# Evaluation of the tuberculosis control programme in prisons and the post-release continuation of tuberculosis treatment in Malaysia

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## ABSTRACT

### Background:

Poorly managed tuberculosis (TB) control programmes in prisons have detrimental health consequences, placing prisoners at an increased risk for TB morbidity and mortality. This situation could further fuel the TB epidemic in the general population when prisoners are released with uncompleted treatment in prisons and default from treatment in the community. Despite the recognised risk, limited information exists about the burden of TB, the performance of TB control programmes, and the continuity of TB care after release from prisons in Malaysia, a country with an increasing TB burden over the past two decades.

### Objectives:

This PhD project was designed to investigate the prevalence and correlates of active TB among new prison entrants, to assess gaps in the performance of the prison's TB programme using standardised parameters, to investigate the proportion of released prisoners who continue treatment in the community, and to evaluate factors influencing the continuation of TB treatment after release from prisons in Malaysia.

### Methods:

In the first study, we screened prisoners entering the largest prison in Malaysia to determine those who needed further TB assessment. All HIV-infected and symptomatic non-HIV infected prisoners were asked to submit sputum specimens to be examined using GeneXpert MTB/RIF (Xpert) or culture. Factors associated with TB disease, define as Xpert- or culture-positive tests, were assessed using regression analyses. In the second study, we developed parameters and assessable indicators to evaluate gaps in the performance of the TB control programme in the same prison. The parameters include policies and human resources; screening, case detection and notification; treatment initiation, follow-up, and outcome; TB care for HIV-infected prisoners; and knowledge about TB. Data gathering tools and data sources (local and international TB guidelines and TB system assessment publications) were utilised to measure the performance indicators under these parameters and determine system performance gaps. In the third study, prisoners who were due to be released from five prisons were recruited and followed up to identify the proportion of former prisoners who continued treatment in the community. Factors associated with failure to register at a TB clinic within 30 days of release were assessed in regression analyses. In the fourth study, factors influencing the continuation

of TB treatment in the community were evaluated in a group of prisoners with previous TB episodes using in-depth interviews. We utilised a thematic framework analysis to identify relevant themes.

## Results:

In the first study, 10,335 participants were recruited. Among HIV-infected prisoners (N=214), 12.6% had TB disease compared with 0.29% of non-HIV-infected prisoners. Among non-HIV-infected prisoners, prevalent TB disease was independently associated with older age, current drug use, a previous TB episode, and being underweight.

In the second study, we found that the national TB guidelines did not include a section on TB in prisons and that there was an average of 2.19 healthcare workers for every 1,000 prisoners. Furthermore, only 54.2% of new entrants were screened for TB, there was a 37.6% case detection ratio, and only 45.5% of TB cases were notified to the national TB programme. While treatment initiation was high (91%), only half (50.7%) were followed up after two months inside the prison, the treatment success rate was 72.8%, the mortality ratio was 125 per 100,000 prisoners, and only 73.3% were offered TB documentation before release. TB care for HIV-infected prisoners was similarly suboptimal with 22.1% screened for TB disease at entry, only 1.6% were provided with preventive therapy, and 12.9% were prescribed HIV treatment while on TB treatment. Knowledge about TB was very limited, particularly among prisoners compared to prison officers (6.8% and 67.2% correctly answered TB questions, respectively).

In the third study, 106 participants recruited. Of these, 47 (44.3%) did not register at a TB clinic to continue treatment after release, and this was independently associated with younger age, pre-incarceration unstable housing and employment, failure to provide contact details, a previous TB episode, and not being supplied with TB documentation at the time of the release from prisons.

In the fourth study, we recruited five prisoners who continued, and seven who discontinued treatment of their TB after release from prisons. Key themes related to the continuation of TB treatment after release were the prison environment and attention to prisoner care, prisoner perception and attitude, the presence of a supportive environment during the transition to the community, social support, and welcoming community healthcare services.

## Conclusion

There is a high prevalence of TB disease among new entrants to prison in Malaysia, likely representing cases missed by the community health services. There are several gaps in the

performance of the TB control programme in prisons; a situation that may promote TB transmission in prisons and the larger general population. Almost half of the prisoners who are released while still on TB treatment abandons treatment after release and that several factors influence whether they continue treatment in the community. These findings warrant the establishment of an effective TB control programme in prisons supported with policy changes, proper funding, trained healthcare workers and adequate communication between the prisons and the public health department.

## ACKNOWLEDGEMENTS

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## THE ROLE OF THE CANDIDATE

My role in the PhD project included the following:

1. Define areas of research and design studies.
2. Perform literature reviews.
3. Development of the project proposal with the support from my supervisors.
4. Submit documents for ethical approvals to the respective ethics committees at the University of Otago and University of Malaya.
5. Design study instruments.
6. Prepare the project budgets.
7. Provide documents for security clearance to do the research in prisons.
8. Perform interviews with the assistance of my research assistant.
9. Travelling to several places in Malaysia to recruit participants.
10. Perform administrative jobs, including data entry, budget allocations and answering to the prison department queries.
11. Communicate with community healthcare facilities to ensure follow-up on released prisoners.
12. Monitoring the quality of translation and data entry performed by my research assistant.
13. Data cleaning and data analysis.
14. Dissemination of initial findings through presentations.
15. Writing the thesis draft and finalisation of the submitted version.

## DISSEMINATION OF THE PROJECT'S FINDINGS

### Oral Presentations

**Al-Darraji HAA,** Kamarulzaman A, Sharples K, Hill P. The diagnostic performance of screening algorithms for tuberculosis among HIV-infected prisoners. Australasian Tuberculosis Conference 2018, Wellington, New Zealand, 30-31 August 2018

**Al-Darraji HAA,** Kamarulzaman A, Sharples K, Hill P. Predictors of failure to continue tuberculosis treatment after release from prisons in Malaysia: A cohort study. 49th Union World Conference on Lung Health, 24-27 October 2018, The Hague, The Netherlands

**Al-Darraji HAA,** Kamarulzaman A, Sharples K, Hill P. Tuberculosis knowledge among prisoners and correctional officers in a prison with high tuberculosis burden in Malaysia. Otago Global Health Institute 11th Annual Conference 27-28 November 2018, Dunedin, New Zealand

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## LIST OF ABBREVIATIONS

**AADK:** National Anti-Drug Agency in Malaysia

**DOT:** Directly Observed Therapy

**HAART:** Highly Active Antiretroviral Therapy

**HIV:** Human Immune Deficiency Virus

**IPT:** Isoniazid Preventive Therapy

**KAP:** Knowledge, Attitude and Practice

**LED FM:** LED Fluorescence Microscopy

**LMIC:** Low- and Middle-Income Countries

**LTBI:** Latent TB infection

**MDR-TB:** Multidrug-resistant Tuberculosis

**MHA:** Ministry of Home Affairs

**MMT:** Methadone Maintenance Therapy

**MOH:** Ministry of Health

**NTP:** National Tuberculosis Programme

**OAT:** Opioid Agonist Therapy

**PLWH:** People Living with HIV

**PWUD:** People who use drugs

**PWID:** People who inject drugs

**TB:** Tuberculosis

**WHO:** World Health Organization

**XDR-TB:** Extensive Drug-Resistant Tuberculosis

**Xpert:** GeneXpert MTB/RIF

# CHAPTER ONE: INTRODUCTION

Prisons, particularly those in low- and middle-income countries (LMIC), are recognised amplifiers of tuberculosis (TB) (1). The World Health Organisation (WHO) estimates that the prevalence of TB in prison is up to 100-fold higher than that of the respective overall population (2). This feature of prisons could partly be explained by the presence of poorly managed TB control programmes in these settings, where TB is not adequately diagnosed and treated and eventually spread to the general population. Additionally, prisoners have an increased risk for TB, being of low socioeconomic background, and have several co-morbidities, including drug use and HIV infection (3). Moreover, prisoners with TB face several challenges in the transition period to the community, including finding employment and housing, and may not prioritise TB care after release (4). Though prisons are recognised settings for TB augmentation and spread to the community, limited information exists about the performance of TB control programmes in prisons and post-release linkage to care, especially in high TB burden countries. This thesis examines the performance of the TB control programme in the largest prison in Malaysia and the continuation of TB treatment after release from prisons in the country.

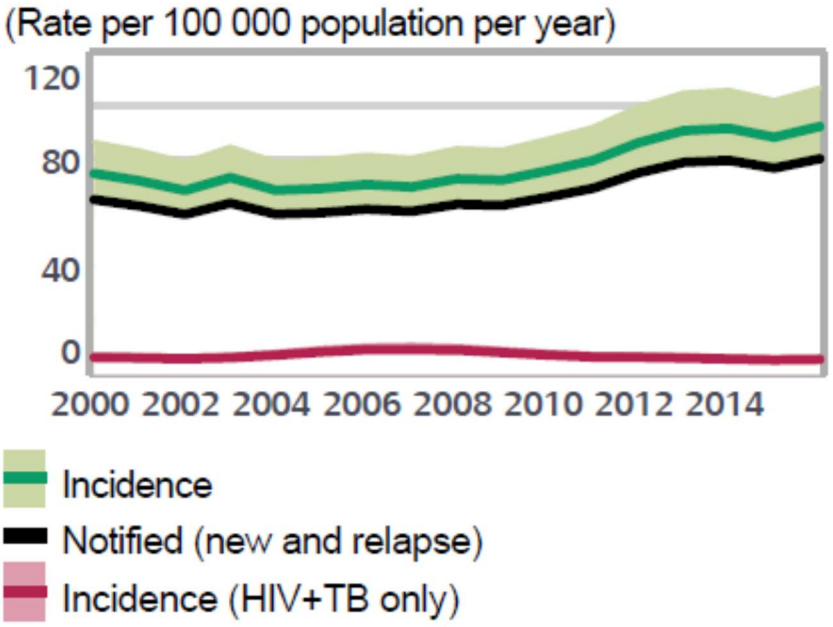
## 1.1 Problem statement

Globally, TB remains one of the major causes of morbidity and mortality, particularly in LMIC (5). In 2016, WHO estimated that there were 10.4 million new TB cases worldwide; only 61% of these incident cases was reported to WHO by the respective health authorities (5). More than half of the global TB burden (56%) was reported in five LMIC Asian countries (India, Indonesia, China, the Philippines, and Pakistan). HIV infection, one of the significant risk factors for TB, was reported in 10% of new TB cases. TB has surpassed HIV infection as the leading cause of human deaths from a single infectious disease with almost 2 million TB-related fatalities annually.

In Malaysia, 29,000 incident TB cases and 1,590 TB-related fatalities were estimated by the WHO to have occurred in 2016 (5). TB control programme in Malaysia has achieved the TB case detection rate goal of >70% set by the Stop TB Partnership (86% of TB cases in Malaysia were reported to the WHO). Despite achieving that goal, the burden of TB has been increasing over the past decade (Figure 1.1). Several factors might have been involved, but failure to address TB among the marginalised sectors of society, including prisoners, people who use

drugs (PWUD), PLWH and illegal migrants, might have considerably contributed to this increase in the TB burden.

**Figure 1.1** The incidence and notification rates of TB cases in Malaysia (WHO, 2017)




This increasing trend in TB burden places Malaysia among the countries that failed to achieve the United Nations' Millennium Development Goals (MDGs) related to TB (Goal 6) by 2015. The goal aimed at halting and start reversing the incidence of TB by 2015 compared to 1990 figures (6).

Limited information exists about the burden of TB across all prisons in Malaysia. Still, recent surveys (2010-2014) in the largest prison in the country revealed a high prevalence of active and latent TB among prisoners. In two separate surveys in 2010 and 2011, the prevalence of latent TB infection (LTBI) among prisoners (N=286) and prison employees (N=420) was 88.8% and 81%, respectively (7,8). No information exists about comparative data from the community in Malaysia, but these figures were several-fold higher than the prevalence of LTBI in the general population in the Western Pacific region (27.9%), where Malaysia is geographically categorised (9). An active case finding survey in the same prison in 2012 revealed a high (N=48, 8.5%) prevalence of TB disease among 559 randomly selected prisoners (10). This survey presented four crucial findings. First, most TB cases (N=34, 71%) were undiagnosed at the time of the study. These are likely cases missed by both the community and the prison's health systems. Second, most TB cases (61.8%) were diagnosed over the three

months after prison entry. This finding may reflect the lack of proper TB screening at the entry to the prison and the probability that most of TB cases in prisons were imported from the community rather than a predominance of transmission in prison. Third, almost two-thirds of prisoners with TB (64.7%) were released to the community before completing the 6-month TB treatment regimen (10). Owing to the poor coordination between the prison health and community health systems, the outcome of TB treatment among released prisoners with TB is not known. Finally, prisoners with HIV infection had a significantly higher prevalence of active TB (24 out of 143, 16.8%) compared to prisoners without HIV infection (24 out of 416, 5.8%). This observation further confirms the importance of targeted TB screening and prevention in this high-risk group (11).

These first observations of the potentially poorly managed TB control programme in prisons in Malaysia provided the foundation to design this PhD project. Healthcare systems in prisons are often neglected and, in many LMIC, are not considered as part of the public health system (12). The prison health system in Malaysia, like most of the health systems in LMIC, is generally understaffed, has limited allocated budget and resources, and is managed by the Ministry of Home Affairs, a government body that focuses on criminal justice rather than the healthcare system management. All these combined with the fact that healthcare delivery is not considered as a priority in prisons may have an influence on the performance of TB screening and treatment in prisons in Malaysia. This situation leads to the augmentation of the burden of TB disease on the resource-limited healthcare system and prisoners alike. In order to improve the healthcare system in prisons in Malaysia, a thorough needs assessment is warranted.

Furthermore, linkage to care after release from prisons is a significant challenge to healthcare systems (13). This is primarily due to the complex issues facing prisoners in the immediate transition period to the community, including reuniting with families, finding housing, searching for employment, maintaining a life without drugs, and avoiding re-incarceration (14). With these challenges, health might not be prioritised. Prisoners released with uncompleted TB treatment may remain infectious and are likely to transmit the disease in the community (15). Moreover, the health of prisoners who do not continue TB care after release from prisons may deteriorate, and they may have an elevated risk of death from fulminant disease. Reports addressing the linkage of prisoners with uncompleted TB treatment to community healthcare are scarce, and no information exists from the Malaysian correctional system. Most published

reports describe the linkage to care for HIV-infected prisoners, mainly in high-income, low TB burden countries (16).

### 1.2 Aim and purpose of the thesis

This thesis aimed to explore the performance of the TB healthcare system in prisons and the continuation of TB treatment after release from prisons in Malaysia. The goal of the project is ultimately to inform policymakers with recommendations about how the current TB situation in prisons in Malaysia could be improved.

The specific objectives of this thesis are to:

1. Assess the proportion of prisoners with active TB at the entry into a prison in Malaysia.
2. Examine gaps in the performance of the TB control programme in a prison in Malaysia.
3. Assess the proportion of released prisoners who continued TB treatment in the community in Malaysia.
4. Investigate factors influencing the continuation of TB treatment after release from prisons in Malaysia.

### 1.3 Overview of the thesis

The thesis comprises seven chapters. The first chapter describes the background of the PhD project and the overall objectives of the project. In contrast, the second chapter discusses the current situation in Malaysia concerning TB in the community and prisons. The second chapter further provides an overview of the country's demographic structure, the TB epidemic and current TB care provided in prisons. This chapter also highlights the post-release care provided for released prisoners with TB in the community.

Chapter Three discusses in detail the first study of the PhD project. The study examined the prevalence of TB at the entry to the largest prison in Malaysia. The chapter provides information on the review of the literature addressing the burden of TB at entry to prisons, the study methodology, the findings, and discussion of these findings.

Chapter Four provides details about the second PhD study, including the literature review, the methodology in designing the parameters and indicators of the performance of TB control

programme in prisons, the findings of the gaps between practice and policy, and discussion of these findings.

The third PhD study "the continuation of TB treatment after release from prisons in Malaysia" is discussed in depth in Chapter Five. This description includes the review of published reports addressing the subject, the methodology used, the findings from the study, and finally, the discussion of these findings.

Chapter Six is dedicated to discussing the fourth PhD study, which involved in-depth interviews of former prisoners with previous uncompleted TB treatment in prisons in Malaysia to examine factors influencing the continuation of TB treatment after release.

Finally, Chapter Seven describes the overall conclusion of the PhD project and provide recommendations to stakeholders about areas to improve in TB care in prisons in Malaysia together with future research to build on these recommendations.

# CHAPTER TWO: SETTING THE CONTEXT- TUBERCULOSIS IN PRISONS IN MALAYSIA

## 2.1 Introduction

This chapter provides an overview of the current geographic, economic, and demographic situation in Malaysia. The chapter also provides details about the current TB epidemic in the country with particular focus on prisons. It also explores what is currently known about post-release continuation of care, particularly for prisoners with TB, in the community in Malaysia.

## 2.2 Country information

### 2.2.1 Geographic and economic situation in Malaysia

Extending over an area of 330,323 $Km^2$, Malaysia is a country in Southeast Asia. The country is composed of two parts: Peninsular (Western) and Northern Borneo (Eastern) parts separated by the South China Sea (Figure 2.1). It gained independence from Britain in 1957 to form a constitutional monarchy and be an independent state in the Commonwealth. The country is a federation of 13 states and three federal territories. The country is bordered by Thailand at the north and Singapore and Indonesia at the south, strategically positioning it to be a critical Southeast Asian hub of trade and development. This location also placed the country in the proximity to a major route of illicit drug trafficking in the area called the Golden Triangle (the area where the borders of Thailand, Myanmar and Laos meet) (17).

The Malaysian economy is considered one of the economic success stories, achieving more than seven per cent growth rate per year over 25 years (18). This economic growth places Malaysia at the level of Upper-Middle Income level according to the World Bank criteria. Despite the improved economy and returns, the government in Malaysia is spending around 4% of the Gross Domestic Product (GDP) on healthcare annually, much less than other Southeast Asian countries, including poorer Thailand and the Philippines. This situation is reflected by the high proportion of out-of-pocket household expenditure on health (almost 40% of healthcare expenditure) (19).

The booming economy starting with the New Economic Plan of the early 1970s has led to the change in the urban-rural population distribution and the influx of migrants (mostly illegally) from the less affluent neighbours, including Indonesia, Nepal, Myanmar and Bangladesh

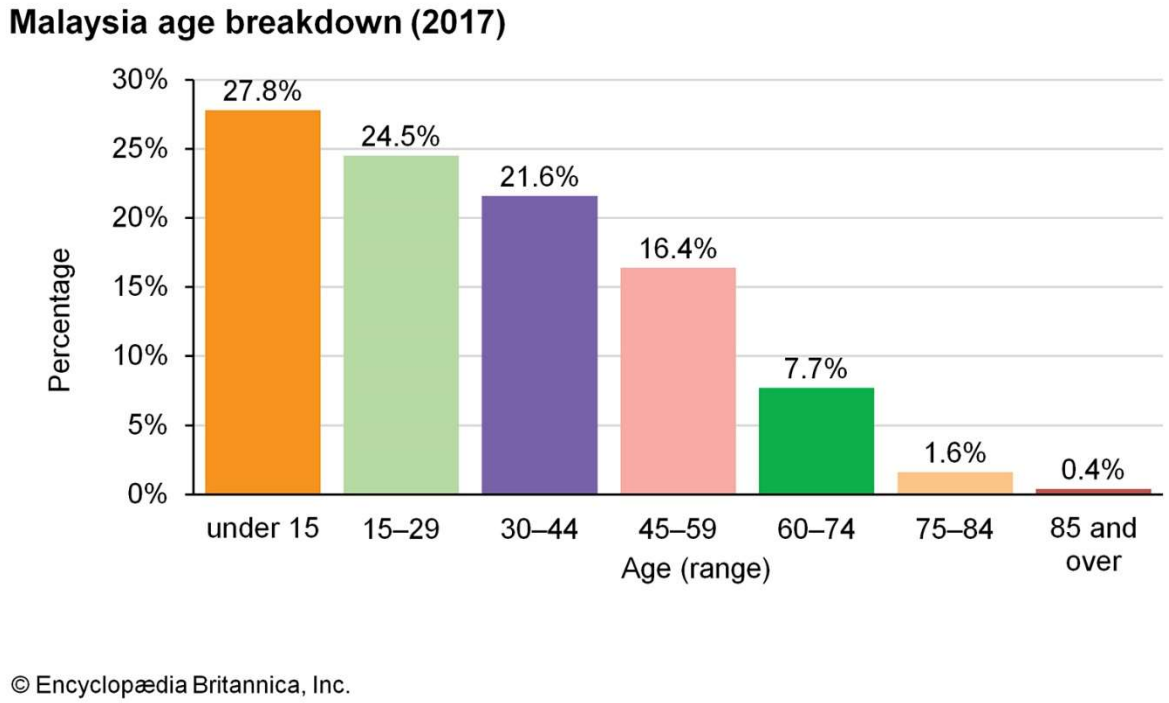
(20). A recent estimate showed that there are 2.1 million documented migrants and likely over 1 million undocumented migrants in the country, making up to 15% of the workforce in the country (18).

**Figure 2.1** Malaysia (Source Encyclopaedia Britannica, Inc.)


### 2.2.2 Demographics of the Malaysian society

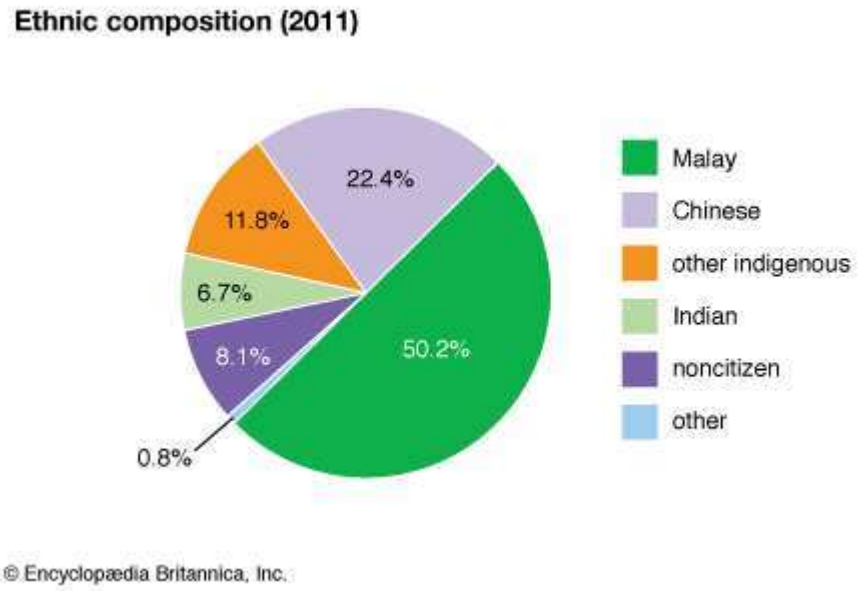
The current census estimates that 32,165,000 people are living in Malaysia with an annual population increase of 1.5% (17). The current population density is 97.4 persons per square kilometre, mostly concentrated in Peninsular Malaysia, particularly in the Klang Valley (the part of the country that includes the capital city, Kuala Lumpur, and part of the Selangor state) (17). Malaysia has a rich racial, cultural, and religious diversity. The majority of the population (74.4%) lives in urban areas, primarily driven by the improved economy in major cities (20). Education is widely accessible, and this is reflected by the high percentage of literacy in the population (96.2% and 93.2% for men and women, respectively). The population of Malaysia remains young, with a median age of 28.3 years (Figure 2.2) (21).

**Figure 2.2** Age group distributions in the Malaysian community (Source: Encyclopaedia Britannica, Inc.).




The Malaysian community is racially diverse and composed of three major ethnic backgrounds (Malay, Chinese, and Indians) in major cities (Figure 2.3). The Malay represents the dominant racial group (50.2%), followed by Chinese (22.4%), other indigenous people (11.8%), non-citizens (8.1%), Indian (6.7%), and others (0.8%) (17).

**Figure 2.3** Ethnic backgrounds of the Malaysian community (Source: Encyclopaedia Britannica, Inc.).




### 2.2.3 The prison population in Malaysia

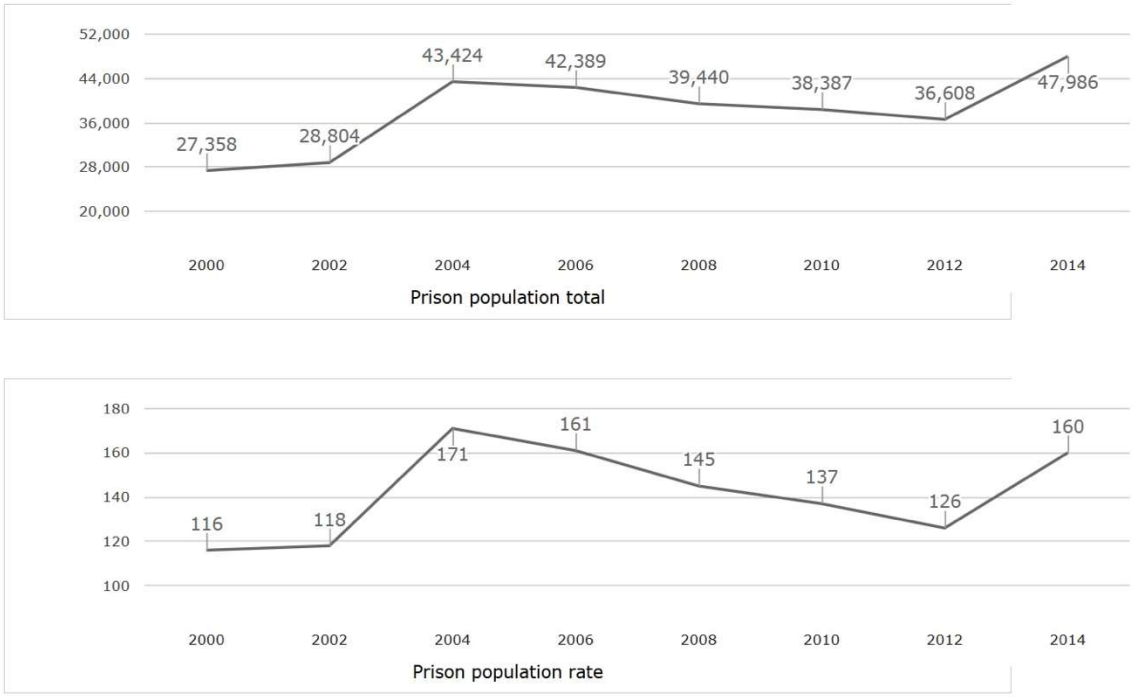
There are several detention facilities managed by departments under the Ministry of Home Affairs (MHA) in Malaysia. As of 2018, 47 correctional institutions were in the country, including 35 prisons, four reformatory centres, five specialised recovery centres, and three schools for juvenile offenders (22). These facilities are managed by the Malaysian Prison Department and may include citizen and non-citizen detainees. The daily census in these institutions is estimated to be 51,602 detainees, exceeding the actual occupancy capacity of these facilities of 45,310 (a 113% occupancy level). Prisoners on remand (shorter stay in correctional institutions) represent 25% of the daily prison population. On the other hand, foreign prisoners represent almost one third (29.1%) of prisoners in Malaysia, most of them due to violation of stay permits (22).

There are additional 28 facilities managed by the National Anti-Drug Agency (AADK) also an agency under the MHA. Residents of these facilities are sentenced by the court to serve a period up to 2 years of compulsory drug rehabilitation. These facilities detain Malaysians only, and the census in these facilities is estimated to be 6,658 in 2010 (23). Access to proper healthcare services was reported to be deficient in these centres (23). The AADK is in the process of phasing out these facilities and replacing them with voluntary rehabilitation centres (24).

Additionally, there are 13 immigration detention centres managed by the MHA's Malaysian Immigration Department (25). These facilities detain illegal migrants in their transit to be repatriated to their home countries, but detainees may spend years before repatriation. Some detainees may be released to the Malaysian community if they are proved to be holders of a refugee status card issued by the United Nations High Commission on Refugees (UNHCR) (26). It is estimated that by the end of 2013, there were 8,857 detainees in these facilities (25). The situation in these facilities was reported to be dire, with over 100 individuals died in two years (2015-2016) (27).

The increase in incarceration rates over the past three decades puts Malaysia among countries with the highest incarceration rates in Southeast Asia at 167 per 100,000 population **(Figure 2.4)** (22). Draconian criminalisation of drug use was reported to be one of the reasons behind this surge in the incarceration rates with more than half (56%) of prisoners in the Malaysian correctional system reportedly being charged for drug-related offences. Of note, 4% of the population is estimated to use illicit drugs (28,29). These regulations followed an illicit drug use surge in the early 1980s, prompting the government to impose harsh laws, including imprisonment for possession, use and trading with drugs in the country. The laws also imposed the death penalty for drug trafficking (30). These regulations introduced compulsory rehabilitation of PWUDs in mandatory detention centres with poor access to evidence-based tools to manage illicit drug use (31). Being the most common route of transmission of HIV infection in Malaysia, criminalisation of drug use has led to the increase in the proportion of prisoners living with HIV in correctional institutions in the country, reaching a prevalence 15 time higher than that of the general population in one prison (14).

**Figure 2.4** Total prison population and rate in Malaysia. (22)




## 2.3 Tuberculosis in Malaysia

### 2.3.1 The epidemiology of tuberculosis in Malaysia

TB remains one of the significant public health problems in Malaysia (32). The incidence rate of TB has been increasing in Malaysia over the past decade and is currently estimated at 92 per 100,000 population (5). Testing for HIV infection among TB cases was high, with around 90% of active TB cases knowing their HIV status. The prevalence of HIV among new TB cases was estimated to be 6% (1,700 TB cases were living with HIV infection) in 2016 (5). Despite strong WHO recommendations to prescribe highly active antiretroviral therapy (HAART) to all HIV infected individuals with TB disease, only a third (31%) of TB/HIV cases received ART in 2016 (5). It was estimated that 1,590 TB-related deaths occurred in Malaysia in 2016, placing TB as the number one killer from infectious diseases in the country, surpassing HIV and dengue fever, two other common infections in the country (33). The prevalence of multidrug-resistant TB (MDR-TB) was estimated to be 1.5% among newly diagnosed TB cases and 3.1% among previously treated cases with a total number of 370 MDR-TB cases in 2016 (5). The MOH in Malaysia reported that the prevalence of MDR-TB had increased four-fold from 2005 to 2011, from 0.3% to 1.3% (34). In 2012, the first Extensive Drug-resistant TB (XDR-TB) case was isolated in Malaysia in a 57-year old individual, bringing an additional burden to the control of

TB in Malaysia (35). TB treatment success, described as a confirmed cure of TB or completion of a full TB regimen, was reported to be 78%, lower than the recommended WHO's target of 85% (36). Successful treatment outcomes were even lower in HIV-infected, previously treated TB cases and cases with MDR-TB at 62%, 55%, and 32%, respectively (5). A thorough examination of causes of unfavourable TB treatment outcomes has shown that mortality (46%) and treatment transfer/default (49%) were the main reasons behind the unsatisfactory treatment success rate in Malaysia (37). With these figures, Malaysia failed to achieve the MDG (Goal 6) set by the United Nations in 2000 to halt and start to reverse the increase in TB incidence and to halve the TB mortality by 2015 compared to 1990 figures (38).

Reasons behind the failure to control TB in Malaysia were not explained anywhere, despite the availability of robust healthcare infrastructures (39). It is likely that several factors were involved, including limited access to TB care among marginalised populations like PLWH, prisoners, and PWUD. (40). Migration, particularly of illegal migrants from the neighbouring high burden countries like Indonesia, Vietnam and Cambodia, might have contributed to this failure to control TB, although statistics consistently show that the fraction of TB contributed by foreign individuals remains constant at around 10% (32).

The National TB Control Programme (NTP) was launched in 1961 and, since 1995, is managed by the Communicable Diseases Department of the MOH (32). Since 1995, the NTP has been decentralised with TB managerial teams in every state. The NTP has adopted the Directly Observed Therapy Short-term (DOT) strategy developed by the WHO to control TB following the declaration of the state of global health emergency because of TB in the early 1990s (41). Under the NTP regulations, it is compulsory to report TB cases within seven days of diagnosis to be entered in the electronic national TB registry. Before the involvement of MOH in delivering healthcare in prisons in Malaysia in 2015, the NTP had no direct involvement in the TB management in Malaysian prisons.

### 2.3.2 Tuberculosis treatment guidelines in Malaysia

The current Clinical Practice Guidelines on Management of Tuberculosis (third edition) was released by the Ministry of Health in Malaysia in 2012, 10 years after its second Edition in 2002 (34). This Edition was labelled as "the first evidence-based TB guideline in Malaysia" and is primarily based on recommendations of the United States' Centre for Disease Control and Prevention (CDC) and WHO TB treatment and prevention guidelines.

The guidelines stressed that individuals with high risk for TB, including prisoners, need to be "considered" for screening for active TB. The guidance, though, provided no further information about the methods to be used for screening in these populations and the logistics needed for running such programmes. Additionally, the guidelines affirmed that all TB cases should be offered simultaneous screening for HIV infection.

The guidelines endorse the use of new diagnostic tools to improve case detection, including the Light Emission Diode Fluorescence Microscopy (LED FM), GeneXpert MTB/RIF (Xpert), and Line-Probe Assay to detect MDR-TB cases.

The guidelines also reaffirmed the endorsement of the WHO's DOTS strategy in prescribing daily short-term TB treatment under direct observation. New TB cases receive standard anti-TB medications for a minimum duration of six months. The medications need to be provided on a daily basis during the intensive and maintenance phases. The guidelines also stressed the direct observation of treatment, "whenever possible", by a government healthcare worker with the possibility of including non-governmental organisations to reinforce compliance. The guidelines stated that if a TB case defaulted treatment, a reminder is sent to the patient and if he/she failed to comply, a home visit is made by a healthcare worker to examine the condition.

The guidelines stressed that screening for latent TB infection (LTBI) need to be restricted to individuals with high risk for TB, including PLWH, immune suppressed, institutionalised individuals (including prisoners), PWUD, recent migrants from high prevalence countries, recent close contact with TB case, and those with fibrotic lesions on chest radiographs. The tuberculin skin test (TST) is the preferred tool for the diagnosis of LTBI. Individuals with LTBI may be offered preventive treatment.

Additionally, all PLWH should be screened for TB disease, and those suspected of having TB disease should submit sputum for culture examination, irrespective of smear microscopy or chest radiography examinations. The guidelines described that the anti-TB regimen should be similar to that used in non-HIV-infected individuals. The timing of HAART use in TB/HIV co-infection is governed by CD4 lymphocyte count assessment: HAART is started during the intensive phase if CD4 <50cells/mL, during the maintenance phase, if CD4 >50cells/mL, and after completing the TB regimen if CD4 >350cells/mL.

No information exists about the mechanism to monitor adherence to these guidelines by either public or private healthcare sector professionals.

### 2.3.3 Tuberculosis in key populations in Malaysia

Studies addressing populations at increased risk of TB in Malaysia are generally scarce (40).

Globally, HIV infection is the strongest risk factor for LTBI and TB disease (42). The WHO estimated that the prevalence of HIV infection among TB cases in Malaysia was 6% in 2016 (5). An approximate finding (7.7%) was reported in a multi-centre study in urban Malaysia, but a higher prevalence (14%) was reported in a rural setting (40). TB and HIV healthcare services are free-of-charge in public health facilities in Malaysia, and treatment for TB and HIV is highly accessible. Despite this, one study revealed that almost half (46.6%) of HIV-infected patients with TB have an unsuccessful TB treatment outcome, mostly due to treatment default (43). The WHO reported that 69% of PLWH were prescribed preventive therapy in Malaysia in 2016, but the exact figure was not provided in the report (5). There is no information on any active TB survey among PLWH in the community in Malaysia.

Illicit drug use, especially through injection, is a recognised risk factor for LTBI and reactivation to TB disease, globally (44). Studies about this risk factor for TB in Malaysia remain limited and are not primarily targeting PWUD, but rather in association with studies addressing HIV infection (40). A study was conducted in a private outpatient clinic caring about PWUD in Johor State in Malaysia, which showed that 9% of attendees of the clinic had a confirmed TB disease (45). A recent study among randomly selected PWUD in a voluntary drug rehabilitation centre in Kuala Lumpur showed a high (86.7%) prevalence of LTBI (46). Given that 1.1% of the Malaysian population is estimated to be PWUDs (47), more focused studies are needed to address this critical risk factor for latent TB infection and TB disease.

Similarly, there are very few studies addressing TB among prisoners in Malaysia. Recent studies have reported a high prevalence of latent TB infection (88.8%) and active TB disease (8.5%) among prisoners in the largest prison in Malaysia (7,10). More discussion on this risk factor is provided later in the chapter.

Despite increased risk and national and international recommendations, limited information exists about tracing contacts of those with active TB disease in Malaysia. A study in the Penang General Hospital revealed that contact tracing process was not prioritised (48), and this was confirmed by a recent review concluding that contact tracing in Malaysia remains suboptimal (49).

Owing to their direct contact with patients with or suspected of having infectious TB, healthcare workers (HCWs) are at increased risk of being infected with TB. Four studies addressed the prevalence and incidence of active and latent TB among HCWs in tertiary settings in Malaysia. The prevalence of latent TB was reported to be 52% in a study using TST and 10.6% using the Interferon Gamma Release Assay (IGRA) (50,51). Two studies reported very high annual incidence of latent TB infection (9.9 per 100 workers) among 769 HCWs in Kuala Lumpur and incidence of TB disease (2804 per 100,000 population) in the Sabah State (52,53). The authors recommended strengthening infection control measures in hospitals in Malaysia.

The association between diabetes mellitus (DM) and TB is well-established, and with the current increasing global trend in DM, the synergistic effect of the two diseases is projected to increase the burden of TB, particularly in high-burden, poorer countries (54). A review of publications on TB in Malaysia revealed that five studies had examined the prevalence of diabetes in TB cases in Malaysia with variable estimates from 14% to 33% (40). Studies looking for the prevalence of TB in diabetes patients in Malaysia showed approximate findings (18-30%) in three studies. These studies were small in size(40).

Cigarette smoking is projected to be a significant factor hindering the efforts to control TB, globally (55). In Malaysia, the prevalence of smoking among adult males was reported to be 46.5% (95% CI: 45.5%-47.4%) (56), and smoking was shown to be prevalent in 40-50% of TB cases in four small studies (40). The effect of tobacco smoking on increasing TB risk was not assessed in any study from Malaysia.

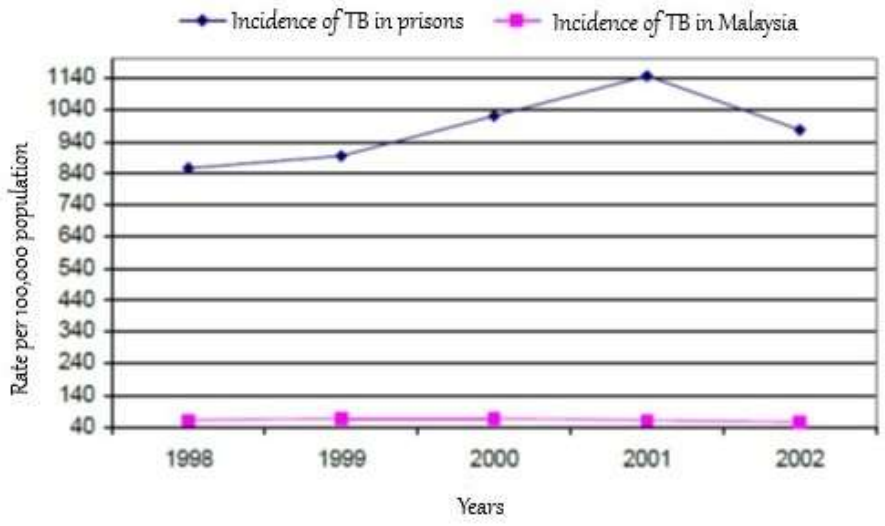
## 2.4 Tuberculosis in prisons in Malaysia

### 2.4.1 The epidemiology of tuberculosis in prisons in Malaysia

The prisons' environment and population facilitate the transmission of TB in these settings, particularly when timely healthcare services are limited (2).

The latest guidelines for screening for TB and HIV in prisons in Malaysia is dating back to 2003. The guidelines reported that the average incidence of TB in prisons in Malaysia over five years (1998-2002) was 978.6 per 100,000 prisoners, which is 15 times higher than the incidence of TB in the general population in Malaysia at the same period **(Figure 2.5)** (57).

**Figure 2.5** The incidence of TB in prisons and community in Malaysia (1998-2002). (57)




| Year | 1998 | 1999 | 2000 | 2001 | 2002 |
|---|---|---|---|---|---|
| Number of TB cases in prisons | 249 | 236 | 268 | 316 | 328 |
| Incidence rate of TB in prisons (per 100,000 prisoners) | 854 | 895 | 1019 | 1148 | 977 |
| Total TB cases in Malaysia | 14,115 | 14,908 | 15,057 | 14,830 | 14,389 |
| Incidence rate of TB in Malaysia (per 100,000 population) | 63.6 | 65.6 | 64.7 | 62.3 | 58.7 |

In 2001, a screening survey among 1857 HIV-infected inmates at prisons and drug detention centres in Selangor State revealed a high (11.7%) prevalence of TB disease (58). Studies from prisons in Malaysia revealed a very high prevalence of LTBI among prisoners in two prisons (87.6% and 88.8% of prisoners in Pengkalan Cepah and Kajang prison, respectively) and prison employees of a central prison (81%) using TST (7,8,59). These findings were, not surprisingly, several folds higher than the prevalence of LTBI in the general population in the region (9).

These prison studies also revealed that LTBI was independently associated with previous incarcerations for prisoners and longer duration in prison employment for prison staff; possibly referring to increased risk of exposure in prisons in Malaysia.

Following-up on these findings, an intensified active TB case finding survey in Kajang prison in Malaysia revealed that most (71%) TB cases in the prison were missed by the prison health authorities, posing a significant risk to other prisoners, prison staff, and the community at large (10). The overall prevalence of TB disease in that survey was high (8.5%). Confirming these findings, studies addressing access to proper healthcare services by individuals in detention in Malaysia showed inadequate healthcare provision, particularly among PLWH. There was a lack of access to TB sputum examination, provision of HAART or opioid addiction treatment in six compulsory drug detention and rehabilitation centres in Malaysia (23). Similarly and despite the high prevalence of infectious diseases among prisoners living with HIV in the largest prison in Malaysia, there was limited access to HAART medications, even among prisoners with advanced HIV (CD4 lymphocyte count $< 200$ cells/mL) (60).

### 2.4.2 The current tuberculosis control practices in prisons in Malaysia

The latest guidelines for screening and management of TB and HIV in correctional settings in Malaysia were written by members from MOH and MHA and date back to 2003 (57). The information provided in the guidelines is not only out-of-date, but also primarily non-evidence based. The guidelines stress on screening prisoners at entry to prisons and contact tracing of passively diagnosed TB cases using symptoms, but no routine surveillance for TB in the incarcerated prisoners. The symptoms included in the screening protocol were two only: cough for two weeks or more and coughing up blood. Using these two symptoms alone may miss many TB cases presenting with other common symptoms or having extrapulmonary TB. They, on the other hand, emphasise the use of chest radiography to exclude TB disease in asymptomatic HIV-infected prisoners at prison entry. The guidelines also recommend the use of sputum smear microscopy examination for symptomatic prisoners to diagnose active TB with no reference to culture examination anywhere in the guidelines. The guidelines stressed the provision of standard TB treatment for those with smear-positive TB, irrespective of the HIV status. The guidelines also stress on the use of direct observation for TB treatment (DOT) and the isolation of TB patients in a dedicated housing block in prisons. The guidelines allow the involvement of non-medically trained prison staff to assist in screening, observation of

treatment and collection of sputum, risking a conflict between their job as correctional officers and offering medical care (57).

These guidelines do not conform with the international guidelines to control TB in prisons, including those developed earlier by WHO (2). The 2001 WHO guidelines stressed the use of multiple modalities (symptoms scoring system, previous episode of TB and radiograph findings) to define TB suspects, to perform entry and routine TB screening, and to utilise culture examination, particularly in the re-treatment group.

Moreover, since their development in 2003, there were no reports that provided information about the adherence to the guidelines protocol by individual prisons in Malaysia. This makes it difficult to assess the efficacy of these interventions in controlling TB in prisons in Malaysia.

### 2.4.3 The health system management in prisons in Malaysia

The health of prisoners in Malaysia is directly managed by the Prison Department. Prior to 2015, the prison department relied on recruiting private healthcare workers (including doctors and medical assistants) to attend to the daily management of medical cases in prisons. These private HCWs were involved in TB screening, maintenance of TB-related medical records, initiation and follow-up of TB treatment and liaison with the public health department to refer patients who require further assessment or care. At the time, the MOH involvement was confined to provision of TB medications, examination of sputum specimens sent by prisons and management of referred case from the prisons to the community healthcare facilities. In 2015, the MOH decided to provide medical officers and medical assistants to replace health providers hired by the Prison Department, but refrained from providing medications or test sputum specimens, unless prisoners are referred to one of its community facilities. Most of the provided medical officers had limited background knowledge about case management in correctional facilities (61).

The TB screening process at entry to prisons in Malaysia is managed by medical assistants who enquire about symptoms among new entrants. Those with symptoms referred to active TB are asked to see a medical officer for further assessment. This process is not universal in all prisons and largely dependent on the availability of human resources. TB case detection, thereafter, is a passive process, depending largely on the self-presentation of prisoners with symptoms (10). Among already incarcerated prisoners, housing units' wardens are the first point of contact in

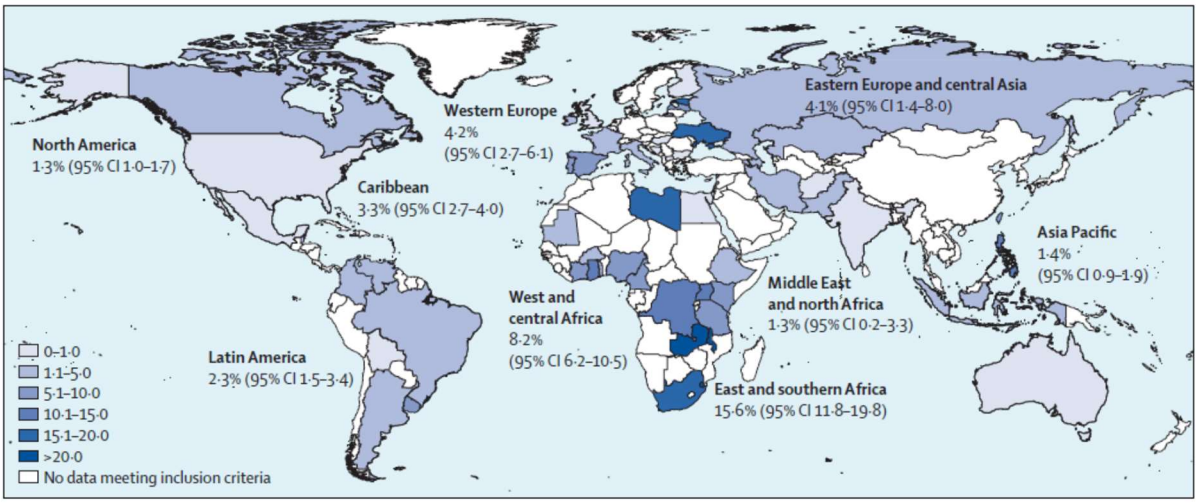
order to arrange for a prison clinic appointment. These prison staff members are not medically trained and might not be able to properly triage prisoners who require further assessment (61). As there are no diagnostic facilities in prisons in Malaysia, prisoners may experience another period of delay if a referral to a community health facility is required. Likewise, treatment and follow-up on prisoners with TB are performed in a community health facility. Prisoners diagnosed with TB in prisons are isolated for two weeks in a communal ward in the prisons' clinic areas. Prisoners with TB who are due to be released before treatment completion are seen at the day of release and provided with a referral letter, a treatment book and up to 7 days of TB treatment; a policy that is not routinely implemented.

### 2.4.4 The epidemiology of HIV infection in prisons in Malaysia

HIV infection in Malaysia is primarily driven by injection drug use (IDU), where around 75% of HIV infection was reported to be IDU-related (62). This group faces regular police surveillance and criminalisation by the law, and they frequently return to being involved in more risky injection behaviours, including sharing of needles (62,63). Owing to the high prevalence of HIV infection among this population, poor nutrition, unhealthy injection environment, and limited access to healthcare services, people who inject drugs (PWID) are also at increased risk of TB (44,64). The prevalence of HIV infection is estimated to be 0.4% among Malaysians aged 15-49 years of age. Although it has improved tremendously over the past three years, HAART coverage remains low at 37% for adults and children living with HIV(65).

The problem of HIV infection is augmented in prisons, where access to proper healthcare services is limited. Harm reduction tools services are almost non-existent. Needle syringe programmes are not permitted, and in most prisons, MMT for opiate addiction is very limited. Mass incarceration of PWUD has driven the HIV infection epidemic inside prisons in several countries, particularly those countries that impose harsh punitive practices against PWUD, including Malaysia (Figure 2.6) (3,62). The prevalence of HIV infection in prisons in Malaysia was reported to be 6%, 15 times higher than that of the general population (14). Access to HAART and management of TB and other opportunistic infections remains generally low (60).

**Figure 2.6** The prevalence of HIV infection among prisoners. (Source: WHO (63))




### 2.4.5 Continuation of healthcare of prisoners after release in Malaysia

Despite its essential contribution to individual and public health, information about the continuation of TB care after release from prisons in Malaysia does not exist. This is likely due to the poor communication between prison and public health departments about released prisoners with uncompleted TB treatment in prisons. Despite TB cases in prisons being notified to public health department, notification of the public health department about the status of released prisoners is not consistent.

Few studies addressed the complex situation inside and outside prisons concerning HIV care in Malaysia. Findings from these studies are important, but not necessarily apply to TB care, warranting the need for TB-relation prison studies. A study reported that several significant community re-entry challenges face soon-to-be-released HIV-infected prisoners in Malaysia including staying out of prisons (60.8%), remaining drug-free (39.2%), finding employment (35.3%) and obtaining HIV care (32.4%) (14). A formative research to develop an evidence-based package to address challenges of soon-to-be-released prisoners in Malaysia showed that half of HIV-infected prisoners injected heroin soon after release from prisons, most within the first post-release week (66). The study also showed that knowledge about HIV risks and the benefits of opioid agonist therapy (OAT) remains low. Prescribing OAT and HAART in prisons was cited to be “hard” by one of the interviewed prison doctors in this study, clearly pointing to the poor access to OAT and HIV care in prisons in Malaysia (66). A more recent study confirmed this assumption and quantified the poor access to HIV healthcare services by

prisoners, both inside and outside prisons in Malaysia. The study showed that most of the HIV-infected prisoners (75.3%) were not engaged in pre-incarceration HIV care, and only 16.7% were prescribed HAART before prison entry. The gap also remained large after prison entry with less than half (48.4%) of those who need HAART (CD4 lymphocyte count less than 350 cells/mL) receiving it eventually (60). Several, non-Malaysian, studies have shown that even with proper access to HIV care in prisons, the benefit of this care might be lost shortly after release from prisons. A systematic review of related studies revealed that HIV care increases following HIV diagnosis in prisons, but declines substantially after release to the community to a level even lower than that before incarceration (67). No similar studies were conducted in Malaysia.

A harm-reduction study in Malaysia reported that prisoners released with a higher dose of MMT (≥ 80mg per day) had significantly higher rates of retention in HIV care in the community (68). The study reported that after 12 months of release, only 21.4% of participants on < 80mg was retained in care compared to 61.5% of those on ≥ 80mg ($p < 0.01$). Of note, MMT use in prisons in Malaysia is limited. The utility of MMT use in improving retention in TB care among PWID was examined elsewhere (69), but no study was conducted to address the efficacy of OAT in improving retention in TB care after release from prisons, globally. Such a study might be of relevance to the situation in Malaysia, given the high prevalence of illicit drug use among prisoners with TB (empiric data provided in this PhD project).

## 2.5 Ethical considerations of research in prisons

Despite the importance of involvement in research studies in order to improve health, prisoners, being a vulnerable group, might be subjected to ethical breaches when recruited for medical research in prisons (70). This is due to the fact that prisoners are deprived of their liberty and, in some places, of choices when it comes to involvement in research. Areas of potential ethical breach in research include privacy issues, coercion, and involvement of prison staff in decisions to enrol a participant in research studies.

The ability to mitigate the influence of the prisons' personnel on prisoners might be difficult in certain situations and requires a rather major approach that involves the participation of all stakeholders in supporting participating prisoners. Several approaches were utilised when performing research in prisons in Malaysia, including the current PhD research. These include the use of codes rather than actual names in the interview forms, de-identification of interview sheets, the provision of detailed information sheets and a robust consent process,

informing both prisoners and prison staff that participation is voluntary, the utilisation of private rooms for interviews, and participation status remaining anonymous. The collected data were de-identified and stored in a secure place in the university. Prisoners who refused to participate in the study were not in any way disadvantaged and their names were not revealed. Prisoners diagnosed with active TB were informed as soon as the results were available and informed of their referral to the prison's doctors for further assessment and treatment.

## 2.6 Conclusion

Malaysia is a country with a broad cultural, geographic, and racial diversity. The country has a reasonably strong economy and a well-structured health system. Despite these features, the country failed to control TB over the past three decades. Several factors might have been involved to contribute to this failure in controlling TB in the country. Information about the burden of TB, particularly among at-risk populations (e.g., PLWH, PWUD, diabetics, immune suppressed and prisoners) remains limited. Failure to address TB in this group of individuals might have contributed to the failure in achieving TB control targets. The influence of migration, particularly from high-burden neighbouring countries, need to be thoroughly examined.

Access to TB-related healthcare services in prisons in Malaysia remains limited. Several managerial steps need to be implemented to achieve structured TB control services in prisons in Malaysia. These steps should start with updating the current TB control guidelines in prisons in Malaysia. Additionally, proper staffing, training of medical personnel, and health education programmes are crucial to achieve the programme's control goals. Appropriate prison-public health communications are required to ensure the post-release continuation of TB care. Finally, finding alternatives to incarcerations, particularly for PWUD might influence overcrowding, and hence TB spread in prisons in Malaysia.

# CHAPTER THREE: THE PREVALENCE AND CORRELATES OF ACTIVE TB AT THE ENTRY TO A PRISON IN MALAYSIA

## 3.1 Introduction

This chapter provides background information, study methodology, findings, and discussion regarding the first study of the PhD project. The study was conducted in the largest prison in Malaysia and was designed based on the observation from an earlier intensified TB case finding survey that most of TB cases were diagnosed in the first three months of entry. This finding is likely attributable to the failure to diagnose active TB at the entrance to the prison. At the time of the survey, there was no formal TB screening at the entry to this prison. The study was conducted as part of studies to define the actual size of the TB burden in the Malaysian correctional system. The study involved the screening for TB of both HIV-infected and non-HIV-infected prisoners using a pre-designed screening algorithm and with the utilisation of new rapid diagnostic tools. The study was conducted over the years of 2013-2015. The student researcher started his PhD study in 2016 and the data from this study were not analysed in full previously nor published in peer-reviewed journals anywhere. Some of the earlier findings were, though, presented to stakeholders in order to support changes in current TB screening practices. Findings from the study will have significant implications for further research and policy changes.

## 3.2 The review of literature

In order to provide background information for the study, a review of globally published peer-reviewed reports was conducted. The review provided information about the previously conducted research studies and information to develop the conceptual framework of this study.

### 3.2.1 The literature review protocol

The review question was set to define the prevalence of TB disease at the entry to prisons, globally and to define factors associated with TB at the entry to prisons. A literature search was conducted using Medline and Embase databases through the Ovid(SP) and Web of Science using a keyword structure (“tuberculosis” AND “prison” AND [“entry” OR “enter” OR “new”]). The search included these keywords anywhere in the text. No restrictions were placed

on the language of the publication, the publication type (journal articles or conference proceedings), the study design, or the year of the publication. Initially conducted at the time of preparing the study in 2013, this thorough search was re-performed in July 2020 to include recent publications. After removing duplicates, the abstracts of collected publications were examined thoroughly for the inclusion in the final literature review. Publications included in the final review must have presented information about the prevalence of active TB at the entry to prisons. Publications that provided information specifically about the prevalence or incidence of active TB disease in already-imprisoned inmates were excluded from the review. Abstracts of publications with languages other than English were translated using google translate, and if that showed eligibility for inclusion in the review, professional translations were sought.

An extraction form was developed to extract information of interest from each study. This form included information about the location of the study, the number of prisons involved, the diagnostic tool to define active TB, the number of prisoners screened, the prevalence of active TB at the entry, the prevalence of HIV among TB cases and factors associated with TB at the entry.

To assess the limitations of reviewed studies, we utilised the GRADE guidelines checklist to evaluate the risk of bias in observational studies (71). Assessed risks of bias include failure to develop and apply appropriate eligibility criteria, flawed measurement of both exposure and outcome, failure to control confounding adequately, and inadequate follow up.

Extracted information was presented on an evidence table (See Table A1).

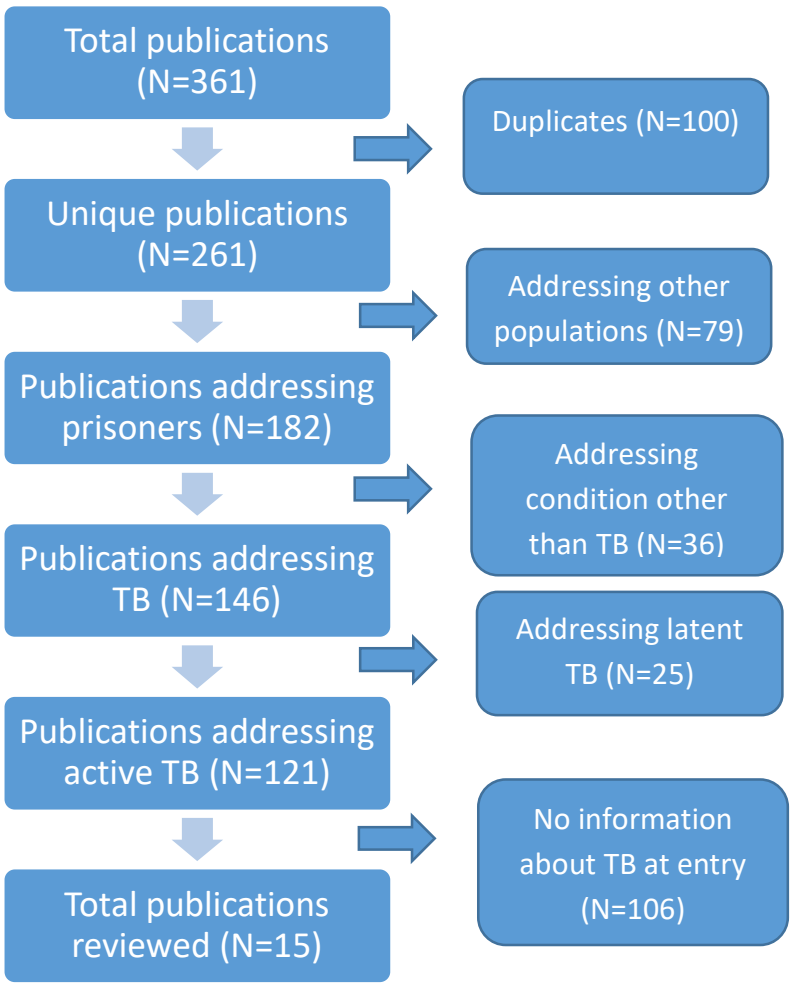
Additionally, we calculated the mean prevalence of TB at entry from the reviewed studies.

### 3.2.2 Description of the studies (see table A1-1)

The search has yielded 361 publications from the three databases: Medline (N=52), Embase (N=114), and Web of Science (N=195). Following the removal of duplicates, 261 unique publications were identified. Upon direct screening of abstracts of the collected publications, 15 reports provided information about the prevalence of active TB disease at entry to prisons, globally. Reasons behind the exclusion of publications (N=246) were not providing information about the prevalence of TB at the entry (N=106), not involving prison population (N=79), addressing diseases other than TB in prisons (N=36) and those that were explicitly conducted to determine the prevalence of latent, rather than active TB at entry (N=25) (Figure 3.1). Table A1-1 provides further detail on the included publications.

Overall, half (N=8) of the studies were conducted in LMIC (Malawi, Bangladesh, Uruguay, Russia, Zambia [2 studies], Brazil, and Ethiopia). There was a heterogeneity in the definition of a TB case with most studies relying on chest radiograph (seven studies), particularly in high-income countries, while the rest of studies utilised smear microscopy or culture to define TB cases.

**Figure 3.1** Flow chart of the literature search and selection.




A survey among correctional facilities in 22 European countries in 2003 revealed that most (91%) prisons in these countries conduct routine entry screening for active TB among prisoners with chest radiograph being the mostly utilised primary screening and diagnostic tool (60%) (72). The median prevalence of TB at entry was 393 per 100,000 entrees (range 42-2362). The study was a review of TB burden and practices in prisons in the region, and no information was

provided about the recruitment process, the definition of the outcome and assessment of factors associated with TB disease among new entrants.

An active case finding using sputum smear microscopy, irrespective of symptoms in a district prison in Malawi in 1997 revealed high (4%) prevalence of smear-positive TB among new entrants of the prison (73). No information was provided about factors associated with active TB disease apart from the fact that active TB was diagnosed mostly among prisoners with a duration of cough of more than three weeks. There is a potential risk of selection bias as no reasons were given to explain that less than half of prisoners provided sputum for examination (only 111 out of 254 entrants [45.3%]).

A chest radiograph-based intensified TB case finding survey among male prisoners upon entry to the New York City correctional system in 1968 revealed an overall prevalence of 2 active TB cases per 1,000 prisoners (74). All prisoners entered the system during that year (N=15,000 prisoners) were screened. The study has several potential bias risks. The authors did not provide details about the definition of TB and the recruitment process, including those with no chest radiograph. Additionally, measurement of the outcome (TB prevalence at entry) was not thoroughly detailed. The study did not provide information about risk factors associated with active TB at prison entry and hence no control to potential confounders.

Another assessment of the efficacy of the new entry screening practices in the correctional system in the State of Georgia (United States) was based on tuberculin test and chest radiograph examination during 1991-1995 (75). The study revealed that the prevalence of active TB at the entry was 113 per 100,000 entrees. This prevalence was ten times higher than the prevalence of active TB in the general population of the State of Georgia (12 per 100,000 population). Most TB cases were men (93%), young (median age 36), and had pulmonary disease (88%). 41% were HIV-infected in an overall HIV prevalence of 3% in the prison population. The retrospective study did not provide information about how TB, the outcome of interest, was defined among new entrants. Though sociodemographic information was collected, no assessment of associated factors with TB were presented in this publication.

Banu S, et al (76) reported findings from an intensified case finding upon entry to a prison in Dhaka, Bangladesh, from October 2005 to February 2010. The study was based on symptom screening as the primary tool to define TB suspects to be further investigated using smear

microscopy and culture among the 100-120 prisoners entering prison each day. TB disease was defined as those with positive culture examination, irrespective of the smear microscopy results. Among the 42,367 prisoners screened upon prison entry, 44 were confirmed active TB cases, giving a prevalence of active TB at the entry of 103 per 100,000 entrees. Of note, most of the TB cases (N=40 [91%]) were infectious (positive on smear microscopy examination). Despite involving the screening of all prisoners who entered the prison during the study period, the study did not collect baseline information about potential risk factors for TB.

A cross-sectional survey among male prisoners entering a prison in the Uruguay (N=1959) in 2016 revealed a prevalence of smear-positive active TB of 660 per 100,000 entrees (77). All entrants were screened using sputum microscopy, and those with positive results were labelled as active TB. No detailed description of the recruitment process was provided. Despite the collection of demographic information, no detail about the associated factors with active TB at entry was given.

Conducted between February and April 2011, an intensified TB case finding among prisoners entering the largest prison in the Zambia using smear microscopy, irrespective of symptoms, revealed a prevalence of active TB of 7300 per 100,000 entrees (26 out of 317 entrees), of whom 17 were bacteriologically confirmed, and nine were clinically diagnosed (78). Active TB was diagnosed either bacteriologically or clinically. The recruitment process was clearly defined, but no risk factors assessment was performed.

In another screening for active TB at entry into three prisons in Zambia using both routine and comprehensive screening revealed an overall prevalence of 2700 per 100,000 entrees (60 out of 2231 prisoners) during a 9-month screening period in 2010, with a significantly higher prevalence of smear-positive TB in the comprehensive entry screening group (3.6% versus 0.3%, $p<0.001$) (79). The recruitment process was detailed, but no information about risk factors for active TB at entry was reported.

Layton MC, et al (80) reported a prevalence of active TB of 767 per 100,000 entrants at the admission facility in Manhattan (New York, the United States) among prisoners entered during May and July 1993 (32 out of 4,172 entrees). Most (78%) were diagnosed before the admission, while seven (22%) were newly diagnosed. The study utilised positive symptoms screening, history of active TB, and abnormal radiographic findings to define those eligible for sputum

examination. The definition of TB cases was not provided, but findings showed the use of both bacteriologic and clinical diagnosis. The recruitment process was detailed, but no assessment of risk factors associated with TB was presented.

An entry screening for active TB using chest radiograph in the Cook County jail in Chicago over 24 months (March 1992 - February 1994) reported a prevalence of 68 per 100,000 entrees (86 out of 126,608 screened at entry) with 11 (16%) been diagnosed with active TB before the entry to the correctional institution (81). Case definition was both clinical and bacteriologic using culture examination. Despite collecting information on a few potential risk factors for TB (homelessness, IV drug use, alcoholism, and HIV), no proper assessment of the effect of these factors was provided.

A retrospective review of entry data from the Federal Bureau of Prisons in 1992 (following the digitalisation of the medical record data) revealed a high prevalence of active TB at entry to prisons in the United States (405 per 100,000 population). Collection of potential risk factors for active TB at the entry to the system was not performed (82).

A review of records of entry screening into two remand prisons (SIZO) in St Petersburg city in Russia, from 2000 to 2002 using chest radiograph was reported. The study showed a high prevalence of active TB at entry to SIZO-1 (average of 1,546 per 100,000 entrees over the three years) and SIZO-4 (average of 806 per 100,000 entrees over the three years). Case definition was both clinical and bacteriologic, and details of the recruitment process were provided. The study did not collect information for risk factor assessment (83).

A two-stage screening survey for active TB at the entry to a prison in Brazil (over two years, 2005-2007) using chest radiograph as a screening tool was reported. The study revealed a stable prevalence of active TB at the entry point: 2.8% (21/754) in the first year and 2.9% (28/954) in the second year (p=0.98). Active TB, the outcome of interest, was defined both clinically and bacteriologically using culture examination. The study collected a few baseline potential risk factors for TB, but their effect was not assessed. These factors include: symptoms, HIV infection, history of previous TB and previous incarceration (84).

A pilot programmatic assessment of TB screening policies at the entry to two prisons in Manchester (United Kingdom) reported no case of active TB among 451 prisoners screened

over two months in 2007 (85). Despite the collection of a few potential risk factors, no assessment of the effect of these risk factors was performed. These factors include history of TB, history of homelessness, history of close contact with a TB case, or coming from a country with high TB prevalence.

Finally, Sahle ET, et al performed a cross-sectional study among 8228 new entrants and 5575 resident prisoners of a large Ethiopian prison in the capital Addis Ababa during the period from August 2014 to November 2011 (86). The study utilised the WHO symptom scoring algorithm for TB in prisons to define those eligible for sputum examination that was performed using smear microscopy, Xpert and, in some selected cases, culture examination. The criteria to select samples for culture examination include smear microscopy positive for AFB and 10% of good quality smear negative samples; likely representing a selection bias. The study reported that nine cases among new entrants were bacteriologically confirmed active TB (a prevalence of 0.11%). The study explored risk factors associated with active TB but did not provide separate analysis for each group (new entrants and resident prisoners) and hence it is not known what factors were associated with active TB at entry to this prison. Overall, active TB was independently associated with a previous TB episode, history of contact with a TB case, and low BMI. The study reported several assessment and selection biases, including the reliance on poor quality sputum specimens, which might explain the lower prevalence of TB compared to previous studies in prisons in Ethiopia.

### 3.2.3 Summary of the literature review

Overall, studies reporting the prevalence of active TB at the entry to prisons remain scarce. The systematic search revealed only 15 unique publications that reported information about findings from screening surveys among prisoners entering prisons, globally.

These studies involved participants from both high- and low-/middle-income countries. Of note, almost one-third of studies was conducted in the United States (N=4) and only one study from Asia (Bangladesh).

The definition of the outcome of interest, TB at prison's entry, varied between studies. For logistic and diagnostic accuracy concerns, most of the studies in high-income countries utilised chest radiograph to define TB suspects. Unless sponsored by an international organisation, TB screening in LMIC is initiated by symptoms followed by sputum smear microscopy, if symptomatic.

Despite using different screening and diagnostic tools, studies showed an overall high prevalence of active TB at entry to prisons, irrespective of the economic state or the TB burden of the country. The TB prevalence ranged between 68-7,300 per 100,000 prisoners, being highest in sub-Saharan Africa's prisons (Zambia and Malawi, in particular).

Reviewed literature tended to link the high prevalence of TB among new entrants to prisons by the characteristics of entered prisoners (poor low socio-economic background, injection drug use, and HIV infection), and the failure of the healthcare system to address TB in this marginalised group.

Assessment of risks of bias in these studies using the GRADE checklist showed that studies conform to the eligibility criteria, but poorly define exposure and outcome variables. The studies also did not properly address potential risk factors of active TB at entry to prisons. Prisoners are usually coming from a low socioeconomic background, having a high prevalence of HIV infection and drug use, and having a history of frequent incarcerations.

Further studies are needed from high burden regions, including Asia, and to examine factors associated with active TB at entry to prisons, which is not addressed by reviewed studies.

## 3.3 MATERIALS AND METHODS

### 3.3.1 Study location

The study was conducted in Kajang prison, the largest prison in Malaysia. The prison is centrally located in the State of Selangor and receives prisoners from all over the country. Built to accommodate 3,500 prisoners, it was housing over 4,000 prisoners, a 120% of its capacity. The prison mainly houses men, but there is a separated facility for women in the prison's complex that is managed by a different correctional team. The number of prisoners entering daily into the prison differs, depending mainly on the availability of spaces in prison, the current law-enforcing operations (against illicit drug use, illegal migrants, …etc), and the transfer rate of prisoners from other prisons. At the time of conducting the study, the health system in prison was managed by the Ministry of Home Affairs, which was dependent on hiring private practitioners to provide daily medical care to prisoners. There were no diagnostic facilities in this prison, and difficult-to-manage cases were referred to a nearby MOH's community hospital for further assessment and management. Similar to other prisons in

Malaysia, HIV testing was mandatory and was conducted within 24 hours of prison entry using finger-prick rapid HIV test. Prisoners with positive HIV rapid test at the prison entry had their status further confirmed by using full venous blood for HIV ELISA testing. Following the confirmation of their diagnosis, prisoners with HIV do not routinely receive further HIV care, including routine active screening for TB, universal assessment of CD4 lymphocyte count, prescription of HAART for those eligible, or universal prescription of isoniazid preventive therapy for those without TB. Following the diagnosis, prisoners with HIV are segregated in a dedicated housing unit. The prevalence of HIV is reported to be high in this prison (6%), possibly due to harsh criminalisation laws targeting drug possession and use in the country (14). TB case finding, on the other hand, was passive, hence the actual prevalence of active TB in this prison was not known. An active TB case finding survey among 442 randomly selected prisoners in this prison in 2013 revealed that the prevalence of active TB in prison was 8.5% (10).

### 3.3.2 The research question

Globally, individuals entering prisons with active TB may contribute largely to the onward transmission and burden of the disease in these settings, particularly in prisons where TB screening at entry does not or poorly managed. A previous intensified TB case finding survey in this prison revealed that most prisoners with active PTB were diagnosed within three months of their entry to the prisons, likely to be TB cases missed at the prison entry (10).

This study was designed to answer the following research questions:

1. What is the prevalence of active PTB in prisoners entering a prison in Malaysia?
2. What are the factors associated with having active TB at prison entry in Malaysia?

### 3.3.3 Study participants and recruitment process

New entrants to the prison were subjected to mandatory HIV testing performed at the prison's clinic. Following the test, prisoners were asked to remain in the clinic's waiting area to receive their results. We approached prisoners to participate in the study after they had completed the HIV test. Each prisoner was assessed initially as to whether they were eligible according to the following criteria.

#### Inclusion criteria

1. New entrants to the prison, irrespective of the nationality, gender, or age.
2. Agree to participate in the study.

### Exclusion criteria

1. Do not understand English or Bahasa Malaysia (language barrier).
2. Unable to give consent (for example, due to psychiatric illnesses).
3. Already entering the prison with active TB disease (NB. This group was excluded from further assessment but recorded to calculate the total number of TB cases at the entry to the prison).
4. Being screened for active TB within the past three months by our research team (involving those who were released and re-entered the prison during the research study period).

Individuals who were excluded from the study were referred to the prison doctors for further assessment. Study enrolment of men was conducted from 26 July to 30 December 2013. Due to limited logistics and the delay in receiving the security clearance to enter the women prison, female prisoners were recruited from 20 June to 28 November 2015.

### 3.3.4 Study methodology

Eligible prisoners were provided with details of the structure, procedures, benefits, and risks of the study and were asked to provide written informed consent, if they agree to participate. No incentives were offered throughout the study. Prisoners who refused to participate in the study were reassured that they would not be disadvantaged or penalised. Prisoners who provided consent were interviewed using a structured questionnaire in a private section or room (whichever available) accessed only by the research team to ensure confidentiality. The questionnaire collected information deemed necessary to explore risk factors of active TB disease (see section 3.3.5). Owing to the high risk of HIV infection; the available resources; and the logistics, we deployed two screening methods depending on the HIV infection status. Participants without HIV infection were considered TB suspects if they presented with a cough for one week or more in addition to one of the TB-related symptoms (sputum production, haemoptysis, fever, night sweats, weight loss, loss of appetite, or chest pain). Those suspected with TB were asked to provide one spot-sputum specimen to be examined using the Xpert assay in prison. A cough threshold of one week, instead of the widely accepted two weeks, was

utilised in concordance with findings from other prison surveys (87) and to include as many as possible of TB suspects.
Prisoners with HIV infection, on the other hand, were asked to provide two sputum specimens (spot and next-day early morning) for Xpert and culture examinations, irrespective of the clinical presentation.

Additionally, participants' body weights and heights were measured, and the body mass index (BMI) was calculated using the standard formula (BMI=body weight [Kg]/body height [meters]$^2$) and presented in Kg/m$^2$ unit.

Participants with HIV infection had their CD4 count lymphocyte count assessed using a point-of-care machine (PIMA, Alere CD4 Analyser, Abbott). This cartridge-based analyser provides CD4 lymphocyte count from capillary blood in 20 minutes.

Constrained by the reference laboratory (University of Malaya Medical Centre's Medical Microbiology Lab) regulations, the use of reference laboratory services (culture examination) was utilised for HIV-infected prisoners only. The laboratory procedures are described in section 3.3.6. Sputum induction facilities were not available inside the prison, and those who were not able to produce sputum were asked to produce sputum the next day. If still unable to do so, they were excluded from the final analysis and referred to the prison's medical officers for further assessment.
Technical issues with Xpert, including software failure, invalid results and problems with cartridge deliveries were encountered in this study and were reported in other settings (88). In these events, we requested from prisoners suspected with TB to submit sputum specimens when the issue is resolved. These unavoidable events were expected to cause disruption in the study flow.

### 3.3.5 Study instruments

Consented participants were interviewed using a structured questionnaire by two trained research assistants. The questionnaire was developed from the conceptual frameworks about risk factors associated with active TB (from other studies) and studies previously conducted in the same prison (7,10,89). The questionnaire was piloted on a sample (N=120) of prisoners at the entry to the prison. The questionnaire contains demographic information, including gender, age, nationality, racial background (for Malaysians), full-time stable employment within the

12 months before prison entry, and the highest educational achievement. The questionnaire also collected information about the history of previous incarceration. Given the increased risk of TB among PWUD, the questionnaire had a dedicated section on the drug use. This section included questions on whether participants had ever used drugs any time before current prison entry or had recently used drugs (within the 30 days before prison entry). The section further explored whether the participant injected drugs at any time during his/her lifetime and whether there was a recent injection drug use (within the 30 days before prison entry). The section also asked the participant whether he/she had used heroin at any time and whether he/she was enrolled in methadone maintenance therapy (MMT) programme before the current prison entry. Participants were asked whether they have a history of previous active TB episode. Additionally, information about the recent use of cigarette smoking and alcohol within 30 days before prison entry was collected.

Participants were asked whether they have had a cough in the past four weeks and whether they had that cough for more than one week. Other explored symptoms were sputum production; blood in sputum; fever; night sweat; loss of appetite; loss of weight; chest pain; shortness of breath and whether they felt lumps in their neck. (See Appendix A2-1 for further information)

### 3.3.6 Sputum processing and laboratory procedures

Participants were asked to provide sputum specimens directly observed by a laboratory technician to ensure good quality sputum. The laboratory technician provided a quick explanation to participants on how to produce proper sputum samples. The instructions included washing mouth with water, taking 2-3 deep breaths, then expectorating in the provided sterile cup. To avoid transmission of potential TB bacilli and due to place constrains, sputum collection was performed in an open yard inside the prison. Direct (unprocessed) sputum specimens from participants were analysed onsite using GeneXpert MTB/RIF v 4.3 (Cepheid, Sunnyvale, CA) according to manufacturer's instructions using 1 mL of sputum samples and 1:2 ratio of processing solution (isopropanol and NaOH). For HIV-infected participants, the remainder of the two specimens was sent to the quality-assured reference laboratory for mycobacterial liquid culture examination. At the reference laboratory, samples were stored at 4°C to be processed the next day. The process included decontamination using N-acetyl-L-cysteine and sodium hydroxide and centrifugation before staining a sample from the deposit using Auramine-O phenol staining for fluorescence microscopy. Irrespective of smear microscopy results, pellets were inoculated into the Mycobacteria Growth Indicator Tube (MGIT) 960 culture system (BD Diagnostics, USA). Molecular genetic Genotype

Mycobacterium CM assay (Hain Lifescience, Germany) was utilised for mycobacterial species identification following positive growth on culture.

### 3.3.7 Study analysis plan

Collected information was entered and cleaned using Microsoft Excel and was eventually transferred and analysed using STATA version 15.1 (StataCorp, Texas, USA).
Active TB disease (the dependent variable) was defined as having a positive result on either Xpert or culture examinations and presented as a proportion of the total screened participants.

Descriptive data were presented as mean and standard deviation or median and interquartile range for continuous variables depending on variable distribution, while categorical variables were presented in proportions.

To examine associated risk factors with TB at prison entry, a generalised linear model (GLM) regression with Poisson family, log link and robust standard error options was utilised. This model allows the presentation of the prevalence ratio for each independent variable with 95% confidence intervals (95% CI). Several multivariable GLM regression model analyses were explored to determine the best fit model depending on the values of Akaike information criterion (AIC) with the use of manual stepwise backward elimination process, whereby independent variables with lowest significance level (p values) were removed sequentially from the models. The model with the lowest AIC was considered the most fit model and presented. Given that screening algorithms were different depending on the HIV status, separate multivariable regression models were analysed for HIV- and non-HIV-infected participants.

Before exploring multivariable models, the strength of association between independent variables was examined using the Chi2 test and Cramer V. A Cramer V value of 0.30 or more was considered a strong association (90). Variables that are strongly associated with several other potential risk factors for active TB were removed from the multivariable regression analyses.

Independent variables were categorised as follows:

1. Age was categorised into these categories: ≤ 30, 31-40, and > 40 years.
2. Gender was categorised as male and female/transgender (due to small number)

3. Nationality and racial background as Malay, Chinese, Indian, other Malaysians, and foreign.
4. Education as none, primary, secondary, or tertiary education.
5. Previous incarcerations as no previous entry, one previous entry, and more than one entry.
6. Drug use as never, non-injecting drug use, and injection drug use.
7. Recent drug use as never, non-injecting, and injection drug use.
8. BMI as underweight (< 18.5 kg/$m^2$) and normal/overweight (≥18.5 kg/$m^2$).
9. For the HIV-infected group analysis, CD4 lymphocyte count analysis was categorised as < 200, 201-500, and > 500 cells/mL.

Symptoms were presented through two WHO symptom screening algorithms. The WHO four-symptom algorithm that was primarily designed to screening HIV-infected individuals considers a person TB suspect if he/she has any of the following symptoms- any duration of a cough, night sweat, fever, or weight loss (11). The WHO clinical scoring algorithm for prisoners that scores symptoms as a cough ≥ 2weeks (2 points), sputum production (2 points), loss of weight (1 point), loss of appetite (1 point), and chest pain (1 point). Participants score five or more were considered as TB suspects (2). Given that symptoms were not utilised to define TB suspects in our HIV-infected participants, these algorithms were included in the regression analyses to examine their association with TB disease. These clinical algorithms were not included in the non-HIV-infected group analyses.

## 3.4 STUDY FINDINGS

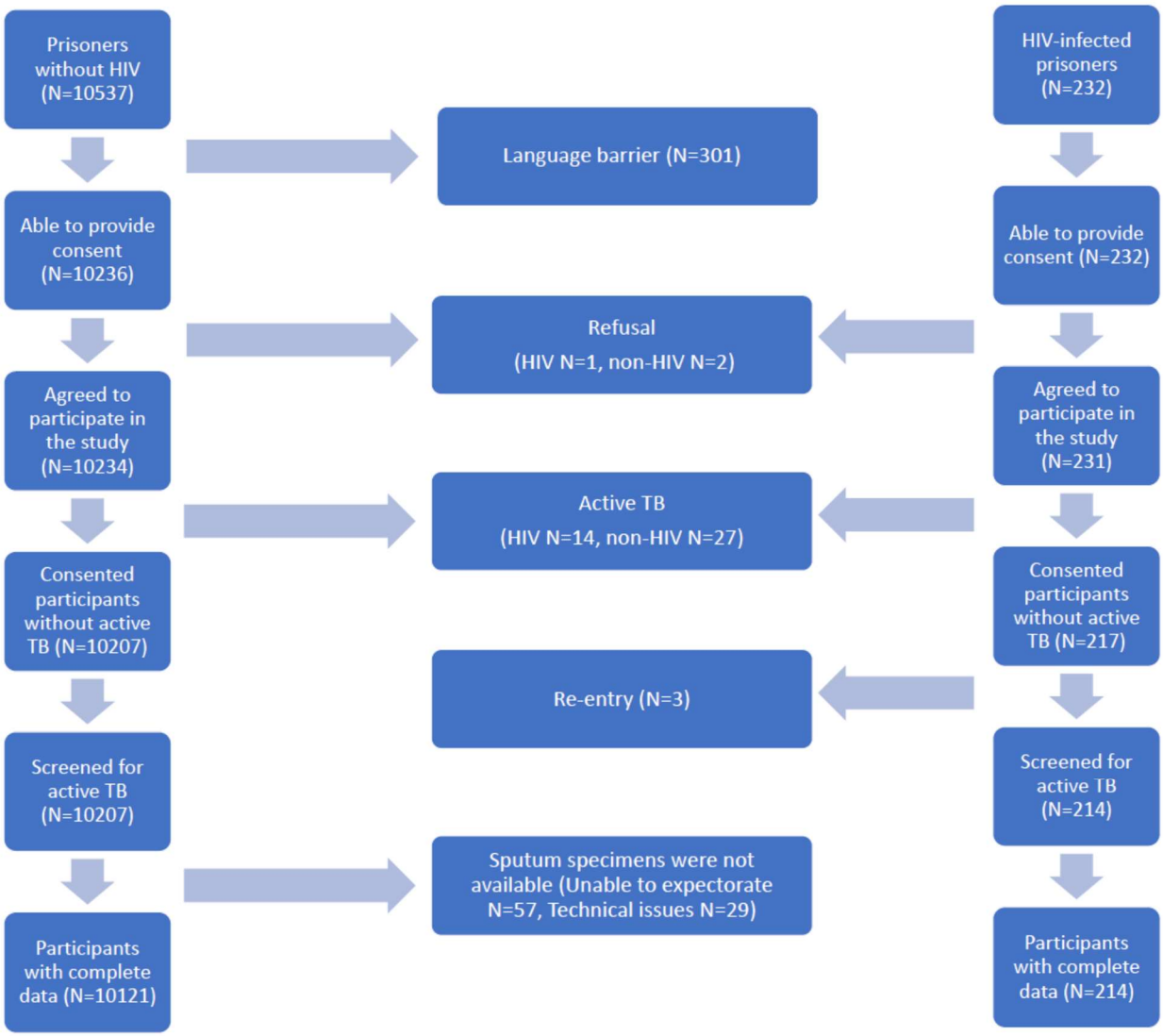
### 3.4.1 Disposition of study participants

During the study periods, 10,769 prisoners entered the prison with a median daily entry of 36 prisoners (IQR 20-75); the daily men entry being considerably higher than that of the women (a median of 76 prisoners compared to 20 prisoners, respectively)

Of the 10,769 prisoners entering the prison during the study period, 301 (2.8%) were excluded due to language barrier (unable to understand English or Bahasa Malaysia), 3 (0.03%) refused to participate in the study, and 41 (0.4%) were active TB cases at entry (diagnosed in the community). During the course of the study enrolment, 3 (0.03%) prisoners re-entered the prison within three months of their release; the second entry was not included in the screening census. Consequently, the total number of prisoners involved in the study was 10,421 (96.8%).

Of these, 1,114 (10.7%) were labelled as TB suspect according to the study protocol. Eighty-six (7.7%) TB suspects did not have sputum examination with either Xpert or culture and were excluded from the final analysis, leaving a total of 10,335 participants in that final analysis (**Figure 3.2)**.

**Figure 3.2:** Disposition of study participants.




### 3.4.2 Characteristics of study participants

Of the included 10,335 prisoners, 8,071 (78.1%) were men. More than half (51.4%) were aged less than 30-years old and 6,399 (61.9%) were foreigners. Just over half (5,662, 54.8%) reported not having stable employment over the past 12 months before current incarceration. Most (58.4%) completed secondary education. Most participants (7,792, 75.4%) did not have

a previous incarceration history, while 1,871 (18.1%) had more than one incarceration before this prison entry. The prison occasionally receives prisoners on remand (awaiting their final sentence and hence no known release date), and 1,218 (11.8%) entered the prison on remand during the study period. For those with known sentence, the median duration of prison stay was 47 days (IQR 17-81) of current incarceration with 8192 (89.8%) spending less than six months in prison.

Most (7,032, 68%) participants reported not using illicit drugs in their lifetime. Among those who used illicit drugs before current entry (N=3,303), 2,571 (77.8%) reported non-injecting routes of using the drugs, while the remaining 731 (22.2%) revealed that they injected drugs at some point during their drug use journey. Most participants who used drugs reported heroin as the primary drug of use (1,953, 59.1%). Despite this, only 238 (7.2%) participants with previous drug use reported being enrolled in MMT before the current incarceration; that is only 11.7% of prisoners with heroin dependence.

Of the total 10,335 participants, 187 (1.8%) reported having a previous history of TB disease. Most (60.5%) participants reported recent cigarette smoking and 1,720 (16.6%) reported recent alcohol drinking. A cough for any duration was reported in 2,454 (23.7%). Most screened prisoners were negative for the WHO's clinical screening algorithm using four symptoms (any duration of cough, fever, night sweat or weight loss) and the WHO's clinical scoring for prisoners (53.7% and 97.8%, respectively). The mean BMI was 22.5 (SD 3.8) $kg/m^2$ with 1132 (11%) were underweight (< 18.5 kg/m2). Participants with confirmed HIV infection represented 2.1% (N=214) of the total analysed sample.

Overall, 56 (0.54%) participants were diagnosed with active TB; 27 (48.2%) were HIV-infected. If the number of prisoners entering the prison with TB disease (N=41) is added, the prevalence of new and previously diagnosed TB at entry to this prison was 0.9%. In the latter calculation, the overall prevalence of TB disease was significantly higher among HIV-infected prisoners compared to those without HIV (17.7% and 0.5%, respectively, p=0.001)

### 3.4.3 The characteristics of participants with HIV infection

In this survey, 214 (2.1%) of the study population were confirmed, HIV-infected participants. Most were men (84.6%) and Malaysians (84.1%). The majority had more than one previous incarceration before the current entry (69.2%) and a history of injection drug use (67.8%).

Although not utilised to define TB suspects, most (66.4%) were symptomatic according to WHO's clinical four-symptom algorithm for HIV-infected individuals. The mean age was 37.5 (SD 8.2), while the mean BMI was 21.45 kg/$m^2$ (SD 3.30). Median CD4 lymphocyte count was 376 cells/mL (IQR 232-526). See Table 3.1 for further information.

**Table 3.1** The demographics of participants living with HIV.

| Predictors | Total (N=214, %) | TB cases (N=27, %) | Crude RR (95% CI) | P |
|---|---|---|---|---|
| **Age** | | | | |
| <30 | 42 (19.6) | 5 (18.5) | 1 | |
| 31-40 | 104 (48.6) | 15 (55.6) | 1.21 (0.47-3.13) | 0.69 |
| >40 | 68 (31.8) | 7 (25.9) | 0.86 (0.29-2.55) | 0.79 |
| **Gender** | | | | |
| Male | 181 (84.6) | 25 (92.6) | 2.28 (0.56-9.19) | 0.25 |
| Female/transgender | 33 (15.4) | 2 (7.4) | 1.00 | |
| **Nationality/Ethnicity** | | | | |
| Foreigner | 34 (15.9) | 4 (14.8) | 1.00 | |
| Malay | 110 (51.4) | 15 (55.6) | 1.16 (0.41-3.27) | 0.78 |
| Chinese | 16 (7.5) | 3 (11.1) | 1.59 (0.40-6.32) | 0.51 |
| Indian | 42 (19.6) | 3 (11.1) | 0.61 (0.14-2.54) | 0.49 |
| Other Malaysians | 12 (5.6) | 2 (7.4) | 1.42 (0.29-6.80) | 0.66 |
| **Stable job in the past 12m** | | | | |
| No | 135 (63.1) | 14 (51.8) | 0.63 (0.31-1.27) | 0.20 |
| Yes | 79 (36.9) | 13 (48.2) | 1.00 | |
| **Education level** | | | | |
| None | 13 (6.1) | 1 (3.7) | 0.50 (0.5-4.88) | 0.55 |
| Primary | 48 (22.4) | 4 (14.8) | 0.54 (0.11-2.65) | 0.45 |
| Secondary | 140 (65.4) | 20 (74.1) | 0.93 (0.24-3.55) | 0.91 |

| | | | | |
|---|---|---|---|---|
| Tertiary | 13 (6.1) | 2 (7.4) | 1.00 | |
| **Previous incarcerations** | | | | |
| None | 48 (22.4) | 5 (18.5) | 1.00 | |
| One previous entry | 18 (8.4) | 2 (7.4) | 1.07 (0.23-5.03) | 0.93 |
| More than one previous entry | 148 (69.2) | 20 (74.1) | 1.30 (0.51-3.28) | 0.58 |
| **Drug use before** | | | | |
| Never | 27 (12.6) | 3 (11.1) | 1.00 | |
| Non-injecting | 42 (19.6) | 3 (11.1) | 0.64 (0.14-3.00) | 0.57 |
| Injecting | 145 (67.8) | 21 (77.8) | 1.30 (0.42-4.08) | 0.65 |
| **Current drug use** | | | | |
| No | 52 (24.3) | 6 (22.2) | 1.00 | |
| Non-injecting | 117 (54.7) | 16 (59.3) | 1.18 (0.49-2.86) | 0.71 |
| Injecting | 45 (21.0) | 5 (18.5) | 0.96 (0.31-2.95) | 0.95 |
| **Heroin use** | | | | ` |
| No | 48 (22.4) | 5 (18.5) | 1.00 | |
| Yes | 166 (77.6) | 22 (81.5) | 1.27 (0.51-3.19) | 0.61 |
| **Pre-incarceration MMT** | | | | |
| No | 188 (87.8) | 23 (85.2) | 1.00 | |
| Yes | 26 (12.2) | 4 (14.8) | 1.26 (0.47-3.36) | 0.65 |
| **Previous TB episode** | | | | |
| No | 177(82.7) | 20 (74.1) | 1.00 | |
| Yes | 37 (17.3) | 7 (25.9) | 1.67 (0.76-3.67) | 0.20 |
| **Current cigarette smoking** | | | | |
| No | 21 (9.8) | 4 (14.8) | 1.00 | |
| Yes | 193 (90.2) | 23 (85.2) | 0.62 (0.24-1.64) | 0.34 |
| **Current alcohol use** | | | | |
| No | 159 (74.3) | 21 (77.8) | 1.00 | |

| | | | | |
|---|---|---|---|---|
| Yes | 55 (25.7) | 6 (22.2) | 0.82 (0.35-1.94) | 0.66 |
| **WHO 4-symptom** | | | | |
| Negative | 72 (33.6) | 7 (25.9) | 1.00 | |
| Positive | 142 (66.4) | 20 (74.1) | 1.45 (0.64-3.27) | 0.37 |
| **WHO clinical scoring for prisoners** | | | | |
| <5 | 185 (86.4) | 18 (66.7) | 1.00 | |
| ≥5 | 29 (13.6) | 9 (33.3) | 3.20 (1.58-6.42) | 0.01 |
| **Body mass index (kg/m$^2$)** | | | | |
| Underweight | 39 (18.2) | 9 (33.3) | 2.24 (1.09-4.62) | 0.03 |
| Normal/overweight | 175 (81.8) | 18 (66.7) | 1.00 | |
| **CD4 Lymphocyte Count (Cells/mL)** | | | | |
| ≤200 | 45(21.0) | 8 (29.6) | 2.27 (0.79-6.52) | 0.13 |
| 201-500 | 104 (48.6) | 14 (51.8) | 1.72 (0.65-4.57) | 0.27 |
| >500 | 64 (29.9) | 5 (18.5) | 1.00 | |

### 3.4.4 Prevalence and associated factors of active TB among HIV-infected prisoners

Of the screened HIV-infected participants, 27 were active TB disease; a prevalence of 12.6% (95% CI 8.5-17.8%) in this sample. Most HIV-infected participants with TB (88.90%) had a prison sentence of less than six months, hence were unable to complete TB treatment inside the prison.

In the univariable GLM regression (Table 3.2), newly diagnosed active TB in this sample was not associated with any of the potential risk factors for TB, except for two variables: 5 points or more on the WHO's clinical scoring algorithm for prisoners (RR 3.2 [95% CI 1.58-6.42]) and underweight (RR 2.24 [95% CI 1.09-4.62]).

Due to the strong association of current smoking, nationality and heroin use with most of the potential risk factors of interest (previous prison entry, history of drug use, and recent drug use) in this sample, we conducted stepwise backward elimination multivariable regression analyses including all variables except those three variables. Of note, these three variables were not associated with active TB in the univariable regression analyses. Newly diagnosed active TB in this HIV-infected sample was independently associated with positive WHO's clinical scoring for prisoners (ARR 2.90 [95% CI 1.48-5.68]) and, marginally with, underweight (ARR 1.91 [95% CI 0.96-3.81]) after adjusting to other variables. (Table 3.2)

**Table 3.2** Multivariable Generalised Linear Regression model of factors associated with TB among HIV-infected participants.

| Variables | Adjusted RR (95% CI) | Significance (p) |
|---|---|---|
| **Pre-incarceration employment** | | |
| Stable | 1.00 | |
| Not stable | 0.61 (0.28-1.06) | 0.152 |
| **WHO clinical scoring for prisoners** | | |
| <5 | 1.00 | |
| ≥5 | 2.90 (1.48-5.68) | 0.002 |
| **Body mass index (kg/m$^2$)** | | |
| Normal/overweight | 1.00 | |
| Underweight | 1.91 (0.96-3.81) | 0.064 |

### 3.4.5 The characteristics of participants not infected with HIV

Out of the total 10,335 participants included in the analysis, 10,121 (97.9%) were not infected with HIV (Table 3.3). Most were younger than 30-year-old (52.1%) and men (78%). Most were non-Malaysians (62.9%). Most enrolled participants without HIV-infection had no previous incarcerations (76.6%) and no history of illicit drug use (69.3%). The majority reported no history of active TB (98.5%). Most participants had normal or high BMI (89.1%). Of note, only 891 (8.8%) prisoners in this sample had a sentence of six months or more in prison.

**Table 3.3** The demographics of participants not infected with HIV.

| **Predictors** | **Total (N=10121)** | **TB cases (N=29, %)** | **Crude RR** | **P** |
|---|---|---|---|---|
| **Age** | | | | |
| <30 | 5270 (52.1) | 4 (13.8) | 1 | |

| | | | | |
|---|---|---|---|---|
| 31-40 | 3082 (30.4) | 12 (41.4) | 5.13 (1.65-15.89) | 0.01 |
| >40 | 1769 (17.5) | 13 (44.8) | 9.68 (3.16-29.66) | 0.01 |
| **Gender** | | | | |
| Male | 7890 (78.0) | 27 (93.1) | 3.82 (0.91-16.04) | 0.07 |
| Female/transgender | 2231 (22.0) | 2 (6.9) | 1.00 | |
| **Nationality/Ethnicity** | | | | |
| Foreigner | 6365 (62.9) | 7 (24.1) | 1.00 | |
| Malay | 2195 (21.7) | 12 (41.4) | 4.97 (1.96-12.60) | 0.01 |
| Chinese | 533 (5.3) | 4 (13.8) | 6.82 (2.00-23.23) | 0.01 |
| Indian | 777 (7.7) | 6 (20.7) | 7.02 (2.36-20.83) | 0.01 |
| Other Malaysians | 251 (2.5) | 0 (0.0) | n/a | n/a |
| **Stable job in the past 12m** | | | | |
| No | 5527 (54.6) | 15 (51.7) | 0.88 (0.43-1.83) | 0.74 |
| Yes | 4569 (45.1) | 14 (48.3) | 1.00 | |
| **Education level** | | | | |
| None | 857 (8.5) | 1 (3.4) | 0.18 (0.02-1.62) | 0.13 |
| Primary | 2744 (27.1) | 13 (44.8) | 0.74 (0.24-2.26) | 0.60 |
| Secondary | 5896 (58.3) | 11 (37.9) | 0.29 (0.09-0.91) | 0.03 |
| Tertiary | 624 (6.2) | 4 (13.8) | 1.00 | |
| **Previous incarcerations** | | | | |
| None | 7744 (76.5) | 11 (37.9) | 1.00 | |
| One previous entry | 654 (6.5) | 3 (10.3) | 3.23 (0.90-11.55) | 0.07 |
| More than one previous entry | 1723 (17.0) | 15 (51.7) | 6.13 (2.82-13.32) | 0.01 |
| **Drug use before** | | | | |
| Never | 7005 (69.2) | 6 (20.7) | 1.00 | |
| Non-injecting | 2529 (25.0) | 15 (51.7) | 6.92 (2.69-17.83) | 0.01 |
| Injecting | 587 (5.8) | 8 (27.6) | 15.91 (5.54-45.71) | 0.01 |

| | | | | |
|---|---|---|---|---|
| **Current drug use** | | | | |
| No | 7734 (76.4) | 8 (27.6) | 1.00 | |
| Non-injecting | 2245 (22.2) | 17 (58.6) | 7.32 (3.16-16.94) | 0.01 |
| Injecting | 142 (1.4) | 4 (13.8) | 27.23 (8.29-89.40) | 0.01 |
| **Heroin use** | | | | ` |
| No | 8334 (82.3) | 9 (31.0) | 1.00 | |
| Yes | 1787 (17.7) | 20 (69.0) | 10.36 (4.73-22.72) | 0.01 |
| **Pre-incarceration MMT** | | | | |
| No | 9909 (97.9) | 25 (86.2) | 1.00 | |
| Yes | 212 (2.1) | 4 (13.8) | 7.48 (2.62-21.30) | 0.01 |
| **Previous TB episode** | | | | |
| No | 9966 (98.5) | 24 (82.8) | 1.00 | |
| Yes | 150 (1.5) | 5 (17.2) | 13.84 (5.35-35.79) | 0.01 |
| **Current cigarette smoking** | | | | |
| No | 4048 (40.0) | 3 (10.3) | 1.00 | |
| Yes | 6057 (59.9) | 26 (89.7) | 5.79 (1.75-19.12) | 0.01 |
| **Current alcohol use** | | | | |
| No | 8440 (83.4) | 22 (75.9) | 1.00 | |
| Yes | 1665 (16.4) | 7 (24.1) | 1.61 (0.69-3.77) | 0.27 |
| **WHO 4-symptom** | | | | |
| Negative | 5476 (54.1) | 0 (0.0) | 1.00 | |
| Positive | 4645 (45.9) | 29 (100.0) | n/a | n/a |
| **WHO clinical scoring for prisoners** | | | | |
| <5 | 9924 (98.0) | 16 (55.2) | 1.00 | |
| ≥5 | 197 (2.0) | 13 (44.8) | 40.93 (19.96-83.93) | 0.01 |
| **Body mass index (kg/m$^2$)** | | | | |

| | | | | |
|---|---|---|---|---|
| Underweight | 1093 (10.8) | 8 (27.6) | 3.14 (1.40-7.08) | 0.01 |
| Normal/overweight | 9023 (89.1) | 21 (72.4) | 1.00 | |

### 3.4.6 Factors associated with active TB among non-HIV-infected prisoners

Of the 10121 enrolled participants without HIV infection, 814 (8%) were suspected of having TB disease as per the study protocol. Twenty-nine (0.29% [95% CI 0.20-0.40%]) participants had positive sputum examination for TB using the Xpert assay. Of note, no newly diagnosed TB case had a sentence of six months or more; hence all 29 TB cases were released before completing TB treatment in prison.

In the univariable GLM regression, newly diagnosed active TB in this sample was associated with several factors (See Table 3.4 for more information):

1. Older age (RR 5.13 [95% CI 1.65-15.89] and 9.68 [95% CI 3.16-29.66] for age groups 31-40 and > 40, respectively).
2. Malaysians compare to foreign nationals (RR 4.97 [95% CI 1.96-12.60], 6.82 [95% CI 2.00-23.23], and 7.02 [95% CI 2.36-20.83] for Malay, Chinese, and Indian ethnicities, respectively).
3. Completed secondary education (RR 0.29 [95% CI 0.09-0.91]).
4. More than one previous entry to prisons (RR 6.13 [95% CI 2.82-13.32]).
5. History of drug use (RR 6.92 [95% CI 2.69-17.83] and 15.91 [95% CI 5.54-45.71] for non-injecting and injecting drug use, respectively).
6. Current drug use (RR 7.32 [95% CI 3.16-16.94] and 27.23 [95% CI 8.29-89.40] for non-injecting and injecting drug use, respectively).
7. Pre-incarceration heroin use (RR 10.36 [95 CI 4.73-22.72]).
8. Pre-incarceration enrolment in MMT programme (RR 7.48 [95% CI 2.62-21.30]).
9. History of active TB disease (RR 13.84 [95% CI 5.35-35.79]).
10. Current cigarette smoking (RR 5.79 [95% 1.75-19.12]).
11. Positive WHO's clinical scoring algorithm for prisoners (RR 40.93 [95% CI 19.96-83.93]).
12. Underweight (RR 3.14 [95% CI 1.40-7.08]).

Heroin use was strongly associated with several other variables, particularly drug use and previous incarcerations. Apart from heroin use, we included all variables in the stepwise backward elimination multivariable regression analysis. In this sample, newly diagnosed active TB was independently associated with older age (ARR 3.54 [95% CI 1.03-12.14] and 4.66 [95% CI 1.38-15.67] for age groups 31-40 and > 40, respectively), current drug use (ARR 4.67 [95% CI 1.85-11.78] and 14.54 [95% CI 3.71-56.99] for non-injecting and injecting drug use, respectively), previous TB episodes (AAR 3.78 [95% CI 1.32-10.80]), completed secondary education (AAR 0.17 [95% CI 0.06-0.53]), and underweight (ARR 2.94 [95% CI 1.12-7.16]). Table 3.4 presents the multivariable regression analysis in the non-HIV-infected sample.

**Table 3.4** Multivariable Generalised Linear Regression model for the associated factors with active TB among prisoners without HIV

| Variable | Adjusted RR (95% CI) | Significance (p) |
|---|---|---|
| **Age** | | |
| ≤30 | 1.00 | |
| 31-40 | 3.54 (1.03-12.14) | 0.04 |
| >40 | 4.66 (1.38-15.67) | 0.01 |
| **Gender** | | |
| Women | 1.00 | |
| Men | 2.70 (0.63-11.44) | 0.18 |
| **Education** | | |
| Tertiary | 1.00 | |
| Secondary | 0.17 (0.06-0.53) | 0.002 |
| Primary | 0.55 (0.19-1.59) | 0.27 |
| None | 0.20 (0.02-1.78) | 0.15 |
| **Current drug use** | | |
| No | 1.00 | |
| Non-injecting drug use | 4.67 (1.85-11.78) | 0.01 |
| Injection drug use | 14.54 (3.71-56.99) | 0.001 |
| **Previous TB** | | |
| No | 1.00 | |
| Yes | 3.78 (1.32-10.80) | 0.01 |
| **Body mass index (kg/m$^2$)** | | |
| Normal/overweight | 1.00 | |
| Underweight | 2.94 (1.21-7.16) | 0.02 |

## 3.5 DISCUSSION

To our knowledge, this is the first study involving an intensified TB case finding at the entry to a prison in Malaysia. A robust screening method was utilised, and logistic shortfalls were addressed during the period of the study. The study showed a prevalence of previously undiagnosed active TB disease of 12.6% and 0.29% in prisoners with and without HIV

infection, respectively. In this study, TB disease in HIV-infected prisoners was independently associated with having a WHO clinical scoring for prisons of five or more and of being underweight. Active TB among prisoners without HIV infection, on the other hand, were independently associated with increasing age, current illicit drug use, previous TB, and being underweight. Active TB among participants without TB was also negatively associated with completing secondary education.

During the time of the survey, 232 (2.1%) prisoners entered the prison with HIV infection, that is five times higher than the prevalence of HIV infection in the general population in Malaysia (0.4%). This higher contribution of HIV-infected prisoners to the prison population is likely attributed to the harsh criminalisation laws on drug possession in Malaysia (14). Additionally, poor access to harm reduction tools by PLWH in the community may force this group to continue the use of illicit drugs (68). Owing to the elevated risk for TB infection and mortality, participants with HIV infection were requested to submit two sputum specimens for thorough bacteriological examination, irrespective of the clinical presentation. The prevalence of active TB in this sample of HIV-infected prisoners was high (12.6%). This figure was three-time higher than the estimated prevalence of active TB (4%) in PLWH in Malaysia at the start of the study (91,92). Several factors might have contributed to this high prevalence of TB in this sample. In addition to drug use, which is a recognised independent risk factor for TB (93), prisoners with HIV in Malaysia have several other factors that increase their risk for TB. These include limited access to HIV-related healthcare, have repeated entries to prisons, and are from low socio-economic background (unemployment, unstable housing, and inadequate education) (10,23,94).
On the other hand, the prevalence of active TB among prisoners without HIV was 0.29%. This figure was three times higher than that of the general population in Malaysia at the time of the survey (0.10%) (5).

Globally, studies addressing TB at entry to prisons are limited, but overwhelmingly showed a high prevalence of TB. The prevalence of active TB in the reviewed 15 studies providing information about the prevalence of TB at prisons' entry ranged between 68-7,300 per 100,000 prisoners. Findings from our study corroborate with findings from studies in similar economic and TB burden status (i.e., LMIC with intermediate to high TB burden). Despite reliance on sputum examination to diagnose TB cases, an intensified TB case finding survey at the entry to a prison in Malawi involving 111 prisoners reported a high (4,000 per 100,000 prisoners)

prevalence of TB that was ten times higher than the incidence of TB in the general population in the year 2000 (400 per 100,000 population) (73,95). Only 18% of study participants agreed to be tested for HIV infection, and among these, one-third was HIV-infected (15 out of 47). The prevalence of TB among HIV-infected prisoners in the sample was not reported. A peer-educator case finding survey in three prisons housing 30% of prisoners in Zambia and involving 799 prisoners at entry reported a TB prevalence of 6,100 per 100,000 population that was significantly higher compared to the routine practise of 800 per 100,000 population (79). Two-thirds of prisoners at entry agreed to be tested for HIV, and among these, 19.6% were HIV-infected. This study did not provide details about the prevalence of TB among HIV-infected prisoners at entry. Another intensified TB case finding survey screened 371 prisoners at the entry to the Lusaka Central Prison in Zambia reported an equally high prevalence of active TB of 7,300 per 100,000 population (78). The prevalence of HIV at entry was 20.5% The study reported that among HIV-infected prisoners, the prevalence of bacteriologically confirmed TB was 7.8%. Both studies from Zambia reported higher prevalence of TB and HIV at the entry to the correctional system compared to the general population (361 per 100,000 population and 11.5%, respectively) (5,96).

The authors attributed this to the poor health of the incarcerated population, including illicit drug use, unemployment, and alcoholism. Similarly, studies from South America revealed a prevalence of TB of 660 and 2,900 per 100,000 prisoners at entry to prisons in Uruguay (1,959 prisoners screened) and Brazil (1708 prisoners screened), respectively (77,84). These figures were considerably higher than the reported national TB prevalence estimates (31 and 44 per 100,000 population in Uruguay and Brazil, respectively). The only study from Asia was conducted in Bangladesh. The study was symptom-based and reported a TB prevalence of 100 per 100,000 prisoners at the entry to a prison in Dhaka. This figure was two times higher than that of the general population (221 per 100,000 population) (76). No information was provided about the prevalence of HIV in that sample. Findings from high-income countries reported equally high prevalence of active TB at entry to prisons in the United States and European correctional systems. Our study is distinct from these studies in utilising new technologies in the diagnosis of active TB, in the systematic screening of HIV-infected prisoners and in involving a large number of prisoners (10,335 prisoners screened).

Findings that new inmates had higher rates of TB compared to the general population they come from might be related to several factors.

First, recidivism is a common occurrence among prisoners, particularly PWUD and prisoners with psychiatric illnesses. A follow-up study over 2.7 years in the Swedish criminal system confirmed this observation and reported that 69% of prisoners with drug use experienced repeated incarcerations following release (97). Similar finding was reported among prisoners with psychiatric illness in the Texas criminal system (98). Prisons lacking the implementation of TB control measures act as reservoir increasing the risk of infection and progression to TB disease among frequent offenders, particularly when other risk factors for TB are also involved (99). This situation contributes to increased TB prevalence not only in prisons, but in the general population at large. A study in the former Soviet Union states projected that for every percentage increase in the incarceration rate there is 0.34% increase in the incidence of TB in the community, further confirming the impact of incarceration on TB in settings with poor TB control (15). Previous studies in the same prison in Malaysia reported a high prevalence of exposure to TB among prisoners and prison staff, possibly referring to ongoing unchecked exposure to TB in prison (7,8). An intensified active TB case finding study following up on these tuberculin surveys confirmed that the overwhelming majority (71%) of TB cases were undiagnosed at the time of the survey (10).

On the other hand, recidivism may impact the level of care provided both in the community and in prisons, particularly to individuals with chronic illnesses. Several examples described the impact of repeated incarcerations on the interruption of HIV care with the loss of previously achieved viral suppression goals, when prisoners re-enter prisons (100). The problem is further augmented among HIV-infected prisoners in Malaysia, where HIV-infected prisoners are segregated in dedicated housing units. This practice in settings with poorly managed TB control programmes may further increase the risk of TB disease in this group of prisoners with multiple risks for TB. A previous survey reported a high prevalence (12%) of undiagnosed active TB among HIV-infected prisoners in the same prison in Malaysia, similar to what was reported in our study (89). In this study, most of the prisoners diagnosed with TB were previously incarcerated (81.5% and 62% of HIV-infected and non-HIV-infected TB cases, respectively). Still, previous incarceration was not an independent risk factor for TB disease in this sample, possibly due to the involvement of other major risk factors. Second, prisons may concentrate individuals who are already at higher risk for active TB disease, including people of low socio-economic background, unemployed, homeless, PWUD, undocumented migrants and HIV-infected (14,101).

Third, community health systems that provide limited access to healthcare services to marginalised population might have missed the opportunity to timely diagnose TB cases in the community before prison entry. Limited information exists about the access of prisoners to community healthcare services, but a recent survey among HIV physicians reported systematic discrimination in HAART prescription against released prisoners with HIV infection (94).

In this study, TB disease among HIV-infected prisoners was not associated with most of the known risk factors for TB including sociodemographic variable, previous TB episodes, previous prison entry, history of drug use, or degree of immune suppression. This finding is possibly because HIV infection in these settings suffices to confer high risk for active TB, independent of other risk factors.

Positive WHO clinical scoring for prisoners was independently associated with active TB among HIV infected prisoners. The utility of this finding, though, might be difficult to be assessed. Despite this association, reliance solely on this clinical algorithm in targeted screening would have led to missing of more than half of TB cases (66.7% and 55.2% of TB cases among HIV-infected and non-infected, respectively). Prison studies, albeit scarce, reported overall poor association between TB disease and clinical presentations. No association between the duration of a cough and active TB was reported in three studies from the Ethiopian correctional system (102–104). In contrast, another study from the same correctional system reported a strong independent association between the duration of cough and active TB (> 4 weeks compared to 2-4 weeks) (105). A mass screening utilising chest radiograph in prison in Brazil reported that none of the clinical screening algorithms, including the WHO clinical scoring for prisons, was reliable (106). The reliance on the WHO clinical scoring would have led to missing 79.1% of active TB cases in that sample. Authors in the study suggested that clinical algorithms in these high-risk settings need to be abandoned and replaced by chest radiograph to control the disease. Telisinghe L, et al. in an expert review highlighted the need for sensitive, evidence-based screening algorithms at the entry to prisons and thereafter as a priority for research (107).

Low BMI (< 18.5 kg/$m^2$), being a surrogate of poor nutritional status or comorbidities, is a recognised risk factor for TB disease and increased risk of death from the disease (108). Underweight could also be an effect of a prolonged course of undiagnosed active TB- a

common occurrence among prisoners in several settings. Few prison studies reported the association of BMI with TB disease. Noeske J, et al. reported the association of active TB with low BMI in a TB survey in prison in the Cameroon (AOR 2.57-6.14) (109). Studies from Ethiopian prisons reported conflicting findings. While a study reported a strong independent association between low BMI and active TB (AOR 16.3 [3.89-67.96]) (103), other studies showed no association (104,105,110) and one study reported an inverse relationship between low BMI and sputum positivity for TB (102). In our study, low BMI was independently associated with TB disease among participants without HIV and just marginally among HIV-infected participants.

The risk of TB infection and disease progression was demonstrated to be increased with age in high burden countries owing to the frequent exposure to the bacilli (111). Given the other associated high-risk factors for TB among prisoners, age might not emerge as a factor independently associated with active TB in the prison population. A study from Ethiopia among 282 prisoners did not show an association of age with active TB disease (103). No association between age and active TB was also witnessed in a TB screening in prison in Hong Kong using CXR in 2001 (N=814) (112). Similar findings were reported from studies in prisons in Ethiopia (104,110). Our study showed that TB disease was independently associated with increasing age among participants without HIV infection.

People who use drugs have increased risk of latent and active TB, possibly due to the interaction with HIV infection and repeated incarcerations in countries that criminalise drug use. Studies have shown that PWUD with TB are more infectious, irrespective of the HIV status and that the prevalence of latent TB among PWUD was reported to be 10%-59% (44,113). This group is also associated with poor access to healthcare services in the community, and poor adherence to treatment regimen, further increase their risk for acquiring TB (44). In our study, prisoners without HIV infection who are current drug users were more likely to be a TB case compared to non-drug users. Most prison studies address the association between illicit drug use and latent TB, rather than active TB. An intensified TB case finding among prisoners in Tajikistan reported the association of active TB with injecting drug use in a univariable level, but not when adjusted to other confounders, possibly due to the effect of HIV infection (114). Studies from Ethiopian prisons reported conflicting results on the association of misuse of Khat plant and TB among prisoners (104,115). To reduce the burden of infectious diseases among PWUD, the WHO calls for the decriminalisation of drug use, the

implementation of non-custodial approaches, and the provision of integrated TB, HIV and drug use treatment in prisons and drug treatment facilities (116). A nationwide screening for TB in prisons in Thailand reported a decline in the prevalence of TB from 1,226 to 363.3 per 100,000 prisoners over six years (117). This decline was partially explained by the penal reforms in the country during that period where PWUD were diverted from prisons to specialised treatment facilities.

Finally, several studies emphasise the impact of establishing a TB case finding surveillance at the entry to prisons on the overall prevalence of active TB in prisons thereafter. Banu S, et al. (76) reported a significant 6-fold decline in TB disease reporting (49 cases during the first quarter and 8 cases in the final quarter of the study period, p=0.001) in a correctional facility in Bangladesh after establishing intensified TB case finding surveys at the entry to the prison during October 2005 to February 2010. Sanchez A, et al. (84) reported that, despite the prevalence of active TB at the entry to the prison remains constant during the two years of establishing an intensified case finding at the entry to a prison in Brazil, the prevalence of active TB in the prison drop significantly from 6% to 2.8% between the first and second systematic screening, respectively ($p<0.0001$). A significant decline (60%) in TB disease in the correctional system in Mongolia was reported following the establishment of multi-level TB screening at entry to jails and prisons over a decade: 2,500 cases and 900 cases per 100,000 population in 2001 and 2010, respectively (118).

Apart from the inherent limitations of the study mentioned above, the study is limited by the small number of TB cases diagnosed in the study. This figure might have influenced the regression analyses, and larger studies are warranted.
The study was conducted in one prison in Malaysia, and despite being the largest in the country, other prisons might have several different challenges and findings that need to be thoroughly examined.

The fact that our study reported a lower prevalence of active TB among prisoners without HIV at prison entry compared to other studies from LMIC is probably attributed to the reliance on symptoms to define TB suspects, which is a proved non-sensitive tool. Moreover, despite being a reliable tool to diagnose TB disease, reliance on a single-specimen Xpert may underestimate the actual prevalence of active TB. A systematic review of the literature revealed a pooled sensitivity of a single Xpert of 89% (119) and the initial multi-centre analysis of Xpert reported

an increase in the sensitivity of the assay with multiple-specimen assessment (120). Technical problems related to the assay may have also influenced the performance of the survey. We were not able to investigate TB in 9.6% (86 out of 900) of TB suspects due to the emergence of technical problems in Xpert: computer software crash and delay in the arrival of cartridges [N=29] and prisoners who were unable to produce sputum (N=57). TB cases might have been missed from these groups. The availability of sputum induction facility in the prison is a safe measure and would have provided information about the TB status of the 57 prisoners with suspicion of TB.

# CHAPTER FOUR: THE PRACTICE-POLICY GAP IN THE MANAGEMENT OF TUBERCULOSIS IN PRISONS IN MALAYSIA

## 4.1 Introduction

This study was conducted in the largest prison in Malaysia and was designed based on several findings from studies in the same prison. The previous studies were intensified TB case finding surveys among prisoners living with and without HIV infection. These surveys revealed that there are no regular screening surveys for TB disease in prison and that most TB cases (71%) were undiagnosed at the time of the studies (10,89). The surveys also noticed the lack of pre-release planning to link prisoners with incomplete TB treatment to the community healthcare services. The objective of this study was to assess certain indicators of TB programme performance that were developed from several resources. This study utilised several study designs, including review of medical records, examination of prison's health records, information from a cohort study, and a knowledge survey to assess these indicators. Findings from the study will have significant implications for further research and policy changes.

## 4.2 The review of literature

### 4.2.1 The literature review protocol

The literature review presented here was designed to answer the question: "Do prisons' TB programmes perform efficiently in controlling TB?". A literature search was conducted in July 2020 using Medline and Embase databases through the Ovid(SP) platform and the Web of Science. Keyword structures ("tuberculosis" AND "prison" AND ["system" OR "program" OR "service"]) were utilised. The search included these keywords anywhere in the text. No restrictions were placed on the language of the publication, the publication type, the study design, or the year of the publication. After removing duplicates, the abstracts of collected publications were examined thoroughly for the inclusion of publications in the final literature review. To be included in the final evaluation, publications must have presented information about the assessment of the performance of TB healthcare services in prisons. The performance parameters of interest include those related to control policies, TB detection, TB treatment outcome, TB/HIV care, and knowledge about TB. Publications conducted specifically to improve a parameter of a TB-related healthcare service, but without an assessment of the pre-intervention situation were excluded. Abstracts of publications written in languages other than

English were initially translated using google translate, and if eligible for inclusion, professional translation was sought.

A form was developed to extract information of interest from each study. This form included information about the location of the study, the number of prisons involved, study designs utilised to obtain the data, and the parameter assessed.
To assess the limitations of reviewed studies, we utilised the GRADE guidelines checklist to evaluate the risk of bias in observational studies (71). Assessed risks of bias include failure to develop and apply appropriate eligibility criteria, flawed measurement of either exposure and outcome, failure to adequately control confounding, and inadequate follow up.
Extracted information was presented in an evidence table (See Table A2).

### 4.2.2 Description of the studies

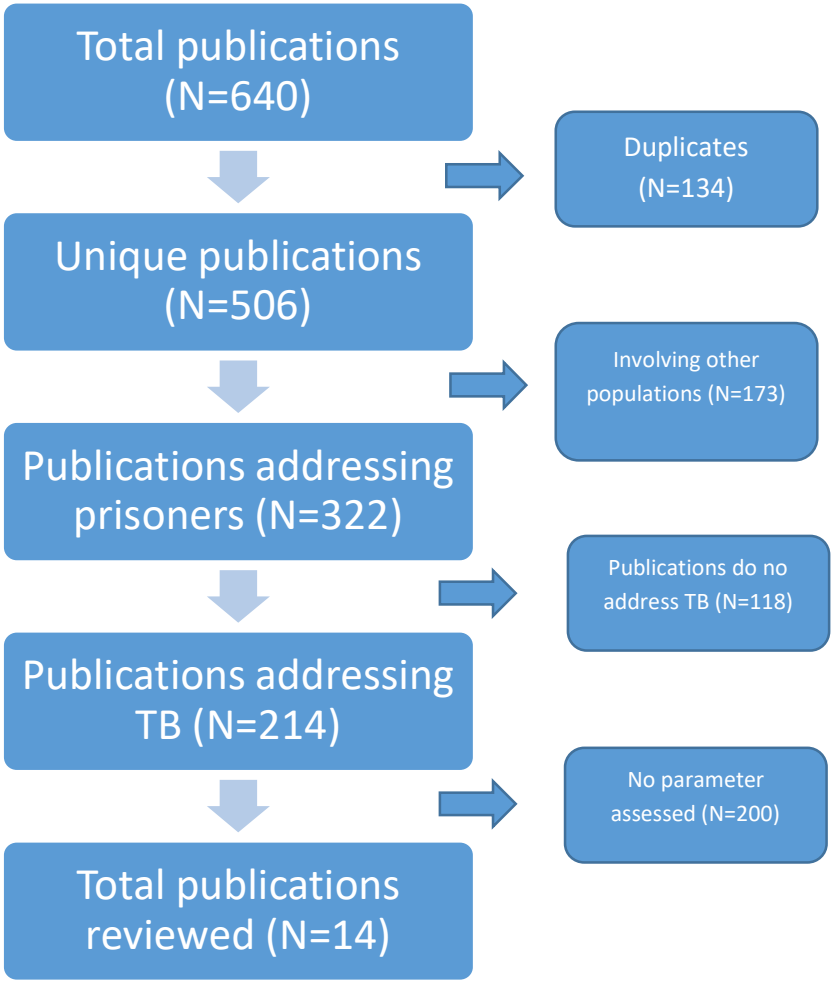
The search yielded 440 publications from the three databases: Medline (N=130), Embase (N=60), and Web of Science (N=450). Following the removal of duplicates, 306 unique publications remained. Upon direct screening of the collected publications, 14 reports provided information about the assessment of TB-related healthcare services in prisons. See Figure 4.1

Overall, of the included 14 publications, nine studies were conducted in LMIC (Ethiopia, Malawi [2 studies], India [2 studies], Zambia [2 studies], Zimbabwe and Brazil), four in high-income countries (EU, US, UK, Spain), and one study involved countries in the Asia-Pacific region with representatives from both LMIC and HIC. All studies were published over the past 20 years (1999-2018)

Adane K, et al (121) retrospectively assessed TB treatment outcome among prisoners in four randomly selected prisons in northern Ethiopia over five years (2000-2015). The authors reported that TB treatment success among prisoners while incarcerated was high (94%). They also revealed that linkage to TB care after transferring to other prisons or the community was non-existent, leading to unknown treatment outcome among released or transferred prisoners. The authors concluded that this might have negative implications on TB control, nationwide. Of note, most (85%) of TB/HIV prisoners in the study were prescribed HAART during TB treatment. HIV infection was not associated with poor treatment outcome in this study. The

study did not explore relevant exposure variables and provided no follow-up to assess treatment outcome among released prisoners with TB.

**Figure 4.1** Flow chart of the literature search and selection.




A review of TB control practices in European prisons in 2002, reported that less than half of contacted countries in the region completed the audit questionnaire (72). Parameters assessed were related to case detection, treatment outcome, and infection control practices. Findings from the study showed that most TB healthcare services in prisons were managed by the Ministry of Justice at the time of the survey (68.2%). Most (90.9% and 63.6%) prisons screened prisoners for TB at intake and during imprisonment, respectively. HIV screening among prisoners was not universal, as only 31.8% of prisons screened all prisoners, and 45.5% of prisons tested prisoners with active TB for HIV infection. TB diagnostic tests were performed mostly in a civilian facility (68.2%), not inside the prison. Overall, the TB treatment success

rate was suboptimal (57.9%). The study was a review of TB burden and practices in prisons in the region, hence no information was provided about the recruitment process of prisoners, definition of the treatment outcomes and assessment of factors associated with TB among prisoners.

A survey among prisons in Asia-Pacific region reported that most TB-related health services in the region were managed by the MOH (69%) (122). Most (86%) prison systems notify TB cases to the national authorities, but only two countries had a specific section about TB control in prisons in the national guidelines. Screening for TB at entry was performed routinely in 33% of prison systems. No information was provided about treatment outcome, but most (78%) prison systems reported providing standard treatment during incarceration. Despite stating that most (76%) prison systems link released prisoners with the community health systems, no information was provided about treatment outcome in this group.

A retrospective comparative assessment of treatment outcome between prisoners and non-prisoners in the US national TB surveillance system was conducted between 1993 and 2003 (123). The study reported a suboptimal treatment success rate (76.8%) among prisoners; no information was provided about the outcome of TB treatment among "moved" prisoners in the system. The study included all TB cases in the prison system during that period. Treatment success, the outcome of interest, was not clearly defined. In this study, exposure variables were not thoroughly collected or examined in association analyses.

An assessment of the TB control practices in prisons in Malawi from 1999 to 2000 highlighted shortfalls in TB systems in several prisons (87). Loss of medical staff from prisons was a significant problem in the system. Despite most prisoners with TB prescribed treatment (95%), treatment success was low (57%). This reduced treatment success rate was attributed to the unknown outcome among released/transferred prisoners (17%) and high (11%) TB-related mortality. The authors recommended a partnership with non-governmental organisations to tackle these problems.

Mehay A, et al (124) reported findings from a review of TB health services in correctional centres in London. The study showed that just over half (53%) of the National Institute for Health and Care Excellence (NICE) standards for care were met by the 12 healthcare providing bodies. Most (8 out of 12) health providers reported a TB policy in place and were able to treat

TB cases in their locations. All health providers reported screening all prisoners at entry using symptoms, but none of those having digital X-ray machines used them for active case finding. No information was provided about treatment outcome, but most (10 out of 12) providers reported they have some contingency, liaison, and handover plan in case of transfer or release.

A thorough assessment of TB control practices in a central prison in Delhi, India, was conducted during 2008 and 2012 (125). Despite having universal screening at entry using symptoms, only half of symptomatic prisoners were investigated. Human resources were confined to a lab technician, a DOT provider and a nodal NTP officer with two visiting chest physicians in a population of 12,417 prisoners. Isolation of prisoners with active TB was universally practised until they were deemed non-infectious, but ventilation in housing units was poor. Treatment success ranged from 10.4% to 71.5% during the 5-year study period. The TB treatment outcome among released prisoners (represents up to 45% of prisoners with TB) was unknown as no follow-up plans were provided. The study did not collect exposure variables and did not provide a clear description of the outcomes of interest, including TB case definition and TB treatment outcome.

A review of TB healthcare practices in 157 prisons in India was conducted (126). It revealed that universal entry screening was observed in only 50% of the prisons and screening in already incarcerated prisoners was regularly practised in 59% of prisons. In terms of human resources, doctors were available in 82% of prisons, but only 65% of them were trained on the regulations of the national TB programme. Only 18% and 54% of prisons had diagnostic and treatment facilities for TB, respectively. Proper services were higher in district level prisons compared to more peripheral prisons. There are several potential risks of bias in the study. The study did not provide reasons for the inclusion of these particular prisons. The study also failed to provide information on several variables assumed to be collected during the study.

A retrospective assessment of TB healthcare services in prisons in Barcelona (Spain) during the period of 1987 to 2000 reported variable adherence to TB treatment (127). Among prisoners diagnosed with TB, 67.3% completed treatment in prisons. Nine (16.4%) died or lost to follow-up and nine continued treatment in the community. No analyses were performed to assess associated factors with the outcome parameters of interest.

A survey among prisoners and prison staff in six Zambian prisons during September 2009 and February 2010 revealed that these prisons were understaffed (14 trained health staff, including one physician for a population of 16,666 prisoners). TB screening in prisons was variable (overall 23% were screened for TB during incarceration), being lower in rural prisons, among female convicts and HIV-infected prisoners. There were no testing and treatment for drug-resistant TB, even among previously treated cases (128).

In a case study during 2014, of the 87 prisons in Zambia, 17 were associated with health services and all, except one clinic provided TB diagnosis or treatment services. These prisons' health services remain understaffed with a total number of 31 healthcare workers in the whole system, mostly driven by nurses (N=16). The prisoner-to-healthcare worker rate was 8.9/10,000 (129). The study did not provide information on the enrolment process or measurement of exposure variables.

In a review of the TB reporting system in a municipality in Brazil, there were 361 TB cases reported from the penitentiary system during 2012 to 2016 (130). The review revealed that only 10.7% of prisoners with TB were provided with TB medications under DOT and almost half (48.3%) had TB medications for less than six months. The study also showed that follow up sputum examination was not performed in most of the months (only 22.2% had sputum examination performed at the second month of treatment). The study further reported a suboptimal cure rate of 68.5% and high treatment default of 21.6% (both were attributed to the poor DOT service in prisons). Finally, the study showed that 7.9% of prisoners with TB were transferred out. No further explanation was provided by the study to explain the low DOT coverage.

Another retrospective review of TB registry among prisoners and the general population diagnosed with TB in Zomba, Malawi between January 2011 and December 2016 (131). The study showed that 27% of the registry came from prisoners and that 93% of prisoners with TB completed treatment, none failed treatment, 5% died, and 1% were not evaluated. The study did not provide information about those who were transferred or released from the prison. Although authors did not information about the choice of the prison, the presentation of findings was good.

A retrospective cohort study was conducted among male prisoners in two major prisons in Harare, Zimbabwe in 2018 (132). The aim of the study was to define the cascade of care among this cohort. The study showed that 91% of symptomatic prisoners were evaluated for TB. Among those diagnosed with TB (N=25), 64% were started on standard TB treatment. TB treatment success, defined as cure from TB or completion of TB treatment, was 75% with 5% died and 4% were lost to follow-up. The authors did not provide information about the reasons behind these shortfalls. The study involved drug-susceptible TB cases only, a potential risk of bias.

There were no sections in these prison TB healthcare assessment studies addressing knowledge about TB. We, hence, conducted an additional review of the literature about knowledge among prisoners and prison employees. Keywords structure utilised was "knowledge" AND "TB" AND "prison", anywhere in the text. The search returned five unique studies, specifically addressing knowledge about TB in prisons. Overall, four of the five studies were conducted in LMIC (Ethiopia [2 studies], Brazil [2 studies]) and one in HIC (UK). All were conducted in the past ten years (2008-2017)

In 2008, prisoners with active TB (N=382) in an eastern Ethiopian prison had modest health knowledge about TB, with only 1.6% describing the cause of TB as a bacterium (133). Most (30.7%) did not know any measure for TB prevention and control. Half did not know about the risks of TB transmission in prison or that anti-TB drugs were provided free of charge. Most (75%), though, knew that TB is transmitted through the air. Limited knowledge was associated with being illiterates (OR 2.1, 95% CI 1.1-4.1), had no past history of TB (OR 2.6, 95% CI 1.5-4.5) and not visited a health institution for TB symptoms (OR 2.5, 95% CI 1.7-3.9). The study presented proper exposure variables but did not control for confounders.

Another study conducted among 615 prisoners in 8 northern Ethiopian prisons in 2016 revealed that only a third (37.7%) mentioned bacterium as the cause of TB (134). Most (88%) correctly mentioned the aerial route of TB transmission. Prisoners who were urban residents (AOR 2.16, 95% CI 1.15-4.06) and not been illiterates (AOR 0.17, 95%CI 0.06-0.46) had better knowledge. The study used robust enrolment process, collection of exposure variables and regression analyses.

Knowledge about TB among 28 surveyed prison staff in the UK correctional system was fair, but weak when it came to knowledge about supporting clients with TB. Most (89%) reported TB presents with prolonged cough and that TB is curable (97%). Most (68%) knew about the correct length of TB treatment, and only a third knew about actions that need to be taken when a client under their care develops TB (135). The recruitment process was not transparent in the study, and the small sample size makes it difficult to interpret or generalise findings.

A cross-sectional study among 140 prisoners and 71 guards in a male prison in Brazil showed that knowledge was not different between the two groups. Knowledge was generally high, with almost 100% knew that TB is curable, and 72% would seek treatment at a health service unit (136).

A follow-up knowledge survey among 141 prisoners and 115 prison employees in Brazil showed that prison staff had a better understanding of the disease, possibly because the majority (63.5%) reported receiving information about TB when employed by the prison authorities. Most prisoners and prison staff answered the TB symptoms section correctly. In the study, 49.6% and 88.7% of prisoners and prison staff, respectively reported that TB is transmitted through air. Almost half (44.3%) of correctional officers also mentioned that TB could be transmitted through sharing dishes and cutlery. Similarly, 40.9% of prison staff reported that to avoid catching TB, you need to avoid sharing meals and silverware. 38.3% of prisoners did not know how to prevent infection with TB. Most prisoners (73.8%) and prison staff (74.8%) mentioned that TB could be cured by treatment from a health centre, but most prisoners (59.6%) did not know the cost of TB treatment (137). The study is limited by the small sample size and the unavailability of detailed analyses and control to confounders.

### 4.2.3 Summary of the literature review

Publications addressing the assessment of TB health services in prisons remain limited, globally. The 14 unique studies that examined at least one element of the TB health services in prisons were mostly audits of prison systems.

Of note, two-thirds of studies were conducted in LMICs. This finding is interesting, given the high TB burden in these communities. Findings from these studies might have an impact on policy changes, like the case of Malawi prison studies, where NTP became directly involved in TB care in prisons following the thorough assessment (87).

Nine studies were conducted to assess TB treatment outcome in prisons (72,87,121,123,125,127,130–132). These studies reported variable findings, but generally low treatment success rates, irrespective of the economic status of the country. This low TB treatment success is largely attributable to the unknown status of prisoners who are released or transferred out. For example, in the retrospective assessment from northern Ethiopian prisons, the overall treatment success was 79.5% but was 94% for those who remained inside prisons (121). Several steps are needed to improve the outcome of TB in the released group, including the involvement of NGOs, as suggested by one study (87).

Similarly, screening for TB in prisons was variable. TB screening at the intake ranged from 33% in the Asia-Pacific region to 100% in India and UK. The tool utilised for screening was symptoms. Universal screening does not mean providing further care as findings from the prison in India showed that despite universal screening, only half of symptomatic prisoners was tested for TB. On the other hand, TB screening among already incarcerated prisoners ranges from 23% to 63%.

Providing staff to manage the TB programme in prisons remains a significant hurdle to achieving TB control targets. The study from Malawi reported that loss of staff was a significant problem of the TB control programme (87). The Indian prison system indicated that the rate of staff working on TB was 4 per 10,000 prisoners (125), while the Zambian prison system had 8 per 10,000 prisoners (128). These figures remain below the required rates for proper health delivery.

Reporting care for TB prisoners living with HIV was low. Only three studies mentioned HIV as a variable of interest, but limited information was provided on the assessment of care (72,121,123). One study from Ethiopia reported high (85%) prescription of HAART for TB/HIV prisoners.

Knowledge about TB among prisoners and prison staff was variable. Knowledge about TB was generally higher among prison staff and those in high-income countries.

None of the studies included in the literature review has meticulously examined the performance of TB programmes in prisons using healthcare parameters and related indicators.

Additionally, there is limited information about the TB programmes in prisons in Asia and certainly none from Malaysia. This observation suggested further assessment of TB programmes in prisons to develop national and global data for policy changes. The objective of this study was to assess TB-related indicators developed from several resources. These indicators include health system support, TB case detection, TB treatment success, TB care for HIV-infected prisoners, and knowledge about TB. Further studies are needed to assess in-depth the performance of TB control programmes in prisons.

## 4.3 MATERIALS AND METHODS

### 4.3.1 Study location

The study was conducted in Kajang prison, the largest prison in Malaysia from January to December 2017. In this prison, the medical records of prisoners diagnosed with active TB are labelled with "TB" on the front page and are archived separately. Additionally, prisoners entering the prison with TB or who are suspected of having TB are similarly labelled as "TB", but they are not necessarily prescribed anti-TB medications. Medical records of prisoners diagnosed with HIV are filed differently and labelled with "HIV" on the front page. There was no electronic medical recording in prison at the time of the study, but the names of prisoners with TB or HIV (from 2009 onward) were kept on MS Excel sheets in the main computer of the prison's clinic. Medical notes, on the other hand, remain paper based. The archiving system is generally suboptimal. Of note, extensive renovation work in the prison's clinic was performed in 2015, leading to reduced clinic organisation and disruption of the filing process.

### 4.3.2 Research questions

The study was designed to evaluate the policy practice gaps in the management of TB in a major prison in Malaysia. Areas that were specifically explored include the public health department support for prisoners with TB, including the availability of updated information and resources; the performance of the prison surveillance system; the performance in relation to successful TB treatment outcome; the TB-related care for HIV-infected prisoners; and the level of knowledge about TB amongst prisoners and prison guards.

### 4.3.3 Study design

This study adopted a health needs assessment framework, (138) along with integrated epidemiological and qualitative tools for data gathering. This framework was developed by TB

experts to assess the gaps between the policy and practice in the management of the latent TB infection in children. This has since been examined in an assessment of the management of LTBI in children in Indonesia, which was published in the Bulletin of the WHO (139). This framework has been utilised in this study given its simplicity to use, being a good tool to easily present subjects for public health assessment, and due to the presence of an expert in this form of framework assessment in the research team (Prof Philip Hill). Programme parameters and related indicators were developed from several resources, including the latest national Malaysian TB guidelines (34), the WHO's TB treatment guidelines (140), the WHO's TB in prisons manual (2), the Malaysian "TB and HIV screening in prisons" document (57), and relevant programme assessment publications (138). Relevant data were obtained from prisoners' medical records, prisons' administrative records, published reports, and directly from correctional officers and prisoners. Data abstraction forms were developed to collect the required information from each reviewed document. Whenever it is needed, a randomiser software (141) was utilised to generate a random sample of prisoners (or officers) to have their files reviewed or be asked to participate in the knowledge survey. The generation of random samples was performed by the PhD student. A trained research assistant searched for the related medical records and reviewed them initially. The PhD student performed the second review and cross-checking. Due to old medical records being more likely to be lost, we planned to include more participants from recent years with the allocation of 15%, 15%, 30%, and 40% of the reviewed record for years 2013-2016, respectively. The "current ideal" was derived from the above-mentioned international and national resources, including relevant publications. The absolute difference between the ideal and the current practise is considered the system indicator performance gap. Sources of each piece of information and the description of the methodology and data collection of each indicator are described below.

**Table 4.1** Parameters and indicators of the prison's system performance in TB control, and basic study designs for assessing them.

| Parameters | Indicators | Study design/details |
|---|---|---|
| 1.Policies and human resources | 1a. The number of sections addressing TB control in prisons in the national guidelines | Review of the national TB management guidelines in Malaysia |

| | | |
|---|---|---|
| | 1b. The number of healthcare workers in prison compared to the total number of prisoners | Prospective interval (monthly) point prevalence of healthcare workers and housed prisoners over 12 months |
| 2. Screening, case detection and notification | 2a. The proportion of prisoners screened for active TB upon prison entry | Prospective examination of medical records of prisoners entering the prison for the reporting of TB screening (N=500) |
| | 2b. The proportion of prevalent TB cases diagnosed by the prison system | Examination of prison's TB records, input from previous intensified TB case finding surveys, and review of medical records of prisoners in the sick prisoners' complex (2013-2016) |
| | 2c. The proportion of TB cases notified to the NTP | Review of medical records of prisoners with TB (2013-2016) and confirmation by the prison's health authorities |
| 3. Treatment initiation, follow-up, and outcome | 3a. The proportion of prisoners with TB provided with standard anti-TB treatment | Review of prison's TB records, the medical records of all prisoners with TB, and medical records of prisoners in the sick prisoners' complex (2013-2016). |
| | 3b. The proportion of prisoners with pulmonary TB tested for sputum after two months of treatment | Review of medical records of all prisoners with TB during 2013-2016 |
| | 3c. The proportion of prisoners with TB cured or completed treatment | Review of medical records of prisoners with TB during 2013-2016 |
| | 3d. The proportion of prisoners with active TB who died during TB | Review of medical records of all prisoners with TB and prison's mortality record (2013-2016) |

| | | |
|---|---|---|
| | treatment in the prison | |
| | 3e. The proportion of prisoners with active TB released before treatment completion who were provided with a proper referral letter, treatment book and seven days of treatment. | Review of medical records of recently released TB cases and the pharmacy records |
| 4. Care of HIV-infected prisoners | 4a. The proportion of HIV-infected prisoners screened for active TB | Review of medical records of prisoners with HIV who entered the prison during 2013-2016 (N=250) |
| | 4b. The proportion of HIV-infected prisoners with no TB offered IPT | Review of medical records of prisoners with HIV entered the prison during 2013-2016 (N=250) |
| | 4c. The proportion of prisoners with active TB prescribed HAART | Review of medical records of prisoners with TB and HIV diagnosed during 2013-2016 |
| 5. Knowledge of TB | 5a. The proportion of prisoners who answered questions about TB knowledge correctly | A cross-sectional study among randomly selected prisoners (N=250) |
| | 5b. The proportion of prison staff who answered questions about TB knowledge correctly | A cross-sectional study among randomly selected prison staff (N=250) |

### 4.3.4 Specific methodology details to gather data for each indicator

### 1. Review of the national TB guidelines in Malaysia (Parameter 1: Indicator 1a)

A joint effort of the MOH Malaysia, Academy of Medicine Malaysia, and the Malaysian Thoracic Society, the latest national TB treatment guidelines document "Management of Tuberculosis, 3rd Edition" was launched in November 2012 and provided the first evidence-based guidelines on management TB in Malaysia. The guidelines were primarily built on WHO and US' CDC guidelines. Given that TB management and control in prisons differs from that in the civil society in several aspects (142), a search in the guidelines was made to report the availability of a chapter or a section detailing TB control practices in prisons.

### 2. Interval prevalence of the healthcare workers (HCW) and prisoners (Parameter 1: Indicator 1b)

A prospective interval prevalence over 12 months (January to December 2017) was conducted to assess the ratio of health workforce to the total number of prisoners. At the beginning of each month, the total number of prisoners is recorded from the muster board at the prison, and the number of working HCW (medical doctors, medical assistants, pharmacists, dentists, and psychiatrists) was recorded from the prison clinics' records. A retrospective method was not utilised in this section due to the weak recording system in prison, where previous HCW records were not available. The number of HCW per 1,000 prisoners was reported for each month, and the average rate was reported. The acceptable rate of HCW to the population in need is $\geq 2.5$ per 1,000 population (143), and the absolute difference between the observed finding and this figure was considered a gap.

### 3. Prospective review of medical records of prisoners following entry (Parameter 2: Indicator 2a)

Medical records of randomly selected prisoners entering the prison from June to December 2017 were reviewed within seven days of their entry to investigate whether they were screened for active TB using TB symptoms. We randomly selected 100 prisoners in each month to review their medical record. A research assistant conducted the initial review, and this was further confirmed by the student researcher. We looked specifically for the reporting of TB related symptoms, including prolonged cough, expectoration, fever, night sweat, weight loss, loss of appetite and chest pain. The proportion of prisoners screened for active TB using symptoms was reported. We estimated that in a population of 4000, the review of the records of 500 prisoners would give an estimate of the proportion with a 5% margin of error, when the estimated proportion is put at 50% (unknown). The ideal approach is that all prisoners entering

the prison are screened for active TB using symptoms (according to the Malaysian guidelines) (57). The absolute difference in findings from this figure is considered a gap.

### 4. Review of medical records of TB cases diagnosed in Kajang prison during the four years (2013-2016)

The list of prisoners with TB incarcerated over the four years was obtained from the prison's clinic, from records of previous TB case finding surveys, and from a search of medical records in the archives. An abstraction form was designed to collect information from the medical records of prisoners with TB. The form included information about the year of TB diagnosis, whether diagnosed inside or outside prison, and dates of entry and release. The form further extracted information about the HIV status and HAART prescription. Furthermore, confirmation of NTP notification, reported sputum smear examination at two months of treatment, and the outcome of TB treatment (cure/completed treatment, failed treatment, released before treatment completion, death) were sought.

The process of data abstraction started with a thorough search for medical records of prisoners with TB diagnosed during 2013 to 2016. Data abstraction was conducted by two individuals (the student researcher and a trained research assistant) independently. In cases of dispute, the decision of the student researcher was taken. If a medical record stated that the prisoner was a case of active TB (confirmed TB in the community, sputum specimen positive for TB bacilli [smear, Xpert or culture]) but was not on treatment, the patient was labelled as "patient was not offered TB medications". Review of the medical records of TB prisoners was conducted to provide the following information:

#### a. Assessment of the average case detection ratio of TB cases in the prison (Parameter 2: Indicator 2b)

The proportion of TB cases diagnosed each year against the mid-year number of prisoners (4,200 prisoners (60)) was assessed for each year (2013-2016), and the average proportion of TB cases was reported. The total number of reported TB cases in the prison for each year (2013-2016) was sought from the prison's TB record, search of actual medical records of prisoners labelled as "TB", and from the records of previous TB case finding surveys. The actual prevalence of TB disease in this prison was derived from an intensified TB case finding survey using Xpert and culture performed in 2013. The study showed that among the recruited 559 participants, 48 were TB cases (prevalence of 8.5%) (10). The average case detection ratio was assessed against that figure. The WHO estimates that, to reach the TB elimination targets, a

minimum of 70% of TB cases need to be detected (36). The absolute difference between the observed finding and this figure was considered a gap.

### b. The proportion of new TB cases notified to the national TB programme (NTP): (Parameter 2: Indicator 2c)

The Malaysian TB and HIV screening in prison document stresses that TB cases diagnosed in prisons need to be notified (usually within seven days from diagnosis) to the NTP (57). A review of medical records was conducted to examine whether the notification forms were filled and sent to the NTP. We estimated that in a population of 500 prisoners with TB, the review of records of 250 prisoners with TB would give an estimate of the proportion with a 5% margin of error (with the estimated proportion put at 50%). The proportion of TB cases with NTP notification was recorded against the total number of TB cases diagnosed in prison. Ideally, 100% of prisoners with TB need to be notified to the NTP. The absolute difference between the observed finding and this figure was considered a gap.

### c. The proportion of TB cases who started on standard anti-TB medications (Parameter 3: Indicator 3a)

Information about starting TB medications for those diagnosed inside the prison or entered the prison with TB was sought from several sources. A review of the medical records of patients with TB, review of the medical records labelled as "TB", review of the medical records of those diagnosed or, if entered with TB, recognised with active TB in previous TB case finding surveys. The proportion of prisoners with TB diagnosis who started treatment inside the prison was reported for each year. Ideally, all (100%) prisoners with TB must have been put on standard TB medications. The absolute difference between the observed finding and this figure was considered a gap.

### d. The proportion of prisoners with TB who were tested at two months of TB treatment (Parameter 3: Indicator 3b)

According to the WHO's TB treatment guidelines, treatment of pulmonary TB cases needs to be monitored using sputum examination at the end of the intensive phase (2 months of four TB medications). Failure to do so may lead to missing cases with potential treatment failure, non-compliance, or cases with drug-resistant TB. Medical records of prisoners with pulmonary TB who remained in prison at or beyond two months were reviewed. We estimated that in a population of 500 prisoners with pulmonary TB, the review of the records of 200 prisoners

would give an estimate of the proportion with a 5% margin of error with an estimated proportion of prisoners tested at two months is placed at 50% (being unknown). Ideally, all prisoners with pulmonary TB need to be examined at two months. The absolute difference between the observed finding and this figure was considered a gap.

### e. TB treatment success among prisoners with TB disease (Parameter 3: Indicator 3c)

TB cases who were cured or completed treatment were considered to have a successful TB treatment outcome. Medical records of prisoners with TB who spent a minimum of six months in prison were reviewed. Information sought was a negative sputum examination at the end of six months of treatment (cure) or simply the completion of the six months without evidence of sputum examination. We estimated that in a population of 300 prisoners with TB staying for six months or more, the review of the records of 100 prisoners with TB would give an estimate of the proportion with an 8% margin of error with an estimated proportion of prisoners with treatment success is placed at 50% (being unknown). WHO estimates that to reach the elimination targets, 85% of TB cases need to have a successful treatment outcome (36). The absolute difference from this figure was reported as a gap.

### f. TB-related mortality rate (for Parameter 3: Indicator 3d)

The proportion of prisoners with active TB who died in prison during TB treatment was sought. This information was obtained from the prison's mortality record and reported per 100,000 prisoners against the mid-year prison population (4,200 prisoners). The average mortality rate in prison (for the four years) was reported. WHO set a target for zero deaths, but in this study, we considered the mortality rate in the Malaysian community (5 per 100,000 population) as the preferred cut-off and absolute difference from this was reported as a gap.

### g. HAART prescription for prisoners with TB/HIV (Parameter 4: Indicator 4c)

The proportion of active TB cases with HIV infection who were prescribed HAART in prison was reported from the examination of medical records of prisoners with TB and HIV. We estimated that in a population of 300 TB/HIV cases, the review of the records of 200 prisoners would give an estimate of the proportion with a 4% margin of error. Ideally, the WHO recommends that all prisoners with TB/HIV should be prescribed and the absolute difference between the observed finding and this figure was considered a gap.

### 5. Prospective examination of medical and pharmacy records of soon-to-be-released prisoners with TB (Parameter 3: Indicator 3e)

The proportions of TB prisoners due to be released who received their referral letter, treatment book and a seven-day treatment before release from prisons, were estimated prospectively in five Malaysian prisons with approximately similar prison populations (Kajang, Sg Udang, Kluang, Seremban, and Tapah). Because these items are made available to prisoners at the prison's pharmacy without documentation, no retrospective information was available for the years 2013-2016. The proportion of prisoners with TB disease who collected these items before the release was reported. We estimated that in a population of 200, the review of the records of 100 prisoners with TB would give an estimate of the proportion with a 6% margin of error with an estimated proportion of prisoners who collected pre-release package was stated at 50% (being unknown). Ideally, all due-to-be-released prisoners should receive the pre-release package of referral forms and treatment, and the absolute difference from this figure was reported as a gap.

### 6. Review of medical records of prisoners with HIV in Kajang prison during the four years (2013-2016)

The list of prisoners with HIV who were incarcerated in prison over the four years was obtained from the prison's clinic records, from records of previous TB case finding surveys, and from a search of medical records in the archives. An abstraction form was designed to collect information from the medical records of prisoners with HIV, and this included information about screening for TB at entry and whether IPT was prescribed.

Review of the medical records of prisoners with HIV was conducted initially by a research assistant and cross-checked by the student researcher to provide the following information:

#### a. Screening for TB disease at entry (Parameter 4: Indicator 4a)

WHO and the Malaysian MOH recommend that HIV-infected individuals need to be screened for TB using 4-symptom clinical algorithm (11,34). We randomly selected prisoners with HIV infection to review their medical records from the list of HIV-infected prisoners provided by the prison. We estimated that with a population of 1,000, the review of the records of 250 prisoners with HIV would give an estimate of the proportion with a 6% margin of error with an estimated proportion of prisoners screened for active TB is placed at 50% (being unknown). The proportion of those screened by the WHO clinical algorithm at entry was reported. Ideally,

all prisoners with HIV should be screened for TB at the entry, and the absolute difference between the observed finding and this figure was considered a gap.

### b. Prescription of IPT (Parameter 4: Indicator 4b)

WHO and the Malaysian MOH recommend that asymptomatic HIV-infected individuals need to be prescribed IPT to prevent the development of TB in this at-risk population (11,34). We utilised the database collected for the previous indicator. We estimated that the review of the records of 250 prisoners with HIV and free of TB at entry would give an estimate of the proportion with a 6% margin of error with an estimated proportion of prisoners prescribed IPT is placed at 50% (being unknown). The proportion of those who started IPT was reported against the total number of HIV-infected prisoners. Ideally, all HIV-infected prisoners without TB (estimated to be 80% from previous surveys) need to be prescribed IPT, and the absolute difference between the observed finding and this figure was considered a gap.

## 7. Cross-sectional knowledge surveys (Parameter 5)

Knowledge about TB was assessed among randomly selected samples of prisoners and correctional officers from the same prison using Knowledge, Attitude and Practice (KAP) surveys developed by WHO (144). We utilised the knowledge part only, which has ten multiple-choice questions to assess basic knowledge about TB, including:

1. What causes TB?
2. Is TB a serious disease?
3. How can we get TB?
4. Who can be affected by TB?
5. How to prevent TB?
6. What can be used to treat TB?
7. What is the length of TB treatment?
8. Can TB be cured?
9. What is the risk of not treating TB?
10. What's the cost of TB treatment in Malaysia?

We estimated that in a population of 4,000 and 1,000, the recruitment of 250 individuals from prisoners and prison staff, respectively would give an estimate of the proportion (with a 5% and 6% margin of error) of participants with good knowledge is placed at 50% (being unknown). All current prisoners and correctional officers were given unique numbers, and the

sample was randomly selected using a randomiser software. To accommodate possible losses, we listed 270 unique numbers from each group to be recruited. We aimed at face-to-face interviews, but this was feasible to prisoners only; correctional officers had several tasks to do during their work, and some were on night shifts at the time of the survey. Recruited prisoners were briefed about the study, asked to provide written informed consent, and were interviewed by a trained research assistant. Correctional officers were provided with a participant's information sheet detailing the study together with a consent form to sign and the questionnaire to be answered by themselves at their convenience. Completed forms were handed back to the research assistant during the morning muster. The proportion of prisoners and correctional officers who answered the 11 questions correctly were calculated separately with 95% CI. We estimated that in a high performing system, 80% of prisoners and 75% of correctional officers need to have answered all questions correctly and the absolute difference between the observed finding and this figure was considered a gap. These figures were adapted from a system analysis paper, given the unavailability of information about the subject (139).

### 4.3.5 Ethical considerations

The protocol of this PhD sub-study was reviewed and approved by the University of Otago's Human Ethics Committee and the University of Malaya Medical Centre's Medical Ethics Committee. The reviewed medical records were anonymised with no personal information collected. When the study involved direct recruitment of a prisoner or a correctional officer, an informed consent process was followed. We stressed to participants that participation is voluntary, and those who refuse to participate would not be disadvantaged.

## 4.4 PROJECT FINDINGS

### 4.4.1 Overview

The study revealed several significant findings. Overall, the study showed that the performance of the TB control programme in this Malaysian prison during 2013-2016 was suboptimal in several aspects. It appears that there is poor public health support shown with the lack of inclusive guidelines to manage TB in these settings and inadequate health staffing. The gap in TB screening, TB case detection and TB notification to NTP was large. TB treatment initiation in prison was high, but treatment follow-up and treatment outcome were suboptimal. The study also revealed poor TB-related care for prisoners living with HIV. Finally, knowledge about TB

is low among both prisoners and prison employees, but considerably lower among prisoners compared to prison employees.

### 4.4.2 Parameter 1: Information and human resources

This parameter involves two indicators:

**a. Chapters/sections in the national TB guidelines addressing TB control in prisons**: Despite recognising prisoners as an important risk group for TB, no section or chapter in the national TB guidelines was dedicated to address TB control in prisons.

**b. The ratio of HCW to prisoners:** Table 4.2 provides details of the ratio of HCW to prisoners for each month. The average HCWs-to-prisoners ratio was 2.19 per 1000 prisoners (95% CI 2.07-2.31)

**Table 4.2** Ratio of healthcare workers in relation to the total number of prisoners

| Month | Prisoners | Medical Doctors | Medical Assistants | Pharmacist | Dentists | Psychiatrists | Total HCW | per 1000 |
|---|---|---|---|---|---|---|---|---|
| JAN 2017 | 3571 | 3 | 4 | 1 | 1 | 0 | 9 | 2.52 |
| FEB 2017 | 3956 | 3 | 4 | 1 | 1 | 0 | 9 | 2.28 |
| MAR 2017 | 4637 | 3 | 4 | 1 | 1 | 0 | 9 | 1.94 |
| APR 2017 | 3903 | 3 | 4 | 1 | 1 | 0 | 9 | 2.31 |
| MAY 2017 | 4237 | 3 | 4 | 1 | 1 | 0 | 9 | 2.12 |
| JUNE 2017 | 3470 | 3 | 4 | 1 | 1 | 0 | 9 | 2.59 |
| JUL 2017 | 3927 | 3 | 4 | 1 | 1 | 0 | 9 | 2.29 |
| AUG 2017 | 4480 | 3 | 4 | 1 | 1 | 0 | 9 | 2.01 |
| SEP 2017 | 4024 | 3 | 4 | 1 | 1 | 0 | 9 | 2.24 |
| OCT 2017 | 4420 | 3 | 4 | 1 | 1 | 0 | 9 | 2.04 |
| NOV 2017 | 4283 | 3 | 3 | 1 | 1 | 0 | 8 | 1.87 |
| DEC 2017 | 3938 | 3 | 3 | 1 | 1 | 0 | 8 | 2.03 |
| | | | | | | | AVERAGE | 2.19 |

### 4.4.3 Parameter 2: Screening, prevalent case detection and notification

This parameter involves the following indicators:

**a. Screening for active TB upon entry to prisons:** Out of the prospectively reviewed records of 701 prisoners who entered the prison during the study period, 380 (54.2%, 95% CI 50.4-57.9%) medical records reported that prisoners were screened for TB disease using symptoms.

**b. TB case detection:** Information about diagnosed TB cases in the prison over the four years from different sources showed that there were 195, 162, 85, and 101 TB cases reported in prison during years of 2013, 2014, 2015, and 2016, respectively. Calculating the prevalent TB cases each year against the average number of housed prisoners (4,200 prisoners) yielded 4.6%, 3.9%, 2.0%, and 2.4% prevalence of TB case for year 2013, 2014, 2015, and 2016, respectively. The average prevalence of TB cases over the four years was 3.2% (95% CI 2.0-4.4), giving a TB case detection rate of 37.6% (95% CI 27.4-48.8) (8.5%).

**c. Notification of TB cases to the NTP:** TB notification of those who received treatment in prison was performed by the prison's health authorities during 2013-2014. During that period, information about the TB notification to the MOH was reported to be complete by the prison authorities. In 2015, the MOH partially took over the health management and imposed a regulation that only community health facilities (MOH) have the right to diagnose and notify TB cases from prisons. Hence, no record was available about TB notification in 2015 and 2016. We were not able to extract this information from the nearby health facilities treating TB cases from prisons. Despite the assurance from the prison's health authorities that TB cases in 2015 and 2016 were reported to NTP by community health facilities, we confined our analysis to the complete information from 2013 and 2014. The proportion of TB cases reported to NTP was 57.7% (101 out of 175) and 33.3% (51 out of 153) in the years 2013 and 2014, respectively. The overall average notification rate was 45.5% (95% CI 21.6-69.4%).

### 4.4.4 Parameter 3: Treatment initiation, follow-up, and outcome

This parameter involves the following indicators:

**a. Prescription of anti-TB medications to TB cases in the prison:** During the four years (2013-2016), 543 prisoners were diagnosed with TB. Of these, 495 (91.1%, 95% CI 88.4-93.3%) prisoners with TB were prescribed TB treatment. TB treatment prescription was constantly high in the four years: 89.7% (175/195), 94.4% (153/162), 90.6% (77/85), and 89.1% (90/101) in years 2013-2016, respectively.

**b. Monitoring anti-TB treatment in prison (two-month sputum examination):** Records from the years 2013-2016 revealed that 325 prisoners with pulmonary TB spent more than two months in prison and were eligible to submit sputum examination at two months of TB treatment. Of these, 165 (50.7%, 95% CI 45.2-56.3%) were reported to have their sputa examined at two months. Rates of sputum examination at two months were variable during the four years: 51.8% (57/110), 61.8% (60/97), 40.3% (23/57), and 41% (25/61) in years 2013-2016, respectively.

**c. TB treatment success rate in prison:** Records from years 2013-2016 showed that 114 prisoners with TB remained in prison for six or more months. Out of these, 83 (72.8%, 95% CI 63.5-80.5%) prisoners completed TB treatment inside the prison. Sputum examinations at the end of the TB treatment were not reported. Prison's medical doctors reported "treatment completed" only. Treatment success rates were variable over the four years: 83.8% (31/37), 82.8% (29/35), 66.6% (10/15), and 48.1% (13/27) in the years 2013-2016, respectively. Table 4.3 provides details of the TB treatment outcome in prison over the four years. Overall, 16.7% completed treatment, 4.2% died during TB treatment, 0.2% failed treatment, 1.8% had no reported outcome, and 76.9% were released before treatment completion inside the prison.

**d. TB-related mortality rate:** During the four years, 21 prisoners on TB treatment died in prison (6, 5, 3, and 7 during years 2013-2016, respectively). The prison's TB-related mortality rate was 143, 119, 71, and 167 per 100,000 prisoners in 2013, 2014, 2015, and 2016, respectively. The average mortality rate of the four years was 125 per 100,000 population (95% CI 85-165 per 100,000 population).

**e. Pre-release provision of documents to continue treatment in the community:** Records of 105 prisoners released with incomplete TB treatment in prisons showed that 77 (73.3%, 95% CI 63.8-81.4%) prisoners were provided with referral letters and treatment books to continue treatment after release.

**Table 4.3** Outcome of TB treatment in the prison

| Year | Success (N, %) | Released (N, %) | Death (N, %) | Failure (N, %) | Not reported | Total |
|---|---|---|---|---|---|---|
| 2013 | 31 (17.7) | 138 (78.9) | 6 (3.4) | 0 (0.0) | 0 (0.0) | 175 (100) |
| 2014 | 29 (19.0) | 118 (77.1) | 5 (3.3) | 0 (0.0) | 1 (0.7) | 153 (100) |
| 2015 | 10 (13.0) | 62 (80.5) | 3 (3.9) | 0 (0.0) | 2 (2.6) | 77 (100) |
| 2016 | 13 (14.4) | 63 (70.0) | 7 (7.8) | 1 (1.1) | 6 (6.7) | 90 (100) |

*Treatment success: completion of a full TB treatment regimen; Released: being released from the prison before treatment completion; Death: Died while on TB treatment inside the prison; Failure: positive sputum microscopy examination at five months of TB treatment; Not reported: no information recorded about the outcome of TB treatment*

### 4.4.5 Parameter 4: TB care of HIV-infected prisoners

This parameter involves three indicators:

**a. Screening of HIV-infected prisoners for active TB:** Records from 244 randomly selected prisoners with HIV revealed that 54 (22.1%, 95% CI 17.2-27.9%) were screened using symptoms at entry to the prison over the four years. Screening rates were variable in the four years: 78.3% (18/23), 70.8% (17/24), 10.7% (8/75), and 9.0% (11/122) were screened over 2013-2016, respectively.

**b. Prescription of IPT to HIV-infected prisoners:** Using the same database created for the indicator (4a), only four (1.6%, 95% CI 0.4%-4.1%) prisoners with HIV were prescribed IPT in the four years.

**c. Prescription of HAART to HIV-infected prisoners with TB:** Records of prisoners with TB showed that there were 201 TB cases co-infected with HIV infection over the four years. Of these, 26 (12.9%, 95% CI 8.6-18.4%) prisoners were prescribed HAART. HAART prescription rates were variable over the four years: 14.1% (10/71), 11.7% (9/77), 10.7% (3/28), and 16% (4/25) during years 2013-2016, respectively.

### 4.4.6 Parameter 5: Knowledge about TB

Of 265 prisoners recruited for the TB knowledge survey, 18 (6.8%, 95% CI 4.1-10.5%) answered >80% of questions correctly, a gap of 73.2% of knowledge from the ideal. Of note, no prisoner answered all questions correctly.

Of 256 correctional officers who completed the knowledge questionnaire, 172 (67.2%, 95% CI 61.1-72.9%) answered correctly >75% of the questions; only 38 (14.8%) correctional officers answered all ten questions correctly.

**Figure 4.2** Frequencies of correct answers in the knowledge survey.

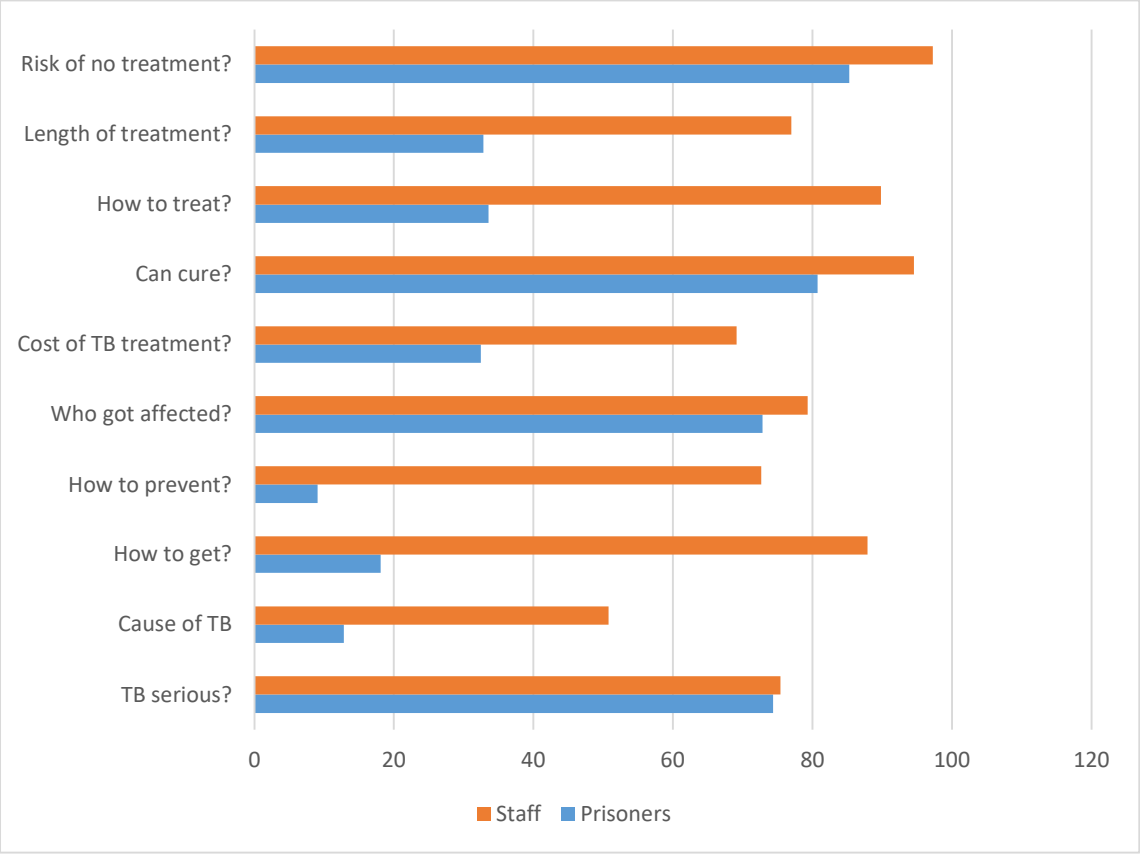



Table 4.4 lists the overall parameters and related indicators of the performance of the TB control programme in prisons in Malaysia

## Table 4.4 Gaps in the system performance in the management of TB in prisons

| Issue | Indicators | Current practice (95% CI) | Ideal | Gap/difference |
|---|---|---|---|---|
| 1.Information and human resources | 1a. The number of sections addressing TB control in prisons in the national guidelines | 0 | 1 | 100% |
| | 1b. The number of healthcare workers in prison compared to the total number of prisoners | 2.19/1000 * (2.07-2.31) | 2.5/ 1000 | 0.31/1000 |
| 2. Screening, prevalent case detection and notification | 2a. The proportion of prisoners screened for active TB upon prison entry | 54.2% (50.4-57.9) | 100% | 45.8% |
| | 2b. The proportion of prevalent TB cases diagnosed by the prison system | 37.6% (27.4-48.8) | 70% | 32.4% |
| | 2c. The proportion of diagnosed TB cases notified to the NTP | 45.5% (21.6-69.4) | 100% | 54.5% |
| 3. Treatment initiation, follow-up, and outcome | 3a. The proportion of prisoners with TB provided with standard anti-TB treatment | 91% (88.4-93.3%) | 100% | 9% |
| | 3b. The proportion of prisoners with pulmonary TB tested for sputum after two months of treatment | 50.7% (45.2-56.3) | 100% | 49.3% |

| | | | | |
|---|---|---|---|---|
| | 3c. The proportion of prisoners with TB cured/completed treatment | 72.8%<br>(63.5-80.5) | 85% | 12.2% |
| | 3d. The proportion of prisoners with active TB who died during TB treatment in the prison | 125/100,000<br>(85-165/100,000) | <5/100,000 | 120/100,000 |
| | 3e. The proportion of prisoners with active TB released before treatment completion who were provided with proper referral letter, treatment book and seven-day treatment. | 73.3%<br>(63.8-81.4) | 100% | 26.7% |
| **4. Care of HIV-infected prisoners** | 4a. The proportion of HIV-infected prisoners screened for active TB | 22.1%<br>(17.2-27.9%) | 100% | 77.9% |
| | 4b. The proportion of HIV-infected prisoners with no TB offered IPT | 1.6%<br>(0.4-4.1) | 80% | 78.4% |
| | 4c. The proportion of prisoners with active TB prescribed HAART | 12.9%<br>(8.6-18.4) | 100% | 87.1% |
| **5. Knowledge of TB** | 5a. The proportion of prisoners who answered questions about knowledge correctly | 6.8%<br>(4.1-10.5) | 80% | 73.2% |

| | | | | |
|---|---|---|---|---|
| | 5b. The proportion of prison staff who answered questions about knowledge correctly | 67.2%<br><br>(61.1-72.9) | 75% | 7.8% |

**See text for relevant calculation*

## 4.5 DISCUSSION

### 4.5.1 Summary

This review of the practice-policy gap in the management of TB in prisons in Malaysia was conducted in the largest prison in the country. The healthcare delivery in this prison is considered by the prison department as being the best in the country. Overall, the study showed wide gaps between the recommendations of established policies and the healthcare practises in the prison. These shortfalls involved most of the assessed parameters, as described below.

### 4.5.2 Inadequate information and human resources

Despite recognising prisoners as a risk group for TB, a thorough examination of the latest national TB management guidelines in Malaysia showed lack of a dedicated "TB in prison" section to address TB control measures and related difficulties, given the difference in resources and environment from the civil society (145).

This observation is likely attributed to the failure to recognise prison's health as a continuum to public health, the lack of expertise in the field, the paucity of evidence (146), or to health being managed by a ministry other than MOH.

Other counties have reported a lack of mentioning prisons in national TB guidelines. A survey in prisons in the Asia-Pacific region revealed that only 2 (15%) of responding prisons (N=15) reported having a specific section for TB control in prisons in the national TB control guidelines (122). In Europe, a similar study showed that around one-third (31.8%) of prisons reported having no TB control guidelines specific for prisons available for their medical staff (72). There is a possibility that these prisons utilise the national guidelines designed for the civil society, but these guidelines may not always apply to settings like prisons. Prison health

authorities should be involved in the development of national TB control guidelines, and a section should be dedicated for TB control in prisons (10,122,142,146).

The average HCW ratio to prisoners in this prison was 2.19 per 1,000 prisoners, a 12.4% gap from the minimum required ratio of 2.5 per 1,000 population in the Western Pacific region (143). The ratio was variable over the 12-month study period that was brought by the fluctuation in the number of prisoners entering the prison each month. This ratio, though, represents an improvement from a previous survey in 2012-2013, which showed a ratio of 0.94 per 1,000 population (147). This improvement has possibly occurred due to the commitment of MOH to provide HCW to the prison system since 2015. In this prison, though, there was only one medical assistant who works on TB who had no prior experience working in the field. Understaffed TB programmes, particularly in, but not confined to prisons, seems to be a global problem (142). One study reported a ratio of 0.87 per 1,000 prisoners in the Zambian correctional system, where not all prisons have dedicated clinics (128). Such understaffed programmes may lead to poor delivery of care and lack of proper healthcare documentation, as noticed in another study from Zambia (129). One study was conducted to assess the challenges facing the NTP in Malaysia reported that the programme is generally understaffed and, with the current situation, cannot offer proper TB management on the peripheral level (148). The study provided an example wherein city with 1.8 million residents; only four healthcare staff were managing TB.

### 4.5.3 Poor TB screening, case detection and notification

In this prison, intake health screening was conducted by a single medical assistant, who is not necessarily the dedicated TB medical assistant of the prison. If a prisoner is suspected of having TB, the medical assistant is usually the one who refers the prisoner to the community health facility for further assessment. Our study showed that only 54.2% (95% CI 50.4-57.9%) of prisoners were screened for active TB at the entry using symptoms, a 45.8% gap from ideal practice. Possible reasons for this gap are the limited human resources in prison, inadequate training of HCW to conduct TB screening, HCW fatigue (screening up to 200 prisoners per day at some point), or to poor reporting and recording practices in the prison. The inadequate entry screening in this prison has been highlighted when a TB case finding survey during 2012-

2013 revealed that 61.8% of undiagnosed TB cases were in prison for less than three months, likely TB cases missed from being diagnosed at the inefficient entry screening (10). Globally, screening for TB at entry to prisons remains variable, mainly depending on the economic status of the country (146). A survey in European prisons reported high (90.9%) screening for TB at entry to prisons in the participating prisons (72). In contrast, a similar survey in the Asia-Pacific region prisons showed that only a third of prisons in the region performed routine screening for TB at the entry to the system (122).

The study revealed that only one-third of the actual number of TB cases was diagnosed by the prison health authorities over the four years. This figure is likely due to the reliance on passive TB case detection in prison. Another potential source of this low case detection rate is underreporting of diagnosed TB cases due to poor documentation. The observed decrease in case detection in 2015 is likely due to the change in staffing (less experienced HCW were deployed after 2015), and the renovation works in the clinic area that reduced the space and delivery of healthcare services (See section 4.3.3 in the findings). Intensified TB case finding surveys are expensive and might not be accessible in areas with limited resources, like prisons in LMICs (146). In high transmission settings like prisons, though, reliance on passive case detection only might be detrimental to the TB control efforts and need to be either abandoned or coupled with active case finding surveys (10). Studies addressing specifically prevalent TB case detection rates do not exist. One study compared the prevalence of TB disease in prison in El Salvador before and after introducing enhanced TB case finding packages and showed that the prevalence of TB after the intervention was comparatively higher than TB prevalence before intervention (1.6% and 0.5%, respectively), reflecting the high prevalence of missed cases (149).

In 2013 and 2014, TB notification to NTP was performed directly by the prison, and despite this, more than half (54.5%) of TB cases were not notified to the NTP. This gap is likely due to the lack of dedicated staff members to perform the notification or to poor documentation in which copies of referral forms are not filed. Notification of TB cases from prisons is crucial to determine the actual prevalence of TB in the country and to plan post-release follow up by the MOH. TB notification to NTP is not universal in prison systems elsewhere, albeit higher than reported in this study, possibly due to poor communication between managing authorities and

the MOH. A survey in prisons in the Asia-Pacific region, where the majority (69%) of health services in prisons are managed by the MOH, showed that 86% of responding prison systems notified TB cases to national authorities (122). A similar survey in prisons in Europe reported that more than two-thirds (68.2%) of responding countries have a proper reporting system that has direct reporting of prison data in the national TB registry (72). In the latter survey, the Ministry of Justice was responsible for healthcare delivery in 68.2% of countries, while MOH was responsible (entirely or partially) for healthcare delivery in 31.8% of countries.

### 4.5.4 High treatment initiation and suboptimal treatment success, but poor treatment monitoring and linkage to post-release care

Most (91%) TB cases were started on standard TB medication in prison during the four years. It is likely that short prison stays, poor communication with community health facilities to confirm TB cases or transfer of prisoners to other prisons before treatment initiation contributed to this figure not been universal. Due to poor documentation in this prison, we were unable to determine specific causes of those who did not start TB treatment. Other prison systems seem to face a similar shortfall. The rate of TB treatment initiation in six prisons in Zambia was differed among prisons (ranging from 89-100%), but on average was high (92%) (150). An important issue raised about the low treatment initiation in the study, and that was high inter-prison transfers and releases. A retrospective assessment of TB treatment outcome in the Ugandan prison system reported very high (99.4%) treatment initiation despite having a high proportion of prisoners on remand (55%), and a high proportion (57.3%) of prisoners with TB transferred or released before treatment completion (151). A review of regional prison systems reported that only 78% of prison systems provide standard TB treatment to prisoners in the Asia Pacific region (122). In contrast, a similar review of the prison systems in Europe showed that standard TB treatment was provided in 81.8% of countries (72).

The study also showed that just over half (50.7%) of eligible prisoners with pulmonary TB submitted sputum examination at two months of TB treatment. Examination of sputum using smear microscopy after two months of TB treatment is a crucial programme indicator to assess those who have potential poor adherence to treatment or at high risk of treatment failure. Several factors might have influenced this low sputum examination, including poor HCW

knowledge about TB control, difficulties in transferring prisoners or specimens to the community health facilities (where testing is performed), and poor prison and public health departments communications. Poor documentation might have also played a role in this poor performance. Other prison systems face similar challenges and report variable findings. Upon implementation of the DOTS strategy in Thailand's prison system during 1999-2002, the average proportion of prisoners with PTB who submitted sputum for examination at 2 or 3 months was reported as generally high (86.9%), but still not ideal (152). It is likely that authors wrongly took into the account the number of prisoners who died or transferred out in their calculations. A retrospective assessment of treatment outcome in four prisons in Ethiopia reported a very high proportion (97%) of prisoners with smear examination at the end of the 2-month intensive phase. The study did not provide information about smear examination in those with smear-negative PTB (one-third of the sample). Our study showed that treatment completion among prisoners who spent a minimum of six months after starting TB treatment in the four years was suboptimal (72.8%). A significant cause of poor treatment outcome in prison was death (details below). We confined our assessment to prisoners who remained in prison during treatment as no information was available about the outcome of TB treatment after release from the prison (on average 76.6% of TB patients were released before treatment completion inside the prison). Relevant literature reported variable finding about TB treatment success, possibly due to the difference in assessment tools. A survey from the Ethiopian correctional system reported a high (94%) treatment success rate among those who remained in the prison while on TB treatment (121). Other prison studies used release/transfer out in their final analysis; this is not ideal as prison systems have no information about prisoners as soon as they are released. The average TB treatment success in the reviewed 16 publications from prisons globally was 65% (range 25-97%) with an average of 26.4% of prisoners in these studies released/transferred before treatment completion. In countries with good health systems (Europe), similar low treatment success rates (average 58% in 10 prison systems) were reported (72). In these prison systems, transfer to another registry (transfer out/release) was the most common driver for low treatment outcome with 18.9% of prisoners been released or transferred.

Our study reported that 21 (4.6%) prisoners with TB died while on treatment in years 2013-2016. This finding gives a TB-related mortality rate in the prison of 125 per 100,000 prisoners, which is a 120 per 100,000 higher than the TB-related mortality rate in the Malaysian

population. Delay in TB diagnosis and treatment initiation might have contributed to this high mortality. The drop in TB-related deaths in 2015 is likely caused by the poor reporting in that year due to the clinic reconstruction work. This high TB-related mortality is presented despite the observation that more than two-thirds of TB cases were released from the prison before treatment completion. Higher rates might be reported if the outcome of TB treatment after release is included. Additionally, documentation and categorisation of deaths in the prison are poorly standardised, leading to the assumption that the mortality rate is even higher than this figure. Our review of global literature showed a high proportion of prisoners died because of TB (an average of 6.1%), irrespective of the geographical or economic status of the country. High TB-related mortality was reported in Thailand prison system, where 17.6% of prisoners died of TB, despite the implementation of proper WHO's DOTS strategy (152). This figure was primarily attributed to the delay in TB diagnosis and hence treatment initiation.

The study revealed that most (73.3% [95% CI 63.8-81.4%]) released prisoners with incomplete TB treatment were provided with the release package, yet a 26.7% gap from the ideal practice. Poor communication between the release correctional officers and the clinics' medical team, particularly during the hectic period of release (on some occasions, around 100 prisoners are released), might not allow the prisoners to be brought to the clinic to get their pre-release package and may explain this shortfall. A similar finding was noted in a review of TB-related health practices in Indian prisons, where decisions on prisoners' transfer or release were made without notifying the medical team to organise their release (125). In a review of TB-related services in prisons in the Asia Pacific region, 24% of prison systems in the region did not perform referral of released prisoners with TB to NTP community facilities (122). On the other hand, most (72.7%) prison systems in Europe reported the organisation of continuation of TB care of released prisoners with the respective public health services before the release of prisoners with uncompleted treatment (72).

### 4.5.5 Poor TB-related care for HIV-infected prisoners

The study revealed that screening for TB among HIV-infected prisoners was low (22.1% [95% CI 17.1-27.9%]) over the four years. A declining trend in TB screening from the years 2013 to 2016 was observed, likely due to the change in staffing after 2015. Similar to overall TB

screening at entry, lack of knowledge among care providers, fatigue of HCW during screening, and unavailability of robust screening algorithms might have contributed to this shortfall in TB screening. Several collaborative works between prison departments and academic institutions have reported successful implementation of integrated TB and HIV programme with improved outcomes. Still, the maintenance of such an expensive programme remains questionable (78). In a survey in 47 community sites from 26 LMICs worldwide, ICF using symptoms was performed in 38% of participating sites, IPT use was implemented in 17%, 62% isolates smear-positive TB cases, and 57% provides HCW with masks (153). The magnitude of HIV infection in prisons is not known, particularly in LMIC, where HIV testing is not performed universally (72,154), hence screening for TB among HIV-infected prisoners remains generally underreported (155).

A small fraction of HIV-infected prisoners (1.6% [95% CI 0.4%-4.1%]) were prescribed IPT during the four years, a gap of 78.4% from the good practice of TB control programmes. The implementation of IPT among PLWH in Malaysia has been slow with previous WHO' Global TB Reports showing low proportion of PLWH was prescribed IPT (5). In addition to this, poor knowledge about IPT among the medical team, short prison stays, and referral difficulties may have contributed to this large gap in IPT prescription. In a review of literature on IPT use in prisons, only 14 studies reported the proportion of enrolled prisoners on IPT and was 57% on average (range 5-93%) (156). In a movement to scale up the use of IPT among HIV-infected prisoners, the WHO issued guidelines using a simple four-symptoms algorithm, which has very high negative predictive value (11). Despite this, the implementation of IPT in prisons remains low, possibly due to the release of recent WHO guidelines that do not recommend prioritisation of prisoners in IPT programmes (157). Adding to this, previous studies concluded the uselessness of IPT programmes in prisons and recommended the diversion of the limited funds toward the screening for active TB in prisons (158).

The average proportion of HIV-infected prisoners with active TB who were prescribed HAART was equally low (12.9% [95% CI 8.6-18.4%]). These findings are in line with findings from the community and prisons in Malaysia. Several implementation issues hamper the universal prescription of HAART to PLWH in Malaysia. In 2016, the NTP Malaysia reported that 6% of incident TB cases in Malaysia were HIV-infected, and only a third (31%) of them

were prescribed HAART (95). This observation is possibly due to the 2011 guidelines which recommend the prescription of HAART to all PLWH with TB but with timing depending on the CD4 lymphocyte count (earlier for PLWH with lower CD4 lymphocytes counts) (159). Prescription of HAART among marginalised populations in the community in Malaysia was even lower, especially in groups like prisoners and PWID, who face discrimination by HIV physicians and experience deferral from HAART prescription (94). A survey in a drug detention centre in Malaysia showed that only 9% of detainees with HIV ever received clinical care, and none were prescribed HAART (23). Another survey among prisoners with HIV infection in Malaysia showed that less than half (48.4%) of prisoners eligible for HAART were prescribed the medication (147). Several factors might have potentially contributed to low HAART prescription for prisoners with TB in our study, including short prison's stay and unavailability of universal CD4 lymphocyte count assessment in prison. No previous publication addressing HAART prescription for TB/HIV cases in prisons exists.

### 4.5.6 Limited knowledge about TB, particularly among prisoners

A very low (6.8% [95% CI 4.1-10.5%]) proportion of prisoners answered >80% of knowledge questions correctly, a gap of 73.2% from the ideal and no prisoner answered all ten questions about TB correctly. On the other hand, 67.2% (95% CI 61.1-72.9%) of correctional officers answered correctly >75% of the questions, a gap of 7.8% from the ideal while only 14.8% of correctional officers answered all ten questions correctly. Educational programmes in prisons might not exist, particularly where resources are limited. In a survey among prison systems in Europe, less than two-thirds of participating prisons reported having an education programme to increase awareness about TB among prisoners and correctional officer (72). Knowledge about TB among prisoners is variable but generally remains low. Surveys in two Ethiopian prisons reported very poor knowledge about TB (e.g. 1.6% and 37.7% mentioned bacteria as the cause of TB in the two prisons) (133,134). Surveys from the prison system in Brazil reported high knowledge about TB among prisoners and correctional officers, with better knowledge among guards compared to prisoners, possibly due to the establishment of a correctional officer education programme in the system. Still, knowledge remained far from ideal (136,137).

Confining the study to a single prison may limit the generalisation of our findings. Kajang prison is the largest in Malaysia and receives prisoners from all over the country. Other prisons might have more experienced staff and different level of resources to implement screening and management plans, and a larger study involving other prisons is warranted.

The poor reporting and recording system in prison might have influenced our findings. Despite deploying several measures to mitigate this effect like using several resources to extract a single information and the use of different study designs to collect information about some indicators to ensure credibility of the data, the influence of this factor cannot be completely ruled out.

We planned to assess more programme indicators, like infection control measures, but evaluation of this indicator was not possible as we were not allowed to present in the prisoner rooms.

The study highlights several policy implications to improve the performance of the TB programme in prisons. Firstly, proper TB management in prisons guidelines need to be developed to direct HCW on appropriate management of TB in these settings. Second, provision of adequate and well-trained staff is crucial to achieve the programme targets. Third, developing a proper reporting and recording system is of utmost importance to provide a platform for programme monitoring and evaluation. Fourth, the establishment of appropriate referring system for sputum examination or the establishment of a TB-directed lab is vital for treatment monitoring. Fifth, essential measures need to be taken to investigate the causes of death among prisoners with TB to improve treatment outcome. Sixth, HIV care needs to be optimised, as TB/HIV cases represent a large section of TB cases. Seventh, government stakeholders need to establish proper communication to improve post-release continuation of treatment. Finally, education programmes targeting both prisoners and prison staff are crucial to controlling TB in prisons in Malaysia.

# CHAPTER FIVE: THE CONTINUATION OF TUBERCULOSIS TREATMENT AMONG PRISONERS RELEASED TO THE COMMUNITY BEFORE COMPLETING TREATMENT IN PRISONS IN MALAYSIA: A PROSPECTIVE COHORT STUDY

## 5.1 Introduction

Released prisoners with uncompleted TB regimen may pose significant TB risks to the general population (15). This group of prisoners may remain infectious, transmitting TB infection to other individuals in the community. The situation is additionally detrimental when drug-resistant TB is involved (160). A study projected that for every 1% increase in incarceration rates, there is a 0.34% increase in TB incidence in the community (15). This effect was partially attributed to the interruption of follow-up on released prisoners with uncompleted TB treatment. Although the study was focused on Eastern Europe and Central Asia countries, these findings might apply to other LMICs where the characteristics of prions are similar. Most prisoners come from a low socio-economic background, and when released to the community face several challenges that might be prioritised over healthcare seeking, further complicating TB treatment in the community. A previous study in Malaysia showed that several challenges face prisoners with HIV infection transitioning to the community, including securing employment, finding housing, reuniting with families, and facing the drug use challenges (14).

In Malaysia, the prison system is not involved in organising linkage to the community healthcare system, and prisoners with uncompleted TB regimen are provided with a referral letter and 7-day dose of TB treatment at the day of release from prisons. The latter needs to be organised by a release officer, who is not always available due to the busy schedule on release days. Additionally, the Malaysian MOH is not directly involved in delivering health to prisoners, and public health facilities are not informed earlier of when and where prisoners with TB are released. This situation leaves the matter of continuing TB treatment in the community to the discretion of prisoners. With this situation, there is no information about the outcome of TB treatment in the community among released prisoners with uncompleted TB regimen. This study was conducted to provide this valuable piece of information to plan further interventions to improve care of released prisoners with TB.

This chapter provides background information, study methodology, findings, and discussion regarding the third study of the PhD project. The study was conducted in five major prisons in Malaysia and utilised a cohort study design to assess the study objectives. Findings from the study will have significant implications for further research and policy changes.

## 5.2 The review of literature

### 5.2.1 The literature review protocol

This review of the literature was conducted to answer the question: "What proportion of released prisoners with uncompleted TB treatment in prisons continue treatment in the community?". To answer the question, we did not confine our search to the post-release period only, but we searched for publications that assessed the TB treatment outcome in prisons, and we extracted information related to post-release continuation of TB treatment after release. A literature search was conducted in July 2020 using Medline and Embase databases through the Ovid(SP) platform and the Web of Science. Keyword structures ("tuberculosis" AND "prison" AND ["release" OR "outcome" OR "continue"]) were utilised. The search included these keywords anywhere in the text. No restrictions were placed on the language of the publication, the publication type, the study design, or the year of the publication. After removing duplicates, the abstracts of collected publications were examined thoroughly by the student researcher for the inclusion of publications in the final literature review. To be included in the final evaluation, publications needed to have presented information about the outcome of TB treatment after release from prisons. Publications that were explicitly conducted to improve the TB treatment outcome after release, but without an assessment of the pre-intervention situation were excluded. Abstracts of publications written in languages other than English were initially translated using google translate and if eligible for inclusion, were formally translated.

An extraction form was developed to extract information of interest from each study. This form included information about the location of the study, the number of prisons involved, participants' demographics, study designs utilised, and findings.

To assess the limitations of reviewed studies, we utilised the GRADE guidelines for observational studies (71). Assessed risks of bias included failure to develop and apply appropriate eligibility criteria, flawed measurement of both exposure and outcome, failure to adequately control confounding, and inadequate follow up.

Extracted information was presented in an evidence table (See Table 5.1).

### 5.2.2 Description of the studies

The search yielded 208 publications from the three databases: Medline (N=5), Embase (N=49), and Web of Science (N=154). Following the removal of duplicates, 172 unique publications remained. Upon direct screening of the collected publications, 12 reports provided information

about treatment completion among release prisoners with TB. Description of the process of publication inclusion is described in Figure 5.1.

Overall, all studies were conducted over the past 20 years (1998-2018). Most (9 out of 12) were conducted in LMIC (Ethiopia, Taiwan, India, Russia, Zambia, Mexico, Thailand, and Uganda). Three studies were conducted in the UK, US, and Spain.

A retrospective assessment among prisoners in northern Ethiopian prisons over five years (2011-2015) reported TB treatment outcome of 496 prisoners (121). Of these, 15% were transferred out/released before treatment completion inside prisons. The review indicated that all transfer out/released were not linked to respective health facilities before release, and they were lost to follow-up in the community. The study did not perform a follow-up survey on released prisoners; hence, this suggestion might not be entirely accurate.

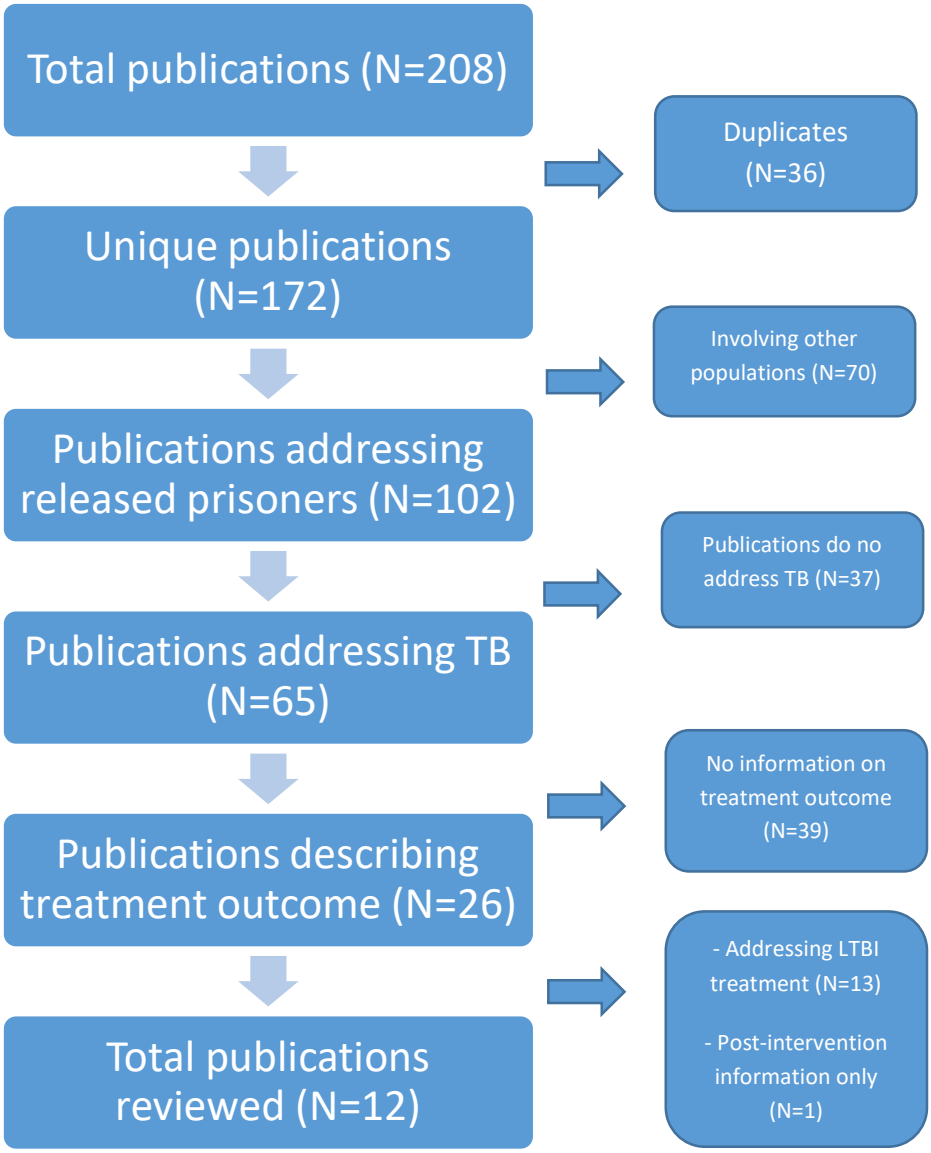
The outcome of TB treatment in registered prisoners with TB in the UK (N=110) between 2004 and 2007 was reviewed retrospectively (160). The study revealed that the treatment completion rate was 55%, while 21% were lost to follow-up due to release to the community. As with the previous study, no details were provided on the process of follow-up on released prisoners with TB.

Another retrospective review of medical records of prisoners with TB treated from September 2010 to August 2015 in a northern Ethiopian prison revealed that among the registered 162 patients, 63.62% had treatment success (161). The study also reported that one-third of prisoners with TB (N=51) were not evaluated and were likely lost-to-follow-up due to release from prison before completion of treatment. No follow-up programme was explained in the publication.

Treatment outcome of the 142 prisoners with TB in the US State of Georgia's Correctional System during 1991-1995 was reviewed and showed a treatment success rate of 65% (75). The study also showed that 39 (27%) were released from prisons before completing treatment. Arrangements with appropriate county TB programmes were made for released prisoners with TB and follow up on released prisoners showed that only 23 (59%) completed TB treatment in the community. Of those who did not complete treatment, one prisoner died, and 15 (38%)

were lost to follow-up. The study deployed the recruitment criteria, but no exposure variables to assess factors associated with failure to continue treatment were collected.

**Figure 5.1** The literature search and selection.




A retrospective review of the outcome of TB treatment in prisoners diagnosed with TB in the Taiwanese correctional system between July 1998 and June 1999 revealed that among 107 TB cases diagnosed, 80.4% completed treatment. The study also reported that 15.9% were lost to follow-up due to release from prisons. No information was provided about the follow-up process on released prisoners, but authors cited another work conducted by them (a conference presentation- not accessible) showing that only a third (38.5%) of released prisoners completed

treatment in the community (162). The study did not examine the association of unsatisfactory treatment completion with exposure variables.

Thirty-three current prisoners and 39 former prisoners with TB in the penitentiary centre in Madrid (Spain) during 1997 were followed up for a year to assess the completion rate of TB treatment in the two groups (163). Due-to-be-released prisoners were assigned to the primary healthcare facility that would provide care in the community. The study reported that the proportion of current prisoners who completed TB treatment was considerably higher compared to released prisoners (69.7% versus 20.5%, respectively). The study also reported that treatment had to be prolonged in 15.2% of current prisoners compared to 46.2% of released prisoners with TB. The analysis revealed that imprisonment throughout TB treatment was the only predictor associated with successful TB treatment completion (OR=12.94, 95% CI 3.38-53.10). No difference in the completion of TB treatment according to age (OR 1.10 [0.34-3.53] for age > 29 compared to 16-29), gender (OR 1.94 [0.12-58.12] for men compared to women), HIV status (OR 1.74 [0.37-8.56]), drug use (OR 1.98 [0.48-8.40]) or the location of TB disease (OR 0.96 [0.23-4.03] for extrapulmonary compared to pulmonary disease) was noticed. The study is small and drawing a conclusion from this small sample size might not be possible. This has been reflected by the wide CI in the analysis of exposure variables. Additionally, the process of selection of participants was not thoroughly explained, raising issues about potential selection bias.

Information from prison authorities and the national TB programme in India was retrospectively reviewed to assess the TB control activities in Tihar prison in Delhi, India, over the period from 2008 to 2012 (125). The study reported that on average, 120 prisoners were started on TB treatment annually during that period. On assessing the outcome of TB treatment among prisoners prescribed TB treatment, a considerable proportion (29.5%) were released before completing treatment in prison. Despite the involvement of the Indian NTP, no information was elicited on the outcome of TB treatment among released prisoners, and this was labelled as “unknown”. This highlights the potential nature of poor reporting and recording system within the TB control activities for prisoners.

A study was conducted to assess barriers to treatment completion among current and former prisoners in three prisons and two community dispensary sites in St Petersburg in Russia in 2002 (4). The study reported that among those who listed an address in St Petersburg (N=80),

only 21 (26.3%) appeared in the dispensary attendance record in the community. The study did not provide detailed information about the recruitment process or the characteristics of prisoners who abandoned treatment. Additionally, the study provided no relevant association analyses with poor treatment continuation; but presented the perspective of current and former prisoners about potential reasons for treatment discontinuation after release.

A retrospective assessment of treatment outcome among prisoners with TB in six prisons in Zambia between October 2010 and September 2011 reported that 345 started TB medications (150). Of these, 11.3% (95% CI 8.2-15.1%) were released to the community before completing treatment and were lost-to-follow-up. The study reported that prisoners were followed-up at the respective TB treatment clinics by Zambian NTP during incarceration, but no detail about the process of follow-up for released prisoners was provided.

A cohort study was conducted among HIV-infected prisoners diagnosed with active TB in prison in Mexico City, Mexico (N=28) from November 2010 to February 2011 (164). Among these, seven prisoners were released before completing treatment in prison, of whom only two completed treatment in the community. The study was limited by the small number of recruited prisoners preventing the analyses of exposure variables.

A prospective assessment of treatment outcome among prisoners housed in 16 prisons in Thailand from June 1999 to May 2002 reported a total of 1158 prisoners started TB treatment (152). Of these, 10.6% (95% CI 4.9-18.1%) were reported as transferred out or released before completing TB treatment (no differentiation was made between the two groups). According to the authors, they were able to reach prisoners transferred to other prisons, but not those who were released. This occurred despite taking additional steps to improve registration in community clinics after release, include pre-release health education, provision of official referral letters and post-release reminders. Possible explanations were that prisoners either provided false addresses or they never returned to their correct home addresses.

A retrospective assessment of treatment outcome among prisoners diagnosed with active TB in the Ugandan prison system from June 2011 to November 2012 showed that 466 prisoners were started on TB treatment during that period (151). Of these, the study reported that 28% were released before completing TB treatment. Most (81%) of the released prisoners with incomplete TB treatment were lost to follow-up in the community. The authors suggested

strategies to prevent default, including halting prison transfers, improved linkage to public health facilities, provide treatment stock for prisoners due to be released, and the use of technologies, like mobile phones as reminders. The study did not assess variables associated with treatment default after release from prisons.

### 5.2.3 Summary of the literature review

Publications addressing the outcome of TB treatment among prisoners after release from prisons remain scarce. This observation is likely due to difficulties in reaching this hard-to-reach population in the community. The database search revealed 12 relevant publications. Most (75%) publications were conducted in LMIC, where the burden of TB is higher and incomplete TB treatment in the community may further fuel the ongoing TB epidemics.

Overall, reviewed publications provided limited information about the outcome of TB treatment among released prisoners, particularly in LMIC, owing to inadequate resources for follow-up. The reviewed publications were limited by the small sample size and by being retrospective. Another major limitation of reviewed studies is that assumptions were made about released prisoners that they were all lost-to-follow-up. This might not be entirely true, particularly with no follow-up process described.

The review of the literature showed that TB treatment continuation after release from prisons ranged from 0-59%, the highest was reported in the study from the US. This highlights the current dangerous situation of poor TB treatment continuation after release and the need for further studies that are focused on addressing the post-release continuation of TB treatment.

## 5.3 METHODS

### 5.3.1 Study design

We utilised a prospective cohort study design to assess the rate of continuation of TB treatment among released prisoners with an uncompleted TB regimen.

### 5.3.2 Study location

The study was conducted in five men's prisons in Malaysia: two in the central region, one in the north and two in the south of the country. These prisons were chosen as more than one-third of TB cases (37.6%, 557/1,479) reported in the 43 correctional facilities in Malaysia in 2016 were housed in these five prisons. The two central prisons were Kajang and Seremban. Kajang prison is the largest prison in Malaysia, housing over 4,000 prisoners at one time, and it was the primary recruitment site. Prisoners' health conditions are attended by three medical doctors and four medical assistants. Seremban prison is located in the State of Negeri Sembilan, about 70 km south of the capital, Kuala Lumpur. Seremban prison is an old colonial-era prison housing around 2,000 prisoners, and it has a medical unit with two medical doctors and two medical assistants to perform day-to-day medical care. The two prisons in the south were Sungai Udang prison in the State of Malacca, a relatively new prison housing around 4,000 prisoners with a medical team of one medical doctor and three medical assistants. The other prison was the newer Kluang prison in the State of Johor equally houses around 4,000 prisoners, which is well-equipped with three medical doctors and four medical assistants. Finally, the prison in the northern region was Tapah in the State of Perak, housing around 4,000 prisoners at one time and had two medical officers and three medical assistants.

The prisons follow the policy of TB symptoms screening at entry (though not universal) and passive case detection thereafter (57). There are no diagnostic facilities in these prisons, and prisoners suspected of TB are referred to the nearby community health facilities for further assessment and treatment initiation. Prisoners diagnosed with active TB are provided with TB medications from the community health facility to continue inside prisons, with few follow-up appointments with the health facility thereafter. No formal counselling or education sessions are provided by prisons' health authorities to prisoners diagnosed with TB disease. At the release date, prisoners with uncompleted TB treatment are escorted by a release officer to the prison's clinic to be briefed about their condition and are provided with a "release package". The "release package" comprises of a formal referral letter to the community clinic of the prisoner's preference, an NTP treatment book, and a 7-day dose of TB medications. As described earlier, the prison system is not involved in arranging linkage of released prisoners with uncompleted TB treatment to a community health facility and leaves it to the discretion of prisoners to decide whether to continue treatment or not. As described earlier, at the time of the implementation of the research study, the MOH was not directly involved in healthcare delivery to prisoners and did not communicate with the prison system to arrange post-release

linkage to care. The MOH role was to provide healthcare workers and management of prisoners with suspected TB in their community facilities if the prisoner is referred.

### 5.3.3 The research questions

The study was designed to answer the following questions:

1. What proportion of prisoners released with uncompleted TB treatment do not continue treatment in the community?
2. What are the factors associated with failure to continue TB treatment after release from prison?

### 5.3.4 Study participants and recruitment process

Prisoners diagnosed with TB are housed in separate housing units in each prison. Demographic information about prisoners with TB was stored in each prison at a local computer. We requested a list of current prisoners with TB from each participating prison every month to identify those who were eligible for enrolment in the study. We specifically requested information on the date of prison entry, the date of expected release from the prison, and the date of starting TB treatment. A trained research assistant reviewed the lists and compiled a complete list of all potential study participants. Prisoners with TB who fulfilled the eligibility criteria were asked to present to each prison's clinic to be briefed about the study. At the clinic, prisoners were provided with patient information sheets and were asked whether they wish to participate at the time of briefing or to have time to review contents and decide later. A prisoner who agreed to participate in the study was asked to review and sign an informed consent form. The form contained information about the design of the study and requests for access to review their medical records and to use their national identity number to check for the continuation of TB treatment in the community (clinics, hospitals, and tertiary referral centre). To ensure confidentiality, the whole process was performed in a private room accessed by the research team only. Prisoners who refused to participate in the study were not in any way disadvantaged. Prisoners who provided written informed consents were interviewed individually using a structured questionnaire (see section 5.3.5 for further information about the study instruments).

Participants fulfilling the following inclusion criteria were enrolled:

1. Prisoners taking treatment for active TB in one of the participating prisons

2. Will be released from the prison before completing 100% of doses of anti-TB medication while inside the prison
3. Agree to participate in the study
4. A Malaysian national or on a resident-class visa (foreign prisoners sent to immigration detention centres for deportation following completion of sentences)
5. Aged 18 and above

Prisoners were enrolled in the study, irrespective of the location of their residence (anywhere in Malaysia).

Unwell prisoners admitted to the community hospital and remained till their release from prisons were excluded from the study.

### 5.3.5 Study instruments

The study instruments were developed based on previous studies, and the student researcher experience in the setting. These instruments were tested on a group of prisoners (N=15). They were written in English and translated by a bilingual research assistant into Bahasa Malaysia. The questionnaire included collection of information within the following sections:

1. Demographics: age, gender, education level, marital status, pre-incarceration housing status, post-release housing plans, pre-incarceration employment, post-release employment plans, and whether a family member visited him during the current incarceration
2. Incarceration history, including dates of entry and expected release, whether there was a previous entry to a correctional facility (jails [housing individuals were awaiting trial verdict], prisons [housing sentenced inmates], or compulsory drug detention centres), times and duration of previous entries (if any), and whether the participant applied for parole or not. These were cross-checked against prison's record.
3. Illicit drug use: ever used drugs before current incarceration, used drugs within 30 days before entry to prison (current drug use), ever injected drugs, injected drugs within 30 days before entry (current injection of drug use), ever used heroin within 30 days before prison entry, enrolled in MMT programme before prison entry, previous MMT enrolment

4. Previous TB episodes: ever had TB before, ever been diagnosed with TB in prisons, the outcome of prior TB treatment in prisons (stopped in prison, stopped after release, completed in prison, completed outside the prison)
5. Current TB episode (cross-checked against prisoner's medical record): date of starting TB treatment, site of TB disease, current stage of TB treatment (intensive or maintenance), where present TB was diagnosed (community facility, jail, this prison, other prisons), how TB treatment is taken (under DOT, self-administered), any adverse events of TB treatment
6. HIV infection- known HIV-infected, previous HAART and current HAART

Participants were requested to provide their full address and a phone number to identify TB clinics in the region.

### 5.3.6 The follow-up process

From 1 March 2017 to 1 May 2018, enrolled participants were interviewed in Bahasa Malaysia by a trained research assistant using a structured questionnaire. This was a one-off process, and no follow-up interviews were performed while incarcerated. To ensure an assessment of real-life practice, no education about TB or incentives were provided to participants throughout the study. Participants, on the other hand, were allowed to gain access to the regular prisons' TB services and the community health facilities, where prisoners are allowed to ask questions about TB and have a description about the treatment plan. During incarceration, a weekly examination of participants' medical records was conducted by the research assistant to check for treatment use in the prison or for hospitalisation around the time of release. At the day of release, the research assistant reviewed medical records to ensure that the release date was not extended and whether the participant had taken his "release package". No contacts with participants were performed at the time of release. Participants are further excluded from the study if during the study, their sentence was extended for any reason (allowing the prisoner to continue treatment in prison), the participant was not offered treatment, or hospitalised around the release date (and released to the community in the hospital).

After release, daily contact was made with the clinic providing TB care nearby the address provided by each participant. If after seven days, the participant did not register at the nearby clinic to continue TB treatment, further contacts were made with other clinics providing TB

care in the District and State, major hospitals in the State, and the tertiary TB referral centre in Kuala Lumpur, in addition to the primary clinic. Information about these centres (the location and contact details) was obtained from the MOH website. During each contact with MOH facilities, we asked specifically about whether the released prisoner has made a visit to the clinic and picked up his TB medications. Additionally, the prison system records were checked to investigate potential re-incarceration during this period. If by 30 days, no information about registration in a TB care-providing facility was elicited, participants were contacted directly using the phone number, if provided, to enquire about their TB treatment status. A participant who failed to register for TB treatment in one of the community facilities within 30 days of release was considered as having "discontinued treatment". For this group, we continued performing once-monthly contact to clinics and checking the prison's record for re-incarceration, in case they were entered in the record in either system. These latter checks were not planned to change the status of treatment outcome of participants, but to have information about what happened after release.

### 5.3.7 Data management

The questionnaire data were entered from the paper form to a Microsoft Excel spreadsheet by the research assistant and cleaned using double entry and verification by the student researcher. The hard copies of the questionnaire were stored in the research centre and used for reference. For the follow-up information (contacts with health facilities), another Excel sheet was created for each participant with daily entry of collected information. The latter information was entered in the master spreadsheet as soon as the status of follow-up was finalised.

Statistical analysis: Categorical variables were presented as proportions, while continuous variables were presented as either mean and standard deviation or median and interquartile range depending on the data skewness. The primary outcome of interest in the study was treatment discontinuation, which is defined as failure to register at a community TB clinic within 30 days of release from prison to continue TB treatment. This is presented as the proportion of those who did not continue treatment against the total number of participants recruited in the study, together with a 95% confidence interval (95% CI). Relative risk regression models were explored to identify variables associated with an increased risk of failure to continue treatment in the community. For the univariable relative risk regression analysis, we used a Poisson regression model (with a log link) and adjusted standard error of

the model to the cluster (five prisons) to account for the binary data. Similar analysis model was utilised in the multivariable regression analysis. A backwards-stepwise approach was used to identify a parsimonious model. AIC was used to inform the choice of the "best" model. The magnitude of correlation between variables was assessed using chi-square and Cramer's V test. The choice of strongly associated variables included in the multivariable regression model was guided by the univariable regression analysis and clinical significance. The analysis was carried out using STATA statistical software version 15.1 (StataCorp LLC, Texas, USA).

Sample size justification: With the estimate of around 1200 TB cases diagnosed each year in the Malaysian correctional system, we estimated that recruiting a sample of 140 prisoners would give an estimate of the proportion of those who failed to continue treatment in the community with a margin of error of 8%. This calculation is based on an exact confidence interval for a proportion. For the second aim, a sample of 140 participants will give 80% power to detect a 3-fold increase in risk at the 5% level for risk factors with a prevalence between 20% and 80%, if the risk of failure to continue treatment is 15-20% in the unexposed group. These calculations were performed in OpenEpi and used a normal approximation. The primary outcome measure was known for all participants (by definition); therefore, the sample size was not inflated for loss to follow-up.

Initially, we planned to recruit the 140 participants from two central prisons, but these were found to be insufficient to recruit the required number after six months of recruitment. We included three more prisons to increase recruitment.

### 5.3.8 Ethical considerations

Participation was entirely voluntary, and those who refused to participate were not in any way disadvantaged. Potential participants were asked to review the consent form and sign it if they agree to participate. We highlighted that the document requests the use of the name and national ID when corresponding with community health facilities to investigate the continuation of treatment. We also requested their consent to review the prison's medical records to assess progress on TB treatment while incarcerated. Interviews were confidential, and prison officers were blinded to the status of participants (prison officers were informed that not all those interviewed will participate). The collected information was kept in secured computers at the University of Malaya and the University of Otago and was not be released to a third party. The identity of the participants was kept confidential, and only the name and national identification number were released to the institutions (community clinics, the tertiary referral centre, drug

rehabilitation centres, hospitals, and prisons) where consent had already been granted by participants. Collected information was stored in a secure computer at the University of Otago (Note: questionnaires are already de-identified).

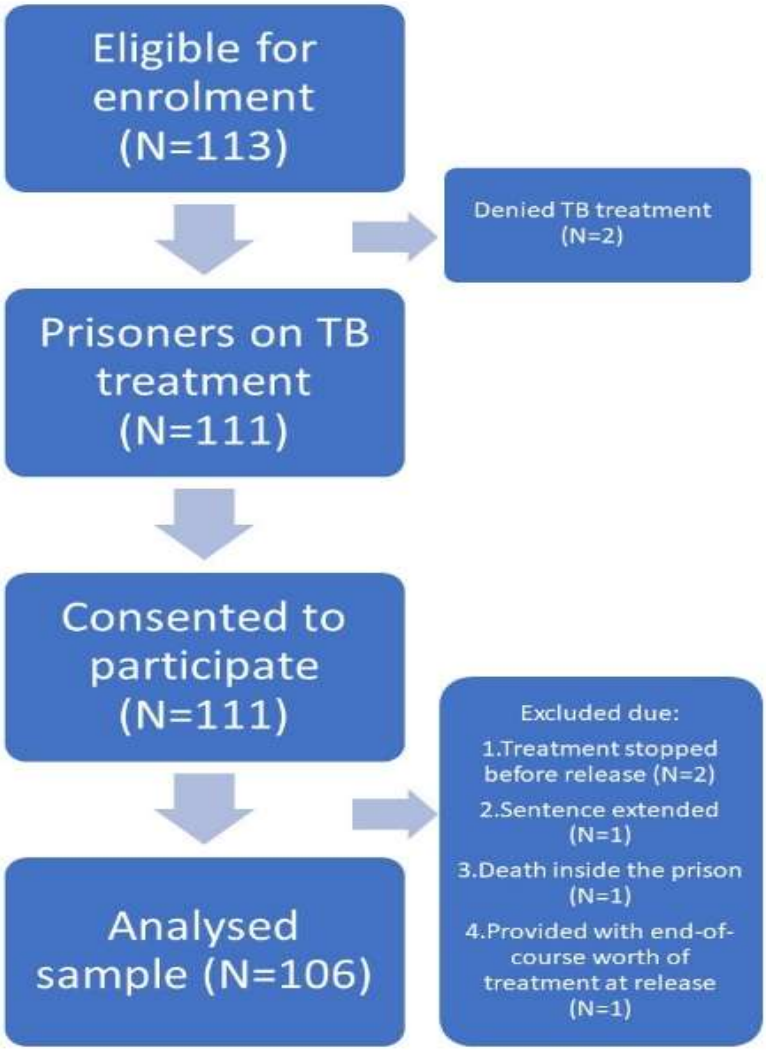
The study protocol was reviewed and approved separately by both the Human Ethics Committee of the University of Otago and the Medical Ethics Committee at the University of Malaya's Medical Centre.

## 5.4 FINDINGS

### 5.4.1 Participants' characteristics

Despite the robustness in defining eligible prisoners for recruitment, only 113 prisoners fulfilled the enrolment criteria during the study period. Out of these, 111 individuals provided consent and were interviewed using the study questionnaire. The two prisoners were confirmed TB disease, but were not offered treatment, likely due to delay in the referral to the community hospital. Additionally, four participants were eventually excluded (see Figure 5.1), and one died while on TB treatment in prison. Ultimately, 106 participants were followed-up in the study.

**Figure 5.2** The recruitment process.




Almost two-thirds (64.1%) of participants were recruited from Kajang prison, the largest prison in Malaysia. Overall, the mean age of participants was 41.5 (SD 10.1) years; most (64.1%) were not married and had completed secondary schooling (76.4%). Most (59.4%) were living in their own or family house before incarceration. Most (61.3%) had full-time stable job before current incarceration, although 48 (45.3%) of the cohort had no plans for post-release employment. Of note, 16% of participants preferred to stay unemployed after release. Most enrolled participants (92.5%) had a previous entry into a correctional facility in Malaysia. Almost all (98.1%) of participants used drugs at some point before current incarceration, and

84.9% reported current drug use (within 30 days before prison's entry). Just over half of participants (54.7%) reported a history of injection drug use. Half of the participants (51.9%) claimed of having a history of previous TB episodes, and only 27 (25.5%) reported a prior diagnosis of TB in the correctional system in Malaysia. Most (81.5%) participants with a previous history of TB in prisons reported discontinuation of treatment after release. Most of the TB cases were diagnosed in the same prison they were housed at (65.1%). Most developed a form of TB treatment adverse event (76.4%, none was life-threatening, including skin rash and gastrointestinal upset). Almost a third (29.2%) of enrolled participants were HIV-infected. Table 5.1 presents the characteristics of participants in each prison. The participants' socio-demographic variables appear to be similar across the five prisons.

**Table 5.1:** Participants' characteristics presented by each participating prison.

| Variables | Total (N=106) | Kajang (N=68) | Sg Udang (N=8) | Kluang (N=18) | Seremban (N=3) | Tapah (N=9) |
|---|---|---|---|---|---|---|
| **Age (years)** | | | | | | |
| ≤30 | 12 (11.3) | 9 (13.2) | 1 (12.5) | 1 (5.6) | 0 (0.0) | 1 (11.1) |
| 31-40 | 37 (34.9) | 25 (36.8) | 2 (25.0) | 5 (27.8) | 2(66.7) | 3 (33.3) |
| 41-50 | 37 (34.9) | 24 (35.3) | 1 (12.5) | 8 (44.4) | 0 (0.0) | 4 (44.5) |
| >50 | 20 (18.9) | 10 (14.7) | 4 (50.0) | 4 (22.2) | 1 (33.3) | 1 (11.1) |
| **Education** | | | | | | |
| None or some primary | 25 (23.6) | 14 (20.6) | 1 (12.5) | 6 (33.3) | 1 (33.3) | 3 (33.3) |
| Secondary or more | 81 (76.4) | 54 (79.4) | 7 (87.5) | 12 (66.7) | 2 (66.7) | 6 (66.7) |
| **Marital status** | | | | | | |
| Married | 38 (35.8) | 24 (35.3) | 3 (37.5) | 6 (33.3) | 1 (33.3) | 4 (44.4) |
| Single | 68 (64.2) | 44 (64.7) | 5 (62.5) | 12 (66.7) | 2 (66.7) | 4 (55.6) |
| **Duration of the current sentence** | | | | | | |
| <6 months | 83 (78.3) | 58 (85.3) | 4 (50.0) | 14 (77.8) | 1 (33.3) | 6 (66.7) |
| ≥6 months | 23 (21.7) | 10 (14.7) | 4 (50.0) | 4 (22.2) | 2 (66.7) | 3 (33.3) |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Prison's visits** | | | | | | |
| At least one | 30 (28.3) | 17 (25) | 4 (50.0) | 4 (22.2) | 1 (33.3) | 4 (44.4) |
| None | 76 (71.7) | 51 (75) | 4 (50.0) | 14 (77.8) | 2 (66.7) | 5 (55.6) |
| **Pre-incarceration Housing** | | | | | | |
| Stable (family or own) | 63 (59.4) | 37 (54.4) | 6 (75.0) | 10 (55.6) | 3 (100.0) | 7 (77.8) |
| Unstable | 43 (40.6) | 31 (45.6) | 2 (25.0) | 8 (44.4) | 0 (0.0) | 2 (22.2) |
| **Post-release housing plans** | | | | | | |
| No plans | 22 (20.7) | 14 (20.6) | 2 (25.0) | 4 (22.2) | 0 (0.0) | 2 (22.2) |
| Return to same place | 84 (79.3) | 54 (79.4) | 6 (75.0) | 14 (77.8) | 3 (100.0) | 7 (77.8) |
| **Pre-incarceration employment** | | | | | | |
| Full-time | 65 (61.3) | 48 (70.6) | 3 (37.5) | 6 (33.3) | 1 (33.3) | 7 (77.8) |
| Part-time or casual | 16 (15.1) | 8 (11.8) | 4 (50.0) | 4 (22.2) | 0 (0.0) | 0 (0.0) |
| Unemployed | 25 (23.6) | 12 (17.6) | 1 (12.5) | 8 (44.5) | 2 (66.7) | 2 (22.2) |
| **Post-release employment plans** | | | | | | |
| Back to same job | 41 (38.7) | 23 (33.8) | 5 (62.5) | 8 (44.5) | 1 (33.3) | 4 (44.4) |
| No idea | 48 (45.3) | 36 (52.9) | 3 (37.5) | 4 (22.2) | 1 (33.3) | 4 (44.4) |
| Stay unemployed | 17 (16.0) | 9 (13.2) | 0 (0.0) | 6 (33.3) | 1 (33.3) | 1 (11.1) |
| **Provided contact details** | | | | | | |
| No | 42 (39.6) | 28 (41.2) | 0 (0.0) | 8 (44.4) | 1 (33.3) | 5 (55.6) |
| Yes | 64 (60.4) | 40 (58.8) | 8 (100.0) | 10 (55.6) | 2 (66.7) | 4 (44.4) |
| **Previous incarceration** | | | | | | |
| Never | 8 (7.2) | 3 (4.4) | 2 (25.0) | 2 (11.1) | 0 (0.0) | 1 (11.1) |

| | | | | | | |
|---|---|---|---|---|---|---|
| Once before | 3 (2.8) | 2 (2.9) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 1 (11.1) |
| More than once | 95 (89.6) | 63 (92.7) | 6 (75.0) | 16 (88.9) | 3 (100.0) | 7 (77.8) |
| **Previous incarceration duration** | | | | | | |
| ≤5 years | 58 (54.7) | 34 (50.0) | 5 (62.5) | 10 (55.6) | 1 (33.3) | 8 (88.9) |
| >5 years | 48 (45.3) | 34 (50.0) | 3 (37.5) | 8 (44.4) | 2 (66.7) | 1 (11.1) |
| **History of drug use** | | | | | | |
| No | 2 (1.9) | 1 (1.5) | 0 (0.0) | 1 (5.6) | 0 (0.0) | 0 (0.0) |
| Yes | 104 (98.1) | 67 (98.5) | 8 (100.0) | 17 (94.4) | 3 (100.0) | 9 (100.0) |
| **Current drug user** | | | | | | |
| No | 16 (15.1) | 9 (13.2) | 1 (12.5) | 2 (11.1) | 1 (33.3) | 3 (33.3) |
| Yes | 90 (84.9) | 59 (86.8) | 7 (87.5) | 16 (88.9) | 2 (66.7) | 6 (66.7) |
| **History of injection drug use** | | | | | | |
| No | 48 (45.3) | 31 (45.6) | 4 (50.0) | 7 (38.9) | 1 (33.3) | 5 (55.6) |
| Yes | 58 (54.7) | 37 (54.4) | 4 (50.0) | 11 (61.1) | 2 (66.7) | 4 (44.4) |
| **Current heroin use** | | | | | | |
| No | 28 (26.4) | 16 (23.5) | 1 (12.5) | 5 (27.8) | 1 (33.3) | 5 (55.6) |
| Yes | 78 (73.6) | 52 (76.5) | 7 (87.5) | 13.72) | 2 (66.7) | 4 (44.4) |
| **Previous TB in prisons** | | | | | | |
| No | 79 (74.5) | 44 (64.7) | 8 (100.0) | 16 (88.9) | 3 (100.0) | 8 (88.9) |
| Yes | 27 (25.5) | 24 (35.3) | 0 (0.0) | 2 (11.1) | 0 (0.0) | 1 (11.1) |
| **HIV infection** | | | | | | |
| No | 75 (70.7) | 45 (66.2) | 8 (100.0) | 12 (66.7) | 2 (66.7) | 8 (88.9) |
| Yes | 31 (29.3) | 23 (33.8) | 0 (0.0) | 6 (33.3) | 1 (33.3) | 1 (11.1) |
| **Release package taken** | | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| No | 28 (26.4) | 28 (41.2) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| Yes | 78 (73.6) | 40 (58.8) | 8 (100.0) | 18 (100.0) | 3 (100.0) | 9 (100.0) |
| **Length of current TB treatment inside prisons** | | | | | | |
| <2 months | 34 (32.1) | 26 (38.2) | 2 (25.0) | 6 (33.3) | 0 (0.0) | 0 (0.0) |
| ≥2 months | 72 (67.9) | 42 (61.8) | 6 (75.0) | 12 (66.7) | 3 (100.0) | 9 (100.0) |
| **Discontinued TB treatment after release** | | | | | | |
| No | 59 (55.7) | 31 (45.6) | 6 (75.0) | 14 (77.8) | 3 (100.0) | 5 (55.6) |
| Yes | 47 (44.3) | 37 (54.4) | 2 (25.0) | 4 (22.2) | 0 (0.0) | 4 (44.4) |

### 5.4.2 Proportion of participants who failed to continue treatment in the community and factors associated with this failure

Of the recruited 106 participants, 47 (44.3%, 95% CI 34.7-54.3%) did not register at a TB clinic to continue treatment within 30 days after release from prison. During the study, 16 (15.1%) participants (irrespective of their continuation status) were re-incarcerated. In the univariable regression analysis, several factors were associated with failure to continue TB treatment after release. These include, younger age (< 30 and 31-40 years), pre-incarceration unstable housing, no provision of contact details, previous TB episodes in prisons, and not taking the release package at the time of release (see table 5.2).

**Table 5.2** Characteristics of participants and univariable regression analysis of variables for association with failure to continue TB treatment in the community.

| Variables | Total (N=106) | Discontinuation (N=47) | RR | P |
|---|---|---|---|---|
| **Age (years)** | | | | |
| ≤30 | 12 (11.3) | 8 (17.0) | 2.67 (1.54-4.60) | 0.01 |

| | | | | |
|---|---|---|---|---|
| 31-40 | 37 (34.9) | 17 (36.2) | 1.84 (1.09-3.11) | 0.02 |
| 41-50 | 37 (34.9) | 17 (36.2) | 1.84 (0.96-3.50) | 0.06 |
| >50 | 20 (18.9) | 5 (10.6) | 1 | |
| **Education** | | | | |
| None or some primary | 25 (23.6) | 10 (21.3) | 0.87 (0.60-1.28) | 0.50 |
| Secondary or more | 81 (76.4) | 37 (78.7) | 1 | |
| **Marital status** | | | | |
| Married | 38 (35.8) | 16 (34.0) | 1 | |
| Single | 68 (64.2) | 31 (66.0) | 1.08 (0.73-1.60) | 0.69 |
| **Duration of the current sentence** | | | | |
| <6 months | 83 (78.3) | 34 (72.3) | 1 | |
| ≥6 months | 23 (21.7) | 13 (27.7) | 1.38 (0.92-2.06) | 0.12 |
| **Prison's visits** | | | | |
| At least one | 30 (28.3) | 14 (29.8) | 1 | |
| None | 76 (71.7) | 33 (70.2) | 0.93 (0.70-1.24) | 0.62 |
| **Pre-incarceration Housing** | | | | |
| Stable (family or own) | 63 (59.4) | 20 (42.6) | 1 | |
| Unstable | 43 (40.6) | 27 (57.4) | 1.98 (1.24-3.15) | 0.01 |
| **Post-release housing plans** | | | | |
| No plans | 22 (20.7) | 10 (21.3) | 1.03 (0.60-1.76) | 0.91 |
| Return to same place | 84 (79.3) | 37 (78.7) | 1 | |
| **Pre-incarceration employment** | | | | |
| Full-time | 65 (61.3) | 30 (63.8) | 1 | |

| | | | | |
|---|---|---|---|---|
| Part-time or casual | 16 (15.1) | 8 (17.0) | 1.08 (0.72-1.62) | 0.70 |
| Unemployed | 25 (23.6) | 9 (19.2) | 0.78 (0.49-1.23) | 0.28 |
| **Post-release employment plans** | | | | |
| Back to same job | 41 (38.7) | 18 (38.3) | 1 | |
| No idea | 48 (45.3) | 22 (46.8) | 1.04 (0.59-1.84) | 0.88 |
| Stay unemployed | 17 (16.0) | 7 (14.9) | 0.94 (0.48-1.82) | 0.85 |
| **Provided contact details** | | | | |
| No | 42 (39.6) | 23 (48.9) | 1.46 (1.23-1.74) | 0.01 |
| Yes | 64 (60.4) | 24 (51.1) | 1 | |
| **Previous incarceration** | | | | |
| Never | 8 (7.2) | 4 (8.5) | 1 | |
| Once before | 3 (2.8) | 2 (4.3) | 1.33 (0.65-2.74) | 0.43 |
| More than once | 95 (89.6) | 41 (87.2) | 0.86 (0.40-1.86) | 0.71 |
| **Previous incarceration duration** | | | | |
| None | 8 (7.6) | 4 (8.5) | 1 | |
| Up to one year | 8 (7.5) | 3 (6.4) | 0.75 (0.51-1.10) | 0.15 |
| More than one year | 90 (84.9) | 40 (85.1) | 0.89 (0.40-1.97) | 0.77 |
| **History of drug use** | | | | |
| No | 2 (1.9) | 0 (0.0) | Not analysable | |
| Yes | 104 (98.1) | 47 (100.0) | | |
| **Current drug user** | | | | |
| No | 16 (15.1) | 6 (12.8) | 1 | |
| Yes | 90 (84.9) | 41 (87.2) | 1.21 (0.81-1.81) | 0.34 |

| | | | | |
|---|---|---|---|---|
| **History of injection drug use** | | | | |
| No | 48 (45.3) | 23 (48.9) | 1 | |
| Yes | 58 (54.7) | 24 (51.1) | 0.86 (0.64-1.16) | 0.34 |
| **Current heroin use** | | | | |
| No | 28 (26.4) | 12 (25.5) | 1 | |
| Yes | 78 (73.6) | 35 (74.5) | 1.05 (0.81-1.35) | 0.72 |
| **Previous TB in prisons** | | | | |
| No | 79 (74.5) | 30 (63.8) | 1 | |
| Yes | 27 (25.5) | 17 (36.2) | 1.66 (1.04-2.62) | 0.03 |
| **Outcome of previous TB** | | | | |
| Completed (inside or outside) | 5 (18.5) | 3 (17.6) | 1 | |
| Discontinue after release | 22 (81.5) | 14 (82.3) | 1.06 (0.98-1.15) | 0.15 |
| **Current TB site** | | | | |
| Pulmonary | 94 (88.7) | 41 (87.2) | 0.87 (0.74-1.03) | 0.11 |
| Extrapulmonary | 12 (11.3) | 6 (12.8) | 1 | |
| **Location of TB diagnosis** | | | | |
| Community clinic | 20 (18.9) | 7 (14.9) | 0.78 (0.61-1.00) | 0.05 |
| Jail | 5 (4.7) | 2 (4.3) | 0.89 (0.35-2.24) | 0.81 |
| Other prisons | 12 (11.3) | 7 (14.9) | 1.30 (0.93-1.81) | 0.12 |
| This prison | 69 (65.1) | 31 (66.0) | 1 | |
| **Development of adverse events** | | | | |
| No | 25 (23.6) | 12 (25.5) | 1 | |
| Yes | 81 (76.4) | 35 (74.5) | 0.90 (0.63-1.28) | 0.56 |

| | | | | |
|---|---|---|---|---|
| **DOT in prisons** | | | | |
| No | 6 (5.7) | 3 (6.4) | 1.14 (0.78-1.65) | 0.50 |
| Yes | 100 (94.3) | 44 (93.6) | 1 | |
| **HIV infection** | | | | |
| No | 74 (70.7) | 32 (68.1) | 1 | |
| Yes | 31 (29.3) | 15 (31.9) | 1.13 (0.83-1.55) | 0.43 |
| **Release package taken** | | | | |
| No | 28 (26.4) | 18 (38.3) | 1.73 (1.17-2.56) | 0.01 |
| Yes | 78 (73.6) | 29 (61.7) | 1 | |
| **Length treatment inside prisons** | | | | |
| <2 months | 34 (32.1) | 16 (34.0) | 1.09 (0.90-1.32) | 0.35 |
| ≥2 months | 72 (67.9) | 31 (66.0) | 1 | |

In the assessment of correlation between exposure variables, previous incarceration was highly correlated with several other variables (age [V=0.31], drug use [V=0.22], recent drug use [V=0.30], previous TB [V=0.20], duration of current sentence [V=0.29], HIV infection [V=0.22], and prison visits [V=0.30]) and was not used in the model. A non-correlated incarceration variable (duration of incarceration) was included in the model. HIV infection was highly correlated with age (V=0.32), injection drug use (V=0.42), duration of incarceration (V=0.27) and prison visits (V=0.17) and was not included in the final analysis. Of note, HIV infection was not associated with the failure to continue TB treatment at the univariable analysis. For drug use, we utilised current drug use in the final model, given its potential influence on healthcare-seeking after release and to the high correlation between the previous history of drug use and other drug use variables. In the multivariable regression analysis, failure to continue TB treatment in the community was positively associated with younger age, unstable housing before current incarceration, casual/part-time job before current incarceration, previous TB episode in prison, not taking the release package and not providing contact details before release (Table 5.3).

**Table 5.3** Multivariable regression analysis of variables for association with failure to continue TB treatment in the community.

| Variables | ARR | P |
|---|---|---|
| **Age (years)** | | |
| ≤30 | 1.91 (1.05-3.43) | 0.03 |
| 31-40 | 1.52 (0.96-2.39) | 0.07 |
| 41-50 | 1.59 (0.81-3.09) | 0.17 |
| >50 | 1 | |
| **Pre-incarceration Housing** | | |
| Stable (family or own) | 1 | |
| Unstable | 1.64 (1.02-2.64) | 0.04 |
| **Pre-incarceration employment** | | |
| Full-time job | 1 | |
| Casual or part-time job | 1.21 (1.03-1.42) | 0.02 |
| Unemployed | 0.85 (0.57-1.26) | 0.42 |
| **Providing contact details** | | |
| Yes | 1 | |
| No | 1.36 (1.14-1.63) | 0.01 |
| **Previous TB diagnosis in prisons** | | |
| No | 1 | |
| Yes | 1.24 (1.04-1.48) | 0.02 |
| **Development of TB treatment adverse events** | | |
| No | | |

| | | |
|---|---|---|
| Yes | 1<br><br>0.78 (0.61-1.01) | <br><br>0.06 |
| **Release package taken**<br><br>Yes<br><br>No | <br><br>1<br><br>1.71 (1.40-2.08) | <br><br><br><br>0.01 |

## 5.5 DISCUSSION

To our knowledge, this is the first study to specifically examine the continuation of TB treatment after release from prison in Malaysia. The study was conducted in five different prisons over 14 months and involved 106 prisoners with TB. Overall, 47 (44.3%, 95% CI 34.7-54.3) prisoners with TB did not continue treatment after release from prison. The study showed that prisoners who failed to continue TB treatment after release were more likely to be younger, have pre-incarceration unstable housing and employment, have a previous TB episode in prisons, do not provide contact details, and do no collect the "release package" before leaving the prison.

Our findings are consistent with reports addressing the continuation of treatment after release from prison systems, globally. Overall, these studies showed that the proportion of released prisoners who continued TB treatment in the community ranges from 0-59%. In a survey in the Taiwan correctional system, release from prisons before completing treatment was the primary cause of adverse treatment outcome with around two-thirds (61.5%) of released prisoners being lost-to-follow-up after release (162). A retrospective assessment of a prison system in the US reported that 27% of prisoners with TB were released from prisons before completing TB treatment and out of these, 38% were lost-to-follow-up after release and did not continue treatment (75). A prospective assessment of TB treatment outcome among prisoners and ex-prisoners in Madrid, Spain, reported that current prisoners had a higher completion rate than released prisoners with uncompleted TB treatment- only 20.5% of the latter group completed treatment in the community (163). Similar findings were reported from a study in Russia where most (73.8%) released prisoners with uncompleted TB treatment did not make any visit to the community dispensary to continue treatment (4). An intensified TB case finding survey among

HIV-infected prisoners in a prison in Mexico City reported that most (71.4%) released prisoner with uncompleted TB treatment did not visit the referred clinic after release (164). Finally, a retrospective analysis in the prison system in Uganda reported high lost to follow-up rate (81%) among released prisoners with uncompleted TB treatment with poor linkage to public health department as a potential cause (151). All these studies shared one statement: the unsuccessful treatment outcome in the community is attributed to poor communication between the prison and public health departments which led to failure to properly link prisoners to community health services.

Adherence to health programmes remains a challenge among prisoners, both inside and outside the correctional facilities. A review of records of the US National TB Surveillance System between 1999 to 2011 showed that prisoners with TB were significantly less likely to complete TB treatment compared to non-incarcerated individuals (75.6% vs 93.7%) (165). This might be related to the effect of release on treatment continuation and hence good treatment outcome. In a study from Spain's correctional system, current imprisonment was the only factor associated with effective completion of TB treatment among prisoners. The study also showed that completion of TB treatment among current prisoners was significantly higher than released prisoners (69.7% and 20.5%, respectively) (166). The problem of poor adherence in this group is not confined to TB disease but extends to other health conditions in this group. Prescribing IPT in jails in the San Francisco correctional system showed that only 3.2% made the visit to community clinic to continue IPT within 30 days of release from jails (167). A similar finding was reported in another US state (Connecticut) where more than half (57%) of released prisoners on IPT had never reported to the assigned chest clinic to continue IPT after release (168). Prisoners with HIV infection have similar problems with post-release adherence to HAART started in prisons. An assessment of post-release access to HAART in the Texas correctional system reported that only 5.4% of released prisoners with HAART filled prescription in clinics within ten days of release from prisons (169). This has major public health impact on HIV management in this marginalised population. A follow-up study in the same correctional system (in Texas) reported that reincarcerated prisoners on HAART showed loss of previously achieved HIV control with significantly lower CD4 lymphocyte counts (mean decrease of 79.4 lymphocytes) and higher HIV viral load (mean increase of 1.5 $\log_{10}$) compared to levels before the previous release (170). These findings were echoed in an assessment of the effect of recidivism on HIV control among prisoners released with HAART

in the State of Connecticut. The study showed that the proportion of prisoners with HIV viral suppression decreased significantly from 52% to 31% with a mean HIV-RNA increased by 0.4 $\log_{10}$ during the duration between prison release and reincarceration (median 329 days), clearly referring to the treatment interruption after release (171).

No similar studies were reported from Malaysia, but a pilot study was launched in 2008 to assess retention in the MMT programme in the community among HIV-infected prisoners released from two prisons in Malaysia. The study showed that only 38.8% (28 out of 72) of prisoners who were released with MMT remain in the programme at the end of the follow-up period (12 months) (172). The authors identified significant retention in care among those released with higher methadone dose and hypothesised that high dose of methadone at release should be considered in a package to assist former prisoners with HIV to adhere to harm reduction interventions.

Individuals with unstable housing, and the homeless in particular, are recognised for having a high risk for TB and poor adherence to TB treatment and care (173). Studies from prisons remain limited, but a study in the Spanish correctional system noticed that homeless and alcoholic former prisoners were only able to complete TB treatment after release if they were admitted to a housing centre in the community. The study included only eight former prisoners, and proper conclusion cannot be made from this small sample size (166). A review of the correctional system in India reported that there was no feedback provided from clinics supposedly caring for released prisoners with TB and this was attributed to the mobility of released prisoners, possibly due to unstable housing or job-seeking (125). A clinical trial in San Francisco reported that pre-incarceration stable housing was independently associated with TB treatment completion in the community (AOR 2.94, 95% CI 1.01-8.58), irrespective of intervention arm (174). Homelessness was a major cause of movement to other treatment jurisdictions (AOR 2.3, 95% CI 1.2-4.3) and treatment default (AOR 2.0, 95% CI 1.2-3.4) among individuals (non-prison population) treated for TB in California (175). Finally, a survey from Indonesia reported that individuals who moved residence within the last year were more likely to default from TB treatment (AOR 9.6, 95% CI 2.2-42) (176).

It is not clear why prisoners with previous TB diagnosis in prison were more likely to default treatment in this study. This observation could reflect the lack of educational and counselling

programmes for TB in prisons in Malaysia or to the increased morbidity and mortality in those with relapsed TB. It could also be attributed to poor care-seeking behaviour in this population with previous history of defaulting TB treatment. Of note, 81% of prisoners with previous TB in prisons defaulted treatment after previous release in this study. Similar observations were made elsewhere. In an assessment of treatment outcome in prison in Ethiopia, an unsuccessful treatment outcome was associated with being a retreatment case (AOR 4.68, 95% CI 1.02-21.40) (121). An evaluation of TB treatment outcome in the general population in Malaysia showed individuals with previous TB were more likely to have unfavourable treatment outcome compared to individuals with new TB cases (AOR 1.63, 95% 1.36-1.94); this association was not noticed with all-cause mortality from TB (37). A study from the Free State in South Africa reported that TB cases on a retreatment regimen were more likely to die from TB compared to new TB cases (AOR 1.3, 95% CI 1.2-1.4); the development of undiagnosed MDR-TB was thought to be the cause (177). Another report among previously treated TB cases in two urban communities in South Africa showed default of current TB treatment was associated with a previous history of active TB, irrespective of previous treatment outcome (178). A follow-up study in another location in South Africa reported that TB cases with previous TB treatment were twice as likely to default TB treatment compared to new cases (AOR 2.0, 95% CI 1.85-2.25) (179).

A study among civilians in Indonesia reported that younger age (< 35 years) was independently associated with non-adherence to TB treatment (176). The authors suggested that young individuals with TB cope less than older people. Two larger studies from Ethiopia and Brazil reported that age had no influence on adherence to TB treatment (180,181). In our cohort, we speculate that younger prisoners might prioritise searching for stable employment or housing in the immediate post-release period over health issues. Similarly, prisoners with previous casual jobs might try to search for stable jobs after release and forget about health appointments. Unemployment was cited as one of the important barriers for non-adherence to TB treatment after release from Russian prisons (4).

A national assessment of treatment outcome among Malaysians diagnosed with TB in 2012 showed that almost half (49%) of individuals with unfavourable TB treatment outcome had defaulted treatment or transferred out (37). That study also reported that the other half of

individuals with unfavourable outcome died because of TB. Given that we were unable to reach most of the prisoners who discontinued treatment and we had no access to national mortality records, we were unable to assess the contribution of death on failure to register at TB clinics after release. This is likely to be an important factor, albeit not necessarily due to TB, given the high prevalence of co-morbidities in this sample. Globally, death in the immediate period after release from prisons has been reported to be high, particularly those drug-related (182–184). A 15-year cohort study from Norway reported that 85% of deaths in the immediate post-release period (7 days) were attributed to drug overdose (182). A systematic review of related publications showed that the risk of death among released prisoners is up to 40 times higher than the general population, citing drug-related causes as a major cause particularly within the seven days after release (184). Enrolment in OST programmes inside the prison and continuation after release was associated with significantly reduced mortality in released prisoners in New South Wales in Australia with a 75% reduction in the risk of death in those with OST exposure in the first four weeks after release from prison (185). Of note, 84.9% of our study cohort were current drug users, 73.6% were heroin users, and only one prisoner was enrolled in the MMT programme in prison. No plans were provided by prison health units to provide MMT inside the prison or to link those prisoners to OST programmes in the community.

Without proper documentation proving the use of TB treatment in prisons, former prisoners might not be offered treatment from healthcare providers who often discriminate against them (94). The correctional system in India reported that administrators who prepare release papers perform this process without notifying the medical staff to arrange for providing the release package for prisoners with TB treatment (125). Indeed, none of the released prisoners with TB in India reported treatment continuation in the community. This situation becomes more difficult when parole is granted as the release date is usually unpredictable. In two surveys in the Ethiopian correctional system, the fate of prisoners with TB released before treatment completion was not known and this was attributed to the lack of proper linkage to community health services (121,161).

There are a considerable number of prisoners (ranging from 33.6-55.5%) who did not provide contact details at the time of the interview and this was independently associated with failure to continue treatment after release from the five prisons in Malaysia. Failure to provide contact

details might have several explanations. Firstly, a prisoner with unstable housing status or being homeless might not be able to provide an address or a phone number for obvious reasons. This might not explain the treatment abandonment in this cohort as both variables are independently associated with failure to continue treatment. Secondly, prisoners might fear police harassment if this piece of information reaches the police, despite reassurance of safeguarding the interview information.

Despite evidence from elsewhere that they are important risk factors for unsuccessful TB treatment outcome and interruption and default, enrolment in DOT inside prisons (166), HIV infection (37), and drug use (43) were not associated with failure to continue treatment in our cohort.

Our study is limited by the small sample size. Despite all efforts to increase the number of participants, including extending the period of the study to 14 months and involvement of 5 major prisons, we were unable to reach the recruitment target of 140 participants. This might have occurred due to poor screening and hence diagnosis of TB in prisons during the study period and to the delay in accessing other prisons (initially, entry was granted to two prisons only). Nonetheless, the high proportion of participants who defaulted treatment after release made the analysis of value. We took all efforts to locate those who did not present to TB clinics after release but that was not successful in knowing their status. We did contact main TB clinics and all major hospitals treating TB in all States, but the chances of registering at smaller and remote clinics remains a possibility. Additionally, there is a possibility that participants provided wrong residential addresses, or they were relocated shortly after release.
Finally, despite the five prisons representing main geographical areas in Peninsular Malaysia, findings might not represent the situation in other prisons in Malaysia.

There are a number of different options to improve TB treatment continuation among released prisoners. Involvement of the NTP in TB control activities in prisons and proper release planning is crucial to improve care and adherence before and after release from prisons. An implementation study in Malawi involved district TB officers in every prison's TB activities meeting, and this might have contributed to the improvement in TB treatment outcome observed among prisoners (87). Incentives, especially monetary, on the other hand might be an option to improve adherence to treatment in group with limited access to employment

opportunities. In a similar setting to Malaysia with a high prevalence of PWID, HIV-infected, and prisoners with unstable housing, providing multi-level incentives improved TB treatment completion after release from prisons in Spain (166). These incentives included: aids for housing and admittance to sociosanitary centres, linkage to MMT programme, and nutritional support. A high (79%) treatment completion rate was reported among released prisoners in this study. The study also highlighted the importance of collaborative efforts between prisons, rehabilitation centres, and public health department to improve this programme. Linkage of the TB and MMT programmes in Ukraine was associated with better adherence and completion (89.5% versus 73.6% for non-MMT group; $p = 0.03$) among PWUD with high prevalence of previous incarceration in six TB treatment centres (69). On the other hand, the establishment of pre-release educational programmes had a modest effect on improving the continuation of TB preventive therapy after release in two US studies. In a RCT, 107 prisoners in San Francisco jail were provided with a pre-release educational package showed similarly low continuation rate of IPT after release to the regular care (37% compared to 24%, respectively) (174). The other trial reported even a lower IPT continuation rate after release from prisons with an overall low (15%) proportion of prisoners on IPT who made the first visit to the chest clinic within 30 days of release (186). Finally, the use of mobile-phone technology is a promising tool to improve adherence to TB treatment. A systematic review of the literature describing the effect of text messages on improving adherence to TB treatment in the community reported paucity of information and low quality of publications (187). Four studies were reviewed and showed inconsistent findings. In these studies, health outcomes (cure rates, smear conversion) or clinic attendance were utilised as a proxy for adherence; not entirely accurate methods to indicate adherence to TB treatment. The use of mobile-phone text reminders coupled with peer educations improved adherence to HAART in a randomised control trial among 242 PLWH in Malaysia (188). Individuals who received text messages were more likely to adhere to HAART than the control group (95.7% [95% CI: 94.39–96.97] and 87.5% [95% CI: 86.14–88.81], respectively).

This study highlights the need for multi-level approaches and the involvement of several governmental and non-governmental bodies to improve the continuation of TB treatment after release from prisons. In similar settings with high drug use and HIV infection, WHO advocates for the integration of drug use, HIV and TB services in “one-stop shopping” centres to improve adherence and remove unnecessary cross-referrals (189). This concept might apply to our

setting, given that most released prisoners with TB in our study were using drugs before current incarceration.

# CHAPTER SIX: BARRIERS AND ENABLERS TO THE CONTINUATION OF TUBERCULOSIS TREATMENT IN THE COMMUNITY AMONG RELEASED PRISONERS IN MALAYSIA: A QUALITATIVE STUDY

## 6.1 Introduction

Globally, adherence to healthcare programmes among released prisoners is generally suboptimal. Several studies have reported that the post-release continuation of treatment for TB, mental health, HIV infection and other chronic illnesses in the community remains low (4,190,191). This situation increases the likelihood of having poor health or death among former prisoners and may have negative consequences on the communities they were released. For instance, prisoners with uncompleted TB treatment in prisons may remain infectious, posing a significant TB risk to the general population (160). In several studies from the USA, reincarcerated prisoners living with HIV infection were found to have lost the benefits gained from adherence to HAART while in prisons, putting them at high risk of developing deadly opportunistic infections (100). Several factors might contribute to the interruption of post-release continuity of care, including factors related to the individuals, their communities, and the caring-providing health systems. Knowledge about these contributory factors may provide insights into the development of interventions to ultimately improve compliance with healthcare programmes.

In Malaysia, prisoners released with uncompleted TB treatment are not provided with a formal follow-up plan in the community, and it is left to the discretion of former prisoners to contact the local health facilities to continue care. No information is available about the proportion of former prisoners who continue TB treatment in the community or factors influencing the continuation of their TB treatment. In this PhD project, both subjects have been addressed (Chapter 5 and 6)

This study was conducted in Kuala Lumpur and was designed to assess factors contributing to the continuation or discontinuation of TB treatment after release from prisons. It is a cross-sectional exploratory study utilising qualitative methods, given the current situation where no baseline information presents.

## 6.2 The review of literature

### 6.2.1 The literature review protocol

This review of the literature was initially conducted to answer the question: “What are the factors that influence (negatively or positively) the continuation of TB treatment after release

from prisons?". A literature search was conducted in July 2020 using Medline and Embase databases (through the Ovid(SP) platform) and the Web of Science. Keywords structure ("tuberculosis" AND "prison" AND "complet*" AND ["factor" OR "barrier"]) was utilised. The search included these keywords anywhere in the text. No restrictions were placed on the language of the publication, the publication type, the study design, or the year of the publication. This search yielded 50 publications with all, but one, were conducted among non-prison population. Given the need to develop a background information about the adherence to health programmes after release from prisons, another literature search was conducted to involve publications that address factors influencing the post-release adherence to HIV care (albeit different from TB in its chronic course, symptoms, and mode of transmission). The search involved the same databases and used the keyword structure of ("HIV" AND "prison" AND "adherence" AND "release") anywhere in the text.

After removing duplicates, the abstracts of collected publications were examined for the inclusion of publications in the final literature review. To be included in the final evaluation, publications needed to provide information about barriers and facilitators to the adherence to HIV or TB care/treatment after release from prisons. Abstracts of publications written in languages other than English were initially translated using google translate, and if eligible for inclusion, professional translation was sought.

An extraction form was developed to extract information of interest from each study. This included information about the location of the study, the number of individuals involved, participants' demographics, and themes developed from the analysis in each study.

### 6.2.2 The review findings

The search yielded 133 publications from the three databases: Medline (N=27), Embase (N=41), and Web of Science (N=65). Following the removal of duplicates, 97 unique publications were yielded. Upon direct screening of the collected publications, there were three publications that provided information about barriers or facilitators to the adherence to HIV treatment and care in the community after release from prison. The three studies were conducted in USA.

The only study that addressed barriers to the continuation of TB treatment after release from prisons was conducted among 40 former prisoners in St Petersburg in Russia (4). Most participants were men (85%), aged 40 on average and were previously treated for TB (69%).

The study did not apply a qualitative methodology, but, although not clear, utilised a semi-structured instrument. Former prisoners considered several factors to leading to treatment non-completion after release- homelessness, unemployment, poverty. alcoholism, and fear of recidivism.

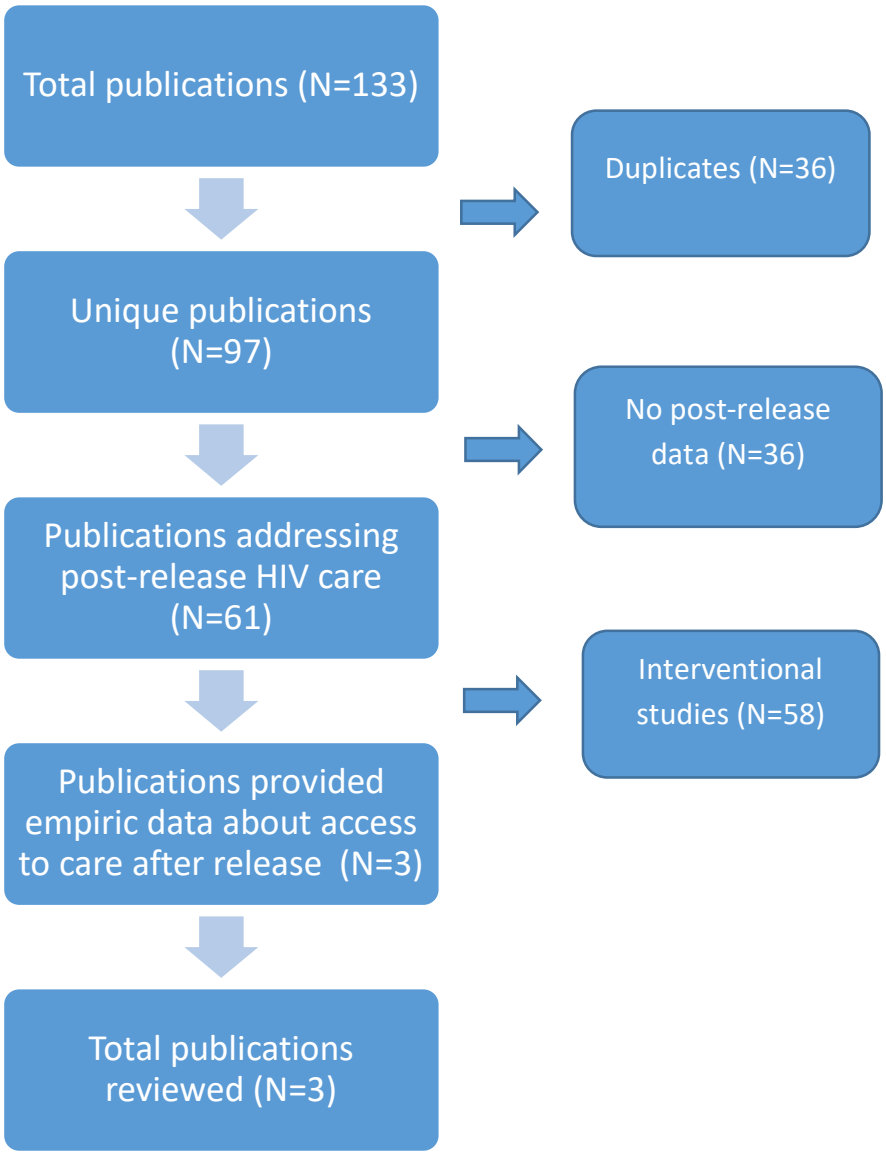
A study involved both in-depth interviews and focus group among 46 former prisoners living with HIV to examine barriers and facilitators to post-release engagement in HIV care and adherence to HAART in two states (Texas and North Carolina) in USA (192). Most (74%) were men, of African American ethnicity (85%) with an average age of 43 (range 23-60). The recognised the challenges in the three areas (pre-release connection to care, challenges during the community re-entry and facilitators to HIV care in the community) and described influencing factors into four sections: individual, interpersonal, community and structural. At the pre-release period, factors like good knowledge and experience about HIV and proper pre-release connecting system have positively influenced engagement in care after release, while a complex and overwhelming post-release HIV care system was considered a barrier to navigate the system after release, particularly among those who spent long time in prisons. Factors that influence engagement in HIV care in the immediate post-release period include prioritisation of drug use over HIV care (some even with the engagement of the health system); homelessness; lack of transportation support (as some prisoners were enrolled in a clinic quite far from their residence); lack of health insurance and financial support; stigma; and competing demands (in which former prisoner with HIV may prioritise). On the other hands, motivated former prisoners focus on their HIV management after release and continue care (to maintain health); the support of family members, friends or even neighbours facilitate adherence to HIV treatment; and former prisoners accessing community programmes and organisations have a better access to HIV care services. The study is limited by the potential recall bias (long duration since release from prisons in some participants) and by the fact that all recruited participants were enrolled in HIV care at the time of the study.

Another focus group study was conducted among 27 former prisoners living with HIV in Los Angeles in California, USA between October 2012 to October 2013 (193). The study has similar demographics to the previous study (most were men [94%], African American [85%] and older than 40). Four overarching facilitating themes were developed from the interviews. These include supportive friends and family members; productive relationships with the community medical and allied health providers; effective coping strategies with immediate

post-release needs, including drug use, securing employment, and relationship issues; participants knowledge about available resources; proper transition support; stable housing; and motivation to have a better life.

Pre- and post-release interviews were conducted among 37 (24 pre-release and 13 post-release) participants in North Carolina, USA. The study reported similar demographics to previous studies. The study developed several overarching themes. Those factors influencing the post-release continuation of HIV care included- battling substance use, challenges with housing and daily needs, development of community networking, being motivated to be healthy, challenges with employment, and the effect of stigma.

**Figure 6.1** The literature search and selection.



### 6.2.2 Summary of the literature review

The literature search returned a limited number of publications that provide information about barriers and facilitators to the continuation of TB or HV care after release from prisons. Only one study described barriers to the continuation of TB treatment after release from prisons and three studies were reported among HIV-infected former prisoners. Several matched themes were developed from these studies, including individual, structural and community factors. In order to improve engagement with healthcare services after release from prisons, these studies recommend the implementation of several multilevel interventions to be deployed.

The review is not only limited by the small number, but also by been conducted in one country (the USA) with the involvement of a majority of male African American former prisoners.

## 6.3 METHODS

### 6.3.1 Study sites

The study was conducted in two locations in Kuala Lumpur from July to December 2017. Former prisoners were recruited in the community and interviewed in a research centre. Current prisoners with a previous history of uncompleted TB treatment were recruited from Kajang prison and were interviewed in a private room in prison.

### 6.3.2 The aim of the study

The study was conducted to investigate factors influencing the continuation of TB treatment after release from a prison in Malaysia.

### 6.3.3 Conceptual framework

A conceptual framework for the study was developed based loosely on the model hypothesised by Becker and Maiman for predicting and explaining compliance behaviour (194). This model was chosen given its relevance to explore the influence of healthcare seeking behaviour together with the integrated modifying factors on the continuation of TB treatment after release from prisons. The model was built on three major components:

1. Readiness to undertake recommended compliance behaviour: including motivations, value of illness threat reduction and the probability that compliance behaviour will reduce the threat.

2. Modifying and enabling factors: including demographics, structural (costs, duration, complexity, side effects), attitudes, interactions with doctors, and enabling factors (previous experience, source of advice or referral).
3. Compliant behaviour.

We hypothesised that given the complexity of the transition period, several factors might be involved affecting the compliance behaviour of participants and all these factors need to be explored. Information from the review of relevant literature and a systematic review of qualitative research studies on adherence to TB treatment in the community (non-prison situation) were utilised to develop areas to be explored during the in-depth interviews (195). The systematic review was conducted in 2005 and included 44 publications that provided a qualitative account of patients', caregivers', or healthcare providers' perceptions about adherence to both preventive and curative TB treatment. The review identified eight major themes from these studies, including organisation of treatment and care for TB patients, interpretation of illness and wellness by patients, financial burdens, knowledge about the treatment, law and immigration, personal characteristics and adherence behaviour, side effects, and family influence. The study highlighted the complex and dynamic nature of the adherence process for a prolonged course like TB treatment. Despite having no data from prison, findings from the systematic review were incorporated in the interview framework, owing to the experience of the student researcher in the field, where similar issues were raised by former prisoners.

### 6.3.4 Participants and recruitment

The study purposively recruited key participants who met the following criteria:

1. Have a history of release from prison before the completion of TB treatment, irrespective of the duration since the release.
2. ≥ 18 years of age.
3. Able to provide independent consent to be interviewed for 45-60 minutes.

The study utilised Kajang prison's TB case records, including data from an intensified TB case finding survey, to recruit former prisoners who did not complete TB treatment inside the prison. Prisoners who previously provided their phone number to the research team (during the case-finding survey) were contacted to ask if they were interested in participating in the study. Out

of the 102 available contact details, only three former prisoners were contactable. Most of the remaining former prisoners provided numbers that were not in service (N=73), others were reported as having died by their family members who still hold their phone numbers (N=7) or were currently reincarcerated (N=19). Former prisoners who agreed to participate in the study were asked to take part in a pre-enrolment assessment over the phone. This assessment was performed to confirm the incarceration dates, date of starting TB treatment, the duration of treatment inside the prison, and whether they continued treatment in the community after release from the prison. At the end of the assessment, former prisoners were asked about a suitable time for the interview. To recruit former prisoners with TB who had no contact details, a snowball technique was utilised. Enrolled participants were asked if they were aware of other former prisoners with TB, and if so, if they could help the research team contact them. Finding that this approach was unsuccessful in recruiting participants from the community, current prisoners with a history of leaving prisons with uncompleted TB treatment were recruited, if they fulfil the recruitment criteria mentioned above.

To explore the diversity in attitude and perception to factors influencing treatment continuation, the study planned to recruit participants from different age groups, gender, ethnicity, and HIV infection status. Studies from the community in Malaysia have reported an influence of age, gender, ethnicity and HIV infection status on TB treatment outcome (40). The research team was not granted access to review TB case records in the women's prison, so the study was confined to men. The Malaysian society is ethnically diverse, with 60% of the population been of the Malay background (see Chapter 1). Other ethnic groups include Chinese, Indian, aboriginals and several other minorities.

### 6.3.5 Ethical considerations

Individuals who agreed to participate in the study were invited to provide a written informed consent process. Interviews were performed in private rooms both in the research centre and in prison. The confidentiality of interviews was maintained throughout the study. Eventually, interview transcripts were de-identified, scanned and stored in a secured computer. Current prisoners who refuse to participate in the study were not disadvantaged. The study protocol was reviewed and approved separately by the ethics committees in the University of Otago and the University of Malaya.

### 6.3.6 Data collection

The student has six years of experience working on TB management and research in correctional settings in Malaysia. During this period, he acquired extensive knowledge about the situation of TB among prisoners during and after incarceration. He also has an intermediate knowledge in Bahasa Malaysia, the official language in Malaysia.

Following the agreement on a suitable time, former prisoners in the community were interviewed in a private room at the University of Malaya's research centre. In contrast, current prisoners were interviewed in a private room inside the prison accessed by the research team only. Interviews in the community were audiotaped, while those in prison were handwritten (the prison department does not allow audio-recording inside the prison).

An interview guide was developed based on the developed conceptual framework (section 6.3.4) to define necessary probes and different levels of probing to complement the interview checklist. The interview checklist included:

1. Background information: this included collection of information about age, the level of education, any previous incarcerations, and the HIV status

2. Experience with TB treatment itself: questions were asked about the acceptability of the medications, whether any adverse events developed while on TB medications and methods of transportation used to get the treatment

3. Social issues: participants were asked about their housing status, the employment status, and drug and alcohol use after release from the prison

4. Family and peer support- whether family visits were made during that incarceration and whether a family member or a friend influenced him to continue/discontinue treatment

5. Experience with the prison health system concerning their TB treatment: whether the prison medical team was supportive, provided him with enough information about TB, and provided a pre-release referral letter and seven days of treatment.

6. Experience with community healthcare facilities from previous interactions with the system, if any: whether the medical and nursing teams were supportive and answered all related questions

7. Knowledge and perception about TB treatment: whether participants have basic knowledge about TB and free TB services in the community.

In-depth interviews were conducted in private rooms to ensure confidentiality. Individuals who initially agreed to participate in the study were provided with a participant information sheet and were briefed about the study process. A written informed consent process followed. The interview guide areas were explored in the two groups, and the interview session took approximately 60 minutes. The interviews were exploratory open-ended (196) and were conducted by the student researcher in English translated into Bahasa Malaysia by a local experienced research assistant (who has a master degree in public health). To ensure information accuracy and completeness, we performed a process of checking and re-checking on translated information throughout the interview. For interviews that were not audiotaped, the questions and answers were handwritten in English by both the student researcher and the research assistant and checked continuously throughout the interview. At the end of each interview, the student researcher went through the transcript to define potential new probes for the subsequent interviews.

Finally, former prisoners in the community were provided with RM50.00 cash as a reimbursement to their time and transportation, but this was not feasible for current prisoners due to prison restrictions on offering money to prisoners or their family members.

### 6.3.7 Data management and analysis

A thematic framework analysis was utilised to analyse data and as detailed by Braun and Clarke (197). This approach was chosen for the flexibility in methodology, accessibility to the non-experienced in qualitative research and simplicity to understand by a wider audience.

Initially, audiotaped records were orthographically transcribed and translated to English by an experienced local research assistant and checked by the student researcher. Non-audiotaped interviews were handwritten by the research assistant and re-checked against the field notes made by the student researcher. Transcripts and translations of all interviews were anonymised, given unique identifiers, and transferred on to MS Word documents.

The second step was reading of transcripts and familiarisation with the data that was performed by the student researcher. At this stage, notes of potential interest were taken for future utilisation in coding.

Nvivo 12 for Windows was used to assist in the coding, a process to identify aspects of relevant data to the research question. During the analysis, the research student used complete coding with a mixed deductive and inductive approach, in which all relevant data of interest were analysed, rather than selective coding of restricted areas. This approach captured all potentially relevant aspects of data to answer the research question through thorough examination of the collected data. Eventually, this approach provided several codes and potential themes.

At the end of the coding process, a search for patterns across the data was performed. Themes, defined as patterns with a central idea, were developed from these patterns. This step was followed by the revision of the developed themes, looking for relationships across themes to develop major ones. Related minor themes were grouped under a major theme that encompassed the issues related to those themes. In general, the development of major themes was based on, but not confined to, the major topics and probes in the interview guide (prison situation, performance of community healthcare, social support, and individuals' attitude). New, unrelated minor themes were described separately. The developed major themes were then defined and named.

The data analysis was finalised by choosing a descriptive, rather than interpretive, model in writing the findings. This method was utilised given its simplicity and straightforward interpretation.

## 6.4 FINDINGS

### 6.4.1 The characteristics of participants

Twelve male participants were recruited: seven discontinued, and five continued TB treatment after release from the prison. Participants had a mean age of 50 and 39 for those who continued and those who discontinued treatment after release, respectively. Most participants were of Malay ethnicity, but the study included participants from other ethnic minorities (Chinese, Indians, and Sabahan). Most did not complete their secondary school. Four participants were HIV-infected. Only three were recruited from the community. Most were diagnosed with TB during the last decade (2000-2010).

**Table 6.1** Characteristics of participants in the qualitative research.

| Characteristics | Continued treatment (N, %) | Did not continue treatment (N, %) |
|---|---|---|
| Number of participants | 5 | 7 |

| | | |
|---|---|---|
| **Age (years)** | | |
| Mean | 50 | 39 |
| Range | 40-65 | 23-55 |
| **Ethnicity** | | |
| Malay | 4 (80%) | 5 (72%) |
| Chinese | 1 (20%) | 0 (0%) |
| Indian | 0 (0%) | 1 (14%) |
| Others | 0 (0%) | 1 (14%) |
| **Education** | | |
| No formal education | 0 (0%) | 1 (14%) |
| Primary | 3 (60%) | 3 (43%) |
| Secondary | 2 (40%) | 3 (43%) |
| Diploma/University level | 0 (0%) | 0 (0%) |
| **HIV infection** | | |
| No | 4 (80%) | 4 (60%) |
| Yes | 1 (20%) | 3 (40%) |
| **Drug use** | | |
| No | 0 (0%) | 0 (0%) |
| Yes | 5 (100%) | 7 (100%) |
| **Recruitment site** | | |
| Community | 1 (20%) | 2 (30%) |
| Prison | 4 (80%) | 5 (70%) |

### 6.4.2 Themes developed from the data analysis

The study identified several major themes that influenced the continuation of TB treatment after release. Prison environment was unanimously described as non-conductive to prisoners who need TB care. The theme "prison is bad for health" encompasses several aspects of the poor healthcare delivery in prisons and its negative influence on patients' interest in the health continuity. These sub-themes include lack of timely attendance to patients with TB, non-existence of TB-related health education and counselling, and lack of provision of documentation of their TB disease before the release to the community. Another identified major theme was "poor perception and attitude" about TB by former prisoners. This theme

encompasses several sub-themes, including the poor perception of been cured by the brief treatment in prison and the poor healthcare-seeking behaviour after release from prisons, but also the high motivation of those who continued treatment to protect themselves and their families. Another major theme "supportive environment during the transition" was identified and encompassed several social aspects of the complex situation during the transition from the prison environment to the community. These include prioritisation of employment and housing on health care seeking, employment commitments, social support (family and friends) in the community, and the influence of drug abuse. A welcoming, non-stigmatising community healthcare system is crucial to ensure treatment continuity after release. This aspect was captured in another major theme that identified issues of the data describing the care provided by the community clinics' staff. Finally, one non-related theme "fear of police harassment" was identified and described separately. These identified themes are described below.

### A. Prison is bad for health

This theme captures the influence of the prison environment on the continuation of TB treatment after release from prison. The process of TB case management, particularly in prisons, might involve other unperceived issues surrounding the detection, treatment prescription and counselling. These may include, but not confined to, cell warden response to prisoner's poor health, acceptance of referral by the prison's clinic, requesting further investigations, referral to a nearby hospital for further assessment, prescription of TB treatment and proper follow up by the prison's health authorities. One participant who discontinued treatment after release expressed his frustration about the prison's attendance to his health needs:

*"It actually depends on the situation .... if I want to meet with the doctor, when in the block, it follows a system just like in schools. The system is according to blocks. It is quite difficult. Sometimes when meeting with the ordinary (non-specialist) doctor [in prison], they just ignore us…. usually, it is quite difficult, because when we say that we have TB, we need to wear the mask to make them believe. Sometimes, when we tell them that we have a history of TB, that we also have a record here with them, they still ignore us."*
*-P02, 33-year-old, discontinued treatment*

Another participant described the lengthy period to get TB treatment in prison:

*"I had a cough with blood, fever and unable to go upstairs…. It took me 1-2 months to be referred to the nearby hospital to get treatment."*
*-P03, 55-year-old, discontinued treatment*

Another critical aspect of TB treatment is to provide prisoners with TB with thorough information about the disease, modes of transmission, risks to others, treatment duration and probable adverse events. This information helps prisoners better understand their condition and can potentially improve their adherence to treatment. One participant, though he knew about the length of treatment, was poorly informed about where to seek TB treatment continuation after release that caused him to discontinue treatment due to other difficulties:

*"I knew the length of TB treatment; it's six months. An academia HIV nurse told me. Two months of Akurit-4, four months rifampin and a vitamin……. If I could take my TB medications at Hospital X [a central hospital in the capital], then it's fine, but I needed to take it at Hospital Y. It is far. I originally took my TB medications in Hospital Y. I needed money to come to Hospital Y. If Hospital X, then it is okay, I can walk too there; it is close."*

*-P06, 42-year-old, discontinued treatment*

Prisoners not provided with these vital elements of knowledge may try to seek them from other, non-professional persons, as described by one participant:

*"When I was in the prison's sickbay, my friend told me about TB. That's all. No counselling or whatsoever by the medical team here in prison."*
*-P10, 36-year-old, discontinued treatment*

Finally, pre-release planning measures that include provision of treatment book, a referral letter and one-week treatment are considered crucial steps in the Malaysian TB control programme in prisons. The implementation of these measures, though, varies from prison to prison. All prisoners who discontinued treatment mentioned that they did not have the chance to receive their pre-release package.

The inadequate response to TB-related health needs seems to be universal among prisoners, including those who continued treatment. This situation was true for immediate attendance to

symptoms and provision of information following TB diagnosis, but not for the provision of the pre-release documentation and medication. Participants depicted the situation of TB care in prisons in their own words:

*"The prison health system is biased. Because the way they treat patients…. I received the information from the specialist TB centre [the prison provided no information about TB]…. Before I was released from the prison, I was given a referral letter and treatment book to continue treatment in the community."*

*-P01, 56-year-old, continued treatment*

Another participant concurred:

*"The prison health system was Ok; they gave me treatment….. No information provided to me inside the prison… They gave the treatment book before my release."*

*-P09, 42-year-old, continued treatment*

Another participant described the process in detail:

*"I had the symptoms for more than three weeks. I used to come every week to the clinic. Almost one month until I got to go for outside treatment, every week, I told them that I have fever, loss of appetite, and a cough with sputum, but they say "later, later". So almost one month I managed to go to the hospital for treatment…. Prison system is OK, but very slow. I gained information about TB both inside and outside….. before release, I was given the treatment book to continue treatment in the community."*

*-P08, 40-year-old, continued treatment*

Two participants provided a contrast of response in two Malaysian prisons:

*"I stayed for eight months in Prison X [a central prison], Then I was transferred to Prison Y [a distant prison]. I was already complaining of 2 months of a cough with fever, but all that they did in Prison X was to listen to my chest…. In Prison Y, they referred me right away to the*

*hospital, and I was called the next day for treatment. The medical assistant at Prison Y told me that treatment for six months. Two months at Prison and four months outside."*

*-P11, 65-year-old, continued treatment*

*"No, the health system in Prison X [a central prison] is not OK. I got my medications when I entered Prison Y [a distant prison], then stopped when I entered Prison X. I didn't get medications. I stopped medications for five days…. Never been told any information about TB, they just told me you have TB and pass me medications."*

*-P12, 51-year-old, continued treatment*

### B. Poor perception and attitude

This theme captures the influence of prisoners' perceptions and attitudes on the continuation of TB treatment after release. Prisoners' response to the health needs after release might be affected by the level of knowledge they gained about the disease and their attitudes towards the received information. The most common misconception among prisoners who discontinue treatment was that they felt healthier after release, and they might not need further TB treatment.

One participant described the reason behind him stopping to seek care after release:

*"When I got released, I was pretty confident that I had already recovered. So, I didn't think all of that. But I thought about that, that disease could give harm to everybody, including my family. But yeah, I thought that I was fully recovered while in prison, as soon I was released, I felt better……. I thought that since I gained weight, so maybe I've already recovered. That's what made me stop the medication……"*

*-P02, 33-year-old, discontinued treatment*

Other participants who become asymptomatic concurred:

*"No [there were no obstacles], I just felt healthy, I didn't have cough anymore. That's it."*

*-P03, 55-year-old, discontinued treatment*

*"That was one of the reasons; I felt like I was okay."*

*-P04, 41-year-old, discontinued treatment*

*"I felt healthy. I felt like TB is not that bad. No negative effect. It is like it won't turn worse. I just realised [I was wrong] after I had started coughing blood after that."*

*-P06, 42-year-old, discontinued treatment*

*"In 2014, my body was still okay. When I got released, I got enough strength; I was not weak. I decided not to take the medication anymore… It is no problem [to go to the clinic in terms of transportation], but I didn't want to go because I felt healthy."*

*-P10, 36-year-old, discontinued treatment*

Another participant was provided with the correct information, but he was in disbelief:

*"I didn't take it seriously [the information that I needed long treatment]. I thought they [healthcare providers in prison] were kidding."*

*-P07, 23-year-old, discontinued treatment*

Another participant thought that if he had prioritised his health over other post-release priorities, he would have continued his medications, but this did not happen:

*"[My salary is per day] Yes, I could have a leave; it's not that I could not. If I put my health as a priority, then I would do it."*
*-P06, 42-year-old, discontinued treatment*

This attitude towards TB-related healthcare was also witnessed in other chronic illnesses as depicted by participants living with HIV

*"I was diagnosed with HIV infection in a clinic, and Dr told me I need to go every 3-4 months [to check my health and do CD4 count], but I didn't feel sick so why going to see the doctor! I didn't know what was CD4 or viral load [at that time]"*

*-P06, 42-year-old, discontinued treatment*

*"[In 2015, I was offered HAART, but] When I was in the ward, I took it. When I went out, no [I did not take medication]. I defaulted two times."*

*-P10, 36-year-old, discontinued treatment*

On the other hand, participants who continued treatment in the community believed that they needed to continue treatment to help themselves and others surrounding them. Participants were motivated to pursue a healthier life after release as described by participants:

*"What motivated me to continue treatment after release was my health condition. I felt healthy again. I couldn't even lift a thing before this…. I moved to another state to avoid getting involved with drugs again to prevent me from taking my TB medications."*

*-P09, 42-year-old, continued treatment*

*"What made me to continue treatment was myself. I wanted good health. I still feel chest pain at previous admission."*

*-P11, 65-year-old, continued treatment*

*"My immediate concern after release is that I wanted to get some rest; I wanted to be healthy before starting a job…… I felt that, not taking my medications is dangerous."*

*-P12, 51-year-old, continued treatment*

Another participant felt obliged to protect family and friends from getting infected

*"I didn't want them [family and friends] to get the infection from me."*

*-P08, 40-year-old, continued treatment*

### C. Supportive environment during transition

This theme captures the influence of social factors (housing, employment, transportation, family/friend support, drug abuse) in the immediate post-release period on the continuation of TB treatment in the community. This is a very complex situation were all these, and other related, factors intertwined.

Finding a job was a significant concern to released prisoners, especially with the perception that most businesses refuse to employ prisoners with incarceration history or with infectious diseases. One participant described his immediate post-release priority in his words:

*"[the most important thing for me after release was] Looking for money, looking for a job….. I didn't have anything [with me after releasing last time] …… I didn't go [to the clinic] because I didn't have any money. I didn't have anything….. I was busy [searching for a job], I didn't have enough time [to go to clinics for any reason]… I needed to get money."*

*-P03, 55-year-old, discontinued treatment*

Other participants concurred:

*"[all that I thought at release was] Looking for a job……. Saving is one of them [reasons I wanted a job], one more thing is because I wanted to help my family."*

*-P04, 41-year-old, discontinued treatment*

*"[after releasing last time] I didn't have money [to use public transportation], and I didn't have the energy to walk to the hospital."*

*-P05, 46-year-old, discontinued treatment*

Another participant mentioned the effect of employment commitment on treatment continuation:

**"***My salary was per day, if I take a leave [to go to the clinic], then no salary."*
*-P06, 42-year-old, discontinued treatment*

One participant summed up the two-sided influence of employment on post-release TB treatment continuation:

*"Firstly, I didn't have any money; I didn't have anything. I just wanted to start my new life, but I didn't have any money. I wanted to go to the clinic and hospital. It just that I wanted to look for a job in a nearby working area… That is the reason why I didn't go to continue my medications….. I couldn't [go to the clinic], when I started working, I forget about that. I was so lazy to go. Because to me, it is troublesome. When the medications [given at the release] were finished, then that's it. I never thought of continuing it. There supposed to be a date for my next appointment but when I started working, I was like; ahh I don't have to…. let's focus on work first."*

*-P02, 33-year-old, discontinued treatment*

As hinted earlier, participants mentioned the transportation been a contributory factor to the failure to continue treatment after release:

*"If I could take my TB medications at Hospital X [a central hospital in the capital], then it is fine, but I needed to take them at Hospital Y. It is far. I originally took my TB medications in Hospital Y. I needed money to come to Hospital Y. If Hospital X, then it is okay, I can walk to there; it is close."*

*-P06, 42-year-old, discontinued treatment*

*"I don't' have any mode of transportation. I can only depend on a bus, so it is quite troublesome for me."*

*-P02, 33-year-old, discontinued treatment*

But transportation did not seem to have a significant influence on other participants:

*"Yes, no problem. [if I wanted to go, the clinic would be] Just nearby, it is easier with the LRT [train]"*
*-P04, 41-year-old, discontinued treatment*

*"No problem [with transportation], [before this episode] there was a nearby bus taking me to the clinic."*
*-P03, 55-year-old, discontinued treatment*

*"It is not a problem [to go to the clinic in terms of transportations], but I didn't want to go because I felt healthy."*

*-P10, 36-year-old, discontinued treatment*

Participants described the difficulties in maintaining a stable housing after release, due to several social pressures. They eventually become homeless, further increasing their challenges during the transition period:

*"I went home; then, as usual, I went to the place I used to go to, Street Y [known as a place for homeless and drug users, among others]. I couldn't stay at my brother's house; he has a wife and children."*
*-P06, 42-year-old, discontinued treatment*

*"No [I didn't have a place to stay at, since 2015]. I was living on the streets, in Area X [in the capital]"*

*-P05, 46-year-old, discontinued treatment*

Housing issues did not seem to be an issue among participants who continued treatment:

*"Yes, when I was released, I returned to my own house in the capital."*

*-P12, 51-year-old, continued treatment*

Participants from the two recruited groups described the excellent support they received from their families and friends to continue TB treatment. Prisoners who discontinued treatment described that they refused to cooperate:

*"They did [reminded me of taking medications]. It was always my mom. Sometimes my sister. But since I followed my friend and working, so nothing was happening, just a reminder. I just can say that I feel better."*
*-P02, 33-year-old, discontinued treatment*

*"My father did ask me to go and see a Dr [after release]. But I didn't go."*
*-P06, 41-year-old, discontinued treatment*

*"Yes [my mom urged me to go to see a doctor], but I just pretended like I went, but I didn't."*
*-P07, 23-year-old, discontinued treatment*

*"Yes, my friend knew I had TB as he needed to sign my treatment book after I take the medications."*

*-P09, 42-year-old, continued treatment*

*"My friend told me that TB could kill and even if I take [illicit] drugs, I still need to take TB medications… he urged me to go and see the doctor after release."*

*-P12, 51-year-old, continued treatment*

Participants gave a good account of the detrimental impact of drug use on their lives, making them lead a drug-dedicated lifestyle.

*"[I have been on drugs for] Long time, since 1998 until now ..... I stopped working [and had unstable housing after starting drugs] ……. I used to steal [to get drugs]…I used all the money [I earn] to buy drugs. Drugs were the reasons of all my previous incarcerations… Yes [I tried to stop drug use], but I already gave up [trying on stopping drugs]. I am already back to illicit drugs again; I was not sure about taking the TB medications."*

*-P03, 55-year-old, discontinued treatment*

*"I mostly use it [my salary] to buy illicit drugs, but not all. I buy food and my clothes…. My priority is drugs. I finish my money on drugs. I don't have money for travel fare ..... [In another previous TB episode, I followed on my appointments] Because I had extra money, then I can come to clinics. I tried to budget. Sometime, the budget does not tally. Health is also important, so do drugs …"*

*-P06, 42-year-old, discontinued treatment*

*"Yes, I wanted to [have a job to] buy drugs……. I didn't want to commit another crime to get money, so I work…. [drugs are so important to me; I used to] nearly spend RM1500-1800 a month on drugs……. It is just the same day or the next day [that I used drugs after release in 2014]."*

*-P10, 36-year-old, discontinued treatment*

The problem of drug abuse seems to be universal among participants with prisoners who continued treatment in the community mentioning similar stories.

*" Yes, I was abusing heroin at that time….. in terms of priority grading, I grade drugs at 10 [out of 10] to me… They [drugs] always have harmful effects. The effect is that I quickly get a disease. The community also has a negative view of me."*

*-P08, 40-year-old, person living with HIV, continued treatment*

One participant who abused drugs decided to take drastic actions to ensure continuation of TB treatment:

*" I used to sell and use drugs….. it was a priority to me…..[after the release] I moved to another state to avoid getting involved with drugs again to prevent me from taking my TB medications."*

*-P09, 42-year-old, continued treatment*

### D. Welcoming community healthcare services

This theme captures the experience of participants with the government-run community healthcare services, including clinics and hospitals that provide TB care.

From their current or previous experience, participants from the two groups agreed that the staff at community health clinics provided non-biased healthcare, and they were comfortable making the visits to these clinics.

*"Okay, doctors [at the community] are all okay. Inside [prison], all are not okay".*

*-P06, 42-year-old, discontinued treatment*

*"Back in 2015 [I completed my TB treatment, as] I was in the community; I could talk and discuss with the doctor about my TB."*

*-P10, 36-year-old, discontinued treatment*

A participant with HIV co-infection provided his account on attending a community health clinic that provides care for TB and HIV infected individuals, among other day-to-day services.
*"They [community health centre] treated me well. No negative views. Some doctors might not even touch an HIV-infected person, but in this centre, they treated us like their family."*

*-P08, 40-year-old, continued treatment*

Few other participants did not have an encounter with the community health clinics to provide their insight, despite being co-infected with HIV

*"I did not have a visit to clinics to judge….. I did not have a CD4 count in the community, only when I come to the prison…"*
*-P05, 46-year-old, living with HIV, discontinued treatment*

### E. Other themes

One participant mentioned that he feared the local police might detain him again, and he preferred to limit his movement to the vicinity of his house.

*"I was afraid of getting caught again, so I didn't have the courage. I just stay at home….. I seldomly go outside, just stay at my home. I was afraid even to go to the shop……They would catch me even if I did nothing."*

*-P06, 41-year-old, discontinued treatment*

## 6.5 DISCUSSION

To our knowledge, this is the first study that has qualitatively assessed factors that influence the continuation of TB treatment after the release from prisons. Several themes were identified from the analysis in this study. First, regardless of the continuation status after release, participants noted delays in their management inside the prison, the limited information provided about TB after diagnosis and employment issues were of concerns. Second, major barriers to the continuation of TB treatment after release identified were poor knowledge about the need of treatment continuation, lack of perception about the risks of discontinuation of TB treatment, job searching and commitment, and unstable housing status. Third, those who continued treatment after release were characterised as having a good knowledge concerning the correct management, a good perception of the consequences of stopping TB treatment and stable housing. Drug and alcohol use might affect the continuation of TB treatment, but it was hard to assess its influence as all 12 participants used drugs before and after prison entry. This study provides vital information to guide initiatives to improve post-release TB treatment continuation in Malaysia and elsewhere.

Factors that influence the continuation of TB treatment after release from prisons have not been thoroughly examined previously. One study from the Russian correctional system reported

barriers to the continuation of TB treatment among 40 former, mostly male, prisoners with TB (4). Participants perceived looking for jobs, homelessness, alcoholism, mistrust of the managing staff and treatment adverse events as significant factors for non-continuation of TB treatment in the community. The study also interviewed six prison staff and three community dispensary staff to view barriers and potential facilitators to improve TB treatment continuation. The staff members reported poor understanding of the nature of illness among prisoners, the perception of being well and cured, limited prisons and community incentives and treatment intolerance as factors leading former prisoners to abandon treatment. The staff members stressed the importance of education and incentives to improve treatment adherence. The study instruments were not open-ended, likely missing other influencing factors in the community.

Knowledge and perception about TB disease emerged as a significant factor influencing the continuation of TB treatment after release from the prison. Prior knowledge and experience with a community HIV care service was one of the facilitating factors to improve engagement in HIV care after release from prisons in the USA (192). Similarly, this echoes findings from several community reports that showed a low level of knowledge about TB as being a major factor associated with non-adherence to TB treatment (198,199). Most participants in our study knew that TB treatment need to be taken for a minimum of six months. Still, information about the impact of non-adherence was not known to participants who discontinued treatment. This perception has influenced the care-seeking behaviour of participants. Finding poor knowledge about TB among prisoners in Ethiopia, a study recommended that in-prison health counselling is crucial to improve adherence to treatment (134). A related theme that developed during the interviews was a poor perception about TB. Participants who discontinued treatment after release did so because they felt healthy, and there is no need for further treatment. This wrong perception has been reported as a significant factor leading to treatment discontinuation in several studies addressing adherence to TB treatment in the non-prison population, particularly in LMICs. A qualitative study examining factors influencing adherence to TB treatment in three randomly-selected health facilities in Eritrea reported the “perception of being cured” as a significant factor among those who discontinued treatment (198). One focus-group study among individuals with TB in four health centres in the Mozambique reported that one of the primary reasons for abandoning TB treatment was the patients’ perception of been well (200). In-depth interviews among 20 individuals with current TB in China reported that the significant emerging theme was “symptoms were elevated, and TB treatment is no longer necessary” as a

factor leading to abandoning TB treatment (201). These findings were further confirmed in a systematic review of qualitative research studies which revealed that eight studies reported feeling better or cured as a factor leading to stopping the TB treatment (195). Collectively, these studies stressed on the importance of improving education and awareness about TB in order to improve adherence to TB treatment.

Social support from a family member or friends is an essential factor in assisting individuals with TB during their treatment course. All but one participant who continued TB treatment were visited by a family member during the previous incarceration. On the other hand, a significant factor that has influenced participants who continued treatment after release was fear of negative consequences on their families' lives. Friends may play an essential role in improving adherence to TB treatment after release. A role that goes beyond the financial support during the illness. Support from a family member, a friend, a case manager or even a neighbour has emerged as one of the major factors facilitating engagement in HIV care after release from prisons in three US studies (192,193,202). Forms of support include financial, emotional, and motivational (one former prisoner received reminders to take medications and attend appointments from a family member). Several publications reported the influence of family and peers support on TB treatment adherence. A systematic review of qualitative studies reported family and friends financial and emotional support as an influential factor affecting the patients' adherence to TB treatment (195). A study from Eretria reported that lack of social support as one of the main barriers to TB treatment adherence (198). None of these studies were conducted among prisoners.

In our study, unstable housing emerged as a factor among participants who discontinued treatment. Two participants who discontinued treatment after release were homeless in the immediate post-release period. On the other hand, all participants who continued treatment after release, except one, were released to their family house. Finding a residence to stay at might be a challenge to released prisoners. Former prisoners in Russia viewed unstable housing and homelessness as one significant barrier to the continuation of TB treatment after release (4). This is likely due to poverty and the constant search for a house and employment.

Finding a job was a significant concern to participants, particularly to those who discontinued treatment after release. In a survey among prisoners with HIV in Malaysia, finding a job after release was one of the major re-entry challenges reported (14). Searching for a job is prioritised

over healthcare by participants who discontinued treatment, given the difficulties in obtaining a job by former prisoners. Being unemployed was reported as one of the significant factors for non-completion of the TB treatment regimen in a survey among former prisoners in Russia (4). A systematic review of reports on adherence to TB treatment reported that there was a conflict between employment and treatment among patients, and some reports highlighted the prioritisation of work over adherence to treatment (195). Other individual studies showed similar findings. An in-depth interview among individuals with TB in Ethiopia showed that loss of employment was a leading source of barriers to adherence to TB treatment. Financial constraints, if not mitigated by family support, create a vulnerable situation for TB treatment interruption in that sample (203). On the other hand, our study suggested that commitment to work may lead to interruption of treatment and default. An assessment of the adherence to TB medications in China reported that one of the emerged factors that led to non-adherence to TB treatment was the patient was busy working (201). Clashes between employment and adherence to TB treatment were reported in an assessment of adherence to TB medications in Eritrea where the loss of employment from illness or time-consuming appointment were major concerns (198).

Studies from elsewhere have found some different factors than identified in our study. A non-qualitative study from a prison system in Russia reported mistrusting of the healthcare staff by former prisoners as one of the factors leading to TB treatment interruption (4). This was probably referring to the community healthcare staff rather than prison staff. Community health services were considered much better than the prison services by most participants in our study. However, few participants, particularly those who discontinued treatment, rated the healthcare delivery in the community as average, almost similar to that in prison. No information exists about discrimination against former prisoners or PWUD in TB clinics. Still, this form of discrimination was reported amongst physicians prescribing HAART to prisoners living with HIV in Malaysia (94).

The use of alcohol and illicit drugs may negatively affect the adherence to TB treatment and other health programmes (204). One participant from a systematic review study reported that she missed doses of TB medications when she is drunk or high on illicit drugs (195). Another cross-sectional survey in Russia reported that substance use disorder was independently associated with poor adherence to TB treatment (205). Of note, history of previous

incarceration was not associated with treatment default. In our study, it was difficult to conclude the effect of illicit drug use on continuation of treatment after release as all participants from the two groups were PWUD who continued drug use after release.

A qualitative assessment from Eritrea reported transportation as a significant barrier to adherence to TB treatment (198). This observation was applicable for those living far away from the closest centre providing TB treatment; some are mountainous areas. In our study, transportation was not considered as a barrier to the continuation of TB treatment after release. This is likely due to the decentralisation of the healthcare system, where most of the primary healthcare centres provide TB services. Additionally, the capital (where all participants live at), is well-connected with a good and affordable public transport system.

The study is limited by the number of participants. We tried to recruit participants from the community using several approaches, but that was not successful. Themes emerged, though, and seemed consistent across the participants. The study is also confined to prisoners of one prison and in the Capital City. Other factors may influence the continuation of TB treatment after release from prisons in other prisons or states. Involvement of women participants might give a broader picture of the barriers and enablers to the continuation of TB treatment after release, but we were not given access to the women's prison. A study with a larger sample size, enrolling participants from other less prosperous states, and recruiting former female prisoners is warranted.

The use of an interpreter might be a potential source of misunderstanding. This was unlikely to influence our findings as the interpreter was local and has a degree in public health. Additionally, we conducted checking and re-checking throughout the interviews.

The study unveiled the complexity of the post-release period and the influence of several factors on the continuation of TB treatment after release from prisons in Malaysia. These findings highlight the need for the establishment of a comprehensive programme that involves both the prison and public health departments to improve adherence to TB treatment after release. This programme may include the establishment of a prison educational programme about TB, the improvement of linkage of soon-to-be-released prisoners with TB to community healthcare services and assisting in employment and housing in the immediate post-release

period. Such a programme requires the involvement of several stakeholders, including the MOH, the prison department, anti-drug agency, non-governmental organisations to achieve the goals set for the programme.

Several different possibilities for intervention have emerged from this study. A systematic review of literature of intervention to improve adherence to TB treatment, albeit not involving prisoners, reported the need for proper education, incentives and enablers, and the use of digital technologies for treatment observation and reminders (206). Studies from other correctional systems examined the impact of interventions on improving adherence to post-release healthcare services. Overall, no single intervention was found to be effective and instead, a holistic approach to the needs of released prisoners is required to achieve excellent retention in care. Accessing nurse-based community services for former offenders to ensure linkage to care and provision of health education and promotion emerged as theme unanimously agreed on by ex-prisoners with health issues in the UK to facilitate continuity of care (207). Proper discharge planning may largely influence adherence to healthcare regimen after release. Offering pre-release linkage to community care was associated with higher rates of retention in care among female prisoners in the USA (208). Simple discharge planning that included sending medical records of soon-to-be-released prisoners with HIV to the community clinic was associated with increased likelihood to initiate HIV care within 30 days after release (OR 1.5, 95% CI 1.1-2.1) compared to those who did not receive such a service in the Texas correctional system (209).

Therefore, in the Malaysian setting, an integrated intervention focusing on prisoner education, improving the post-release linkage to care, financial incentives, and co-location of services (like TB, HIV, drug use care) needs to be explored.

# CHAPTER SEVEN: SUMMARY, CONCLUSION, RECOMMENDATIONS AND FUTURE RESEARCH

## 7.1 Summary of findings and conclusion

The control of TB in current and former prisoners is a complex process. Though information about TB in prisons in Malaysia, a country with an increasing TB burden, remains limited, other countries have reported a high burden of TB among the new prisoners (Chapter 3). Similarly, no information exists about the performance of TB control programmes in the Malaysian prisons, but several countries reported poorly managed TB programmes in their prison systems, irrespective of the geographic or economic status of the country (Chapter 5). Both factors (high TB burden at entry and poorly managed TB control programme) create a perfect environment for the amplification of TB transmission in prison systems. With the addition of poor release planning and lack of continuity of post-release care for prisoners with TB (Chapter 6), prisons further augment the burden of the disease in the community. Elements of the TB management cascade; including TB screening at entry to prisons, comprehensive prison TB management programmes and effective release policies are not thoroughly examined in most LMIC, including Malaysia. This PhD project was designed to provide information about the burden of TB at prison entry, the performance of TB control programme in Malaysian prisons, and to expand our understanding of TB care after release from prisons. The data provided by the PhD studies are novel, being the first studies with such an orientation conducted in Malaysian prisons. Ultimately, these findings will assist policymakers and other stakeholders in improving policies to control TB in prisons in Malaysia and potentially elsewhere.

### High TB burden at entry and poorly managed TB control programme in prisons

Our findings showed that there was a high prevalence of TB among the new entrants to a prison in Malaysia with a prevalence of over three times higher than that in the general population (Chapter 3). This finding affirms the earlier assumption that TB at the prison entry is the major contributor to the TB burden in prisons in Malaysia (10). Prisoners without HIV infection who were diagnosed with TB were more likely to be drug users and underweight, two main elements that highlight the background of prisoners with TB and suitable targets for future TB control

measures in prisons. We further showed that the prison's entry screening programme was suboptimal with just over half of prisoners screened at the entry (Chapter 4). This observation probably explains the low case detection rate in prison with only over one-third of prevalent cases diagnosed. The situation was far worse for HIV-infected prisoners who are known to have a higher risk for TB (in our study, one in eight was a TB case). Assessment of associated risk factors showed no association with examined TB risk factors among HIV-infected prisoners, likely confirming that being PLWH confers high risk for TB (Chapter 3). The study showed inadequate screening for TB in HIV-infected prisoners, no preventive therapy programme, and limited access to HIV treatment for TB patients (one in eight of TB/HIV cases was offered HAART). These findings demonstrate that prisons in Malaysia are not following the national and international recommendations concerning PLWH, including universal screening for TB among PLWH, offering IPT to those without symptoms, and universal provision of HAART, irrespective of the immunologic or virologic status. Managerial and funding issues might have played a role, given that the MOH was not directly involved in healthcare delivery in prisons. Another factor that might have influenced the provision of IPT or HAART is the perception that prisoners with a short prison stay would default their treatment after release. This could have been resolved if proper release planning that caters for the individual needs was implemented. Additionally, the study showed that there was a lack of prison-related TB section in the national TB guidelines and constrains in the number of dedicated and trained medical staff for TB control, which might have additionally influenced the at-entry TB screening and release planning programmes (Chapter 4). Despite direct involvement in medical staff recruitment only, the MOH provided poorly trained medical team in TB management and care that are probably not equipped to manage a complex TB control programme in prisons. Our study showed that a high proportion of prisoners diagnosed with TB were prescribed standard TB treatment. Still, there was a low NTP notification rate, poor treatment follow-up inside the prison (evident by the low rate of sputum examination after two months of treatment) and suboptimal treatment success. The prison lacks a proper reporting and recording system, which might have contributed to these shortfalls. The influence on treatment outcome is evident by the considerable proportion of the unreported treatment outcome of TB patients inside the prison. The other contributing factor to poor treatment outcomes was the high mortality rate, which was 25 times higher than in the general population in Malaysia. This observation could not be explained by the presence of HIV infection only, suggesting that TB mortality in prison is potentially related to delayed diagnosis and poor management of cases inside the prison.

In the final stage of the TB management cascade, released prisoners with uncompleted TB treatment need to be offered proper documentation to continue TB in the community. Still, our study found that this was not universal. Given the poor communication between the prison and public health departments, these documents are crucial to allow prisoners to register to continue TB in the community, as we have shown in one of the PhD studies (Chapter 5). The process of release in overcrowded prisons, like the studied prison, is a hectic process with, in some instances, up to one hundred prisoners released in one day. Poor communication between the release unit and the prison's clinic might have contributed to the failure to universally provide these documents, particularly in such a complicated situation. This observation was reported elsewhere in a similar setting (125).

Finally, our study showed that prison staff members and prisoners, in particular, had limited knowledge about TB, making them not equipped to participate in the passive case detection currently practised in the Malaysian prisons. Of note, there were no TB educational programmes or TB counselling sessions in prisons in Malaysia at the time of the study, which might explain this shortfall.

Together these findings highlight several important issues that have negatively influenced the TB management in Malaysian prisons. First, the poor reporting and recording system in prisons has not only affected the performance of TB control programme in prisons in Malaysia but caused difficulties in obtaining information for our research, such that other resources were needed to examine the targeted parameters. Second, poor management of human resources was evident by the provision of medical personnel not trained in correctional health to the prison. Finally, the unavailability of an education and counselling programme about TB in prisons makes it difficult for the prisoners and prison officers to participate in the TB management practices.

### A high default rate after release from prisons and several factors that influence this rate

Our initial studies showed that most prisoners with TB in Malaysia were released from prisons before completing TB treatment (Chapter 3 and 4). Both the MOH and the prison health authorities are not involved in pre-release follow-up arrangements and leave it to the discretion of prisoners to arrange an appointment with the community health facilities. This practice was

noticed in other countries with similar poor continuation of care in the community (Chapter 5). Findings from our community study showed that almost half of prisoners with an uncompleted TB regimen in prison abandoned treatment after release (Chapter 5). Several factors were involved, highlighting the complex post-release situation. These include poor housing, lack of employment, and not being provided with the documentation before release. Several other factors might have been involved, including mortality from TB, but we were unable to assess this factor due to the inability to access the national death registry. These findings were echoed in our last study that was designed to examine factors influencing the continuation of TB treatment after release. The study involved an in-depth interview of prisoners with previous uncompleted TB treatment in prisons. The developed themes showed that the poor communication with prisoners in prisons and community clinics might have negatively influenced treatment continuation after release. This factor, along with the poor knowledge about TB described earlier (Chapter 4), might have affected healthcare-seeking behaviour concerning TB treatment continuation after release. An unsupportive environment in the transitional period, including a lack of housing and employment, and poor social support were significant influencers of the continuation of TB treatment (Chapter 6).

Post-release studies are challenging to conduct, given the obstacles faced in reaching this population (former prisoners). This affected further recruitment of former prisoners to assess factors that influenced the continuation of TB treatment after release from prisons. Despite this, these studies provide, for the first time, information about the post-release situation of prisoners with uncompleted TB treatment and major-related risk factors.

## 7.2 Recommendations

Findings from the PhD project revealed the shortfalls in the management of TB from diagnosis to release in prisons in Malaysia and show the need to strengthen the TB control programme in the Malaysian correctional system. We provide the following recommendations to achieve this goal:

1. The establishment of an effective TB case finding surveillance system at the entry to prisons coupled with routine TB case finding surveys, thereafter. Findings from a study in Malaysia and other LMIC reported the poor performance of passive case detection in controlling TB in closed settings, like prisons and that passive case detection needs to be abandoned (10).

2. To achieve the first recommendation, there is a need to establish an evidence-based screening algorithm together with updated guidelines for TB control in prisons to optimise the use of limited resources.

3. The health of HIV-infected prisoners need to be prioritised, including active screening surveys, the provision of preventive therapy to eligible prisoners and of HAART to eligible prisoners, including all TB/HIV patients.

4. The urgent development of a proper reporting, recording, and filing system in prisons with potential utilisation of digital technology to optimise TB case management. The current lack of such a system might have potentially contributed to several aspects of the poor TB system performance.

5. The development of proper communication between the prison and public health departments and the involvement of the public health department in every correctional health activity is crucial to improve TB management inside the prison and to perform follow-up after release from prisons.

6. There is a need to establish an education and counselling programme targeting prisoners with and without TB to improve adherence to treatment inside and outside the prisons.

7. Involvement of governmental and non-governmental agencies in providing support (financial, employment, and housing) during the immediate post-release period for all prisoners to prioritise health and to motivate them to attend healthcare appointments.

8. Prioritisation of drug rehabilitation programmes in prisons and the continuation of such programmes after release from prisons is crucial. The relocation of TB, HIV, and drug abuse services in a one-stop-shop model (as proposed by WHO (189)) is relevant to the Malaysian situation and will likely improve the care for the three diseases.

### 7.3 Further research

Findings from the PhD project provide a platform for further studies to be conducted in the correctional system in Malaysia. Three key studies are proposed, as follows:

**1. The impact of intensified tuberculosis case finding at entry to prison on the incidence of TB among HIV-infected prisoners in Malaysia**

This cohort study was developed as a follow-up on the first study of this project (Chapter 3) and is confined to HIV infected prisoners only. Prisoners have been followed up for 12 months with interval active TB screening on third, sixth, and 12$^{th}$ months following the initial assessment.

### 2. The implementation of an electronic reporting and recording system in prisons in Malaysia and its effect on tuberculosis case management in prisons

This study has been proposed during the initial research (Chapter 3) and stressed during the subsequent research studies (Chapter 4, 5 and 6), but no funding was available to pursue the project further. This proposed study is an implementation science project in which a digital reporting and recording system is designed and implemented, and programme outcomes are followed over a period of time.

### 3. Randomised controlled trial of interventions to improve adherence to tuberculosis treatment after release from prisons in Malaysia

Based on the findings from the post-release studies (Chapter 5 and 6). Possible interventions include: TB education programme, provision of incentives, the establishment of a prison drug rehabilitation programme, providing short-term accommodation for released prisoners without stable housing, and mobile phone reminders.

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**APPENDIX 1**

**Tables of the reviews of literature**

**Table A1-1:** Studies addressed the prevalence of active TB at entry to prisons

**Table A1-2:** Reports addressing the gaps in policy-practice of TB care in prison

**Table A1-3:** Reports addressed the continuation of TB treatment after release from prisons

**Table A1-1 Studies addressing the prevalence of active TB at entry to prison**

| Publication | Country | Number of prisons | Number of prisoners | TB Prevalence at entry | Study design | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Inadequate follow up |
|---|---|---|---|---|---|---|---|---|---|
| Abeles H, et al (1970) | United States | 1 | 1500 | 200/100,000 | Cross-sectional | Proper- All entrants screened | Unclear- Definition of TB and measurement of outcome was not described | Not done- No assessment of risk factors was performed | Not provided |
| Aerts A, et al (2006) | European region | 22 | N/A | 393/100,000 | Review | Unclear- No information about eligibility criteria | Unclear- TB definition was not provided | Not done- No assessment of risk factors was performed | Not provided |
| Banjeree A, et al (2000) | Malawi | 1 | 111 | 4000/100,000 | Cross-sectional | Unclear- Only 111 out of 254 entrants submitted sputum | Proper- TB was defined as positive sputum microscopy | Not done-No assessment of risk factors performed | Not provided |

| Publication | Country | Number of prisons | Number of prisoners | TB prevalence at entry | Study design | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Inadequate follow up |
|---|---|---|---|---|---|---|---|---|---|
| Banu S, et al (2015) | Bangladesh | 1 | 42367 | 103/100,000 | Cross-sectional | Proper- All new entrants screened | Proper- clear definition of TB | Not done- No assessment of risk factors was performed | Proper- symptomatic prisoners were followed up till culture results |
| Bock NN, et al (1998) | United States | 1 | 87518 | 113/100,000 | Review | Proper- all inmates were screened by symptoms at entry | Not proper-TB definition was not explained | Not done- No assessment of risks was performed | Proper- Suspected TB cases were followed up till culture results |
| Calero G, et al (2017) | Uruguay | 1 | 1959 | 660/100,000 | Cross-sectional | Proper- all new entrants were screened by sputum microscopy | Not proper- TB was defined, but no description of recruitment process; No detailed risk factor data were collected | Not done- No assessment of risk factors was performed | Not provided |

| Publication | Country | Number of prisons | Number of prisoners | TB prevalence at entry | Study design | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Inadequate follow up |
|---|---|---|---|---|---|---|---|---|---|
| Henostroza G, et al (2013) | Zambia | 1 | 317 | 7300/100,000 | Cross-sectional | Proper- all new entrants were screened | Proper- TB was clearly defined; no risk factors collected | Not done | Proper- follow up on sputum examination |
| Layton MC, et al (1997) | United States | 1 | 4172 | 767/100,000 | Cross-sectional | Proper- All new entrants screened clinically and by CXR | Unclear- TB definition was not clearly provided; Risk factors were not collected | Not done | Proper- follow up on sputum examination |
| Lobacheva T, et al (2015) | Russia | 2 | N/A | 1176/100,000 | Review | Proper- all inmates were screened by CXR at entry | Proper- TB was clearly defined; clear description of recruitment process; Incomplete- No detailed risk factor data were collected | Not done- | Proper- follow up on sputum examination |

| Publication | Country | Number of prisons | Number of prisoners | TB prevalence at entry | Study design | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Inadequate follow up |
|---|---|---|---|---|---|---|---|---|---|
| Maggard KR, et al (2015) | Zambia | 3 | 2231 | 6100/100,000 | Cross-sectional | Proper- all inmates were screened at entry | Proper- TB was clearly defined; clear description of recruitment process | Not done- No assessment of risk factors | Proper- follow up on sputum examination |
| Puisis M, et al (1996) | United States | 1 | 126608 | 68/100,000 | Cross-sectional | Proper- all inmates were screened at entry | Proper- TB was clearly defined; clear description of recruitment process | No proper analysis of collected risk factors | Proper- follow up on sputum examination |
| Sanchez A, et al (2013) | Brazil | 1 | 1708 | 2900/100,000 | Cross-sectional | Proper- all inmates were screened at entry | Proper- TB was clearly defined; clear description of recruitment process | No proper analysis of collected risk factors was performed | Proper- follow up on sputum examination |

| Publication | Country | Number of prisons | Number of prisoners | TB prevalence at entry | Study design | Apply eligibility | Measurement of exposure and | Control confounding | Inadequate follow up |
|---|---|---|---|---|---|---|---|---|---|
| Takashima HT, et al (1996) | United States | 1 | N/A | 405/100,000 | Review | Proper- all inmates were screened at entry | Proper- TB was clearly defined; clear description of recruitment process | Not done- No assessment of risk factors | Not provided |
| Thompson C, et al (2009) | United Kingdom | 2 | 451 | 0/100,000 | Cross-sectional | Proper- all inmates were screened at entry | Proper- TB was clearly defined; clear description of recruitment process | Not done- No assessment of risk factors | Not provided |
| Sahle ET, et al (2019) (86) | Ethiopia | 1 | 8228 | 109/100,000 | Cross-sectional | Yes- all entrants were screened during the period | Yes | Yes | Not necessary |

**Table A1-2 Reports addressing the gaps in policy-practice of TB care in prison**

| Publication | Country | Prisons | Study design | Demographics | Parameter assessed | Findings | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Follow up |
|---|---|---|---|---|---|---|---|---|---|---|
| Adane K, et al (2018) | Ethiopia | 4 | Review | Men (97%); Age <25 (40%) | TB treatment outcome | Cured (11.5%), Completed treatment (68%), lost-to-follow (2.5%), treatment failure (1.6%), died (1.4%), transferred out (15%) | Adequate | Outcome of interest was clear; more exposure variables are needed | No analysis was performed | Not adequate for release prisoners |
| Aerts A, et al (2006) | European region | 22 | Review | Not applicable | TB screening and treatment outcome | Screening at entry (90.9%), Treatment success (57.9%) | No details provided | No details provided | No analysis was performed | No details provided |
| Dhuria M, et al (2016) | India | 1 | Review | Men (96.1%) | Screening practices and treatment outcome | All prisoners screened with symptoms; treatment success (10.4% to 71.5%), transferred out (14% to 45%) | Not all symptomatic were investigated | Not clear measurements of exposure or outcome variables | No analysis was performed | Not adequate for released prisoners |

| Publication | Country | prisons | Study design | Demographics | Parameter assessed | Findings | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Follow up |
|---|---|---|---|---|---|---|---|---|---|---|
| Harries, et al (2004) | Malawi | 1 | Review | Not provided | Treatment initiation and outcome | 95% registered for treatment; 57% completed treatment; 11% died | No details provided | Proper definition of outcome variables; no exposure variables provided | No analysis was performed | Not adequate for released prisoners |
| Levy M, et al (1999) | Asia-Pacific region | 15 | Review | Not provided | TB screening and treatment policies | 86% report TB to NTP; 13% has TB section in national guidelines; 33% screened prisoners at entry | No details provided | No details provided | No analysis was performed | No details provided |
| MacNeil, et al (2005) | United States | n/a | Review | N= 7820; 89.4% Men; 77% US born; Median age 37 | Treatment outcome | 76.8% completed treatment | Adequate- All TB cases over 5 years | Not adequate- outcome variable was not adequately defined; no adequate exposure variables were examined | Not adequate analysis provided | Not adequate for moved prisoners |

| Publication | Country | Prisons | Study design | Demographics | Parameter assessed | Findings | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Follow up |
|---|---|---|---|---|---|---|---|---|---|---|
| Mehay, et al (2016) | United Kingdom | 9 | Review | n/a | Conforming to national guidelines | 53% of targets met | Adequate-healthcare providers | Outcome variables were adequately defined | No analysis was performed | No details provided |
| Prasad BM, et al (2017) | India | 157 | Cross-sectional | N= 200,000 inmates | TB screening, availability of medical doctors | 50% of prisons screen at entry; 82% or prisons has doctors | Inadequate-prison inclusion process not clear | Inadequate-outcomes not fully described | No analysis was performed | Adequate |
| Rodrigo T, et al (2002) | Spain | n/a | Review record review | N=59 TB cases | Treatment delay and outcome | Diagnostic delay=18-32 days; 67.3% completed treatment, 16.4% died or lost to follow | Adequate-TB cases diagnosed in prisons | Adequate for the outcome, but no exposure variables collected | No analysis was performed | Adequate-follow up in the community |

| Publication | Country | Prisons | Study design | Demographics | Parameter assessed | Findings | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Follow up |
|---|---|---|---|---|---|---|---|---|---|---|
| Todrys KW, et al (2011) | Zambia | 6 | Mixed method | 246 prisoners and 30 prison officers | Staffing, TB screening, isolation | Staff inadequate, Screening was variable, isolation is rare | Adequate | Adequate for the outcome, but no exposure variables collected | No analysis was performed | No details provided |
| Topp SM, et al (2017) | Zambia | 87 | Mixed method | Not provided | Staffing | Understaffed (8.9/10,000) | Adequate | Adequate for the outcome, but no exposure variables collected | No analysis was performed | No details provided |
| Abebe DS, et al (2011) | Ethiopia | 3 | Cross-sectional | Men (95%), Under 45 (78.3%) | TB knowledge among prisoners | Overall limited knowledge | Adequate | Adequate | Not performed | No details provided |
| Adane K, et al (2017) | Ethiopia | 8 | Cross-sectional | Men (97%), Mean age 28 | TB knowledge among prisoners | Overall limited knowledge | Adequate | Adequate | Adequate | No details provided |

| Publication | Country | Prisons | Study design | Demographics | Parameter assessed | Findings | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Follow up |
|---|---|---|---|---|---|---|---|---|---|---|
| Roy A, et al (2008) | United Kingdom | n/a | Cross-sectional | N=28 | TB knowledge among prison guards | Overall limited knowledge | Inadequate-recruitment process unclear | Adequate for the outcome, but no exposure variables collected | Not performed | Follow up performed |
| Ferreira S, et al (2011) | Brazil | 1 | Cross-sectional | 140 prisoners and 71 guards | TB knowledge among prisoners and guards | Overall adequate knowledge | Inadequate-recruitment process unclear | Adequate for the outcome, but no exposure | Not performed | No details provided |
| Ferreira S, et al (2013) | Brazil | 1 | Cross-sectional | 141 prisoners and 115 employees | TB knowledge among prisoners and employees | Knowledge was by far better among employees | Inadequate-sample was small | Adequate for the outcome, but no exposure | Not performed | No details provided |

| Publication | Country | Prisons | Study design | Demographics | Parameter assessed | Findings | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Follow up |
|---|---|---|---|---|---|---|---|---|---|---|
| Ferriera MRL, et al (2019) | Brazil | 1 | Cross-sectional | 97% men<br>25-30 years (41.6%)<br>27.5% HIV | Use of diagnostic tools, follow up | 57% did not have CXR; 69.1% did not have culture examination; 10.7% on DOT | Adequate | No performed | No analysis was performed | No details provided |
| Singano V, et al (2020) | Malawi | 1 | Retrospective review | All men; median age 35; N=446 | Treatment outcome | 93% Success; 5% died; 1% not evaluated | Adequate | Thorough | Performed | Not required |
| Mandizvidza A, et al (2020) | Zimbabwe | 2 | Prospective cohort | N=405 | Treatment initiation, treatment outcome | 64% started on TB medications; 74% treatment success; 5% died; 4% LTFU | Adequate | Not collected | Not performed | Adequate-follow up |

**Table A1-3: Reports addressed the continuation of TB treatment after release from prisons**

| Publication | Country | Prisons | Study design | Demographics | Findings | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Follow-up |
|---|---|---|---|---|---|---|---|---|---|
| Adane K, et al (2018) | Ethiopia | 4 | Retrospective record review | Men (97%); Age <25 (40%) | transferred out/released (15%); all LTFU | Adequate | Adequate | Inadequate | Not adequate |
| Anderson C, et al (2010) | United Kingdom | Nation-wide | Retrospective record review | 93% men, 47% UK-born | 21% released; all LTFU | Adequate | No details | No analysis | Not adequate |
| Berihun YA, et al (2018) | Ethiopia | 1 | Retrospective record review | All men, mean age 30.2 years, 3.7% HIV+ | 51 (31.5%) released; all LTFU | Adequate | Adequate | Adequate | Not adequate |
| Bock NN, et al (1998) | United States | 1 | Retrospective record review | 93% men, median age 36 years, 41% HIV+ | 27% released; 59% continued treatment | Adequate | Adequate | No analysis | Adequate |

| Publication | Country | Prisons | Study design | Demographics | Findings | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Follow-up |
|---|---|---|---|---|---|---|---|---|---|
| Chiang CY, et al (2002) | Taiwan | 29 | Retrospective record review | 93.5% men | 15.9% released; all LTFU | Adequate | Not adequate | No analysis | Not adequate |
| De la HOZ KF, et al (2001) | Spain | | Cohort | 97% men, 75.8% HIV+, IDU 70.9% | 20.5% continued treatment | Adequate | Not adequate | Not adequate | Adequate |
| Dhuria M, et al (2016) | India | 1 | Retrospective review | 96.1% men, 49.1% age group 21-30 | 29.5% released; all LTFU | Adequate | Not adequate | No analysis | Not adequate |
| Fry RS, et al (2005) | Russia | 1 | Cohort | Mean age 40.71, men 85% | N= 80 released; 26.3% continued treatment | Inadequate | Not adequate | No analysis | No info |

| Publication | Country | Prisons | Study design | Demographics | Findings | Apply eligibility criteria | Measurement of exposure and outcome | Control confounding | Follow-up |
|---|---|---|---|---|---|---|---|---|---|
| Hatwiinda S, et al (2018) | Zambia | 6 | Retrospective record review | Mean age 38, 96.8% men, 33% HIV+ | 11% released; all LTFU | Adequate | Not adequate | No analysis | Not adequate |
| Hernandez-Leon C, et al (2012) | Mexico | 1 | Cohort | All men, median age 33.5 | N=28; Released N=7; 2 continued treatment | Adequate | Not adequate | No analysis | Not adequate |
| Nateniyom S, et al (2004) | Thailand | 16 | Cohort | Not provided | 10.6% transferred/released; all LTFU | Adequate | Not adequate | No analysis | No info |
| Schwitters A, et al (2014) | Uganda | 233 | Retrospective record review | 98% men, 38% in age group 18-29, 57.1% HIV+ | 20% released; 81% LTFU | Adequate | Not adequate | No analysis | Adequate |

**APPENDIX 2**

**THE RESEARCH QUESTIONNAIRES AND FORMS**

**FORM 2-1.** SCREENING FOR TUBERCULOSIS AMONG NEW PRISON ENTRANTS IN MALAYSIA.

**FROM 2-2** DATA EXTRACTION FORM FOR TB CASES FROM 2013-2016.

**FORM 2-3:** ASSESSMENT OF KNOWLEDGE OF TB AMONG PRISONERS AND PRISON STAFF.

**FORM 2-4** THE CONTINUATION OF TUBERCULOSIS TREATMENT AMONG PRISONERS RELEASED TO THE COMMUNITY BEFORE COMPLETING TREATMENT IN PRISONS IN MALAYSIA: A PROSPECTIVE COHORT STUDY

**FORM 2-5** INTERVIEW GUIDE.

**Form 2-1:** SCREENING FOR TUBERCULOSIS AMONG NEW PRISON ENTRANS IN MALAYSIA

********** **RESEARCH TEAM ONLY**********

**[SD01] Participant ID:**

**[SD02] Date of interview:** / /

**[SD03] Name: .....**

**[SD04] Date of Birth: .....** **[SD04a] Age: ……**

**[SD05] Gender:** □ 1 Male □ 2 Female □ 3 Transgender

**[SD06] Prison Number:**

□□□□□□□□□□

**[SD07] IC/ Passport/ UNHCR Number:**

□□□□□□□□□□□□

**[SD08] Date of Incarceration:** □□ □□ □□

**[SD09] Date of Release:** □□ □□ □□

**[SD10] Nationality:**

□1 Malaysian
□2 Others: .....

**[SD11] Ethnicity:** ***(Only for Malaysian citizen)***

□ 1 Malay □ 2 Chinese □ 3 Indian

□ 4 Others: .....

**[SD12] Stable employment during past 12 months before incarceration:**

□ 0 No □ 1 Yes

**[SD13] Years spent in education:** .....

**[SD14] Previous Incarceration** □ 0 No □ 1 Yes [SD15a] Times: .....

**[SD15] Used illicit drug (any time)** □ 0 No *(SKIP to SD21)*

□ 1 Yes *(Proceed with the interview)*

**[SD16] 30 days before incarceration** □ 0 No □ 1 Yes

**[SD17] Injected drugs (any time)** □ 0 No □ 1 Yes

**[SD18] Injected 30 days before incarceration** □ 0 No □ 1 Yes

**[SD19] Heroin use before entry** □ 0 No □ 1 Yes

**[SD20] Enrolled in MMT programme** □ 0 No □ 1 Yes

**[SD21] Previous TB episode** □ 0 No *(SKIP to SD22)*

□ 1 Yes ([SD21a] Which year:.....)

**[SD22] Known HIV Case** □ 0 No *(SKIP to SD25)*

□ 1 Yes

**[SD23] ART used before entry** □ 0 No □ 1 Yes

**[SD24] Have you done CD4 before?** □ 0 No □ 1 Yes

**Before incarceration, did you.....**

| | | | |
|---|---|---|---|
| **[SD25]** | **Smoke cigarette 30 days before entry** | □ 0 No | □ 1 Yes |
| **[SD26]** | **Drink alcohol 30 days before entry** | □ 0 No | □ 1 Yes |

**<u>Tuberculosis Symptoms</u>**

**[SYM1] Do you have cough?** □ **0 No**

□ **1 Yes ([SYM1a] For how many days?.....)**

**[SYM2] COUGH > 1 WEEK** □ **0 No** □ **1 Yes**

**[SYM3] Sputum production** □ **0 No** □ **1 Yes**

**[SYM4] Bloody sputum** □ **0 No** □ **1 Yes**

**[SYM5] Fever** □ **0 No** □ **1 Yes**

**[SYM6] Night sweat** □ **0 No** □ **1 Yes**

**[SYM7] Appetite loss** □ **0 No** □ **1 Yes**

**[SYM8] Weight loss** □ **0 No** □ **1 Yes**

**[SYM9] Chest pain** □ **0 No** □ **1 Yes**

**[SYM10] Shortness of breath** □ **0 No** □ **1 Yes**

**[SYM11] Lymph nodes** □ **0 No** □ **1 Yes**

**Weight: ….....…..... KG** **Height: ...……..... CM** **BMI.....**

**<u>Lab results:</u>**

| **Sample** | **GeneXpert** | | | **Culture** | | |
|---|---|---|---|---|---|---|
| **Sputum #1** | **[XP1]** | □ **0 Neg** | □ **1 Pos** | **[CT1]** | □ **0 Neg** | □ **1 Pos** |
| **Sputum #2** | **[XP2]** | □ **0 Neg** | □ **1 Pos** | **[CT2]** | □ **0 Neg** | □ **1 Pos** |

| **Type of test** | | **Result** | |
|---|---|---|---|
| **[SP1]** | **HIV Rapid Test** | □ **0 Neg** | □ **1 Pos** |
| **[SP2]** | **CD4 lymphocytes count:** | **..... cells/µL** | |

**FROM 2-2** DATA EXTRACTION FORM FOR TB CASES FROM 2013-2016

**Date of data extraction** / /

**Study ID**

**Prison number**

**NRIC number:**

**Date of entry** / /

**Date of release** / /

**TB case has medical record**

□ 0 No □ 1 Yes

**Is the case HIV co-infected?**

□ 0 No □ 1 Yes □ 2 Not known/not reported

**Case entered the prison with TB (diagnosed in the community)**

□ 0 No □ 1 Yes

**Date of diagnosis of TB** / /

**Case provided with standard TB treatment**

□ 0 No □ 1 Yes

**Case has a copy of form TBIS 10A-1 for TB notification**

□ 0 No □ 1 Yes

**Case submitted sputum examination at 2-month of treatment**

□ 0 No □ 1 Yes □ 2 Released

**If HIV-infected, was he prescribed HAART:**

□ 0 No □ 1 Yes

**Outcome of TB treatment**

1. Completed treatment inside the prison
2. Released before treatment completion
3. Failed treatment
4. Died
5. Not reported

**FORM 2-3:** ASSESSMENT OF KNOWLEDGE OF TB AMONG PRISONERS AND PRISON STAFF

**Date of the interview:**

**Participant number:**

**A. How old are you?**

1. Under 30
2. 31-40
3. 41-50
4. Over 50

**B. What is your gender?**

1. Male
2. Female
3. Transgender

**C. What is the highest level of education you have completed?**

1. No school
2. Elementary
3. High school
4. Diploma
5. College
6. Higher education (professional or post-graduate
7. Literacy classes only

**D. What causes TB? (Please check all appropriate)**

1. A germ (e.g., virus, bacteria, parasite)
2. Bad air (e.g., haze)
3. Smoking

4. A curse

5. Others

6. Do not know

**E. What are the signs and symptoms of TB? (Please check all appropriate)**

1. Rash

2. Cough

3. Cough lasts longer than 3 weeks

4. Coughing up blood

5. Severe headache

6. Nausea

7. Weight loss

8. Fever

9. Chest pain

8. Shortness of breath

9. Ongoing fatigue

10. Others

11. Do not know

**F. How can a person get TB? (Please check all appropriate)**

1. Through handshakes

2. Through sharing dishes

3. Through the air when a person with TB coughs

4. Through eating

5. Through touching items in public places

6. Others

7. Do not know

**G. How can a person prevent getting TB? (Please check all appropriate)**

1. Avoid shaking hands
2. Covering mouth and nose coughing
3. Avoid sharing dishes
4. Washing hands after toughing items in public
5. Closing windows at home
6. Through good nutrition
7. By praying
8. Others
9. Do not know

**H. Who can be infected with TB? (Please check all appropriate)**

1. Only poor people
2. Only homeless
3. Only alcoholics
4. Only drug users
5. Only people with HIV
6. Only people who have been in prison
7. Others
8. Anybody

**I. Can TB be cured?**

1. Yes
2. No
3. Do not know

**J. How can someone with TB be cured? (Please check all appropriate)**

1. Herbal medicine
2. Home rest without medicine
3. Praying

4. Special treatment from the health centre

5. Others

6. Do not know

**K. What is the cost of TB treatment?**

1. Very expensive

2. Free

3. Do not know

**L. How long does TB treatment last?**

1. Two weeks

2. Two months

3. Six months or more

4. One year or more

5. Do not know

**M. Risk of not taking treatment (Please check all appropriate)**

1. Nothing will happen

2. Feeling sick

3. Death

4. Cured

5. Do not know

**FORM 2-4** The continuation of tuberculosis treatment among prisoners released to the community before completing treatment in prisons in Malaysia: a prospective cohort study

## Part 1: Background

**[BG1] Study ID:**

**[BG2] Date of birth:**

**[BG3] What is your gender?**

- ☐ Male
- ☐ Female
- ☐ Transgender
- ☐ Prefer not to say

**[BG4] How many years you spent in formal education?**

| | | |
|---|---|---|
| | | Years |

[BG5] Family background

**[BG5a] What best describes your marital status?**

- ☐ Single, never married
- ☐ Currently married
- ☐ Previously married (divorced, separated, widowed)
- ☐ Others

**[BG5b] Do you have children?**

- ☐ Yes
- ☐ No

**[BG5c] How many times have you been visited by an immediate family member (parents, siblings, wife, or children) over the past 6 months during current incarceration?**

| | | |
|---|---|---|
| | | Times |

**[BG5d] Are you returning to live with your family (wife and children or parents and siblings) after release?**

- ☐ Yes
- ☐ No

**[BG6] Housing**

**[BG6a] What best describes your housing status before current incarceration?**

- ☐ Staying in own house
- ☐ Staying with other family members in a family home
- ☐ Renting a housing unit, including a house, on a long-term basis (annual)
- ☐ Renting a room/bed on a short-term basis (weekly-monthly)
- ☐ Staying in job quarters, rehab centres, care centres
- ☐ Living on streets
- ☐ Others, specify…….

**[BG6b] After release, are you planning to:**

- ☐ Return to same place stayed at before release
- ☐ Have no housing arrangements
- ☐ Stay at another place (ANSWER [BG6c])

**[BG6c] Other places**

- ☐ Staying with other family members in a family home
- ☐ Renting a housing unit, including a house, on a long-term basis (annual)
- ☐ Renting a room/bed on a short-term basis (weekly-monthly)
- ☐ Staying in job quarters, rehab centres, care centres
- ☐ Living on streets
- ☐ Others, specify……

**[BG6d] Please provide your full address for the place you are returning to:**

Unit number:

Street number:

Suburb:

City and postcode:

State:

**[BG6e] Please provide an operating telephone number that we can reach you through, if needed (belongs either to you, your family member, or your friend)**

**[BG7] Employment**

**[BG7a] What best describes your employment status in the past 12 months before prison entry?**

- ☐ Had a full-time job(s)
- ☐ Had part-time or casual job(s)
- ☐ Unemployed [SKIP to BG7c]

**[BG7b] What was your average monthly income in Malaysian Ringgit before prison entry over the past 6 months?**

**[BG7c] What best describes your planning for employment after release?**

- ☐ Back to the same job
- ☐ Doing a different job
- ☐ Prefer to stay unemployed
- ☐ Have no idea

**Part 2: Incarceration history**

[INCAR1] Current incarceration section*:

[INCAR2] Date of entry to prison:

[INCAR3] Date of release:

[INCAR4] Have you been incarcerated before?

- ☐ Yes
- ☐ No [SKIP to INCAR5]

| | | |
|---|---|---|
| [INCAR4a] | How many times of previous jail# entry? | |
| [INCAR4b] | How many times of previous prison# entry? | |
| [INCAR4c] | How many times of previous entry to compulsory drug detention centres? | |
| [INCAR4d] | Total times of previous incarcerations (jail, prison, drug detention centres) | |
| [INCAR4e] | What is the total duration of previous jail entries (weeks)? | |
| [INCAR4f] | What is the total duration of previous prison entries (weeks)? | |
| [INCAR4g] | What is the total duration of previous entries to compulsory drug detention centres (weeks)? | |

| | | |
|---|---|---|
| [INCAR4h] | Total duration of previous incarcerations (weeks) | |

**[INCAR5] Have you applied for parole during this incarceration?**

- ☐ Yes
- ☐ No

[Notes: * The Malaysian law section of the prisoners' sentence, # Jail: Short detention centre housing individuals awaiting trial (remand), # Prison: Long detention centre housing individuals who has already sentenced]

## Part 3: Drug abuse

**[Drug1] Have you EVER used illicit drugs before?**

- ☐ Yes
- ☐ No [SKIP TO PART 4]

**[Drug2] Have you used illicit drugs within the 30 days before prison entry?**

- ☐ Yes
- ☐ No

**[Drug3] Have you EVER injected drugs?**

- ☐ Yes
- ☐ No [Go to Drug5]

**[Drug4] Have you injected drugs within the 30 days before prison entry?**

- ☐ Yes
- ☐ No

**[Drug5] Have you used heroin within the 30 days before prison entry?**

- ☐ Yes
- ☐ No

**[Drug6] Are you currently enrolled in a Methadone Maintenance (MMT) programme?**

- ☐ Yes
- ☐ No [SKIP to Drug8]

**[Drug7] Current dose of methadone**

**[Drug8] Have you had previous enrolment in an MMT, whether in prisons or the community?**

- ☐ Yes
- ☐ No [SKIP to Part 4]

**[Drug9] Have you stopped taking previous MMT prescription?**

- ☐ Yes
- ☐ No [SKIP to Part 4]

[Drug10] What were reasons for stopping previous MMT prescription?

- ☐ Incarceration
- ☐ Job commitment
- ☐ No transportation
- ☐ Uncooperative staff at the centre
- ☐ Fear of police harassment
- ☐ Adverse events, including affecting my daily life activities and my TB and HIV treatment
- ☐ Do not need it anymore
- ☐ Others, specify……

**<u>Part 4: History of previous TB episodes</u>**

**[PREV1] Have you been diagnosed with TB before?**

- ☐ Yes
- ☐ No [SKIP to Part 5]

**[PREV2] Have you ever been diagnosed with TB in a prison before current incarceration?**

- ☐ Yes
- ☐ No [SKIP to Part 5]

**[PREV3] What happened to your previous TB in prison treatment regimen?**

- ☐ Stopped TB treatment in the prison
- ☐ Stopped TB treatment after release
- ☐ Completed treatment while in the prison
- ☐ Completed treatment outside the prison

**[PREV4] Reasons for stopping previous TB treatment**

- ☐ Incarceration
- ☐ Job commitment
- ☐ No transportation
- ☐ Uncooperative staff at prisons or treatment centres
- ☐ Adverse events, including affecting my daily life activities and HIV treatment
- ☐ Do not need it anymore, feeling better
- ☐ Others, specify……..

## Part 5: Current TB

**[TB1] Date of start of current TB treatment:**

**[TB2] Site of TB disease**

- ☐ Pulmonary
- ☐ Extra-pulmonary, specify……

**[TB3] Current stage of TB treatment**

- ☐ Intensive (usually first two months)
- ☐ Maintenance

**[TB4] Where was your current TB been diagnosed?**

- ☐ Community clinic
- ☐ Jail
- ☐ This prison
- ☐ Other prisons

**[TB5] How do you take your TB medications currently?**

- ☐ By myself at my cell
- ☐ Under direct observation of a healthcare worker

**[TB6] Adverse events developed during the treatment**

- ☐ Yes
- ☐ No [SKIP TO PART 6]

**[TB7] What adverse event developed? (Tick as many as applicable)**

- ☐ Skin allergies
- ☐ Liver damage

- ☐ Gastric upset
- ☐ Numbness on extremities
- ☐ "Burning" of methadone
- ☐ Affect HIV treatment

**Part 6: HIV infection**

**[HIV1] Are you infected with HIV?**

- ☐ Yes
- ☐ No [END OF QUESTIONNAIRE]

**[HIV2] Where did you know about your HIV status?**

- ☐ Community
- ☐ A correctional facility

**[HIV3] Have you ever been prescribed HIV treatment before?**

- ☐ Yes
- ☐ No [END OF QUESTIONNAIRE]

**[HIV4] Have you stopped previous prescription of HIV treatment?**

- ☐ Yes
- ☐ No [SKIP to HIV5]

**[HIV4] Reasons for stopping HIV treatment, if any?**

- ☐ Adverse events, including bad dreams, numbness…
- ☐ Job commitment
- ☐ Poor staff attitude
- ☐ No transportation
- ☐ Incarceration
- ☐ Do not need it anymore, feeling well
- ☐ Too many pills (I have other illnesses)
- ☐ Other,……..(Specify)

**[HIV5] Are you currently prescribed HIV treatment?**

- ☐ Yes
- ☐ No

**[HIV9] Name the HIV clinic you are planning to follow up with after release**

Name……..…….address…….……

**********END OF QUESTIONNAIRE**********

**FORM 5-2 INTERVIEW GUIDE**

***Barriers and enablers to the continuity of tuberculosis treatment in the community among released prisoners in Malaysia: A qualitative study***

A. Introduction:

Hi

I am Dr. Haider Al-Darraji, a researcher who will go through the discussion with you today. This is my research assistant……. who will assist me with the discussion and provide further explanation in Bahasa Malaysia.

You've been invited to participate in the interview because you had been released from a prison before completing your TB treatment and you either were (*one of the following statements):* 1) have continued with that treatment in the community OR 2) have stopped that treatment in the community. We will discuss over the next 45-60 minutes circumstances surrounding your condition to continue/stop treatment. The aim is to learn from you about your experiences to help address the needs of released prisoners with active TB in the future. Our discussion will be audiotaped, but no one else will have access to your data, apart from the research team. Your interview will not include identifying details such as your name or address; instead, you will be allocated an ID number for the study. Please feel free to express yourself, add any comments, or ask questions throughout this session. You will be reimbursed for your time at the end of the session.

B. Background information

C. Experience with TB treatment (prolonged treatment, adverse events..)

D. Housing, employment, and transportation planning

E. Family connection and support

F. Experience with prison health system

G. Experience with community healthcare facilities

H. Drug and alcohol use problems

I. Conclusion:

- Do you have anything else to add?

Thank you for your time and your valuable participation