Hospital.

If they answers yes to any of these questions, you should refer them urgently to the mental health clinic at XXX.

Are there any Questions?

The Zambart SARS-CoV-2 guidelines

Introduction

On 6th April 2020, Zambart decided to suspend all ongoing study field activities and not to start new or resume other activities in line with the rising number of the SARS-CoV-2 cases and the public health measures introduced by the government of the republic of Zambia to stem the spread of the SARS-CoV-2 virus. However, government has since eased the measures and various sectors of the economy and social life have opened. In view of this, Zambart management has decided to resume field activities in July 2020 as well as ease restrictions on staff access to field and head offices. However, this is contingent on the strict observance of public health and safety measures that should be put in place.

The Zambart SARS-CoV-2 guidelines provide guidance regarding how to prepare for the resumption of office and field activities and how to ensure the protection of both the Zambart personnel and study participants. Individual study standard operating procedures (SOP) outlining the measures to be implemented are appended to this document.

Overall responsibility for the activities outlined below is the research directorate Prof Helen Ayles, Dr Kwame Shanaube and Dr Musonda Simwinga

Head Office

Preparations for opening head office

Responsible Officer: Kombe Kenani along with the custodians

a. Hand washing stations should be available to all staff so that they can wash their hands with soap and water as needed throughout the day (One at the main gate; one at the entrance to the main building, the lab and prefab)
b. Hand sanitizer, containing a minimum of 62% alcohol, should be available to all personnel
c. Disinfecting
    a. Disinfectant should be available for disinfection of surfaces and equipment
    b. 0.5% sodium hypochlorite solution should be prepared daily by mixing 72mL Jik with 428mL water in pre-marked 500mL bottles
    c. .
d. Cleaning schedule
    a. A cleaning schedule should be established to ensure that all surfaces and equipment are cleaned and disinfected multiple times (e.g., every 2-4 hours) throughout the work day
    b. The schedule should include disinfection of toilets and sinks, door knobs and handles, telephones, refrigerators, coffee and tea pots, microwave ovens, etc.
e. Room space
    a. Each room should be assessed to determine the best configuration of desks and the maximum safe number of occupants based on size and ventilation
f. Occupancy may have to be reduced by as much as 50% in order to provide safe distance (2m) between employees.

g. Orient desks so that employees are not directly facing each other
h. The common water dispenser should not be used for this period.
i. Recording of attendance- all staff should sign in and out of head office to facilitate contact tracing should this be necessary
j. Remove the remote controls for the air-conditioners and store them safely to prevent usage

Personal Protective Equipment (PPE) and hygiene practices for head office staff

Responsibility for ALL staff

a. Head office staff should continue to work from home as much as possible and only attend the office when it is necessary to do so. This will assist in decongesting the office.
b. Head Office personnel should wash their hands with soap and water before entering the office and regularly throughout the day as they come in and out of the office building
c. Head Office personnel should regularly sanitize their hands while in their respective offices
d. Head Office personnel should wear a mask or face covering at all times indoors and whenever social distancing cannot be observed (minimum of 2 meters).
e. Windows should be opened to increase ventilation.
f. Head office staff should bring their own drinking water to the office and should also bring their own eating utensils which they can wash and keep at their desk to avoid additional cleaning needs
g. Head office staff are responsible for keeping their own work spaces clean and sanitized to reduce the work of the custodians
h. PPE to be used is as per chart appendix 1
i. Any person with any symptoms (fever, cough, loss of taste or smell) or any person who has been knowingly exposed to a confirmed case MUST stay at home for 14 days. They must inform their line manager and HR. Any person diagnosed with COVID-19 must stay at home until at least 7 days after a positive test or their last fever

Vehicles and drivers

a. All Zambart vehicles should be disinfected on a regular basis using 0.5% sodium hypochlorite solution or other appropriate disinfectant
b. At a minimum, the interior and door handles should be disinfected in the morning, between every passenger, and at the end of the day
c. Zambart drivers should wear face coverings see PPE guidance chart appendix 1

d. Records of passengers carried and contact details must be kept for each trip should contact tracing be necessary

Visitors to Zambart Head Offices

a. Only essential visitors should be allowed to enter Zambart work space

b. Deliveries should be left outside the office where they will be unpacked, and disinfected if necessary, by Zambart staff wearing appropriate PPE

Face-to-face meetings

a. Face to face meetings should be kept to a minimum and should be authorized by supervisors

b. Face to face meetings should take place in well ventilated rooms with required physical distancing

c. Whenever possible, meetings should be held in the garden to maximize space and ventilation

Dealing with cases at Head Office

a. Any confirmed case MUST be reported immediately to the Director of Research
b. Contact public health officers/ rapid response team (ZNPHI contact numbers: 909. 0974493553. 0964638726 and 09538898941)
c. Close the offices when a staff member tests positive for SARS-CoV-2 who has been in the office over a period of 72 hours prior to symptoms or a positive test.
d. Disinfect all the offices and the premises which will then be available for use after a period of 72 hours
e. Using the contact tracing register, all staff who were in contact with the case will need to self-isolate for 14 days

Field Activities/ Offices

Responsible Persons: The study manager is responsible for ensuring all study sites are ready for activities and all procedures are followed

Assessment of field offices/ spaces for readiness to reopen and ongoing inspection

a. All field offices/ studies should have relevant SOPs and all staff should be oriented
b. All field offices/ studies should be inspected before reopening and appropriate identification of maximum numbers of people who can safely use each space will be determined and documented
c. All regulations for head office apply for field offices (see section above)
d. All supervisory visits will constitute an inspection (Ongoing inspection)
e. Monthly t inspections shall be conducted by study managers (see PPE assessment checklist, appendix 2)
f. An inspection log/ report should be produced
g. A contact log should be kept where all individuals should be recorded as they enter and leave a space so that contact tracing can be conducted if necessary

Recommended PPE and hygiene practices for field staff

The recommended PPE for field staff is based on the expected level of exposure to study participants, and to the procedures being carried out. PPE should be worn as per the chart in appendix 1. Staff are recommended to maintain good hygiene and this may require the wearing of scrubs/work only clothes and shoes. Long hair should be tied back and in some circumstances hair can be covered with scarf/wraps which can be washed daily.

a. All used disposable PPE must be discarded in clearly-marked biohazard bags. Note: Do not discard biohazard waste in standard bin liners and do not discard ordinary trash in biohazard bags.
b. Disposal of PPE and doffing of PPE should follow standard operating procedures see appendices
c. Reusable PPE (e.g., reusable gowns/aprons and cloth masks) should be washed at the end of every work day at a temperature exceeding 40^{o}C and whenever they become soiled or contaminated.
d. Googles/visors should be cleaned and disinfected with bleach solution or alcohol at the end of each session
e. Personnel should wash their hands with soap and water or use hand sanitizer (?) before putting on PPE and after removing PPE, between participants (if possible), whenever they believe their hands have become contaminated, and at regular intervals throughout the work day

Hand-washing stations

a. Hand washing stations should be available to all field staff and participants so that they can wash their hands with soap and water as needed throughout the day
b. Hand washing stations should be placed at the entrance to offices, hubs, MFSs. The number of hand washing stations per location will differ depending on the set up e.g MFSs may require more than one hand washing station
c. Used water from hand washing stations should be disposed of regularly taking into account hygiene and the environmental control measures

Hand sanitizing

a. All field offices should stock enough sanitizer for field staff (bulk buying)
b. Hand sanitizer should be available to all field staff and used whenever hand washing with soap and water is unavailable or impractical (e.g., between every participant or procedure)
c. All outreach field staff (Research assistants, enumerators etc) should carry enough sanitizer with them throughout the day
d. Outreach field staff should ensure that their participants are wearing face masks all the time.
e. Hand sanitizer should be alcohol-based with a minimum alcohol content of 62%

Disinfecting and cleaning

a. All personnel should have access to liquid disinfectant to regularly disinfect surfaces and equipment
b. Disinfectant should be prepared on a daily basis to ensure its effectiveness
c. A cleaning schedule should be established to ensure that all surfaces and equipment are cleaned and disinfected multiple times
d. The schedule should include disinfection of toilets and sinks, door knobs and handles, telephones, refrigerators and other items at the office, MFS or hub
e. Each room/ space should be assessed to determine the best configuration of desks and the maximum safe number of occupants based on size and ventilation

Actions to take if field staff test positive for SARS-CoV-2

a. Any staff testing positive for COVID must inform their manager IMMEDIATELY and this must be reported upwards to the research director.
b. Contact public health officers/ rapid response team (909. 0974493553. 0964638726 and 09538898941)
c. Suspend all the field activities staff was involved in for the 72 hours prior to symptoms/positive test (e.g close MFS, Hub) and ensure a full clean. The site can re-open after 72 hours
d. Conduct contact tracing- i.e identify if staff was in contact with other field teams and participants at a time when they could have been infectious and not wearing appropriate PPE. Decisions on isolation of other staff and reopening of any field sites will be dependent on the findings of the contact tracing.

Management of symptomatic staff

a. Any staff with any symptoms of illness (e.g., fever, chills, cough, headache, muscle aches, loss of smell and/or taste) MUST stay at home, and report to the designated officer/ supervisor who may decide to conduct testing
b. Any staff who develop symptoms while at work should report to the designated officer/ supervisor, go home immediately, isolate and follow government guidelines
c. Track employee health and record all illnesses even if they seem unrelated to Covid-19. Maintain confidentiality

Requirements/ Measurements

Item	Content
Hand sanitizer,	62% alcohol
Disinfectant	0.5% sodium hypochlorite solution; prepared by mixing 72mL Jik with 428mL water in pre-marked 500mL bottles
Room space	Arrange seating distanced to 2m unless sitting back to back when distance can be reduced to 1m

Special Considerations

Responsible Persons: PI's are responsible for ensuring all studies consider specific risks and protect vulnerable staff

Assessment of specific risks for each study

For each study the PI should complete a risk assessment (appendix 6) to identify any specific risks due to the nature of the study and its operation. This risk assessment should be completed on the specified template and submitted to the regulatory affairs manager for submission to necessary ethics and regulatory authorities. Updated risk assessments may be necessary as the study and/or the situation on the ground changes.

Assessment of staff risks

Since different individuals have different risks from COVID-19 it may be necessary to consider specific risk assessment based on age, co-existing conditions etc. All staff should be made aware of their specific risk and asked to declare whether they consider themselves to be at higher risk. The PI or their delegate must assess each case using the COVID-age assessment tool (appendix 7) and make a consideration of whether additional safeguarding measures are necessary, which may include re-assignment to alternative positions which have a lower risk.

Staff Responsibilities

Staff should also be made aware of their personal responsibility to their research participants, their colleagues and to Zambart and encouraged to consider all of their actions within and outside of the work environment that may put themselves or others at a higher risk. Any staff who have any contact with a known case of COVID, without

PPE, should be encouraged to report this and to self-isolate for a period of 14 days. This self-isolation period will be at full pay to ensure compliance but all staff must take every precaution to avoid being in this position, which includes avoidance of overcrowded situations, following all government advice including mask-wearing and hand washing. Any staff member found to be repeatedly breaching regulations may be subject to disciplinary action, which may include termination of employment if their actions are such that they could endanger others.

Staff Testing

Zambart will endeavour to provide regular testing for all staff whose roles make face to face work or field work unavoidable. Staff will be required to comply with any request for testing as a condition of their employment in such roles. Please refer to Appendix 8 for the testing SOP.

Appendix 1: PPE Guidance chart

	Hand wash at start of day, before eating or drinking, after touching mask at any time & at end of day	Cloth mask if in a space with anyone else	Fluid resistant surgical mask (sessional use)	N95 mask (sessional use)	Visor/Goggles (sessional use)	Scrubs	Apron & Gloves	Disposable Gowns & Gloves
Office work/Drivers without contact with participants	✓	✓						
Contact with study participants who are well, questionnaires & discussions	✓	✓						
Community screening for symptomatic individuals, interviews	✓		✓		✓	✓		
Sputum collection, swab collection from symptomatics	✓			✓	✓	✓	✓	
Laboratory work with blood samples, or processed denatured samples (PPE according to usual practices)	✓		✓					✓
Laboratory work on sputum/swabs (not in cabinet) e.g. lab staff in MFS or COVID labs/cat 2/3 labs	✓		✓ Depending on cabinet	✓ Depending on cabinet	✓ Depending on cabinet	✓		✓

Appendix 2: PPE assessment checklist

Zambart PPE Assessment Checklist

Location	
Name of assessor	
Position of assessor	
Date	

	Question/ observation	Notes
1	Are relevant SOPS available? Have all staff been oriented?	
2	Are hand washing stations with soap available and placed in appropriate places?	
3	What information/ material is available on COVID-19? Is material visible? Is it adequate?	
4	Is there a contact tracing register? Are all staff/ participants signing in and out? Is there a likelihood that some staff/ participants do not sign in and out based on their type of work/ physical arrangement?	
5	Do all vehicles have contact tracing registers? Are records of passengers being kept?	
6	Is a cleaning schedule available? How often are surfaces and equipment cleaned and disinfected?	
7	Are staff maintain good hygiene? How involved are staff at cleaning their work stations/ desks?	
8	Are staff observing social distancing in their rooms/ work stations and when they are attending to participants?	
9	Are staff keeping their work stations/ rooms well ventilated?	
10	Are participants/ visitors observing social distancing?	
11	Are staff/ participants correctly wearing their masks?	
12	Do staff have hand sanitizers with them?	
13	Do supervisors know the protocols to follow when a member of staff becomes symptomatic?	
14	Other observations	

Appendix 3: How to wear cloth mask

Appendix 4: How to wear a medical mask

Appendix 5: How to hand wash

How to Handwash?

WASH HANDS WHEN VISIBLY SOILED! OTHERWISE, USE HANDRUB

Duration of the entire procedure: 40-60 seconds

0

Wet hands with water;

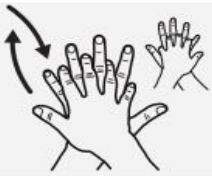
1

Apply enough soap to cover all hand surfaces;

2

Rub hands palm to palm;

3



Right palm over left dorsum with interlaced fingers and vice versa;

4

Palm to palm with fingers interlaced;

5

Backs of fingers to opposing palms with fingers interlocked;

6

Rotational rubbing of left thumb clasped in right palm and vice versa;

7

Rotational rubbing, backwards and forwards with clasped fingers of right hand in left palm and vice versa;

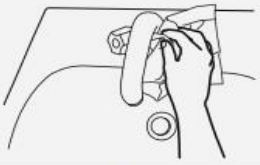
8

Rinse hands with water;

9

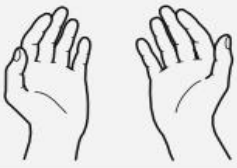
Dry hands thoroughly with a single use towel;

10



Use towel to turn off faucet;

11



Your hands are now safe.

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WHO acknowledges the Hôpitaux Universitaires de Geneve (HUG), in particular the members of the Infection Control Programme, for their active participation in developing this material.

May 2009

Appendix 6:- Zambart COVID-19 Risk Assessment form

Study Title:

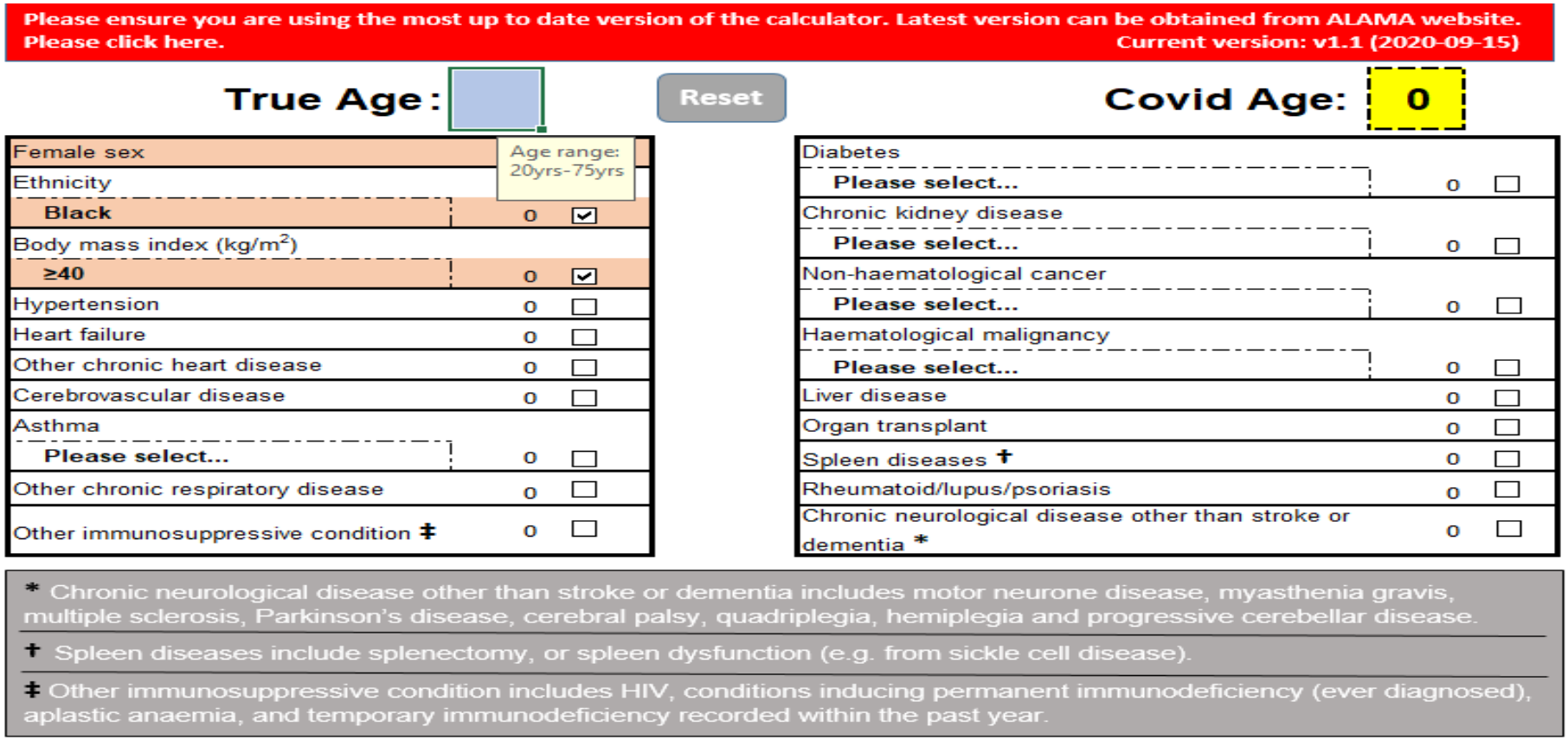
Risk	Description of risk	Mitigation plans
1. Risks to participants		
2. Risks to staff		
3. Risks to Zambart		

I, as the PI have discussed these risks with my study team and will ensure that all mitigation actions will be conducted to the best of my ability

Signed: **Date**

Appendix 7: Individual Risk assessment

Individuals have different risks depending on age, ethnicity and pre-existing conditions. One way of assessing this is by a COVID-age scoring system[3]. The tool for doing this is an excel worksheet, that can be found on the shared drive at Zambart or can be downloaded here **Alama risk tables 20200924.** *The imagine below shows how tool looks like*



Please ensure you are using the most up to date version of the calculator. Latest version can be obtained from ALAMA website. Please click here. **Current version: v1.1 (2020-09-15)**

True Age : **Reset** **Covid Age: 0**

Age range: 20yrs-75yrs

Female sex		
Ethnicity		
Black	0	☑
Body mass index (kg/m^2)		
≥40	0	☑
Hypertension	0	☐
Heart failure	0	☐
Other chronic heart disease	0	☐
Cerebrovascular disease	0	☐
Asthma		
Please select...	0	☐
Other chronic respiratory disease	0	☐
Other immunosuppressive condition ‡	0	☐

Diabetes		
Please select...	0	☐
Chronic kidney disease		
Please select...	0	☐
Non-haematological cancer		
Please select...	0	☐
Haematological malignancy		
Please select...	0	☐
Liver disease	0	☐
Organ transplant	0	☐
Spleen diseases †	0	☐
Rheumatoid/lupus/psoriasis	0	☐
Chronic neurological disease other than stroke or dementia *	0	☐

* Chronic neurological disease other than stroke or dementia includes motor neurone disease, myasthenia gravis, multiple sclerosis, Parkinson's disease, cerebral palsy, quadriplegia, hemiplegia and progressive cerebellar disease.

† Spleen diseases include splenectomy, or spleen dysfunction (e.g. from sickle cell disease).

‡ Other immunosuppressive condition includes HIV, conditions inducing permanent immunodeficiency (ever diagnosed), aplastic anaemia, and temporary immunodeficiency recorded within the past year.

[3] Assessment of workers personal vulnerability to COVID-19 using "COVID age". Coggon et al https://doi.org/10.1101/2020.05.21.20108969

The Covid-age for Zambart should be interpreted according to the following table

Vulnerability level Covid Age	**Interpretation**	**Consideration for workplace**
Very High 85 or greater	This person is at high risk of illness or death if they contract COVID	Ideally work from home Where this is not possible, reassign their role to lower risk role. Ensure good hygiene and mask wearing at all times in a work environment
High Covid age 70-85	This person is at increased risk of illness or death if they contract Covid	Limit risk by considering if they can work from home or work with limited contact with others Ensure good hygiene and mask wearing at all times in a work environment
Moderate Covid age 50-70	This person may be at increased risk of illness or death if they contract Covid	The increased risk should be explained to the staff member and they must take all measures to reduce it by personally ensuring good hygiene and mask wearing at all times, avoiding exposure etc
Low Covid age below 50	This person is not at higher risk than average for illness and death form Covid	While not at increased risk, good hygiene and mask wearing must be emphasized. All staff have a duty to protect themselves and others form Covid and so should follow all instructions on this

For each study/department the PI/delegate/line managers must complete the COVID age for all workers and submit completed lists of Covid age to HR for safe keeping. Managers should use the opportunity to discuss with staff the contents of this SOP and to re-emphasis the roles and responsibilities of staff during the pandemic.

Appendix 8: Zambart Staff SARS-CoV-2 Testing SOP

Introduction: To ensure Zambart staff and client safety and prevent disease transmission during the Covid-19 pandemic, we will periodically screen selected staff for Covid-19 infection.

Purpose: The purpose of this SOP is to describe the procedure for testing Zambart staff for Covid-19 infection using the Xpert Xpress SARS-CoV-2 assay.

Scope: This SOP applies to Zambart personnel responsible for collecting and testing specimens from Zambart staff for Covid-19 using the PrimeStore MTM molecular transport.

Biosafety precautions: Standard Precautions should be observed at all times. All biological specimens should be treated as potentially infectious. Personnel responsible for collecting and testing specimens must wear appropriate personal protective equipment (PPE), follow appropriate PPE donning and doffing steps, and practice proper hand hygiene.

Materials and equipment:

-Personal protective equipment (PPE): Personnel collecting and testing specimens must wear a gown, gloves, surgical mask, and face shield.

-Sterile swabs with breakable stems appropriate for anterior nasal and oropharyngeal specimen collection.

-PrimeStore MTM Molecular transport medium, 1.5mL per tube.

-Zip-lock biohazard specimen bags

- Xpert® Xpress SARS-CoV-2 assay cartridges

Specimen collection procedure (anterior nasal and oropharyngeal):

1. Disinfect hands by washing with soap and water or by using alcohol sanitizing gel.
2. Don all required PPE (gown, gloves, surgical mask, and face shield).
3. Remove a sterile swab from the wrapper, being careful not to touch the collection pad.
4. Anterior nasal swabbing: Insert the entire collection pad into the nostril, but do not insert the swab further than 1.5cm into the nose (see diagram).
5. Slowly rotate the swab in a circular path against the inside of the nostril at least 4 times for a total of 15 seconds.
6. Gently remove the swab.
7. Oropharyngeal swabbing: Using the same swab, gently insert the swab into the back of the throat and the tonsillar area (see diagram). Rub the swab over both tonsillar pillars and the posterior oropharynx. Avoid touching the tongue, teeth, and gums.
8. Insert the used swab into a tube containing 1.5mL of PrimeStore MTM molecular transport and snap off the stem at the break-point. Tighten the cap securely and invert the tube x 10 to mix the contents thoroughly.
9. Ensure that the tube is labelled with the correct employee ID number.

10. Place the tube into a zip-lock biohazard specimen bag and transport to the Xpert testing site.
11. Specimens collected in PrimeStore MTM molecular transport are stable at ambient temperature and do not require cold-chain conditions. If specimens are not going to be tested the same day they are collected, they can be stored at 2-8C.
12. Be sure to disinfect your hands and all PPE, and change gloves, before collecting a specimen from another subject.

Testing procedure (full procedure in the Xpert Xpress SARS-CoV-2 assay SOP):

1. The specimens will be tested using the Xpert Xpress SARS-CoV-2 assay.
2. Inside a BSC or ventilated work station (VWS), vortex the specimen collection tube x 10 seconds or invert x 10 to mix the sample thoroughly.
3. Inside a BSC or ventilated work station (VWS), use a disposable pipet provided with the test kit to transfer 300uL of liquid from the collection tube to an Xpert Xpress SARS-CoV-2 cartridge.
4. Enter the test subject ID number into the Xpert software and scan the cartridge barcode.
5. Start the test within 30 minutes of adding the specimen to the cartridge.
6. Record the test result on the appropriate form and forward the results to the designated authority as soon as possible.
7. In the event of an error or failure, repeat the test one time using the same specimen. If the second test also fails, then request a new specimen.

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