

# **Socio-Economic Analysis of Tuberculosis in Sikkim**

**A Dissertation Submitted**

**To**

**Sikkim University**



**In Partial Fulfilment of the Requirement for the Degree of  
Master of Philosophy**

**By**

**PREVISHIKA RAI**

**DEPARTMENT OF GEOGRAPHY**

**SCHOOL OF HUMAN SCIENCES**

**SIKKIM UNIVERSITY**

**GANGTOK**

**February, 2020**

Date: 07/02/2020

### **Declaration**

I, **Previshika Rai**, hereby declare that the research work embodied in the dissertation titled "**Socio-Economic Analysis of Tuberculosis in Sikkim**" submitted to Sikkim University for the award the degree of Master of Philosophy, is my original work and it has not been submitted earlier to this or any other University for any degree.

*Previshika Rai*  
07/02/2020

**Previshika Rai**

**18/M. Phil/GOG/02**

**Department of Geography**

**School of Human Sciences**

साम्दुर, तादोंग -737102  
सिक्किम, भारत  
03592-251212, 251415, 251656  
फैक्स -251067  
वेबसाइट - [www.cus.ac.in](http://www.cus.ac.in)



सिक्किम विश्वविद्यालय  
SIKKIM UNIVERSITY

6<sup>th</sup> Mile, Samdur, Tadong -737102  
Gangtok, Sikkim, India  
Ph. 03592-251212, 251415, 251656  
Telefax: 251067  
Website: [www.cus.ac.in](http://www.cus.ac.in)

(भारत के संसद के अधिनियम द्वारा वर्ष 2007 में स्थापित और नैक (एनएएसी) द्वारा वर्ष 2015 में प्रत्यायित केंद्रीय विश्वविद्यालय)  
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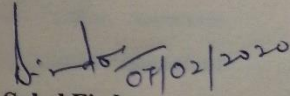
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All the assistance and the help received during the course of investigation have been duly acknowledge by him.

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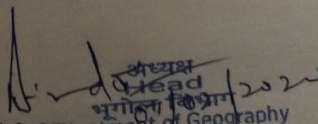
Place: Gangtok

  
Date: 07/02/2020  
Dr. Sohel Firdos

(Supervisor)

Associate Professor

Department of Geography

  
Date: 07/02/2020  
Dr. Sohel Firdos

(Head of the Department)

Department of Geography

School of Human Sciences



सिक्किम विश्वविद्यालय  
सिक्किम, भारत  
फोन - 03592-251212, 251415, 251656  
फैक्स - 251067  
वेबसाइट - [www.cus.ac.in](http://www.cus.ac.in)



6<sup>th</sup> Mile, Samdur, Tadong -737102  
Gangtok, Sikkim, India  
Ph. 03592-251212, 251415, 251656  
Telefax: 251067  
Website: [www.cus.ac.in](http://www.cus.ac.in)

## सिक्किम विश्वविद्यालय SIKKIM UNIVERSITY

(भारत के संसद के अधिनियम द्वारा वर्ष 2007 में स्थापित और नेक (एनएएसी) द्वारा वर्ष 2015 में प्रत्यायित केंद्रीय विश्वविद्यालय)  
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**“Socio-Economic Analysis of Tuberculosis in Sikkim”**

Submitted by **Previshika Rai** under the supervision of (**Dr. Sohel Firdos, Associate Professor, Head of the Department, Gangtok, Department of Geography, School of Human Sciences, Sikkim University**).

*Previshika Rai*

Signature of the Scholar

Previshika Rai

*Sohel Firdos* 07.02.2020

Countersigned by Supervisor

*I. F. Chandel*

Vetted by Librarian

**Dedication**

*To My Beloved Parents...*

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***Previshika Rai***

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## **Abbreviations**

AIDS: Acquired Immunodeficiency Syndrome

ASHA: Accredited Social Health Activists

CBNAAT: Cartridge Based Nucleic Acid Amplification Test

CTD: Central Tuberculosis Division

DOTS: Directly Observed Treatment Short Course

HIV: Human Immunodeficiency Syndrome

IRL: International Reference Laboratory

MDR-TB: Multi Drug Resistance – Tuberculosis

NPY: Nikshay Poshan Yojana

NRHM: National Rural Health Mission

NSP: National Strategic Plan

NSP: New Sputum Positive

PHC: Public Healthcare Centres

PHCP: Public Healthcare Provider

PMDT: Programmatic Management of Drug Resistant Tuberculosis

RNTCP: Revised NATIONAL Tuberculosis Control Programme

RR: Ramification Resistance

SEA: South East Asia

SGD: Sustainable Development Goals

TB: Tuberculosis

UN: United Nations

XDR: Extensively Drug Resistance

# Chapter I

## Introduction

### 1.1 Introduction

The fundamental inter-connection has always been seen between geography and health. One's health experiences are directly influenced by where one is born, lives, studies and works and even the air we inhale, the food that is available to consume, the viruses that one is exposed to and the health services that are accessible (Dummer, 2008, p.1177).

The social settings, natural environments and spatial location have their own important role to play in shaping the health and wellbeing of an individual and society. Geography of health is a sub-discipline of social geography and sees health and its related issues from a holistic perspective encircling space and society, with the conceptual understanding of the role and significance of place, its settings, location and geography in health, wellbeing and disease. It pursues to explore health from different contexts such as social, political, and cultural within a spatial organization framework (Dummer, 2008).

Health is always considered as wealth. It is one of the important pillars for anyone to have a quality life. It is one of the fundamental values, which determine the quality of human life, wellbeing of an individual or society as a whole. According to the Oxford dictionary, the meaning of health is "*the state of being free from illness or injury*" (Brüssow, 2013). But various studies in the field of health have been broadening the definition of health. Some scholars have also requested that the World Health Organization should think again about the Health definition (Saracci, 1997). The social science researchers have been discussing that the conceptual understanding of health is beyond the presence or absence of illness and have broadened the area by incorporating the notion of wellbeing including "*social, economic and psychological wellbeing*" (Harris, 2010).



Definition of health as given by World Health Organization also suggests that *“the healthy state of any human is only when they are in the state of complete physical, mental and social wellbeing of an individual or society and not merely the absence of disease or illness”* (WHO,1948). According to Anthamattena and Hazen (2011), the dissimilarity between the sickness and health is however subjective as medical science has identified an infectious agent that causes disease which encourages the change from normal to sick one and many other definitions of the health includes the idea of that a person should not only be physically well but also mentally and socially well.

Good health increases one's efficiency to contribute to their own development (individual), development of a family, society or a nation as whole generating productivity and economic prosperity of a country. Health is a significant factor in the development of the nation, as maximum levels of population health is inter-related with national income. Health is very much interconnected with the progress of socio-economic and health has been acknowledged as one of the welfare mechanisms (Satpathy and Bansal, 1982). Even for centuries, health and environment have also been linked subjectively with environmental risk factors. Space and society have an overwhelming relation while talking about health conditions and the spread of diseases.

In any society being ill or being affected by any disease seems difficult and affects the daily flow of life and the questioning where? Could determine its causes and impact. As medical science describes, the disease as to any condition which interferes with the normal functioning of the body and harms the health. The disease has been impacting the human society since ancient period. The morbidity and mortality rate have been increased by numerous infectious diseases due to the lack of knowledge about the disease and infrastructures. Even in the period of modern medicine, society still suffers from infectious diseases and has been a great threat to human life.

Advancement in the science and technology and modern medicine has brought a drastic change in the improvement in the life expectancy and the treatment of the disease but despite the advancement, such diseases are still a threat to the humankind. Therefore, the social approaches and healthcare came with a critical understanding of failing to incorporate other important influences on health such as the structure of the society and the influence of the culture and different perspectives of how one perceives and treat diseases and those who are sick.

There are numbers of incidence of diseases worldwide which is increasing in an unexpected manner. Diseases such as HIV/ AIDS, tuberculosis or TB etc. are considered to be distressing public health problems. Tuberculosis is one such disease which causes an enormous burden to morbidity and mortality around the world. In 1990s, the World Health Organization (WHO) has published a report on the “*Global burden of disease*”, which has hierarchized tuberculosis to be a seventh most illness triggering disease in the world (WHO, 1996).

Tuberculosis is a transmittable disease, transmitted either by person to person via infected sputum Mycobacterium tuberculosis or through human consumption of animal products infected with the disease named Mycobacterium Bovis through pasteurization of milk, financial concessions to farmers. Tuberculosis mostly affects the lungs and also affects many other organs of the body.

According to Sethi in a book called “*Eradicating TB in India; challenges, perspectives and solution*” (2015), only after decades of epidemiological research, it is realized that communicable diseases like TB, which is as much social as personal, requires more than drugs. Prior to the easy availability of vaccines and antibiotics, TB treatment involved shifting the patient to a more salubrious climate, rest in a sanatorium (spatial

aspects) and a healthy diet. The persistence of the disease could possibly contribute by all critical social goods such as the requirement for better diet (nutrition) with no pollution hygienic environment and clean water which can be contradictory to the better accessibility of medical facilities.

Spatially, tuberculosis has been related to the factors such as micro-environment, crowded living conditions, urbanization and migration which are often intensified by social, cultural, economic and political factors as socioeconomic status, housing, indoor air pollution, tobacco smoke, malnutrition, excessive alcohol use, social stigma, social exclusion or marginalization, family relationship, tradition and cultural practices, patient/ health care relationships, access to health care facilities etc. (Schmidt, 2008).

To mostly talk about the Tuberculosis (TB), it is a communicable disease caused by the bacillus *Mycobacterium tuberculosis* and spread through the air by a person suffering from TB (Tiwari et al. 2006). Such a phenomenon brought the interest of the geographer worldwide to study the geography of Tuberculosis, which basically study mortality and morbidity of tuberculosis with a geographic dimension.

There are a number of incidences of TB in the world which attracted the researcher to study causes, impacts, preventions of TB through the different dimension of the study. Among that, TB has been studied by the geographers through its own way of understanding in global, national and regional scales. India has been present at the forefront of tuberculosis control and research since the start of the 20<sup>th</sup> century (WHO, 2010). As stated by Tiwari et al. (2006), around one-fifth of the tuberculosis patients worldwide are in India and for developing countries like India it is a difficult task to eradicate Tuberculosis. In the article named "*Tuberculosis Current Situation, Challenges and Overview of its Control Programs in India*" Gursimrat K Sandhu

(2011), has stated that tuberculosis can be termed as one of the oldest diseases where he even ranked tuberculosis as in the second position after HIV/AIDS among the 10 killer diseases.

Sikkim has not also been left out when it comes to incidences of Tuberculosis as it comes among those regions which have been facing frequent incidents of diseases like tuberculosis. Najar et. al., (2013) through their study, they found out that in Sikkim a variety of risk factors are contributing to different infectious and non-infectious diseases and noted that TB, cholera, conjunctivitis, gastroenteritis as a most prevalent infectious disease in the health profile of Sikkim.

According to Dolma et. al., (2013), there is a total number of 6827 TB cases recorded for pulmonary tuberculosis and observed 27.1% of the total retreatment rate in the state as they found a survey conducted in all the four districts of Sikkim from 2002 to 2010. As Tobgay et al. (2011) have discussed in his article 'Predictors of treatment delay for TB in Sikkim' the factors related with delays between commencements of symptoms, patients delay to medical facilities and delay in diagnosis of tuberculosis are connected with self-medication.

Agarwal (2015) examined over 1000 new tuberculosis incidents being registered in the state health profile despite the various activities by RNTCP (Revised National Tuberculosis Control Programme) to control the risk and its decline in casualty. He also discussed the failure of the state in achieving the targeted cure rate of 85% with only 72% of success rate in the year 2014.

In the developing nation like India and particularly Sikkim, such spatial and social factors may have overwhelming causes and impacts on tuberculosis. Sikkim has been facing the increasing morbidity and mortality rate despite the fact that the Revised

national tuberculosis control programme (RNTCP) has been initiated since 2002 and each district in Sikkim has TB centres (District TB centre or DTC) for diagnosis and treatment of tuberculosis and state has state TB cell in Gangtok under the Department of Health care, Human service and Family Welfare, Government of Sikkim. According to State TB cell report (2012), Tuberculosis cases are seen to be more than 1800 which occurs every year in Sikkim. According to the Tb India Report, 2018 (Ministry of Health and Family Welfare – Central TB Division), in 2017 the total TB patients notified were 1,827,959 in national level and 1271 in Sikkim among which 90 per cent of the patient is registered as new TB patients.

## **1.2 Review of Literature**

### **1.2.1 Conceptual Understanding**

Geography as a subject has its vast area of relation with other disciplines as it can connect with all phenomenon on the earth surface. Since the beginning of the discipline, with the paradigm shifts, geographical knowledge has also bordered its concept till now. However, the entire geographical ideas surround around one of the predominant concepts of geography i.e. geographical idea basically study that earth is a home for a living organism and to learn all those fundamentals which have supported them.

Geography has always been seen from distinct perspectives, as even in physical and human geography and human geography more overlook into the interconnection between the environment and the humans, the spatial distribution of human phenomenon and how they come about, the social and economic differences between various areas of the world. Health geography has basically been categorized in the arena of human geography, to be more specific in Social geography and it has always been concerned with the role of geography in health.

According to the Anthamatten and Hazen (2011), a geographic approach to the study of health offers a critical perspective to the issues concerning how changing relationship between people and their environment influence human health, wherein Ellen C. Semple's definition "Human geography is the study of the changing relationship between the un-resting man and the unstable earth" fit perfectly, which moreover explains that humans are always coming up with new discoveries or inventions which directly or indirectly has been affecting environment or vice versa. Such a relationship with environment and human is very important even in the incidence of diseases. Not just environmental impacts but also the human phenomenon and their social and economic distinction across the world which knowingly or unknowingly affects human health.

Anthamatten and Hazen (2011) further stated that health issues such as the emergence of infectious disease, the potential influence of global warming on human health, and the escalating strain of increasing long life and chronic situations on health care systems are of rising significance in an increasingly populated and interrelated biosphere. However, considering health through a geographic lens has been neglected in the discourse of geography.

According to Luginah et al. (2015), the study of geography of health offers an exceptional lens to the study of health as it just not spotlight on the distributive features of disease and disease services, but also expanding the discussion to more multifaceted idea of place; with this, health-related occurrence is understood through a give-and-take relationship between people and their settings and thus a scrutiny of health must put together both contextual and compositional factors. To put in further, he discusses that health geography can present a spatial perceptive of a health of an individual, the distributional pattern of disease in an area, and the effect of an environment on health



as well as disease, while also contributing an understanding and insight into the influence of culture, inequality and representation on place and health.

The conceptual understanding of the geography of health has further discussed by Pearce, Andrews and Crook (2018), as they stated geographers have an extensive presence of enriching our understanding of many of the most pressing and complex issues of the day. In the health arena, geographers are not only providing insight to some of the key global public- health challenges such as tobacco use, overweightness, and the transmission of infectious diseases, but also identifying the implications for health and wellbeing of a much wider set of social, political and environmental concerns, including transnational migration, globalization, the financial crises and climate change.

Majority of the existing research on health through geographical perspective have contributed or contributing much in the understanding of the health and its relationship with geography. Geographers have worked on infectious diseases such as cholera, malaria, influenza, measles and hepatitis for a long time. Geographers have now been gathering their attention towards other burdening diseases like HIV/ AIDS, Tuberculosis etc.

### **1.2.2 Dichotomy: Medical Geography or Geography of Health**

When it comes to the uses of terminology; Medical geography or Geography of health, it has always been confusing for those who think it can be used interchangeably. However, it's has become important to understand medical geography and geography of health separately. As in many other disciplines, even in geography fashion and emphasis changes (Kearns and Moon, 2002) and such changes have long been

recognized as an important element for the development of knowledge and scientific thoughts (Kuhn, 1962; Lakatos and Musgrave, 1970).

To start with, the term medical geography was first used by a physician named Leonhard Ludwig Finke in the late 18<sup>th</sup> century (Askari et al., 2016) he was attempting to relate human diseases, cultural and lived environments (Barrett, 1980). However, the beginning of the idea can be marked out from the time of Hippocrates. Since then the environmental factors are seen as a cause of different disease and started to include in the studies of prevention and cure of disease.

According to Johnston et al. (1994), medical geography has a simple definition as given in the dictionary of human geography: *“the application of geographical perspectives and methods to the study of health, disease and health care”*. As Askari et al. (2016) conceptualize the idea of medical geography in their article *“Conceptualizing Medical Geography”* it is clear that Medical geography is a sub-discipline of geography which studies the relationship between environment and health, lifestyle and health, inequalities in the distribution of health infrastructures.

According to De Vise (1973), medical geographers seek the answers of the questions like who gets what, where and why with the respect of illness and appropriate care. Likewise, Mc Glashan (1972) stated that *“A medical geography is a tool and but rarely an end itself. It is the application of geographical methods and skills to medical problems. One may consider geographical evidence of a medical hypothesis”*. Much later in 1991, Gesler highlighted that in medical geography, *“where a hospital lies within a spatial distribution is given more importance than what goes on within that particular hospital”*.

Meade et al. (1988) explain medical geography to be as a matter of spatial and ecological perspectives on disease and health care services. Medical geography concentrates on the tension between the natural and social sciences in that it copes with both the physical and human aspect which can have an effect on the physical and mental health of the human population (Eyles, 1993). To complement that Mayer and Meade (1994) addresses that the conventional focus of the medical geography is the connection between biomedical phenomenon and the role of the environment. Sui (2007) explains that medical geography is a big-tent concept which incorporates all the geographic aspects of health and disease that have been studied by medical geographers, epidemiologist and public health researchers.

Geography of health and medical geography are sometimes used interchangeably rather being the fact that they are not similar. According to Dorn et.al (2010), dualism is somehow doubted between the core of health and medical geography. Medical geography is moreover scientific and traditional which has little fewer introductions to the “*cultural*” and “*social*” aspects of the human geography and those gaps are in the process of fulfilling by the new sub-discipline health geography recently.

In 2010 in the book called “*A companion to health and medical geography*” Kearns and Collins have discussed about the particular theme i.e. Health Geography advocated that those researchers who identify themselves as health geographers note the shift since the late 1980s from fundamental concerns with the medical world towards an increased interest in wellbeing and broader social models of health and health care. Robin Kearns, a health geographer in New Zealand, opened a discussion in the early 1990s, disagreeing that “*geography of health*” should be recognized together with medical geography to reflect new “*post- medical*” concerns and the significance of engaging with social theory and cultural geography. Kearns's conceptual model is strongly based

on health rather than medicine (Kearns, 1993). This “*post-medical*” challenge wanted to shift the sub-discipline from a concern with disease and diseases services towards a focus on health and wellness (Kearns and Moon, 2002).

According to Moon (2009), the traditional view of the subject matter of health and medical geography led great emphasis on the biomedical model of health which is deeply rooted in the scientific discipline of medical and some could deny the monotonous idea and brought critics to it on both social and scientific perspectives.

Kearns and Collins (2010) argue that “*geography of health is a broad field with the geographers' evolving methods, empirical foci and philosophical takes on health and medicine*”. As they further discuss, the geography of health basically has connections with the medical geography as it is where it emerged and have the interest in pathological concerns (mortality and morbidity) and sites and systems of care i.e. hospitals and other health care services.

There is a long-recorded history of interest when it comes to place and health in the geography of health (Dunn and Cummins, 2007). Kearns in 1993 came up with the article entitled “*Place and health: towards a reformed medical geography*” which became an opening of the debate. In this article, Kearns has deliberated that the new dimension of “*medical geography*” will study the influence of disease and health-related provisions for both individual wellbeing and cooperative involvement of place by communities. Curtis (2004) thinks that the geography of health is focused on the ways that the health of populations is differentiated between places and the range of factors that explains these differences.

Kearns and Moon (2002) make out three different themes that have become known within this new geography of health: the emergence of ‘*place*’ as a framework for

understanding health or social construction of place, the adoption of self-consciously socio-cultural theoretical positions, and the evolution of critical geographers of health. The concept of the “*therapeutic landscape*” has been incorporated by health geographers and formed into an important, and cumulative, body of recent research (Smyth, 2005).

Dyck and Dossa (2007) aim to contribute to the literature in health geography that is framed by recent work that seeks to investigate the role of everyday activity in producing meaning and experiences of space as “*healthy*” or its opposite. With the idea of “*Sense of the place*”, the geographer has made an effort to approach the intricate linkages between well-being of people and residential location (McCreanor et al., 2006). The place is not only physical but has a deep connection with self (Wiersma, 2008).

William (1999) explains that health and medical geographers are not simply presentation place as a physical landscape, but the meaning is all the time more being observing as the key to the importance of places as “*it is the subjective experiences that people have within a place that gives them significance*”.

One of the strengths of considering health as a place-based phenomenon is to move beyond a biomedical interpretation of disease as the simple interaction between a causative agent and a patient to think about the broader context in which the condition has arisen. In this framework, one can think of fundamental questions like why some landscapes encourage healing, how certain places become symbolic of disease, or how mental health can be influenced by attachment to place. This shifting emphasis of the geography of health from a focus on disease towards an emphasis on a broader definition of health is now well recognized among health geographers. The term

*“Medical geography”*, which used to name the sub-discipline, has been contested in response to what some see as an overemphasis on disease and biomedical approaches to health at the cost of considering influences such as social context and individual’s distinct experience (Anthamatten and Hazen 2011).

However, as numerous scholars have noted, accepting the value of a new post-medical geography of health should not undermine the value of the more traditional approaches of medical geography. For many, the term *“Health Geography”* has become a broad title that refers to both the traditional theme of study associated with medical geography and the expansion of the sub-discipline along new *“post-medical”* way (ibid.). It is hereby become important to build the understanding of the subject from its root i.e. its evolution.

### **1.2.3 Historical Background medical/ health geography**

The primitive human conceived diseases and suffering of entire human being and other catastrophes as the *“wrath of God”* due to their limited knowledge. The concept of disease on which the ancient people's trust was dependent is known as the *“supernatural theory of disease”* (Nepal 2009).

With the development of the knowledge, Greek Philosophers were among the initial to recommend that the world could be explained using empirical observation. Some scholars began to argue that geographical differences were responsible for a pattern in disease and that people's relationships with their environment could be manipulated to influence health (Anthamatten and Hazen 2011). Since Hippocrates (circa 460-360 BCE) the link between human's health and the environment has been determined in medical science, although health geography is a relatively recent field of research (Perez et al 2016).



The primary source of such new idea in medical science was a body of work known as Hippocratic Corpus which discuss medical ethics, holistic medicine, and environmental influences on health and section are titled “*On Air, water, and Places*” (Anthamatten and Hazen 2011).

The relationship between health and geography was further discussed by McLeod (2000), as the Cholera Outbreak incident of London in 1854. In medical geography, Snow’s case of the “*Broad Street cholera outbreak*” is a known example of the discipline in accomplishment. Such studies provide the idea that health conditions, body types and personalities are directly attributed to environmental factors, especially climate. Hippocrates is often described as an early supporter of environmental determinism (Anthamatten and Hazen 2011).

August Hirsch's contribution enriched the medical geography as he published two volumes in German language relating to medical geography between 1860 and 1964. Then, he again published the second edition and it was in an English version which was in III volumes entitled “*Handbook of Geographical and Historical Pathology*” in between the year of 1883 and 1886, where he highlighted that the distribution of each of the disease was related to the local environment of the place where they occurred (Khan 1971). This idea was prominently dominated with the discovery that microbes enter human bodies and can cause alteration that outcomes in disease (sometimes called germ theory).

Pavlovsky wrote of a “*Landscape Epidemiology*” where the author has enclosed “*the attentions of infectious, zoonotic diseases by examining the connotations of plants, animal and insect, soil and precipitation regime and other elements of the natural landscape*” (Meade et al. 1977).

May (1958), discussed that the outcome of patients in Asia often contrasted from the prescribed outcome in the European textbooks feeding his interest in understanding the influence of the environment on human health.

All the studies on health and geography were focusing on disease and biomedical approaches to health at the expense of considering influence such as social context and individual experiences. Robin Kearns, a health geographer in New Zealand, opened this debate in the early 1990s, arguing that “*geography of health*” should be recognized alongside medical geography which reflects a new approach of “post-medical” and its implication with the engages of social theory and cultural geography (Kearns 1993).

The post medical approach to health and health care reject the positivist view that health and disease can be explained simply by the presence or absence of a pathogen, and instead considered the role of a person’s broader social and psychological life (Anthamatten and Hazen 2011).

Geographers then emphasize to include a place in health geography. Place here refers both to a unique locale and to the senses of place associated with it, referring to its social significance and values imbued by individual and communities (Curtis 2004). Definition of place during the Hippocratic tradition was simply a container for attributes such as particular climate and vegetation (environment). The quantitative revolution of the 1960s led to an emphasis on abstract space as new approaches to health geography have emphasized the spatial construction of society and social processes (Kearns 1993).

#### **1.2.4 Theoretical Understanding to Health Geography**

- **Positivist Approach**

The positivist approach in health study relies on accurate measurement and recording and searches for statistical regularities and associations. The concern in positivist approaches to the geography of health is usually to detect areal patterns or to model the

way in which health outcomes or disease incidence varies spatially: people only appear as a number that composes spatially varying rates (Gatrell and Elliott 2015).

Gould and Wallace (1994) have researched the spread of the Human Immunodeficiency Virus (HIV) through mapping the cumulative incidents of AIDS cause across the United States and also analysing the number of cases reported in the New York region shows the positivist knowledge in doing research.

Cliff, Haggett and Ord (1986), goes beyond statistical description to build mathematical models of diffusion processes, with the longer-term view of forecasting the future spread of diseases such as measles and influenza. Positivist idea on the geography of health has an overemphasis on objectivity. It basically looks at the matter with the lens of biomedical or disease approach.

- **Socialist Approach**

Geographers have sometimes referred to this socialist (subjective) perspective as humanistic since they implicitly address human beliefs, value, meaning and intentions. In socialist account, the emphasis is on the meaning of the illness or disease to the individual (Gatrell and Elliott 2015).

Socialist approach to health considers the ways in which human health and wellbeing are influenced by social rather than biological factors. *“Space and place are considered not only as physical entities, such as parks or neighbourhoods but also as social space, allowing for the investigation of factors such as social exclusion and individuals' positions within social hierarchies”* (Anthamatten and Hazen 2011).

While studying the social aspects of health in geography we come across different social factors which directly or indirectly have its influence on health aspects. One of the important social aspects of health could be the socio-economic environment. Wealth affects health both directly, through enabling access to resources such as high-quality

healthcare and nutritious foods, and indirectly, through the influence of aspects of the built and social landscape on health behaviours. Increasingly, health researchers have begun to appreciate the often-subtle ways in which social factors mediate and complicate the relationship between health and wealth.

With increasing economic disparities social disparities in health within and among countries is widening up. Global socioeconomic inequalities are boosting global health inequalities. Poorer segment of the population within a country may struggle to meet basic needs, which results in health problems such as malnutrition and infectious disease (Braveman and Tarimo, 2009).

Similarly, culture and identity also have its reason to be included in the social approaches to health. The term 'culture' refers to the belief and practice acquired from a society which is lived by a particular group of people. The individual perceives their understanding and learns to operate within them (Helman, 2007). Health Geographers focuses on both how culture influences health and how health influences culture (Gesler and Kearns, 2002).

Culture can also affect health explicitly through driving beliefs about which behaviours are "*healthy*" or "*unhealthy*". To provide an example pregnant women and new mothers are often expected to follow pregnancy-related eating practices. In one study Chinese immigrants in Sydney, Australia, over 90% of interviewer had followed some sort of cultural practice related to food in the first six weeks after the delivery of their baby (Matthey et al., 2002).

According to Anthamatten and Hazen (2011), the biomedical approaches are based on concepts such as germ theory, anatomical understanding of the functioning of the human body, and particularly the positivist idea that knowledge is derived from the

objective measurement. The positivist idea of health has forgotten the other aspects like social and culture. Culture not only influences health by encouraging or discouraging particular practices. Rather a postmodern perspective suggests that the very concept of health is constructed.

Every individual has a personality and set of experiences from which a unique identity is constructed. Significant aspects of identity include gender, class, race, ethnicity, and sexuality and have great influences on health.

One of the most important social aspects, which significantly influence the health of any area, would be the power and politics of health. A major focus of social approaches to health in consideration of health inequalities, many of which arise through power differentials (Anthamatten and Hazen 2011). Geographers have made an explicit connection between power and space through analysis of issues such as territoriality, control of resources, and surveillance, all of which can be considered in terms of their impacts on health (Curtis, 2004).

- **Structuralism Approach**

Structuralism approach derives much of their impetus from Marxist theories of oppression, domain, and class conflict, where inequalities are embedded in society. Some authors offer an explicitly Marxist interpretation of health and health care especially in the context of the late nineteenth and early twentieth-century colonialism (Ferguson 1979).

There are, however, other deep structures embedded in society that are based on conflict and power relations, of which the most obvious is the role played by male power (patriarchy) in structuring Women's health. Geography of health went through several paradigm shifts in its theoretical understanding and research methods, as purely being

scientific in the positivist tradition, and to incorporate humanistic approach after the quantitative revolution.

- **Post-structuralism Approach**

According to Gatrell and Elliott (2015), some geographers with other social scientist including health researchers have begun to engage with the theoretical development such as post structuralism since last few decades. As they said this perspective is concerned with how knowledge and experience are constructed in the context of power relation. Such perspective has illuminated work on health “risk”, on representation of the body and social groups, and on what it means to be a healthy citizen.

### **1.2.5 Geographies of Tuberculosis**

Initially, there was a number of researches works which contributed to the understanding of tuberculosis as merely an infectious disease. However, lately, the researcher has been adding different dimensions to the study of Tuberculosis. Apart from a biomedical perspective, sociologist, economist, ecologist etc. put forward their idea of tuberculosis in their own perspective on it. Geography of tuberculosis hereby analysis the different dimension of tuberculosis through placing health geography as its main focus.

Ever since the geographers started gathering their attention towards the relationship between geography and health/disease various research were added to literature in this field. In terms of medical geography, there appear to be a number of studies outlining the spatial distinctions of infections (Kearns, 1996; Meade and Earickson, 2000). Similarly, in 1950, Jacques May also attempted to explain infectious disease by delineating the differing ecologies that contributed towards its incidence.

Further, researchers also attempted to model the spatial diffusion of diseases such as measles in Cornwall (Haggett, 1976) and Iceland (Cliff et al., 1981). Yet these models



were not satisfying, given that they assumed that individuals had the same likelihood of developing disease thus ignoring social, economic, psychological and environmental conditions (Jones and Moon, 1987).

Although tuberculosis has been well documented within wider works of the biomedical literature, there are only a few medical and health geographers who have done particular research on the disease.

Among those geographic researches on tuberculosis, the dominant emphasis is the discipline of the spatial distribution of the disease, often aided by Geographic Information System (GIS) (Alak, 2009). In a similar way, Moonan et al. (2006) use GIS assist with screening endeavours designed to identify those at high risk of developing TB.

Further, the social dimension of the geography of Tuberculosis are relatively few in number, it has been used as a case study within two leading textbooks. Curtis (2004) uses the concept of "*landscape*" to structure her discussion on the variety of dimension that forms geography of tuberculosis including epidemiological, socio-economic inequality, healthcare use, power and therapeutic landscape. Another textbook was published by Jones and Moon (1987) where they have considered the social causes of TB, seeking to counter biomedical notions that understanding the biology of the disease will result in control of the illness. The authors contend that a social explanation of TB, such as one including rapid social change, economic inequality and low income explains why TB is endemic in many developing nations and not in more developed countries.

In Britain, Elender (1998), examined the association of TB with the ethnicity, poverty and AIDS and found a strong positive association of TB mortality and overcrowding at the household level rather than at district level. A number of geographers have studied

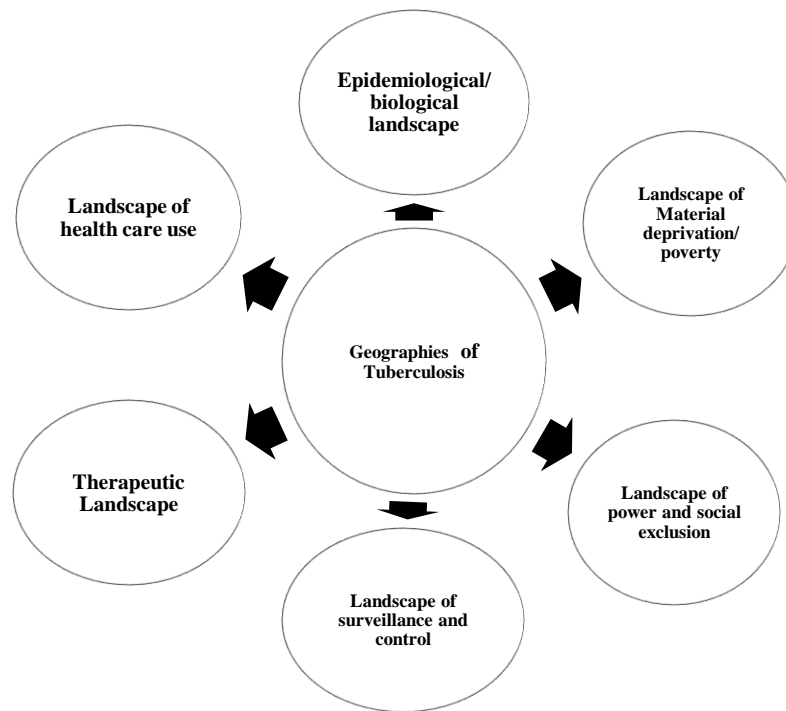
the historical dimension of TB particularly during times when rates were very high. Grineski et al., (2006) has researched on TB which seeks to understand the social dimension of the disease, especially the way in which class and race shaped historical TB experiences in Phoenix, Arizona.

The social determinants of tuberculosis have become an important phenomenon in the world today. *Mycobacterium tuberculosis* can infect anyone but predominantly affect the poor (Story, et al, 2006). Globally, 98% of the deaths from tuberculosis are in poorest countries (WHO, 2000). Marmet (2005) discuss that if the main determining factor of disease are social, so must be the cure and remedies as well. Furthermore, in order to control the epidemics of tuberculosis effectively it is important to tackle the disease among the socially excluded groups (Story, 2006).

Department of gender and women health WHO (2003) on "*Gender and Tuberculosis*" highlights the idea of gender dimensions of tuberculosis and suggest it to be significant for overcoming hindrance for effective coverage, prevention and treatment of the disease. It argues that the socioeconomic consequences of the disease differ by gender difference in role and responsibilities and division of labour.

As much of the literature on the resurgence of TB and Multidrug-Resistant TB (MDR TB) focuses on behavioural and biological aspect neglecting social and cultural content. Gandy and Zumla argue that 'the principal motor behind the resurgence of tuberculosis has been the sharp rise in global poverty which has understanding many of the public health advances of the twentieth century' (Gandy and Zumla, 2002).

**Figure 1.1. Geographies of Tuberculosis**



Source: Curtis S. (2004), Health and Inequality; Geographical Perspectives

### **1.3 Statement of the problem**

Health geography is an emerging area of research and there are numerous researches works to make us understand what health geography is and even various case studies are carried out to understand the geographical factor to any particular health problem. The highlighting research problem here could be the confusions in understanding the role of medical geography and the geography of health as such. Throughout the understanding by reviewing the literature, it has been clear that medical geography as such is a sub-discipline of social geography which studied the spatial pattern of the disease and health care services.

As discussed by Kearns (1993), Medical geographers took space as merely a container where the pattern of the disease can be mapped out. However, as he further argues that place can be taken as lived experiences of an individual or community which has a

meaning to it. Such postmodern approaches to the geography of health have led some scholars to question that idea of health as a wholly biological phenomenon, encouraging to consider instead how health and disease can be socially constructed, with a different cultural understanding of health and disease leading to a very different idea about health (Anthamatten and Hazen, 2011).

Rather being the fact that tuberculosis is a biologically explained communicable disease it is also not ignorable that the major determinants could be social as well. There are many biological and social explanations for the understanding of tuberculosis being a global burden even being the fact that it is curable and preventive. According to the World Health Organization report by the director-general (2000), globally 98% of deaths recorded due to tuberculosis are in the poorest countries and in the rich countries, tuberculosis mainly occurs among the people born abroad and are socially excluded (Story, 2006). So, the general perspective of tuberculosis as given by the social science researchers is that the socially excluded or marginalized people are most vulnerable to tuberculosis as they termed tuberculosis as a "*poor man disease*".

Sikkim as a place has its own meaning and understanding when comes to the incidences and prevalence of tuberculosis. Sikkim has been recognizing as one the prominent region to occur tuberculosis and most of the cases are that the people are directly diagnosing with MDR TB, and to some extent, the state has even seen the cases of XDR TB and the factors contributing to such cases and its impacts are still unspecified. Tuberculosis being one the communicable disease has a deep relationship with its surrounding society which may determine the social and economic life of an individual and the community. Such meaning of tuberculosis in social life in a place like Sikkim has become an important aspect. Incidents in Sikkim could be caused by both environmental as well as social factors however the spatial understanding of the pattern

or spread is hereby important as well. Therefore, the socio-economic analysis is important in the study of incidences and prevalence of tuberculosis in Sikkim.

#### **1.4 The Rationale of the Study**

Particularly, most of the studies of tuberculosis in Sikkim have been focused on medical approaches and have been neglected the other approaches such as social, cultural and geographic factors. Tuberculosis is a distressing public health concern across the world despite being the fact that it is preventive and curable. The reports such as Revised National Tuberculosis Control Programme (2018) shows the morbidity and mortality of tuberculosis are increasing with increasing global burden, however, the qualitative impacts or causes are mostly unseen in the study. Tuberculosis caused an estimated 1.3 million deaths among HIV negative people and further 374,000 deaths among the persons infected with HIV in 2016 (Global Tuberculosis Report, 2017).

To become sick with tuberculosis can have high socio-economic stress on individual and society as such. A person with tuberculosis could be socially stigmatized, socially excluded or marginalized. To bio-medical approach, tuberculosis might only refer to a mere disease however it can have a different meaning while looking through the lens of social approach. Social, cultural, economic dimensions of tuberculosis will further be analysed in spatial organization. Tuberculosis could be both factor and causes of social exclusion and marginalization of people in the society and mostly in Sikkim, it has become important to understand whether the general definition of tuberculosis as poor man disease is prevalent? Or it has impacted all the social groups?

The geographical analysis of the social aspect of the tuberculosis is important for explaining the socio-spatial relation of disease. Geographically, Sikkim is a small state with the area having 7096 sq. km and a total population around 6 lakhs. However,

India's map of tuberculosis shows an alarming position of Sikkim with increasing cases of pulmonary tuberculosis as well as a rapid increase in multi-drug resistant tuberculosis (MDR).

Therefore, this study seeks to understand the social and spatial factors of tuberculosis. It will look for the understanding of the spatial variation of tuberculosis and further the socio-economic conditions of the patients and society which may be responsible for the spread of the disease. This study is significant for geographical analysis of the incidence of tuberculosis incorporating social factors and impacts.

### **1.5 Objectives**

The board objectives of the study are as follows:

1. To examine the spatial variations in the incidence of tuberculosis.
2. To study the socio-economic factors that are responsible for the cause and spread of tuberculosis.
3. To review the health policies and health care services of tuberculosis.

### **1.6 Research Questions**

1. Are there any spatial variations in the incidence of tuberculosis?
2. What are the socio-economic factors that can be responsible for the cause and spread of tuberculosis? Is there any role of other factors such as consumption pattern, micro-environment, overcrowding, occupation, etc. in the incidence of tuberculosis in Sikkim?
3. What are the socio-economic profiles of tuberculosis patients in Sikkim? Is the general definition of tuberculosis as 'poor man disease' applicable in Sikkim?
4. How is the health care policies and services in Sikkim and does it have any influence in the Tuberculosis in Sikkim?

### **1.7 Ethical concerns and consideration**

For the purpose of this study, data were collected from both secondary sources as well as primary sources. All the referred secondary sources are cited properly. All the participants involved in this study were introduced clearly with the aims and objectives of the study. While interviewing, all the respondents were well informed about the study and permission were asked to them. They were interviewed in the language they were comfortable with. The recordings of interviewed (audio-writhing) were done with their consent. The comfortability of the respondent was maintained with confidentiality. The real names of the respondent are not reviled in the study for confidentiality purpose. The researchers ensured that the data collected would be solely used for academic purpose.

### **1.8 Methods**

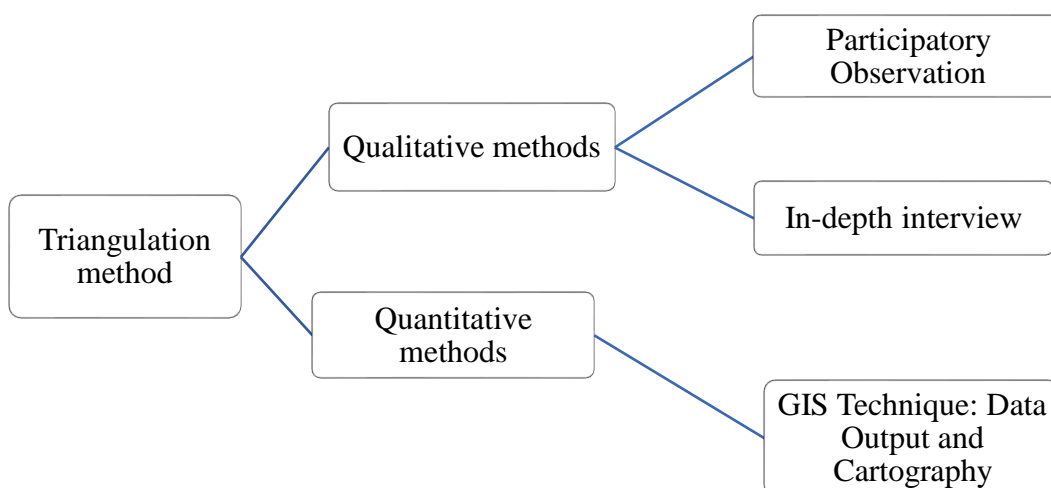
The study has tried to analyse the incidence, causes and impact of tuberculosis in Sikkim through geographical perspective. For this purpose, the adoption of the triangulation method found more appropriate for the study and development of the conclusion. Within the triangulation methodological framework, the study has basically focused on concurrent triangulation design of method, where both qualitative and quantitative research has taken place at the same time supplementing each other. Qualitative research has been adopted done for exploring things, whereas quantitative research for validating and testing things. The sources of data are primary as well as secondary.

The methods adopted for qualitative study are Participatory Observation and in-depth interview. Participatory observation helped to look into the scenario or lived experience of the infected patients, their family members, neighbours of and infected patients and

public health care provider such as doctors and workers at TB centre through their lens and an in-depth interview helped in understanding their perspectives on tuberculosis.

The quantitative data are presented in the study in the forms of tables, figures and maps the method used is GIS techniques. GIS techniques are used in mapping the location area (East and North Districts of Sikkim), locating District TB centres and State TB cell. The Microsoft Excel is used to calculate the basic features of the data along with suitable graphics analysis.

**Figure 1.2. Methods**



**1.9 Sources of Data:**

**Table 1.1. Sources of Data**

Secondary data sources:
<ul style="list-style-type: none"> <li>● Revised National Tuberculosis Control Program (RNTCP)</li> <li>● Census of India (2011)</li> <li>● India, National Family and Health Survey report</li> </ul>



<ul style="list-style-type: none"> <li>● Ministry of Health and Family Welfare, Government of India</li> <li>● Sikkim, National Family and Health Survey report</li> <li>● Global Tuberculosis Report, World Health Organization</li> <li>● Department of Health care, Human Service and family welfare, Government of Sikkim.</li> <li>● Hospital Records; STNM Multispecialty Hospital, Central Referral Hospital, DOT Centres.</li> </ul>
Primary data sources:
<ul style="list-style-type: none"> <li>● In-depth Interview</li> <li>● Participatory Observation</li> </ul>

### **1.10 Study Area and Sampling Design:**

Among the four districts of the Sikkim, only two districts have been considered for the study i.e. East Sikkim and North Sikkim. The rationale behind the selection of the area is basically in the understanding infrastructural development (health care services and other infrastructures), urbanization, and density of the population etc. East district is well developed and connected, rapid urbanization as compared to other districts and the capital of the state is also located in this district i.e. Gangtok, well-established hospitals such as STNM multispecialty Hospital and Central Referral Hospital along with Singtam Hospital and G.P Pant Hospital, Sazong are located in the east district.

Whereas north district of Sikkim has a different scenario north Sikkim is least densely populated district among all the districts, urbanization is slow as compared to the east district, the infrastructural development is very low and there is only one hospital i.e.

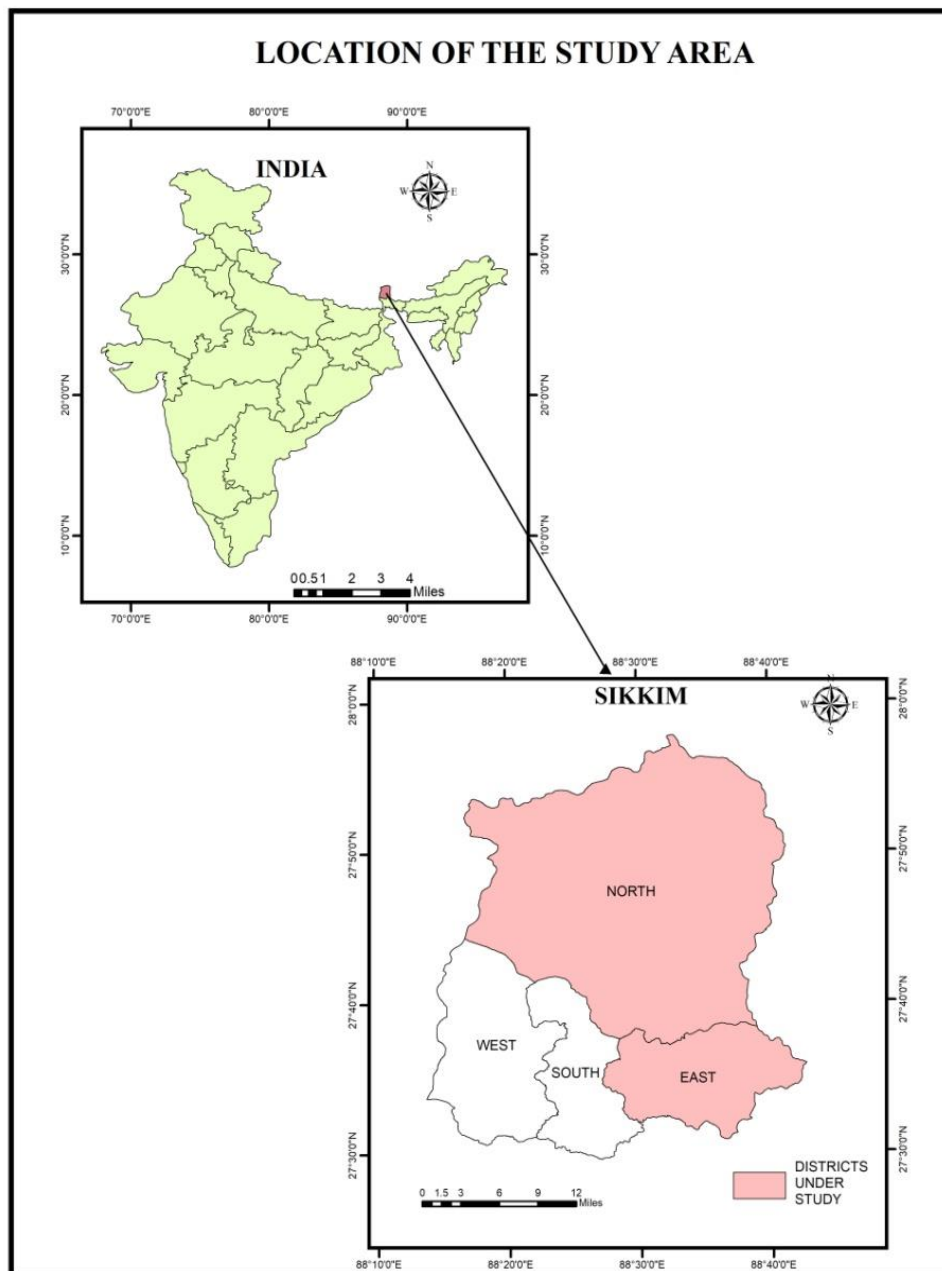
Mangan Hospital. While talking about the PHCs East district has 8 PHCs and north district has only 3. These two districts may have different socio-economic conditions as they have different access to infrastructural development as most of the administrative offices, renowned educational institutions and well-connected transport and communication facilities.

The purposive sampling design is applied for the study. The sample size for an in-depth interview is considered 20. 10 respondents will be from the east district and 10 respondents will be from the north district and the target group has be medical public healthcare provider (doctors and workers in TB cell), infected patients, a family member of the infected patients and local people or neighbouring people.

**Table 1.2. Study Area and Sampling Design**

Sikkim			
East District		North District	
Sample Size	Target Group	Sample Size	Target Group
2	Public healthcare provider (Doctors and workers in TB cell)	2	Public healthcare provider (Doctors and workers in TB cell)
3	Local people or Neighboring people	3	Local people or Neighboring people
5	Infected Patients	5	Infected Patients

## Map 1. Location of the Study Area



### 1. 11 Organization of chapters

The study will be divided into five chapters and the organization of the chapters is done in the following sequence:

1. Chapter one contains the introductory part of the study, starting with the introduction followed by reviews of literature(s) based on the various themes and aspects such as conceptual understanding, medical geography, geography of health, tuberculosis etc. and the statement of the problem as well as rationale of the study is also drawn. The chapter also contains the objective of the study and methods used to obtain the said objectives, sources of data with field area and sample design.
2. Chapter two presented the study on spatial variation in the incidence of tuberculosis in global, national and regional level with special reference to Sikkim, a factor associated with it and the impacts.
3. Chapter three presented the study of socio-economic factors which may be responsible for the causes and spread of tuberculosis and its impact in Sikkim.
4. Chapter four highlighted the health care policies, services and facilities in the state and the country. It has also tried to incorporate the role of stakeholder and community towards eradicating tuberculosis in Sikkim.
5. Chapter five has conclude the study with a summary of the findings and also looked into the development of possible and positive arguments and recommendations for understanding and control of tuberculosis in the state (Sikkim).

## Chapter: II

### **Incidence and Prevalence of Tuberculosis: A Spatial Perspective**

#### **2.1: Introduction**

The term geography has been principally related to the study of three characteristic features, the study of a man-environment relationship, the characteristic of the place, and the spatial relationship analysis. The connection between man and environment has been key approaches to all kinds and even to the biomedical one that studies disease and health. The relationship between health and geographies are closely linked. The pattern of any disease varies from country to country or from one region to another. The quality of air, water, land, etc. is not distributed in a uniform manner over the space, which is the reason why even the spatial pattern of disease is not uniform. (Choudhary, 2006)

As per the Curtis (2004), on her book namely “Health and inequality: A geographical perspective” has highlighted the five theoretical dimensions of the geography of health i.e. therapeutic landscape (healing places, wellness, and complementary therapies), landscape of power (surveillance, exclusion, and social control), landscape of poverty and wealth, landscape of consumption (care and commodification) and ecological landscape (population, air, water, and ground). The processes that contribute to tuberculosis infection can we interpret from these five theoretical dimensions.

The transmission of tuberculosis often occurs within a home or communities which eventually leads to diverse spatial patterns. The ongoing tuberculosis transmission or the setting of risk factors of TB could be reciprocated by spatial clustering of TB and

results do varies substantially according to the availability of data, the analysis methods applied and the changing aspects of the population. (Shaweno et. al. 2018)

The spatial pattern of the spread of tuberculosis varies around the world. As mentioned earlier, TB often occurs within households or communities, because the prolonged time of the contact with the infected patient is typically required for infection to happen, producing the potential for localized clusters to progress. However, a geospatial cluster of TB is not always because of the ongoing individual contact with shared risk factors but may also be the resulted from the reaction of latent infection in a group of people with shared risk factors. (Verma et. al. 2007 and Haase et. al. 2007).

Spatial analysis with the identification of areas with high TB rates (clusters), followed by characterization of the drivers of the changing aspects in these clusters, have been encouraged for targeted TB control and increased use of existing TB control tools (Theron et. al. (2015), Yates et. al. (2016)). TB can be differentiating from other infectious diseases in numerous ways that are likely to influence apparent spatial clustering (Shaweno et. al. 2018). Thus, TB infection acquired in a given location may progress to TB disease in an entirely different region, such that clustering of cases may not necessarily indicate intense transmission but could rather reflect the aggregation of population groups at higher risk of disease, such as migrants (McBryde, et. al. 2012). Similarly, TB infection acquired from workplaces and other congregate settings can be wrongly attributed to residential exposure, as only an individual's residence information is typically recorded on TB surveillance documents in many settings (Middlekoop et. al. (2009 &2014). Identification of different spatial distribution of TB cases and depicting its causes can help to inform the targeted group, make it an attractive approach (Keshavjee et. al. 2012).

In this chapter, the geographical dimension of tuberculosis all over the world with special reference to Sikkim is considered. It has mainly explored the discussion related to the relevance of landscape for the understanding of tuberculosis and its impact on humans. The spatial variation shows the patterns, be it density, distribution, in the incidence of tuberculosis for a better understanding of the trend of infectious tuberculosis.

## **2.2 Tuberculosis and its History**

During the 1800s, the advice given to patients infected with tuberculosis was; “just sleep and eat nutritious food”, or formerly known as consumption (Keshavjee et. al., 2012). Tuberculosis (TB) is caused by bacteria (*Mycobacterium tuberculosis*) that most often affect lungs leading to severe cough; fever, night sweats, or weight loss (WHO. Int.). Although, since 150 million years, *Mycobacteria* were supposed to exist (Haymann, 1984), *Mycobacterium tuberculosis* is younger species, aged about more than 70000 years predating human emergence from Africa (Comos, et. al., 2013) and disease itself is supposed to be known for centuries (Dainel et. al., 1999). However, the term “tuberculosis” was coined by Johann Schonlein only in 1834 (Centres for disease control and prevention, 2019).

Tuberculosis is the oldest recognized infectious disease known to mankind since the ancient period. The existence of *Mycobacterium Tuberculosis* has been found in relics from ancient Egypt, Indian and China. Spinal tuberculosis was found among the Egyptian mummies known as Pott’s disease which dates back to 2400-3400 B.C as per the pieces of evidence from the archaeological survey. Before it being termed as tuberculosis this disease was recognized with various names such as Phthisis, the white plague, consumption, etc.

Various written documents connected to tuberculosis are related to Hebraism, as the ancient Hebrew word schachepheth is used in the biblical books of Deuteronomy and Leviticus in order to describe tuberculosis (Daniel et. al., 1999). During ancient Greece, tuberculosis was well known and called Phthisis, and Hippocrates described it as a fatal disease especially for young adults. Discoveries of early scholars who studied tuberculosis during this era are considered as excellent. In Greece, Isocrates was the first author supporting that TB was an infectious disease, while Aristotle suggested the contagious nature of “*king’s evil*” in pigs and oxen. In Roman times, TB is known as Celso, Aretaeus of Cappadocia and Caelius Aurelianus, but it was known that it shares the same aetiology of extrapulmonary manifestations such as scrofula, Pott’s disease and TB lupus (Adams, 1849).

During middle ages, evidence of TB of the cervical lymph nodes or lymph nodes of the neck was as termed scrofula and believed that kings of England or France could cure scrofula simply by their royal touch. In the 18<sup>th</sup> century, tuberculosis infection became very rampant over western Europe, with a prevalence as high as 900 deaths per 100,000 the risk factors led to the rise in the infection were believed to be poorly ventilated and overcrowded housing, primitive sanitation, malnutrition. Those who assumed this disease to be a contagious made guidelines to prevent its spread. For example, in Italy and Spain, the people infected with the disease were isolated and after their deaths, their beds and rooms were burned and re-plastered (Dowling 1977).

For the first time in 1720, the infectious origin of TB was estimated by an English Physician Benjamin Marten, in his publication “*A new theory of Consumption*” (Daniel, 1997 and Barberis, et al., 2017). Frith in 2014 and Barberis et al., in 2017 have highlighted the important debate which was concerning to different theories of the etiopathological origin of phthisis, at the beginning of the 19<sup>th</sup> century. The argument



was about whether to consider an infectious disease as generally considered in southern Europe, a hereditary one or as stated in Northern Europe or a form of cancer. On the other side, the discussion was about scrofula, tubercles, and phthisis as a separate disease or a manifestation of the same disease.

Similarly, a number of researchers such as Matthew Baille, Sir Percivall Pott, Philipp Friedrich Hermann Klencke, Jean-Antoine Villemin, etc. have discussed the idea of Tuberculosis. Only on 24 March 1882, the famous scientist Robert Koch presented his discovery of mycobacterium tuberculosis to the Society of Physiology in Berlin. The Piquet, and Mantoux tuberculin skin tests, Albert Calmette and Camille Guerin (BGC) vaccine, Selman Waksman streptomycin, and other anti-tuberculous drugs were also developed later the discovery. Koch has contributed to the analysis of the aetiology of tuberculosis and he was awarded the Noble Prize in Medicine in 1905 for his scientific research. (Daniel, 2000 and Gradmann, 2001)

Tuberculosis has its long lining history throughout much of known human history. When Koch discovered the tubercle bacillus to be the aetiology agent, Clemens Von Pirquet the test called tuberculin skin test was established in 1907 and also the sanatoria were developed the patient suffering from tuberculosis during late 19<sup>th</sup> century and of early 20<sup>th</sup> century. Public health measures were then started to regulate the spread of tuberculosis infection as followed by the discovery of bacterial cause. Similarly, in 1944 and 1952 the streptomycin and isoniazid were discovered and with such discovery, the contemporary time's treatment of tuberculosis got foreshowed. (Daniel, 2006)

There are comparatively lots of improvements in the course of tuberculosis treatment and control with numerous discoveries and development about tuberculosis over the

world. However, tuberculosis remains a worrisome disease and a major threat to the world.

### **2.3 Global Epidemiology of Tuberculosis**

Public health plays a significant role in shaping the socio-economic profile of any society. Tuberculosis is a communicable disease has become a major cause of ill health and a huge public health problem around the globe with grave socio-economic consequences. It remains a central issue of the globe, despite being a curable disease with all information available about the causes of infection, drugs, and treatment.

Tuberculosis is considered as one of the top ten causes of death worldwide and the foremost cause of mortality from a single infectious agent (ranking above HIV/AIDS). About a quarter of the total world's population is infected with "*Mycobacterium tuberculosis*" and thus there is a high risk of developing tuberculosis disease (Global tuberculosis report, 2015). In the year 1993, the World Health Organisation (WHO) declared TB as an emerging global problem because of the rapid increase of the disease worldwide. DOTS (Directly Observed Treatment) strategy was introduced as a cost-effective way to achieve a global target of 70% case detection and 85% cure rate by the year 2005 and improve and maintain this performance from 2006 (WHO Report, 2012).

It has become the main concern all around the world that tuberculosis kills more people than any other infectious disease like malaria etc. (WHO Report, 2012). In 2005, there were 8.8 million new cases of tuberculosis and by 2008 there were 9.0 million cases. As per the World Health Organisation (WHO), "*one-third of the world's population is infected with tuberculosis and 8.4 million cases of Tuberculosis occur globally with approximately 2 million deaths every year*" (Kim et. al. 2020). Worldwide, around 10 million people fall ill with tuberculosis each year. According to the recent World Health

Organisation (WHO) Global TB report (2019), an estimated 10.0 million people (range, 9.0- 11.1 million) fell ill with tuberculosis in 2018, a number that has been relatively stable in recent years. It is also considered to be one of the top causes of mortality among persons living with human immunodeficiency virus (HIV) infection, accounting for approximately 40% of deaths in this population (Gupta et. al., 2002.).

In 2017, an estimated 10 million incident cases of TB and 1.57 million TB deaths occurred, representing 1.8% and 3.9% declines, respectively, from 2016, numbers of TB cases and disease incidence were highest in the WHO South-East Asia and Africa regions, and 9% of cases occurred among persons with HIV infection (WHO, Global TB Report, 2018). Rifampicin-resistant (RR) or multidrug-resistant (MDR) (resistance to at least both isoniazid and rifampicin) TB occurred among 3.6% and 18% of new and previously treated TB cases, respectively (5.6% among all cases). Overall progress in global TB elimination was modest in 2017, consistent with that in recent years; intensified efforts to improve TB diagnosis, treatment, and prevention are required to meet global targets for 2020–2035 (Global TB Report, 2019).

Since 2007, TB has been the leading cause of death from a single infectious agent, ranking above HIV/ AIDS. Globally, there were 1.2 million (range, 1.1–1.3 million) TB deaths among HIV-negative people in 2018 (a 27% reduction from 1.7 million in 2000) and an additional 251 000 deaths (range, 223 000–281 000) among HIV-positive people (a 60% reduction from 620 000 in 2000).

For many decades the intensity, incidences, and prevalence of tuberculosis has followed the same spatial pattern. According to Dye and Borgdorff (2008), Global Epidemiology and Control of Tuberculosis has the highest rate of fatality is in Africa, but the highest rate of incidence is in countries with a growing population such as India, China,

Indonesia, and Pakistan. Incidence is increasing in sub-Saharan Africa and parts of Eastern Europe, predominantly countries of the ex-Soviet Union, and is declining in the west and central Europe, North America, Latin America, the Middle East, and Southeast Asia.

Even the recent report shows that geographically, most TB cases in 2018 were in the World Health Organization (WHO) regions of South-East Asia (44%), Africa (24%) and the Western Pacific (18%), with smaller shares in the Eastern Mediterranean (8%), the Americas (3%) and Europe (3%). Eight countries accounted for two-thirds of the global total: India (27%), China (9%), Indonesia (8%), the Philippines (6%), Pakistan (6%), Nigeria (4%), Bangladesh (4%) and South Africa (3%) (Global TB report, 2019).

It has been shown in the series of World Health Organisation's Global TB Report that there is connection between the spatial pattern of tuberculosis and the socio-economic factors as most of the incidents and the prevalence of the tuberculosis are concentrated around some portion of the world and that is what shows the increasing morbidity and mortality rate of the disease in the global scenario. It has been clearly written on the global TB report of 2019, that regions like Europe have the low rate of TB mortality, but the regions of developing or underdeveloped countries have the highest rate of TB mortality as well as TB morbidity (Global TB report, 2017, 18, 19).

Accordingly, Global TB Report (2019) has estimated the 30 high tuberculosis burden countries (Table 2.1) and are accounted for 87% of all estimated incident cases worldwide, and eight of these countries accounted for two-thirds of the global total: India (27%), China (9%), Indonesia (8%), the Philippines (6%), Pakistan (6%), Nigeria (4%), Bangladesh (4%) and South Africa (3%).

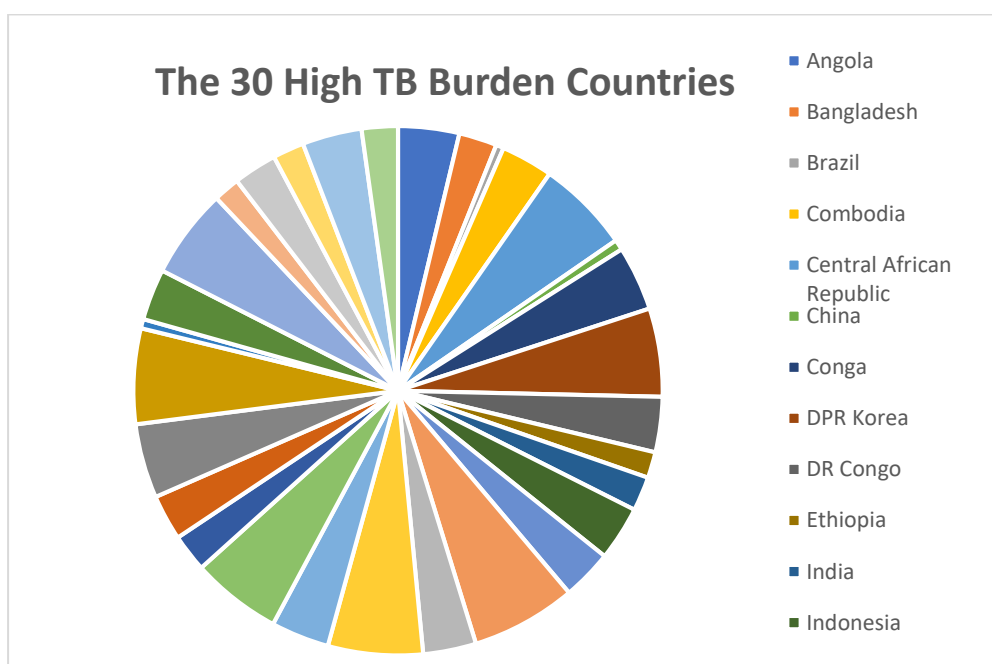
**Table 2.1: The 30 High TB Burden Countries** (*Green coloured are the countries from the WHO SEA Region*)

Countries	Total TB Incidence		
	Best Estimate (in thousand)	Uncertainty Interval (in thousand)	Percentage (%)
Angola	355	230-507	3.73
Bangladesh	221	161-291	2.32
Brazil	45	39-52	0.47
Cambodia	302	169-473	3.18
Central African Republic	540	349-771	5.68
China	61	52-70	0.64
Conga	375	238-543	3.94
DPR Korea	513	446-548	5.39
DR Congo	321	208-458	3.38
Ethiopia	151	107-204	1.59
India	199	136-273	2.09
Indonesia	316	288-345	3.32
Kenya	292	179-432	3.07
Lesotho	611	395-872	6.43
Liberia	308	199-440	3.24
Mozambique	551	356-787	5.79
Myanmar	338	222-477	3.55

Namibia	524	375-697	5.51
Nigeria	219	143-311	2.30
Pakistan	265	188-355	2.79
Papua New Guinea	432	352-521	4.54
Philippines	554	311-866	5.83
Russian Federation	54	35-77	0.57
Sierra Leone	298	191-427	3.13
South Africa	520	373-691	5.47
Thailand	153	116-195	1.61
UR Tanzania	253	119-435	2.66
Viet Nam	182	116-263	1.91
Zambia	346	225-493	3.64
Zimbabwe	210	155-272	2.21

Source: WHO, Global TB Report, 2019

**Fig 2.1: The 30 High TB Burden Countries**



Among the six regions of World Health Organisation, as mentioned above South-east Asia region accounts for the highest cases of tuberculosis and this region has eleven member countries and they are Bangladesh, Bhutan, Democratic People’s Republic of Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor-Leste. The World Health Organisation’s South-East Asia (SEA) Region accounts for 26% of the world’s population. The scenario of this region in terms of tuberculosis is alarming as in 2017, an estimated 4.4 million people were detected with Tuberculosis and the cases of death due to TB as projected was 638 000 and this alone is more than half of global TB mortality.

The case gets worse with the fact that estimated number of 192 000 Rifampicin-resistant (RR) and multi-drug-resistant TB (MDR-TB) cases accounting for more than 34% of global burden occurred in the Region in 2017, of which less than 52 000 were notified in the same year. Along with that treatment success for new and relapse, TB cases was 75% (for those initiated on treatment in 2016), amongst the lowest in the Regions of the world (World Health Organisation Global TB Report, 2018). Among the 30 high TB (and MDR-TB) burden countries Six countries are located in the South-East Asia (SEA) Region: India, Democratic People’s Republic of Korea, Bangladesh, Indonesia, Myanmar and Thailand.

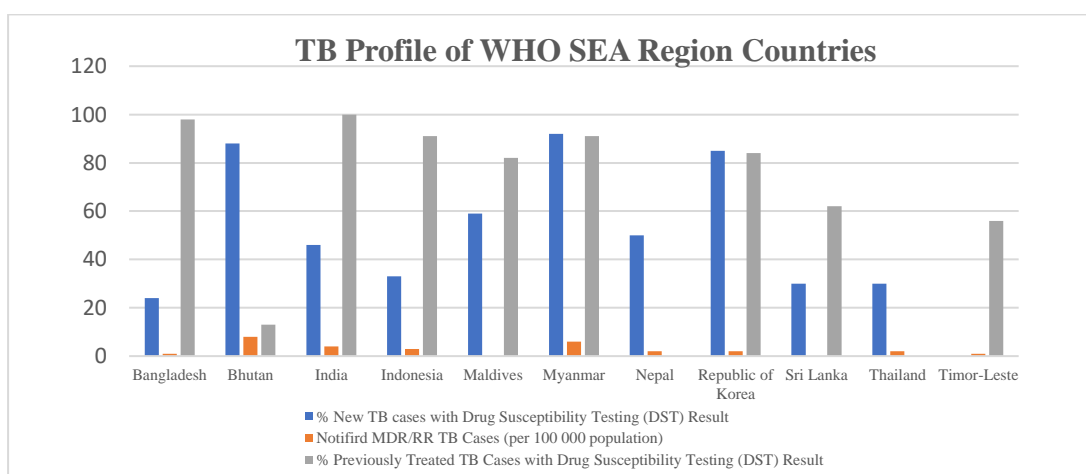
**Table 2.2: TB Profile of WHO SEA Region Countries, 2018**

<b>Country</b>	<b>Notified MDR/RR TB Cases (per 100 000 population)</b>	<b>% New TB cases with Drug Susceptibility</b>	<b>% Previously Treated TB Cases with Drug Susceptibility</b>
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		Testing (DST) Result	Testing (DST) Result
Bangladesh	1	24	98
Bhutan	8	88	13
India	4	46	100
Indonesia	3	33	91
Maldives	0	59	82
Myanmar	6	92	91
Nepal	2	50	
Republic of Korea	2	85	84
Sri Lanka	0	30	62
Thailand	2	30	
Timor-Leste	1	0	56

Source: World Health Organisation, TB Data, 2018

**Fig 2.2: TB Profile of WHO SEA Region Countries, 2018**



Source: World Health Organisation, TB Data, 2018



However, there was considerable variation among countries, ranging from less than one TB death per 100,000 population in many high-income countries to 40 or more deaths per 100,000 population in much of the WHO African Region and in two high TB burden countries in Asia (the Democratic People's Republic of Korea and Papua New Guinea) (Global TB Report 2019).

The increase in TB morbidity and mortality rate is impulse by an increase in the number of HIV positive people and zoonotic tuberculosis. In 2018, the global Case Fatality Ratio (calculated as the combined number of TB deaths in HIV-negative people and HIV-positive people, divided by the total number of incident cases in both HIV-negative and HIV-positive people) was 15%, down from 22% in 2000 and 16% in 2015. It varied widely among countries, from under 5% in a few countries to more than 20% in most countries in the WHO African Region. The United Nations' (UN) Sustainable Development Goals and the World Health Organization's (WHO's) End TB Strategy have defined ambitious targets for 2020–2035, including a 35% reduction in the absolute number of TB deaths and a 20% reduction in TB incidence by 2020, compared with 2015. Since 2000, the World Health Organisation has produced annual TB estimates for all countries. Global and regional disease estimates were evaluated for 2017 to determine progress toward meeting targets.

Global targets and milestones for reductions in the burden of TB disease have been set as part of the Sustainable Development Goals (SDGs) and WHO's End TB Strategy. SDG 3 includes a target to end the global TB epidemic by 2030. The End TB Strategy includes targets of a 90% reduction in TB deaths and an 80% reduction in the TB incidence rate (new and relapse cases per 100 000 population per year) between 2015 and 2030, with 2020 milestones of a 35% reduction in TB deaths and a 20% reduction in TB incidence rates.

Currently, the world as a whole, most WHO regions and many high TB burden countries are not on track to reach the 2020 milestones of the End TB Strategy. Globally, the average rate of decline in the TB incidence rate was 1.6% per year in the period 2000–2018, and 2.0% between 2017 and 2018. The cumulative reduction between 2015 and 2018 was only 6.3%. The global reduction in the number of TB deaths between 2015 and 2018 was 11%.

The WHO European Region is on track to achieve the 2020 milestones; between 2015 and 2018 the cumulative reduction in the incidence rate was 15% and the number of TB deaths fell by 24%. Incidence and deaths are also falling relatively fast in the WHO African Region (4.1% and 5.6%, respectively, per year), with cumulative reductions of 12% for incidence and 16% for deaths between 2015 and 2018. Seven high TB burden countries are on track to achieve the 2020 milestones for both incidence and deaths: Kenya, Lesotho, Myanmar, the Russian Federation, South Africa, the United Republic of Tanzania and Zimbabwe.

Faster reductions in TB incidence and deaths require improvements in access to diagnosis and care within the context of progress towards universal health coverage, action on broader determinants of TB incidence (e.g. levels of undernutrition, poverty, smoking, and diabetes) and a new treatment or vaccine to substantially lower the risk of developing TB in people who have a latent TB infection.

The burden of drug-resistant TB is of major interest and concern at global, regional and country levels. In 2018, there were approximately half a million (range, 417 000–556 000) new cases of rifampicin-resistant TB (of which 78% had multidrug-resistant TB). The three countries with the largest share of the global burden were India (27%), China (14%) and the Russian Federation (9%). Globally, 3.4% of new TB cases and 18% of

previously treated cases had MDR/RRTB, with the highest proportions (>50% in previously treated cases) in countries of the former Soviet Union.

Sources of data to inform estimates of TB disease burden have improved considerably in recent years. Two recent examples are repeat national TB prevalence surveys in Myanmar and Viet Nam, which showed impressive reductions over a 10-year period. Nonetheless, improvements are still needed, especially in the availability of data to reliably track TB mortality in the WHO African Region.

*When an HIV-positive person dies from TB disease, the underlying cause is classified as HIV in the international classification of diseases system.*

### **2.3.1 Drug-resistant Tuberculosis**

Resistance to tuberculosis (TB) drugs is a formidable obstacle to effective tuberculosis care and prevention. It also threatens the progress made in tuberculosis care and control worldwide. When tuberculosis bacteria start resisting anti-tuberculosis drugs then it is called Drug-resistant tuberculosis. Drug-resistance occurs due to the improper use of antibiotics in the chemotherapy of drug-susceptible TB patients.

There are three major categories used for global surveillance and treatment. Multi-drug resistant TB (MDR-TB) is TB that is resistant to both important anti-tuberculosis drugs namely Rifampicin and Isoniazid and requires treatment with a second-line regimen. Rifampicin-resistant TB (RR-TB) also requires treatment with second-line drugs. Extensively drug-resistance TB (XDR-TB) is a form of TB which is resistant to at least four of the core anti-TB drugs. It involves resistance to the two most powerful anti-tuberculosis drugs, isoniazid, and rifampicin, also known as multidrug-resistance (MDR-TB), in addition to resistance to any of the fluoroquinolones (such as ofloxacin

or moxifloxacin) and to at least one of three injectable second-line drugs (amikacin, capreomycin or kanamycin).

Globally in 2018, an estimated 3.4 % of new cases and 18% of previously treated cases had MDR/RR-TB. The highest proportion of new and previously treated TB is in several countries of the former Soviet Union (above 25% new cases and above 50% in previously treated cases).

Overall, there were an estimated 484, 000 (range, 417,000- 556, 000) incident cases of MDR/RR-TB in 2018. In 2018, there were about 214,000 deaths from MDR/RR-TB. By the end of 2018, at least one case of XDR-TB had been reported by 131 WHO member states. Over the past 15 years, 128 countries (including 117 member states) and five territories have reported representative data from continuous surveillance or surveys regarding the proportion of MDR-TB cases that had XDR-TB.

Drug-resistance TB has increased the risk to the health of the public, threatening TB care and control worldwide. The inappropriate routine of anti-biotics and carelessness of the patients is a result of a number of actions including, administration of improper treatment regimens and failure to ensure that patients complete the whole course of treatment.

Essentially, drug-resistance TB arises in areas with weak TB control Programmes. The worst part of drug-resistance is a patient who develops active disease with a drug-resistance TB strain can transmit this form of TB to another individual.

#### **2.4 Tuberculosis Scenario in India**

Spatial variation and pattern of tuberculosis vary around the world and even within the countries and a region. India, the world's second-most populous country, accounts for a quarter of the world's annual incidence of TB (Standards for TB Care in India, 2014,

WHO). India is ranked as the highest-burden country accounting for one-fifth of the global incidence and two-third of the total cases in South East Asian countries. In terms of TB incidence rates, India ranks 17th among the high burden countries and is considered to be one of the leading causes of death among the population in India ([www.who.int](http://www.who.int) 2019).

As per the TBC (Tuberculosis Control) India reports, it has been estimated that tuberculosis is one of the communicable diseases which has the highest rate of mortality (Ministry of Health and Family Welfare, 2015). This report highlights that nearly 2 persons on an average of three minutes out of 1000 individuals die every day. This report has been further substantiated by the Global Tuberculosis Report, WHO, which shows that approximately 38% of Indians die annually due to this infectious pathogen [38,000 individuals out of a population of 1,00,000 individuals] (Global Tuberculosis Report, WHO, 2014).

India continued to remain at the top of the list of patients with tuberculosis, according to a report by the World Health Organisation on October 17, 2019 and has the most number of drug-resistant TB cases. Estimated people of 10 million had TB in 2018 and was alone 27% of the world total. (Down to earth, 18, Oct 2019)

According to WHO 2019 Global TB Report, the situation has come to be even more threatening as the more cases of drug-resistant tuberculosis are increasing and the data says that total TB incidence in 2018 is estimated to be 2690 (range 1840-3700) thousand and estimated proportion of TB cases with MDR/RR-TB of new cases is 2.8% (range 2.3-3-5) and previously treated cases is 14% (range 14-14).

Total 2,155, 894 TB cases were notified in 2018 (both new and relapse). India accounts for 27% of the total 130,000 drug-resistant TB cases while China had 14 % and the Russian federation had 9 %.

**Table 2.3: Estimated TB Burden 2018**

Estimated TB Burden (2018)	Number	Rate per 100,000 population
Incidence of Tb cases (includes HIV + TB)	2.690 million	199
Incidence (HIV + TB only)	92,000	6.6
Incidence (MDR/RR-TB)	130, 000	9.6
Mortality (excludes HIV+TB)	440,000	32
Mortality (HIV+TB only)	9,700	0.72

Source: WHO, 2019, Global TB Report

Spatially the incidence and prevalence of tuberculosis in India vary from state to state as per the size of the area and its population.

**Table 2.4: State wise TB cases from both Private and Public Sector (2017 and 2018) with notified Pediatric cases (2018).**

States	Population	TB patients notified public	TB patients notified public	TB patients notified private	TB patients notified private	Pediatric Patients notified (2018)

		sector (2018)	sector (2017)	sector (2018)	sector (2017)	
Andaman and Nicobar Islands	387466	539	270	19	22	37
Andhra Pradesh	51834544	65192	67074	25932	16044	3,641
Arunachal Pradesh	1581877	3417	3139	2	15	462
Assam	34183941	37936	36720	4960	3454	1664
Bihar	120092000	63642	54995	41288	41494	10, 691
Chandigarh	1146798	5361	5664	335	266	368
Chhattisgarh	29033682	30119	30593	12912	10679	2396
Dadra and Nagar Haveli	442143	794	893	5	70	40
Daman and Diu	313258	460	381	37	76	17
Delhi	18534932	77,175	60772	16405	5121	9729
Goa	1522877	1944	1563	548	372	91
Gujarat	67673985	106451	109422	48100	39639	8962
Haryana	28602354	50311	34104	15437	6647	3414
Himachal Pradesh	7355160	15129	15715	1356	736	671

Jammu and Kashmir	14335893	11708	9420	1187	1056	906
Jharkhand	38031010	37764	36861	10724	7267	2750
Karnataka	66868115	68657	69199	14437	11988	4532
Kerala	34208129	20990	14522	3567	8232	1530
Lakshadweep	65864	19	46	0	0	2
Madhya Pradesh	81741779	120771	117583	39373	16750	14007
Maharashtra	122765975	140068	124900	69574	67558	13699
Manipur	30,34,285	2151	1691	776	1114	156
Meghalaya	3505055	4382	3353	485	608	417
Mizoram	1223413	2513	2201	57	44	219
Nagaland	2050220	3542	2284	727	729	344
Odisha	45349185	46629	67162	3674	3969	2351
Puducherry	1440247	3466	1601	23	3	117
Punjab	30006214	43975	38977	10426	6336	3069
Rajasthan	77400659	113972	84774	46196	21179	9767
Sikkim	649841	1418	1232	20	39	85
Tamil Nadu	79338612	75415	74256	29502	19071	5086
Telangana	37061723	42084	31828	10246	7395	1805
Tripura	3893295	2575	1685	4	8	54
Uttar Pradesh	225116729	305626	244074	114808	666967	25359
Uttarakhand	11294981	17806	13012	4556	3748	1224
West Bengal	98055985	89503	82209	14642	3748	1224



India Total	1340092226	1613504	1444175	542390	383784	133059
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Source: TB statistics India

In 2018, India was able to achieve a Total Notification of 21.5 Lakh TB cases of which 25 % was from the private sector. The majority of the TB burden is among the working-age group. 89% of TB cases come from the age group of 15-69 years. About 2/3 of the TB cases are Males.

Uttar Pradesh, with 17% of the population of the country, is the largest contributor to the TB cases in with 20% of the total notifications, accounting to about 4.2 Lakh cases (187 cases/ lakh population). Two states Delhi and Chandigarh stand apart from all other states & UTs with regard to the Notification rate relative to their resident population. Their annual notification is 504 cases/lakh population and 496 cases/lakh population. This is because patients residing in many other parts of the countries are diagnosed/ notified are from these two UTs.

The tuberculosis scenario in India is not as it is expected as the notifications of new cases rose from 1.2 million to 2.0 million between 2013 and 2018 (+60%). The TB mortality rate was 449, 000 in 2018, according to the global TB report (2019) which aims to reduce it to 3 lakhs by 2022. The top factor responsible for TB as blamed by the report is alcoholism followed by smoking, undernourishment, diabetes, and HIV. (Down to earth, 2019)

## **2.5 Tuberculosis Scenario in Sikkim**

In Sikkim, disease-related with inadequate sanitation, tuberculosis, alcoholism conditions, goitre, etc. has been seen often in the state health profile (Lama, 2001). Substantial humidity and frequent rainfall create favourable environment optimal

growth conditions for infectious pathogens like *Mycobacterium tuberculosis*, *Salmonella*, *Shigella*, etc. (Mirski, et. al., 2012).

Sikkim experiences varied weather conditions ranging from Tundra to Temperate type of climate. The climate plays a very crucial role which has a direct impact on human health as it influences the incidence of infection and their proliferation among the patients (Mirski et. al., 2012; Epstein, 2001). These types of climatic conditions are very conducive for the Tuberculosis pathogen to propagate and proliferate. Tuberculosis is a major health concern of the state.

Tuberculosis is a major health concern of the state. According to Sikkim Human Development Report 2001 death of patients from Tuberculosis were recorded higher than the other diseases or illness that were prevalent at that time in the state referral hospital i.e., Sir Thutob Namgyal Memorial (STNM) hospital (Sikkim Human Development Report, 2001). Despite the inception of modern treatment and public health intervention tuberculosis still remains or is the significant public health threat in the Sikkim state as over 1000 new case of TB incidences is being reported every year (Agarwal, 2015).

As stated by scholars like Epstein (2001) and Mirski, et. al., (2012) that the type of climatic condition unfolding to a certain geographical location plays a vital role in having an impact on human health. Sikkim experiences various weather conditions and frequent rainfall and these types of climate encourage the tuberculosis pathogens to proliferate and disseminate. Investigation reports on the Sikkim Tuberculosis health database relate that during the study from 2002 to 2010 in all the four districts of Sikkim; a total of 6827 cases were registered for pulmonary tuberculosis. Out of these cases, 6051 (88.6 %) were cured; 205 (3%) had died; 399 (5.8%) had failed; 124 (1.8%)

had defaulted and 48(0.7%) were lost to follow up. The total retreatment rate of Sikkim is 1855 (27.1%) (Dolma, et. al., 2013).

The delay in seeking health care and the case of those patients who were lost to follow up leads to the higher transmission and spread of the disease thus resulting in the increase in a number of cases of tuberculosis incidence (Rai, et al., 2014).

According to the article published in “the Hindu”, Sikkim has inched closer to Mumbai in multi-drug resistant TB cases which shows a more alarming scenario of increasing TB cases with MDR-TB (Srivastava, 2016).

**Table 2.5: Case Notification Drug-sensitive (DS) TB and Drug-resistant (DR) TB verified data from all five District Tuberculosis Centers (DTCs), 2018**

<b>DTC</b>	<b>Population (in Lakhs)</b>	<b>DSTB</b>	<b>DR TB</b>	<b>2018</b>
<b>Gangtok</b>	2.01	404	132(7)	536(36%)
<b>Singtam</b>	1.01	253	42	295(20%)
<b>South</b>	1.56	272	29	301(20%)
<b>West</b>	1.45	209	25(1)	234(16%)
<b>North</b>	0.46	95	15	110(7%)
<b>State</b>	6.49	1233	243	1476(24)

Source: Central TB Division

(Data slightly varies with India TB report, 2019 as the above data is of 2018)

**Table 2.6: Nikshay, TB Notification District Wise Notified TB Cases from 1/1/2018-3/1/2018**

<b>District Wise Total Notified for state Sikkim from 01/01/2018 To 31/12/2018</b>		
<b>District</b>	<b>Total Public Notified</b>	<b>Total Private Notified</b>
East Sikkim	791	8
North District	84	0
Singtam	126	7
South District	278	1
West District	224	1
<b>Total</b>	<b>1503</b>	<b>17</b>

Source: Nikshay, TB Notification (Central TB Division)

According to the India TB Report, 2019, total patient notifies were 1438 among which 812 were male and 626 were female (transgender 0). Most of the patients notified were of new cases (1167) than that of previous cases (114). Such a number of TB infected populations show the upsetting problem in public health scenarios.

Spatial understanding of the pattern of tuberculosis gives the depth idea of the transmission of tuberculosis, its causes, and its impact. The Global TB report, 2019 shows that the major TB burden countries and regions are basically those of developing or underdeveloped countries. Among the six World Health Organisation (WHO)

regions, most of the TB cases are seen with African, south-east Asia and Western Pacific regions.

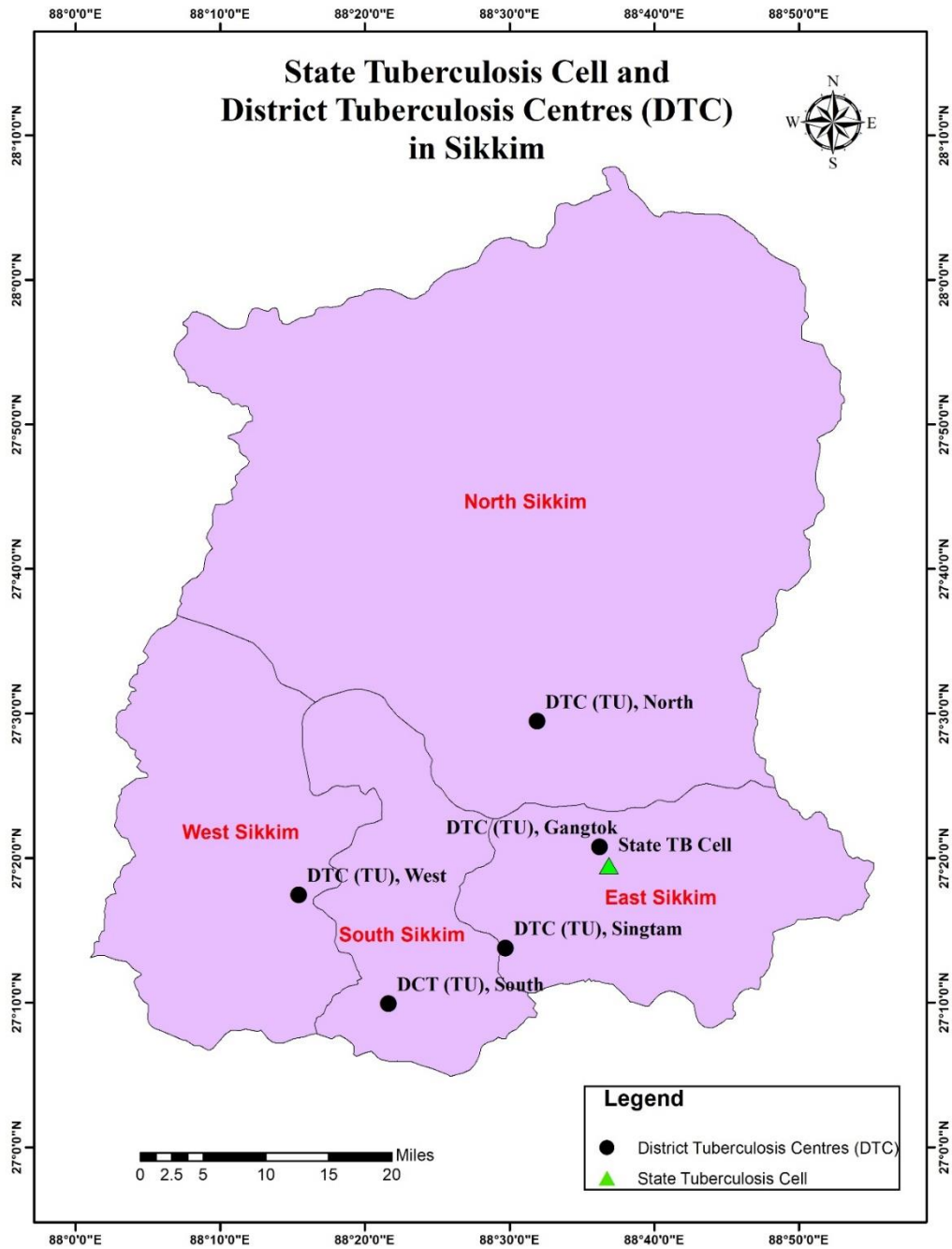
Global targets and milestones for reductions in the burden of tuberculosis (TB) disease have been set as part of the Sustainable Development Goals (SDGs) and the World Health Organization's (WHO's) End TB Strategy (Global TB Report, Chapter 3, 2019).

Sustainable Development Goal 3 includes a target to end the global TB epidemic by 2030, with the TB incidence rate (new and relapse cases per 100 000 population per year) defined as the indicator for measurement of progress. The 2030 targets set in the End TB Strategy are a 90% reduction in TB deaths and an 80% reduction in the TB incidence rate, compared with levels in 2015. The End TB Strategy has also set targets for 2035 and milestones for 2020 and 2025.

India has been practising different measures to eliminate tuberculosis in the country. One of the important programs started by the government of India is the Revised National Tuberculosis Control Program (RNTCP) under which many successes have been seen in eliminating TB. Similarly, RNTCP watch over all the states of India, including Sikkim.

With reference to the above reports and discussion, the proposed study has focused on exploring and understanding the spatial pattern of tuberculosis in Sikkim and draws an analysis of socio-cultural and economic correlates of the Tuberculosis infected people and others.

**Map 2.1: State TB Cell and DTC (District TB Centres) in Sikkim.**



## Chapter III

### **Tuberculosis in Sikkim: Socio-Economic Determinants**

#### **3.1 Introduction**

“When the diseased body is cured, and health is restored, life will be blissful. When a diseased soul is cured our next life will be blissful”

*... Lord Ra Riaz Gohar Sahi<sup>1</sup>*

Health is the most important part of everyday life. Health has been considered an integral component of any development process and means to improve the quality of life of the people. Development here can mean anything to be it physical wellbeing, economic or social of individual, local, national or global. Anthamatten and Hazen have raised important questions related to the socio-economic environment and health outcomes as they question; why is it that the poor man is likely to experience worse health than the rich? And how do economic factors interrelate with the social environment in ways that influence health? The relationship between lack of material resources such as food, housing, and health facilities and poor health seems fairly straightforward. Up to a certain threshold, providing people with the resources required to lead a healthy life is likely to improve health outcomes (Anthamatten and Hazen, 2011).

Health can be an important part of the socio-economic conditions of the people and even the World Health Organization (WHO) conference (1987) viewed health as the

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<sup>1</sup> Lord Ra Riaz Gohar Shahi is a spiritual personality and a founder of the spiritual movement RAGS International (known as Messiah Foundation International) and Anjuman Serfaroshane-Islam.

most important worldwide social goal (Who.int, 2020). Additionally, with the essence of social justice, the World Health Organization (WHO) set up the Commission on social determinants of health in 2005 with the aim of promoting health equity, and also to stand-in a global movement to achieve it (Cdc.gov, 2019).

Poor health and poverty has always seen to be linked with each other and usually, the health outcomes of the poor countries are not at its good condition than that of the rich countries, and within countries socially and economically advantaged people have a tendency to be not as much healthy than the rich (Pearce and Dorling, 2009, Wagstaaff, 2000). Anthamatten and Hazen explain that *“For individuals, material affluence may provide the means to obtain a better diet, sanitary and safe living conditions, access to superior healthcare, and the ability to avoid dangerous working conditions. At a societal scale, material wealth enables the construction of well-functioning infrastructure, the development and enforcement of health-promoting legalization, and funding for health-related research”* (Anthamatten and Hazen, 2011).

The sturdy relation between health condition of population and the socio-economic condition has been even directly indicated in the World Health Organization’s conference in 1987, by saying that *“by 2000 everyone should enjoy a certain level of health which will permit them to lead a socially and economically productive life”*. Therefore, health is considered an essential element for building strong societies, with social development which will lead to healthier-quality of life and condition more favourable to world peace (Singh, 2011).

Likewise, it is also significant to know that everything takes place over a particular space, and it is essential to have an understanding of the role of space and place in social relations. As this chapter is concerned with the socio-economic indicators and its relationship, however, it is also become a primary concern to have an understanding



that all the processes are taking place over a place or space. Dear and Wolch (1987), argue that the social relations relevant to health variation are constituted, constrained and mediated through space which eventually has a direct or indirect relationship with the health of an individual or population. Jones and Moon (1987), argue for a realist approach to the study of geographical health variation which would consider underlying social structures as well as individual human agency. Place interacts in a complex way with social processes (Curtis, 1998).

Geographies of health are often related to the environment, food habits, and behaviour. In the case of tuberculosis, the contractibility of the disease is moreover related to the misbehaviour, environmental conditions, socio-economic conditions and various other factors associated with the socio-economy of an individual. The development of the disease is often determined by the socio-economic conditions as the very socio-economy is the result of social fact, to quote Emile Durkheim “*The condition of Health can be proximately linked with social conditions*” (Durkheim,1982).

Likewise, geographies of health and occurrence of the disease are looked upon as the manifestations of socio-economic conditions or differences prevalent in the society and region both within and outside. Similarly, other factors like cultural practices and perception of society and individuals towards disease are also important for the incidence of the particular disease.

Similarly, the social condition of an individual is often linked to the economy, the condition of health is also related to social conditions and the economy. Therefore, to highlight “*Social Fact*” (Durkheim,1982), holds the key in highlighting the socio-economic relationship between tuberculosis and perceptions towards tuberculosis in society.

However, geographies of health (or geographies of tuberculosis as mentioned by Curtis on her book namely “*Health and Inequalities; Geographical Perspective*”) reflect culture, values, and beliefs and in the contemporary development related to health and healthcare for tuberculosis, culture holds the central position in highlighting the development of society and people as a social fact. This study has particularly attempted to examine the idea of Curtis’s “*Geography of tuberculosis*”. As per Curtis’s Geography of Tuberculosis basically is the combination of the other six aspects (as mentioned in chapters one and two) through the lens of Geography where she has mentioned as Landscape (Curtis, 2004).

On the other hand, quantification of such variables and factors are often neglected and unrecorded leading to unavailability of information related to socio-economic relations and perceptions especially in case of tuberculosis, which has a vital and important role in understanding the prevalence, incidence and dynamics of the disease in Sikkim at large.

Therefore, against this backdrop, this chapter attempts to highlight and analyze the variables and perceptions embedded as narratives in relation to socio-economic implications of tuberculosis in Sikkim with special reference to East and North. The interviews are analyzed on a thematic basis.

### **3.2 Social Determinants of Health**

A global burden of disease or unhealthy conditions of an individual or a population varies from place to place. A health is affected by series of factors which is known as determinants of health, which includes, who they are; individual factors (age, sex, genetic factors), what they do; smoking, physical activities, alcohol, diet, and also the conditions in which people are born, grow, live, work and age; social and community

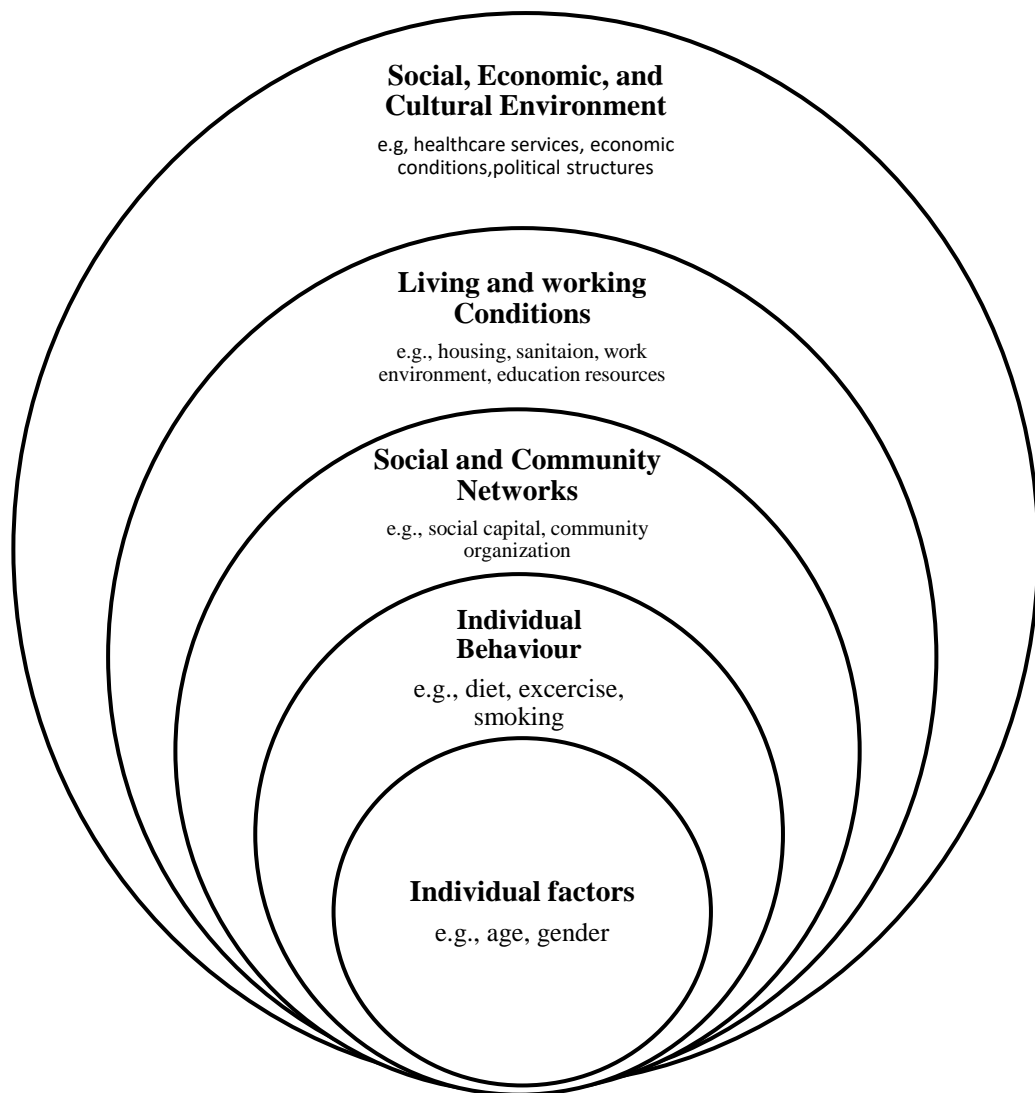
networks, socio-economic, cultural and environmental conditions in people live in and also health systems and these are together called social determinants of health (WHO). Social factors, as is totally different from the concept of biological factors, is now widely accepted to be equally important as other factors in determining health (Jain, 2018).

Social determinants are functions of the situations in which people live, work and grow; basically, shaped by the dissemination of resources and power (WHO; Commission of social determinants of health, 2008). It has been a very essential matter for the understanding of health in a better way as it influences the health of an individual or of the population at large. Before blaming an individual for not having good health or appreciating them for their good health is not appropriate as the setting of people's living environment does control their health condition. Individuals do not hold any power to directly control many of the determinants or things that make people healthy or not.

The pattern of how money, power, and resources are distributed have the capability to mould the social determinants of health in the international, national or local level. They have a striking influence on health inequities, which are the discriminating and inevitable health differences among the different groups of people within countries or between countries.

There are different social determinants of health and have different levels and complex interactions that eventually influence health and wellbeing. To understand that numbers of frameworks have been put forward. One of the important frameworks given by the World Health Organization (Commission for social determinants of Health) has been mostly followed and is shown in the given figure below.

**Fig: 3.1 Social Determinants of Health**



Source: Adapted from Dhalgren and Whitehead (1991) by Anthamatten and Hazen (2011). Social determinants of health are defined as a condition, which is moulded by political, social, and economic forces (WHO). Such forces are not evenly arranged over the space, and the ruthless combination of poor policies and programs, unfair economic arrangements and bad governance may lead to unfavourable conditions on space and vice versa. In an ideal world, the socio-economic conditions of society should be in

such a manner where its citizens can enjoy a favourable set of social resources and are also distributed fairly (Islam, 2019).

The quality, quantity, and distribution of these resources over space, together, to a large extent, determine citizen's health and wellbeing. Space which has a full opportunity to have an education, a healthy living environment, nutrition, healthcare, and employment are some of those resources (Islam, 2019) which helps in the process of building quality life.

The concept of social determinants of health has been on many debates as Graham argues that "*the social determinants of health concept has attained a dual meaning referring both the social factors promoting or undermining the health of individuals and populations as well as to the social processes underlying the unequal positions in society*" (Graham, 2004). As Graham further discusses, he pointed out that the fundamental idea of social determinants of health also refers to the determinants of health and at the same time to the determinants of inequalities in health (Graham, 2004). Additionally, Islam (2019) discusses that the concept of social determinates of health is considered to have two magnitudes - one is social development that regulate health and the other is the equivalent distribution of those factors (Islam, 2019).

Further, as Islam (2019) extents his discussion, he says that the more one gets deeper into the concept the more it gets confusing. Although, at first the concept was restricted to certain factors only, such as living environment, education, nutrition, and employment, however, recently the list has grown considerably be it in peer-reviewed literature and academic textbooks. Even the term social itself remains vague (McQueen, 2009), which makes it more difficult to define with a definite boundary. Although socioeconomic status is a major element that is often used to represent 'social', and the meaning of socio-economic may vary over space at varying settings.

### 3.2.1 Socio-Economy and Health

Health and socio-economic factors have an indivisible relation and have both cause and impact on each other. The study of health now has been widely connected to the socio-economic indicators, such as education, occupational social class, income, ownership of wealth, and deprivation and these are probably the most often used indicators of current socio-economic determinants of health. Socio-economic indicators offer a contextual to the understanding of health scenario of any area. According to the National Health Profile of India 2010, socio-economic indicators mostly provide data related to gender, poverty, education, amenities, housing, employment, and other economic indicators. The associations between socioeconomic indicators and the achievement of health goals could be easily recognizable with the help of these indicators for a nation as well as states.

According to Curtis (1998), some studies of contextual effects have suggested that the health of individuals with similar social characteristics varies according to the socio-economic setting in which they live. The analysis of mortality data from the longitudinal study and of data on reported health from the *Health and Lifestyle Survey (HALS)* (Blaxter, 1990) showed that for individuals of similar social class, health measures varied in association with conditions in their residential area (defined using the ward cluster typologies of Webber 1977, Craig 1987). These studies both pointed to differences between individuals living in rural or- semi-rural areas, and individuals in declining urban/ industrial areas (where health tended to be poorer).

The effect of socio-economic context also emerges from analyses showing that the small area ecological links between health and deprivation depend on the wider geographic context. Curtis (1998), further discusses that there is some evidence that health disadvantage is exacerbated in a socially and economically improvised setting,

particularly in declining industrial areas. The theoretical framework offered by Macintyre et al. (1993), supported by theories concerning the ecological impact of the habitus on patterns of consumption and lifestyle, provides a theoretical basis for supposing that individual health experience might be negatively affected by living in an area of high levels of socio-economic deprivation and industrial decline.

Health and its relationship with socio-economic settings over a certain area define a lot more. The commonly studied socio-economic determinants of health provide an understanding of how social and economic settings determine health, considering material deprivation, income inequality, culture, education, employment, gender, social class, race, caste, etc.

### **3.3: Tuberculosis and socio-economic environment**

Tuberculosis is an infectious disease and is also considered to be a social illness. The relationship between the socio-economic setting and tuberculosis has a long history being associated with each other internationally (Gandy, 2003). Socially marginalized groups and poverty has a strong association with tuberculosis. Exposure to the disease is more common in certain socio-economic groups and the course of the disease can be more rapid or more services in the individual with specific risk factors (Lonnroth et. al, 2009). One of the key objectives of the stop End TB is to reduce the socio-economic burden and the human suffering associated with tuberculosis with the universal access to quality diagnosis and treatment (Stop End TB). In World Health Organisation's Global TB report, 2005, the four different barriers associated with tuberculosis have been discussed while "*addressing the poverty in TB Control*" and they are geographical, social/cultural, health system and economic barriers. The socio-economic condition of an individual, community, state or country does have cause and impact on the incidence/prevalence of tuberculosis.

In Sikkim, as well, the cases of tuberculosis with the increase in the cases of MDR-TB particularly have threatened the public health scenario and most of the studies do have tried to analyse the factors behind it, be through bio-medical approach or social approach. This study put forward the socio-economic analysis and the factors associated, and the basic considerate indicators are Social; cultural, stigmatization and discrimination, social support, gender, age, education, knowledge of the disease, etc. and the economic factors include material deprivation, income (inequality), employment/occupation, etc. Other factors such as environmental, psychological or even political factors play an important role in the case of tuberculosis. An attempt has been made to identify the socio-economic profile of the respondents while trying to cover all the research questions. Most of the data are portrayed in a narrative manner.

### **3.4 Socio-Economic Environment and Tuberculosis in Sikkim**

Wealth has its effects on health both directly through allowing access to resources basically such as high-quality healthcare services and nutritious food and indirectly through the influences of characteristics of the built and social landscape on health behaviours. Social factors have been important in any health studies as many health researchers have begun to appreciate it to mediate and complicate the relationship between health and wealth. This study has tried to put forward the answer to the question of ‘how the socio-economic landscape of Sikkim arbitrates the health outcomes in Sikkim, tuberculosis in particular.

It is true all over the world that tuberculosis burden is high and morbidity and mortality of tuberculosis also high on a global scale and it has shown in the second chapter of this study it has been shown that what is the geographical scale of tuberculosis or how tuberculosis is distributed over the world. So, with those ideas, it is clear that



tuberculosis has a great association with the socio-economy of a particular place and India has come under one of the highest tuberculosis burden countries.

However, even in India, the distribution of tuberculosis has seen to vary state to state and factors behind it could be many be its population size, geographical, economic, social, etc. and this study has particularly zoomed out only two regions (east and north district) of state Sikkim, India. Although tuberculosis is not a new disease in Sikkim, and it has a long back history of epidemiology, in recent time tuberculosis has become the biggest threat to public health.

Both the quantitative figures of tuberculosis and qualitative outcomes of tuberculosis have been a serious matter to discuss in Sikkim as well. The concern of tuberculosis does not totally rest upon bio-medical term, it is interrelated with other factors which directly or indirectly are the cause of tuberculosis or has an impact on tuberculosis. With this idea, the socio-economic aspect of tuberculosis in Sikkim (North and East Districts) has tried to analyse the narration of the respondents which was collected with the help of interviews from the field. The study has been thematized in the following themes;

The named respondent is also categorized on three categories that are Public healthcare Provider (PHCP), Patients(P), and Guardian or Local People (G/LP) and they will only be referred in numbers.

### ***1. Material Deprivation and Poverty:***

According to Stop TB Department of World Health Organization, globally 90 % of the cases of tuberculosis and deaths occur in the low and lower-middle-income countries (i.e. the annual GNP per capita is less than US\$ 2995) and 76% of the world population lives in these countries. Similarly, low-income countries (i.e. the annual GNP per capita

is less than US\$ 755) mostly accounts for 65% of TB cases and 71% of deaths and 42% of the world's population lives in these countries.

Spence, et al. (1993, 759-761), has done the research to understand the relationship between tuberculosis and poverty and also to examine whether or not the historical perception of having a link between them still exist. The result of their research came out as tuberculosis still does remain strongly associated with poverty. Historically, respiratory and infectious diseases have been specifically seen to be related to poverty and particularly tuberculosis (Winkelstein et al., 1967). Material deprivation or poverty could be due to many things that eventually become a leading cause of tuberculosis.

According to World Health Organisation's ethical concerns, TB is a disease of poverty and they focus on the social justice of everyone which means the caring for the most vulnerable and marginalized and addressing the social determinants which underlie the TB epidemic. (World Health Organisation, 2015)

- *Income inequality*: Unequal income leads to unequal opportunities.

There is a number of studies that show the relationship between inequality in income and tuberculosis. Even though sufficient resources are available to an individual in order to acquire or sustain a healthy lifestyle, inequality in income and social status may influence health outcomes as much as material wealth. A study by Pearce and Dorling (2009) spectacles that the recent shreds of evidence have advocated that affluent members of non-egalitarian societies might suffer poorer health than that their affluent counterparts in more equal societies. In Sikkim, income inequalities have an effect on the incidence/prevalence of tuberculosis directly or indirectly. It has been seen that the most of the tuberculosis patients are from the low-income categories or per se middle-class families and to advocate one of the respondents (official healthcare worker) said:

“it has been recorded since Many years that the most of the cases of tuberculosis mostly come from middle-class family background, and it is very little cases which have been noticed to come from a well to do family background. The specific reason has not yet proven yet it a general observation that tuberculosis has been rampant among the low-income background people” (PHCP1).

The relationship between the low income and stress of tuberculosis has been seen everywhere and even in Sikkim. Most of the population who are infected with tuberculosis do belong to a low-income group in Sikkim and it is one of the components in supplementing the impact. Most of the socio-economic profile of the respondents was of the low-income group and it does mean that low-income impacts on tuberculosis however it does not mean that it is the only reason behind the cause of tuberculosis. Tuberculosis has been always associated as a ‘poor man disease’ and has claimed in many studies that the low the economic profile the higher the cases of tuberculosis and vice versa.

- *Employment*

Evidence exists for an inverse association between unemployment and a wide range of health outcomes (Jin et al. 1995; Dooley et al. 1996; Mathers & Schofield 1998). Of all the measures of SES, however, employment is the most prone to concerns regarding causality, since there is clear evidence that ill-health often causes unemployment rather than vice versa. Some longitudinal studies attempt to adjust for this by selecting a population that is either exogenously been made unemployed (the closing-factory method), or about to enter the workforce (students leaving school) or through panel population surveys (Dooley et al. 1996). These methods are rarely employed, but those studies that have used these approaches have found robust relationships between unemployment and poor health.

At the aggregate level, in addition to these individual-level, compositional effects, there is also the possibility of a contextual effect of high unemployment rates through their impact on the community – either physically or psychologically. Interaction between the two levels is also possible. It has been observed from the field that most of the patients are at the age group of economically productive (15-59 years). During the processes of treatment, they become totally unemployed as they are not willing to perform any kind of job and the treatment course of tuberculosis usually takes 9- 11 months. It has also been noticed that there are a number of cases of relapse, so the duration of treatment has also been increased as per the process of treatment.

- *Institutions or Infrastructural Deprivation:*

Deprivation could be of anything however when studying about tuberculosis, deprivation to such basic amenities could have an important role to play such as infrastructures or institutions deprivation; hospital, health care, and services department, etc. along with transport facilities, electricity, media, and communication, etc.

In the case of Sikkim, as per the field areas adopted for this study two districts east and north districts, have different characteristics in many ways. In terms of material deprivation, particularly the institutional and infrastructural east district of Sikkim is way more facilitated than the North district. East being the more developed district and the official bridge to other states and also the capital town Gangtok being located here is obviously way more aided with all other facilities than that of North district (less developed). Similarly, other deprivation to material like poor living conditions, poorly ventilated housing, etc.

A lack of basic health services, inadequate living condition, and poor nutrition all contributes to the spread of TB and its influence upon the community. As per the Stop TB Department of the World Health Organization, TB is considered to be a disease of poverty and often said that “Poverty fuels tuberculosis”. It is widely accepted that the poorer the community, the greater the likelihood of being infected with the TB germ and developing clinical disease.

Deprive of good food quality and health care services is common in poor communities. The absence of health facilities and services to diagnose or treat patients further leads to a longer delay between disease and cure perpetuating the spread of tuberculosis. In Sikkim, the overall health care facilities are more advanced in the east district as compared to the north district, and particularly in terms of tuberculosis, the rapid sputum test machine CBNAAT (Cartridge-based Nucleic Acid Amplification Test) has only been recently introduced in the State.

Poor nutrition and an inadequate diet weaken the immune system and increase the change of infection and development of active TB. Overcrowded and poorly ventilated home and work environments make TB transmission more likely. The reciprocal relationship has always been existing between tuberculosis and poverty. This relationship is more somehow been aided by other factors such as social, cultural etc.

## ***2. Cultural Factors***

The socio-cultural barriers, economic barriers, and health system barriers are reported as three major barriers in the adherence to the treatment of tuberculosis (The Social Action Plan RNTCP, 2013). In the following report, it has been stated that a gap between biomedical knowledge and tradition leads to delay in diagnosis and treatment initiation.

*“When someone is sick at first, we do not take them directly to the hospital as some diseases can be treated at our own either by giving the patient some antibiotic available nearby or by taking them to the traditional healer. Only if it becomes severe or if it cannot be treated at home is mostly taken to the hospital. (G1).”*

The cultural influences of health-seeking behaviour have a major impact on the delay in the diagnosis and treatment of tuberculosis in Sikkim. The customs and traditions which directly or indirectly impact the food habit or consumption pattern of a community or overall Sikkim have been supplementing in the impacts of tuberculosis.

*“When my uncle passed away (not because of TB), everyone had to skip meal for almost a week due to some ritual processes including aunt (his wife), during this process it resulted my aunt fell sick, initially it was thought to be gastritis as she along with other family member’s meal timing was irregular. However, my aunt fell so sick later on that she was taken to the hospital, and found out that she was infected with tuberculosis and now has developed a disease- MDR-TB” (G2).*

### **3. Gender**

Gender a socially constructed term referring to roles, behaviours, activities, and attributes that a given society considers appropriate for men and women (WHO, 2018).

It always played an important role in society. The genders have different attributes and responsibilities they are accountable for. Gender roles are socially constructed and usually framed as an extension of biologically determined social functions. The main focus is on the impact of variation on the risk factors between men and women because of the orientation of the society. A study conducted in South India in 2008, found that women are stigmatized when it comes to marriage (Ganapathy, 2008).

*“Being a woman, a mother, a wife and a daughter in law, I have lots of responsibilities. I have been admitted to hospital for 3 months now and even my husband is here taking care of me and children are not getting good care because of my ill health (P1).”*

By the observation from the field, it has been seen that most of the admitted TB patients at the hospital were female.

#### **4. Age**

It has been seen from numerous studies that tuberculosis affects the economically most productive age group of individuals not only in India but all over the world (Gupta et al., 2000). There is a study conducted in Sri Lanka wherein defaulters were mainly young age people i.e. 30-39-year-old age groups about 24% compare to the other age group in the study (Pinidiyapathirage, 2008). Affecting the most economically productive age group hence results in the high economic cost to the nation as a whole (Rajeswari et al., 2001).

*“I am 24 years old and I fell ill when I was in the last semester of my graduation. In the beginning, I had no clue that the symptoms that I had would be of tuberculosis and to be specific MDR-TB because I had just a small bruise on my neck (below-left ear) and no clue of being any dangerous. I was medicating it myself as I thought it to be mumps but it was not recovering then my mother suggested me to once get a check-up by the doctor to be sure if it is not anything serious then doctor suggested me to get tuberculosis test. I was not expecting it but the report came to be positive with extrapulmonary (Gland) MDR-TB. I felt so bad that I even cried Infront of the doctor. Many thoughts were coming to my mind as I was at the end of my graduation and after graduation, I should have been working and helping my parents however I am stuck at bed for almost three years now (relapse case) and I am engaging my parents as well either physically or economically (P2).”* She was completely cured of her

extrapulmonary gland MDR-TB but after being the cure for 3 months she was again infected with pulmonary MDR-TB (extrapulmonary TB is not an airborne disease as pulmonary TB).

The cases as such are high in Sikkim and most of the respondent were of working age (15-59 years). When a disease like tuberculosis spread over the working-age group it will have a very bad impact on the economy of house, village, state, country and as well as of the world.

### **5. Education**

A study conducted in Orissa in a Tertiary Level Hospital showed that patients with higher literacy levels had better knowledge and understanding about the disease. They had better treatment outcomes because of treatment adherence (Moharana, et al., 2008). Due to a lack of education, people are mostly not aware of the cause and impact of tuberculosis. As stated by one of the respondents *“Moreover, the myths of the tuberculosis are spreading instead of the facts”* (PHCP 2). According to him the facts of tuberculosis is important to reach to each and every people and all the risk factors related to TB should be well known by everyone so that everyone can prevent themselves. As he further stated *“Multi-drug resistant tuberculosis (MDR-TB) has become a serious matter in Sikkim yet the main reason is not yet proved however in a general idea in Sikkim poverty do play some role in the development of tuberculosis but rather than that the cause of spread would mainly due to contact with the infected person. It is not possible to identify who is infected and who is not without a tuberculosis test or without knowing their medical history until they develop it as a disease and become sick. So it is for sure that if anyone who often goes to crowded area or any public area and comes in contact with the pulmonary TB infected person it is easy to get infected and with that, if someone’s immune system is weak then it is easy to develop*



*a disease as your immune system cannot fight the bacteria.” All such risk factors and prevention measures are important in order to fight with tuberculosis and to stop its spread.*

Similarly, education also plays an important role in terms to fight with the discouragement and depression as one of the respondents says *“I am not well educated and I did not have any knowledge about MDR-TB and when my daughter was diagnosed with MDR-TB I was mentally depressed then my daughter and thought that it is something very dangerous and incurable. My daughter was doing graduation and was on 4<sup>th</sup> semester when she was diagnosed with MDR-TB. She did some research about the disease from the internet and even shared all the information about MDR-TB with me and also told me not to be scared or depressed as it is curable and also she takes care of all the preventive measures and risk factors related to preventing other from infection especially me since I am taking care of her.” (G3)*

Another incident told by one of the respondents related to the role of education in case of tuberculosis was that *“I was feeling sick and I tried to search the diseases related to my symptoms on the internet before going to the hospital, as the hospital is far from home and the transportation facilities are not always available. Then the diseases related to my symptoms turned out to be similar to tuberculosis. So, the immediate next day I went to hospital since causes to my illness was not sure so I went to the general medicine ward, at first the doctor took a general check-up procedure and misunderstood it to be a seasonal fever. At first, I felt happy as it turned out to be wrong, however, I wanted to sure ask a doctor to perform a TB test. When the final report of tuberculosis, as doubted it turned out that I was surely infected with tuberculosis but wasn't expecting it to be MDR-TB” (P3).*

## **6. Knowledge of the disease**

The knowledge of the disease can play an important role in the adherence to the treatment. Several studies have been conducted to show the correlation between knowledge of the disease and its outcome. It has been reported in the Social Action Plan of RNTCP, 2013 that there are three major barriers in adherence to the treatment. These include socio-cultural barriers, economic barriers and health system barriers (RNTCP, 2013). In the report, it has been stated that a gap between biomedical knowledge and tradition which leads to delay in diagnosis and treatment commencement.

When asked the respondents if they have any knowledge about TB as a general and MDR-TB and XDR-TB in particular, then most of the respondents' answer was that they had no clear knowledge. Most amusing one was that one of the MDR-TB patient (female, age- 19years old) who was then admitted to the hospital (relapse case) was herself unaware of the facts of the MDR-TB, and she directly said that *"I do know that I am infected with pulmonary MDR-TB and have little knowledge about TB as a whole, but I have no idea what is MDR-TB. When I was diagnosed with MDR-TB I was staying at Gangtok as I was getting trained on beauty parlour, the doctor informed me that I am should go to my respective area's hospital due to rules and regulation and was transferred here. Doctors informed me that I am infected with MDR-TB and should be admitted to the and provided me with some dos and don'ts information but I neither bother to ask doctor nor did they to as what exactly is tuberculosis."* (P4).

As per the narration above it is clear that the patient has no idea what exactly is MDR-TB and neither that how harmful it could be if she neglects it.

## **7. Stigma and Discrimination**

Stigmatization has always been predominant in human society for as long as the existence of human race has traced out. It is so imprinted into the mindset of human that it may almost be considered a conventional part of human society. The stigmatization of the things that are considered out of the custom by the social order has always been a serious obstruction to the development of society as a whole.

Conducting a survey on the prevalence of stigmatization of the MDR-TB had not such different conclusion. It was found that stigmatization of the disease was even more unescapable in poor households with a patient of this disease. The reasons behind it could vary, among which fear of contraction of the disease and lack of knowledge regarding the disease was the main culprit. Refusal to establish any form of communication with the infected or diseased, and refusal to share the same space as the infected, etc. are only some of the forms of stigmatization seen.

As one of the respondents shared her story and experience of fear of being infected as being close contact with the patient frequently as also as how it impacted or was showing the result of being in close contact with the TB patient, *“My friend was shifting to a new room at Tadong. I helped her in shifting her belongings. But then we came to know that the neighbour was infected with MDR. The washroom that was allocated to my friend was to be shared with the patient and her family. The patient was using the washroom frequently and naturally, we were afraid to use the same washroom. The patient seemed extremely weak. We felt sorry for her health condition but also, we were highly disturbed after seeing her. We were so overwhelmed with the fear of getting infected that my friend started giving second thoughts on shifting there as a tenant. And finally, my friend decided to shift to some other place. Later we came to know that the patient and her family were made to vacate the room. Though we felt bad for them, shifting to a hospital or some other place was probably good for them and more for the*

*people living in that building. There were kids in the building and the rooms were in close quarters. After knowing that the results of the patient's husband were positive, the tenants were even more scared and so the patient along with her family had to leave the building. The whole episode was depressing to me and more to them for they were not just losing health but a great deal of support from society.” (LP 4)*

Sometimes it goes as far as putting the infected under quarantine. All these have a very negative affected individual both mentally as well as physically. The person may be deterred to not seek any medical help initially for the fear of revealing his condition and the stigmatization that follows. And hence, a simple infection of TB that could be treated, had he sought help earlier progresses to a deadly form of the disease that is MDR-TB which is most likely fatal.

The result of stigma has been seen affecting health-seeking behaviours, as patients were seen being hesitant, and thus they chose not to disclose their TB status to their family members and friends due to the fear of avoidance (Pathak, 2011).

*“Being a Patient of MDR-TB, it is not easy to deal with the situation of physical, social and psychological pressure. I have experienced social discrimination as well; being the fact it is a contagious disease everyone should be aware of risk factors and should take preventive measures, however, society should not treat them badly. In such a harsh time of my treatment period, I really needed love and care instead of discrimination. I am now fully recovered even though people will be talking about me at the back and try to avoid me as much as possible. when people are sick because of the TB along with economical, they need physical, social and mental support. The drugs given to TB patient are of high dosages and it makes the patient mentally depressed and will start taking small things like a big issue which eventually even leads to other cases such as*

*one being suicidal. TB infected people are also considered to be a minority group.”*  
(P5).

Tuberculosis is such disease, where not only the disease but other factors too kill the people, one being prominent a suicide. Well, the exact date of the suicide cases is related to tuberculosis is not found however such cases are not that unknown to anyone in Sikkim. Suicide and MDR TB cases are increasing quite frequently in Sikkim. As the local people respondent number 6 shared the story of one such case that she witnessed at her neighbourhood, she said *‘I am so overwhelmed to witness such a horrific incident in my neighbourhood. My neighbour was living with her other three siblings and she was the only one to earn for their livelihood as she was the eldest among all of them and others are still students. She once very got sick and went to the hospital for her checkup. After the report, the doctor told her that she has tuberculosis disease and she should get medicated as soon as possible. She was told to get admitted to hospital but she came back home. The other day we got the news that she killed herself as she could not bear the stress of her being sick. We made the analysis that she could have been very depressed after getting the report of her being sick with tuberculosis as she was the only one to take care of her family financially.’* (LP 6)

There are many cases of suicide-related to TB, as observed there are even such cases where the patients have killed themselves even after they are getting full treatment support and care by doctors, nurses, family and friends.

### ***8. Social Support***

Various studies and researches works have described how the role of family members and the community have its huge influence in the process of diagnosis and treatment of TB. In a one of the research works conducted to comprehend the association between treatment procedure and social support, it was mentioned that social support during the

treatment process of TB, may contribute to enhancement the quality of life of diseased patients (Companion handbook to WHO guidelines for the programmatic management of drugs-resistant tuberculosis, n.d., 2014).

According to patient respondent number 6, *“I am recovered MDR TB patient and without my family support, I could not have been even alive. The process of treatment is the worst part I must say, the number of drugs which we have to take first make us mentally depress. Above that, the dosages of the drug are very high which will make us feel nausea, depression, and weak. It is not easy to take such number of drugs daily above its side effects. In those periods, the suicidal thoughts use to hunt me, as being sick with such disease carries many other consequences. But with the support and care of my family member, I overcame this disease and now I am fully recovered. (P 6)*

Patient respondent number 7 also discussed her ongoing treatment process and said that *“I am suffering from MDR TB and I no idea how I came to develop this disease. I am an undergraduate student and was staying at Gangtok for education. At Central Referral Hospital, Manipal, I was diagnosed with MDR TB and got admitted there for one week and then was referred to the District tuberculosis centre (North). At first, I was frightened to hear that news and but my parents comforted me. But now I am not frightened to overcome it and even so I have lots of supports from friends and family. The process of the treatment itself is so exhausting however I have only four months to go then I will be recovered. Yes, it is true that the along with economical support the social support is equally important otherwise the treatment prosses gets worse. Although I feel so lucky that I am getting the moral support and their supports gives me strength and motivation in order to cope with the disease” (P 7).*

### 3.4.3 Other Factors:

- *Consumption Pattern*

As discussed above, most of the infected population are under adulthood and people from this age group are mostly engaged as students, employees, wage labourers, etc. In Sikkim, fast food culture is prevalent and has a huge market so the mostly have seen to prefer fast foods due to time constraints and as well as carelessness and laziness. Such unhealthy consumption has been resulting as a weak immune system as one of PHCP respondent number 2 highlighted that *“an individual should have three colours in his or her diet i.e. green, yellow and white, and lacking such nutritious food in diet results in the infection of TB.” (PHCP 2)*

Even the consumption of alcohol, tobacco, cigarettes, etc. makes our immune system weak. According to one of the respondents who is a government Public Health care provider, *“most of the infected patients with low income are a wage labours, their stories are mostly like they work all day without having proper diet and then in the evening they just drink alcohol and sleep with having dinner which has resulted in them to be easily infected with tuberculosis”.* (PHCP 4)

- *Micro Environment*

Tuberculosis is an airborne disease and the risk of being infected is higher than other non-contagious diseases and micro-environment could intensify the causes or impact of tuberculosis. When the communication between infected and non-infected people is quite frequent then the risk to tuberculosis is also high. According to field data, most of the interviewee (patients) or other patients got infected while their stay in Gangtok for education, work, etc. and Gangtok could be a micro-environment (frequent communication among people) than the north district which is often known as less

distributed as well as densely populated district as compared to east (high dense and distributed population).

One of the prime examples of micro-environment and the prevalence and incidence of tuberculosis resulting in MDR and XDR cases has been reported from a small village in the east of Sikkim “Nimtar”. As discussed above microenvironment plays an important in overall wellbeing and health care, similarly, one of the important factors in case of micro-environment and its role in incidences and prevalence of tuberculosis in case of Nimtar village as complaint by most of the locals residing in the area has been the location of the dumping ground for solid waste.

*“Before the establishment of the dumping ground, there were very few cases of tuberculosis recorded in the village. With time the dumping ground located in this area has been causing many serious health-related issues. The fouls mail and untreated waste can be one of the important causes for the rise of tuberculosis in our village...”*  
(LP 5)

Therefore, as discussed above the role of micro-environment becomes important in relation to time to understand the spatial variation of tuberculosis. Small area, poor ventilated, congested area or any other micro space could be one the important risk factor of infection to tuberculosis.



## **Chapter IV**

### **Tuberculosis and Health Care**

#### **4.1 Introduction**

One of the important mechanisms of holistic development approach incorporates health care services and policy, likewise the very Constitution of India highlights Health and Health care policy(s) to be under States Subject. Similarly, in the contemporary scenario health and health care services has been one of the important and most contested matter of debate in both developed and developing nations around the world.

Health care and policy(s) integrates conveniences, quality and preconditions along with involvement of various stakeholders in framing, planning and attaining the said health care goals, therefore, experts from various spheres of expertise, academia, disciplines and professions are often incorporated in planning procedures for health and health care service. Public health officials, medical professionals', academicians and owing to the contemporary scenario of health geographies medical geographers are often involved in planning policies related to health and services.

Therefore, this chapter discusses the healthcare facilities in the world and country in general and Sikkim in particular with added emphasis to tuberculosis, highlighting the major policies, services and role of various institution and stake holders. All the major health concerns are dealt by World Health Organisation in a global then by National authorities and concern local governments.

#### **4.2 Development of Health Care in Sikkim**

Sikkim – the landlocked state of the Northeast India is a multi-ethnic and multi-linguistic zone where there has been an amalgamation of diverse cultures at the helm

of 21st century. A small state bounded on the four sides by Nepal in the West, Bhutan in the East, Tibet in the North and Darjeeling districts of West Bengal in the South. The health care institutions in the state are well framed in accordance with the Health care policy of the government. Sikkim as a state has progressed considerably in terms of health care over the years be it in terms of health institutions or services after it became the part and parcel of the Indian union. Prior to its merger with India, healthcare in Sikkim was in shambles.

Likewise, Sikkim as a protectorate of British gained priority and importance in terms of health and overall development in the health sector during the 19<sup>th</sup> century. As (McKay, 2004) highlights, that it was after the British ventured into Sikkim, under the first political officer of Sikkim J.C. White, health care services were instigated in a larger scale in Sikkim. Thorough importance and emphasis were laid forward with organisation of free health and medical camps for the general masses in Sikkim. Therefore, this ultimately led to the establishment of a post for medical officer in Sikkim.

Likewise, after the beginning of first medical camp which was organised under the patronage of political officer to Sikkim, simultaneously various health centres and dispensaries were set up in Sikkim to provide service to the population at large which incorporated basic health care facilities at that period of time.

First public hospital of Sikkim was set up by the then Chogyal (King) of Sikkim Sir Tashi Namgyal in the year 1917, which till this date is known as Sir Thothub Namgyal Memorial Hospital, located in the present capital i.e. Gangtok. The very institution for providing service in terms of better health care was later upgraded with added specialised departments and infrastructure. Tuberculosis has been one of the concerning

public health issue in Sikkim since long, therefore with the efforts of the then Chogyal and his concern for rising Tuberculosis. Tuberculosis ward for catering service to the infected population was added in the hospital in the year 1920.

Further, with the establishment of the first public hospital in the year 1917, the state in the contemporary times has standardised its priority towards health and healthcare services in the state and has shown considerable amount of growth and substantial development in health care and services.

In relation to tuberculosis the state has its state TB cell at Gangtok in east district and the district tuberculosis centre has been setup in Namchi, with further plans to expand and provide care and treatment for tuberculosis the government has proposed the setting up of tuberculosis hospital in Mangan (in the process of construction), which is located in the North district of the state, along with the government institutions there are there are few private medical institutions or clinics operating in the state that is catering to the health needs of the people (Department of Health Care, Human Services & Family Welfare, Government of Sikkim, 2014; Department of Economics, Statistics, Monitoring and Evaluation Govt of Sikkim, 2013).

**Table. 4.1. No. Of Health Institutions in Sikkim**

SL.NO.	HEALTH INSTITUTION	EAST	WEST	NORTH	SOUTH	STATE
1	State Referral Hospital STNM (Multi-Speciality Hospital)	1	-	-	-	1
2	District Hospital	1	1	1	1	4

3	Community Health Centre	1	-	-	1	2
4	Primary Health Centre	6	7	5	6	24
5	Primary Health Sub Centre	48	41	19	39	147
6	District Tuberculosis Centre	2	1	1	1	5
7	Centre Referral Hospital Manipal Tadong (Ppp.)	1	-	-	-	1
	<b>Total</b>	<b>60</b>	<b>50</b>	<b>26</b>	<b>48</b>	<b>184</b>

Source: Health and Family Welfare Department, Government of Sikkim.

### 4.3 Public Policy and Tuberculosis

Sikkim over the years has observed significant growth in terms of health and health sector and has developed and recorded unmet growth in providing healthcare services in the state.

As according to (Sikkim Human Development Report,2001) there are various services being offered to the general masses in the state under the policy of health and family welfare schemes, various primary health care centres and hospitals are catering to the needs of the people in disseminating the benefits related to health free of cost. Likewise, 1 PHCs is covering 2000 people in the state for providing healthcare services which comes under the national norm for establishment of health centres for common people under the guide lines of government of India.

It is evident that government has a significant role in eradicating any disease through proper and efficient framing of plans and policies. Likewise, the role of government has always been related to Human Resource Development in terms of Health Care Services. Similarly, through effective planning and policy framing, and the active role of government, many of the health problems be it Malaria, Child Mortality, HIV (Human Immunodeficiency virus) and many more has been addressed and controlled to a larger extent.

After Independence, even in the country and Sikkim most of the communicable diseases has been controlled with the development of quality health services. Tuberculosis, in this regard has been one of the major threats in spheres of public health and various policies and plans has been formulated in relation to time to combat tuberculosis. Likewise, as per the policy of the government and role of state in combating tuberculosis RNTCP, Revised National Tuberculosis Control Programme has been framed by the experts and policy makers with the vision of controlling and eradicating tuberculosis.

Similarly, the role and effectiveness of RNTCP in controlling and minimising the effectiveness of this particular programme cannot be overlooked. This programme has moreover helped in minimising the mortality rate related to tuberculosis. In terms of public health policy adopted by the government RNTCP has been of the effective tool in controlling the rate and incidence of tuberculosis in Sikkim. This very policy incorporates the primary objective of 85% cure rate by identifying the infected people and providing extensive assistance and treatment, which is in purview of its larger objective of eradicating tuberculosis.

#### **4.4 RNTCP as a Tool**

Revised National Tuberculosis Programme was introduced in the year 1993, involving the states of West Bengal, Maharashtra, Kerala, Gujrat, along with national capital Delhi. Likewise, 2.35million people was target to be covered under this programme in the initial phase. As according to (Dolma et al., 2013). RNTCP is regarded as one of the major programmes concerning the treatment of tuberculosis in the world, which covers more than 1.00,000 patients in a month, in compliance with DOTS for better treatment and cure of tuberculosis.

Similarly, as according to the report compiled by (Ministry of Health & Family Welfare, Government of India, 2011) after the implementation of RNTCP the mortality rate has been reduced up to 5 lakhs despite the notable growth of population in the country.

Likewise, RNTCP has helped improve the healthcare and accessibility to medication and treatment across the country, under National Rural Health Mission concerning the general healthcare (Civil Society Perspective of TB Care & Control in India: Challenges & Solution Report ,2011).

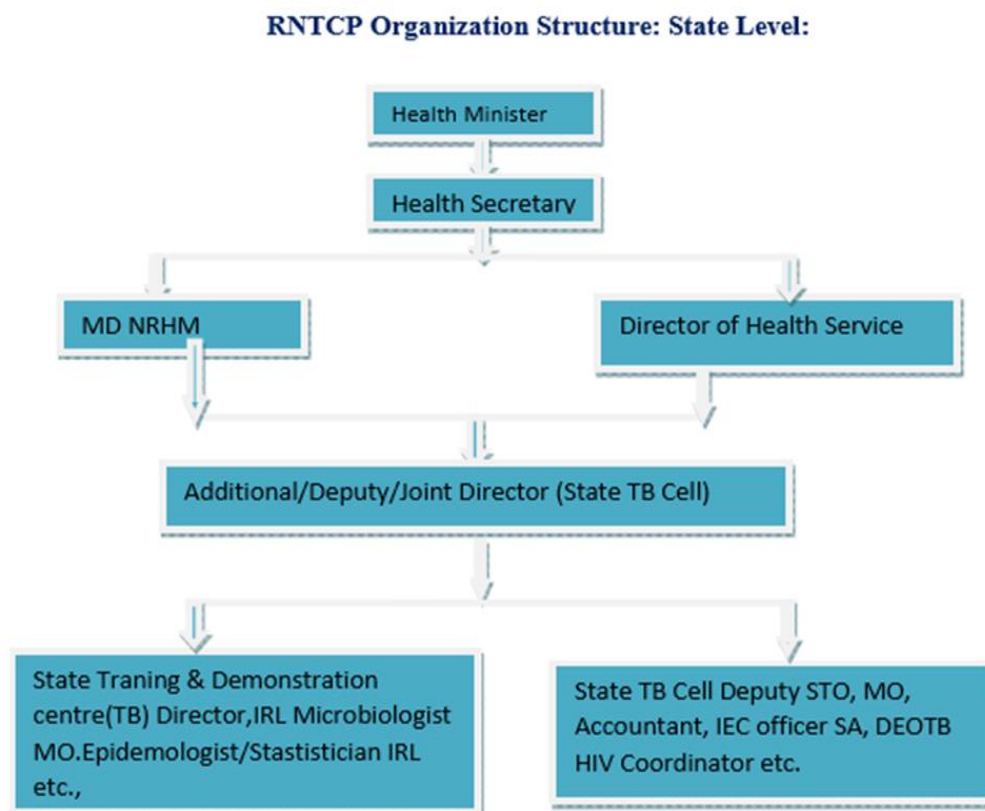
##### **4.4.1: To highlight the broader objectives of RNTCP includes:**

- i) To achieve and maintain the cure rate of at least 85% among new sputum positive (NSP) patients.
- ii) To maintain and detect tuberculosis cases at least 70% of estimated NSP cases in the community.

The organizational structure of RNTCP in the state level has been shown in the Figure 4.4.1.

**Figure 4.4.1: The Organization Structure of RNTCP at the State level:**

RNTCP Organization Structure: State Level:



Source: RNTCP, Government of India

***New initiatives by RNTCP:***

- 1. All TB patients are now registered online portal known as NIKSHAY. A unique patient ID is created against which all incentives and schemes based DBT payments are disbursed.*
- 2. From 1<sup>st</sup> April 2018, in order to ensure TB patients to have nutritional foods during their long TB treatment, the financial incentives of Rs 500/- per month and Rs 2500/- per month provided to eligible TB patients by Government of India (GoI) and by Government of Sikkim (GoS), respectively.*

3. *Treatment regimen for Drug sensitive TB (DSTB) shifted from intermittent DOTS (Thrice a week therapy) to daily DOTS therapy since February 2017.*
4. *Under universal drug sensitivity test (DST) now every TB patient (wherever sample is possible) must be subjected to at least one form DST technology to ascertain at least Rifampicin sensitivity of TB bacilli.*
5. *Since Dec 2018, as per the office order of Central TB Division (CTD), New Delhi the injection Streptomycin is removed from previously treatment regimen.*
6. *In order to ensure increase TB notification by private practitioners (PP) a financial incentive of Rs 1000 is provided for every confirm TB patient notified by such PP to RNTCP.*
7. *Active case finding has been incorporated in routine RNTCP activities and has been going on for key and vulnerable populations in all five RNTCP districts across the state.*
8. *German Leprosy and TB Relief Association (GLRA) India is supporting MDR TB patients with low BMI (less than 18.5) with nutritional kit in the form protein powder.*

Source: Health and Family Welfare, Government of Sikkim.

#### **4.4.2: RNTCP in Sikkim**

RNTCP was applied in Sikkim during the beginning of 2002, adopting the developed and globally recognised strategy for enhanced and quality diagnostics and treatment for tuberculosis infected people which today is covering every district of Sikkim at large. According to RNTCP Annual Report (2011), the cases of tuberculosis relapse, incidence or death due to tuberculosis has been recorded to be minimal in the state, yet



the spread of new tuberculosis cases has remained high in relation to positive detection (RNTCP, Annual Report 2011). Further, RNTCP has been applied with the vision of eradicating tuberculosis in the state.

Likewise, with the implementation of RNTCP, various infrastructure developments both in terms of institutional development and technologically has been upgraded in the state to meet the objectives of RNTCP as highlighted above. The tuberculosis cell in the state has been formed to overlook the functioning of RNTCP in the state headed by Additional Director-cum State TB Officer under which the District Tuberculosis Officers oversee the TB control activities of the all the four districts.

TB control programme where registration of patients is done have been set up in the state and at present there are 31 microscopic centres out of which 20 are designated funded by dual source. Programme components are funded by World Bank via Central TB Division DGHS, as centrally sponsored scheme. *State Government provides funds for basic infrastructure for delivering services and payments of salaries for regular and MR employees. The funds provided by World Bank are channelled through State Health Societies –NRHM (RNTCP).* (Interview, Dr. Yamphel. Gangtok, 2019).

Similarly, Funds are received in State Health Society and allocated to Districts Health Societies as per RNTCP guidelines (State TB Cell, 2014; Department of Health Care, Human Services & Family Welfare Department, Govt of Sikkim 2014).

RNTCP has been playing a significant role in controlling the disease. It has implemented PMDT (Programmatic Management of Drug Resistant TB) DOTS Plus erstwhile in all the four districts of the state. The PMDT is programmatic management of MDR TB patients using the RNTCP standardized regimen of second line drugs

supplied by government of India. Further the programme has achieved following milestone in managing such patients:

a) Intermediated Reference Laboratory (IRL) has been established and all the equipment's have been installed and shall be functioning soon. The Gene X Pert machine (it is a fully automated machine for diagnosis of MDR TB within 2 hrs) shall be established at IRL, STNM. Microbiologists and laboratory have been trained at TRC (TB Research Centre), Chennai and NTI, Bangalore.

b) The ten bedded DR-TB Centre (MDR TB ward) is established at STNM hospital complex and is plan and functioning since February 2012 for the management of MDRTB patients registered under PMDT.

c) The state Level Coordination Committee and the DOTS plus Site Committee have been established.

d) Central registration for MDR TB patients has been established at STNM hospital to ensure the proper follow up of MDR TB patients registered under the state.

The RNTCP, in Sikkim has been contributing a lot in controlling or curbing the distressing health issues like tuberculosis. The ASHA or Accredited Social Health Activists, initiated under NRHM (National Rural Health Mission) also has a significant role in controlling tuberculosis. They provide TB drug or medicine to the people infected by the disease at the doorsteps particularly in the rural areas. However, despite of such programme and health activists' disease like tuberculosis is spreading and increasing day by day and.

Though RNTCP at present records promising result in cure rate of the disease, it also aims at improving and achieving 85% cure rate of such case. However, to maintain this, the programme had set up five strategies (2013-2014) which are as follows:

- a) Strengthen the quality of DOTS in the state.
- b) Expedite the functioning of the Intermediate Reference Laboratory for the culture and sensitivity testing for DOT-Plus programme and subsequently to incorporate liquid culture and other latest molecular methods.
- c) Enhancement and intensification of the Advocacy, Communication and Social Mobilization (ACSM) activities at community level.
- d) Plans for elimination of TB with three broad components: a) TB Central Registry b) Community Participatory Education Programme c) Migrant Labour Monitoring Programme. The elimination level was placed at less than 1 case per 10,000 populations by 2017.
- e) Establishing additional DOTS Plus site at Namchi Districts Hospital (State TB cell, 2014). In the light of above discussion, it can be said that under RNTCP the state has made achievement in terms of infrastructure, and management of MDR TB patients. However, against the milieu of such achievements under RNTCP, prowl the harsh realities of Tuberculosis still being the dominant disease constituting major public health issues as over 1000 new case of TB is been reported annually (Agarwal, 2015).

With the implementation of WHO recommended TB strategy called Directly Observed Treatment Short course (DOTS), Revised National Tuberculosis Control Programme in Sikkim was established with objectives of

1. To detect and maintain at least 90% of the estimated all forms of TB cases from the community.
2. Achieve and maintain at least a cure rate of 90% in new cases & 85% in previously treated TB cases.

RNTCP Sikkim have implemented Daily DOTS Therapy as per the recommendation given by Central TB Division (CTD), since Feb 2017 using Fixed Dose Combination (FDC) of anti TB drugs. This aims to reduce the morbidity and mortality with early diagnosis and treatment of all TB cases thus eradicating the chain of disease transmission in the community.

In order to reach the above-mentioned aims a defined infrastructure has been set up in the state and they are 1. State TB Cell (1), 2. District TB Centre (5), 3. Tuberculosis Unit (TU) (5), 4. Designated Microscopy Centres (MC)-32 (including 1 at NHPC Hospital at Balutar, Singtam).

**Table 4.2: Infrastructures related to TB in Sikkim**

DTC cum	DMCs	PHSC DOT	ICDS DOT	Community	Total DOT
Tus		Centres	Centres	DOT Centres	Centres
Gangtok	6	26	94	5	131
Singtam	5	22	128	0	156
South	7	39	104	40	190
West	8	40	101	11	160
North	5	19	30	8	62
State	31	146	457	64	699

Source: Health and Family Welfare Department, Government of Sikkim.

- Intermediate Reference Laboratory (IRL)-01-At present it is equipped with rapid molecular technology also known as CBNAAT (Gene X Pert), Solid Culture and DST. Further Liquid Culture and DST will be started soon for

which proficiency testing is being done. Another rapid molecular technology known as Line Probe Assay (LPA) shall be incorporated soon for which essential civil works is completed.

6. 1 Nodal DRTB Centre at STNM Hospital (10 bedded) and 4 District DR TB Centre (5 bedded) (including one at CRH Manipal). The DR TB Centre at Namchi DH has 30 beds facility
7. CBNAAT site -08(including one installed in RNTCP MMU Vehicle).
8. State TB Training & Demonstration Centre (STDC)-01(being upgraded).
9. Sate Drug Store (SDS)-01.
10. Besides above 50 bedded TB block attached with Mangan District Hospital is functional and another 50 bedded TB block attached with Gyalshing District Hospital is being constructed.

In Sikkim every year more than 1500 TB cases are registered with annual incidence rate of 205 per lakh per year. It is also responsible for causing almost 38 deaths with annually death rate of around 6 per lakh population per year. Despite of having a small population of only 6.49 lakhs (projected population forwarded by Central TB Division, New Delhi and same is being used for ascertaining various programme indicators for assessment of programme performance), the trend of drug resistant TB is comparatively higher as compared to national average. Every year almost 37 per lakh population are being diagnosed with drug resistant form of TB as compared to national rate of 11 per lakh population.

*Since 2<sup>nd</sup> quarter 2018, under the direction of CTD, New Delhi a shorter regimen of 9-11 months duration for DR TB patients has been started. (Health and Family Welfare Department, Government of Sikkim)*

**Table 4.3: Details of TB beneficiaries under Nikshay Poshan Yojana (NPY) Since 1<sup>st</sup> April 2018 to 31<sup>st</sup> March 2019**

Scheme name	Total eligible notified	Beneficiaries out of total	Total beneficiaries paid	Amount paid (Rs)
Scheme name	1752		1468	27,12,500

Source: Health and Family Welfare Department, Government of Sikkim

In Sikkim, all TB related schemes and plans are adopted from the plans of Revised National Tuberculosis Control Programme (RNCTP). In order to achieve the general aim of eliminating TB, RNCTP has come up with all possible initiatives. The result of all the plans and measures have shown some impacts however is not showing a good progress as in 2016 total number of DR TB cases registered was 241, then in 2017 number increased up to 262 and recent data of 2018 shows that the number has decreased slowly to 243 (still high than of the 2016).

India has somehow been lacking to tackle the incidences and prevalence of TB. The government of India has announced that they planned to eliminate TB by 2025 during the Union Budget (Kumar, 2017) which is quite ambitious (Pai, et al., 2017) as India falls under the 30 high TB burden countries. Although, as a result the plan has been named as National Strategic Plan (NSP) for eliminating TB by 2025.

*Nikshay: An online TB reporting system for medical practitioner and clinical establishment and was started in the year 2012 in India. It aims to increase the reporting of TB and also collect all the unreported TB cases, especially from the private sectors.*

#### **4.5 National Strategic Plan for TB elimination (2017-2025)**

Ministry of Health and Family Welfare, Government of India has taken a great initiative while coming up with the National Strategic Plan (NSP) which designed with the targeted time period of 2017 to 2025 with the aim to achieve the goals of ending TB in India by 2025. This plan is a complementary plan of WHO to end TB and addresses essential steps of achieving the sustainable development goals (SDG) and End TB Strategy with the determined by the four pillars of “*Detect, Treat, Prevent and Build*” for India.

In order to achieve the targeted goals, NSP has started with the first pillar of detection of disease. The plan is on the early diagnosis of the all forms of Tb cases with giving them the treatment as early as possible with the regimen called drug sensitivity test (DST). Followed by the second pillar of “*treat*”, the NSP is supporting the patient with financial incentives and also as nutritional support. Similarly, as prevent the incidence of TB and also to cut down the chain of disease transmission in the society numbers of measures have taken up such as active case finding programs in the key population, screening of close contact of active TB disease and to provide prophylactic treatment to eligible person with Latent TB infection (children less than 6 years old and people living with HIV infection after

excluding presence of active TB disease in them) and also to implement various airborne infection control measures in the health care setting. (NSP, India)

#### **4.6 The End TB Strategy: The Global Scale**

Being a parent institution related to all kinds of health topic, World Health Organisation has always come up with different goals and strategies to control, stop and eradicate tuberculosis epidemic. According to WHO, the fight against tuberculosis needs to accelerate, especially for those most affected by it: the poorest, socially marginalised more vulnerable and unequally served, and further claims that TB is a public health plague, a threat to health security and a development challenge.

Therefore, to deal with such scourge, the World Health Organisation has come up with a new and holistic goal called “*The End TB Strategy*” which is ratified by the World Health Assembly of all 194 member countries in 2014 covering the time period of 2016-2035.

According to Margaret Chan, Director General of WHO, “*Everyone with TB should have access to the innovative tools and services they need for rapid diagnosis, treatment and care. This is a matter of social justice, fundamental to our goal of universal health coverage. Given the prevalence of drug-resistant tuberculosis, ensuring high quality and complete care will also benefit global health security. I call for intensified global solidarity and action to ensure the success of this transformative End TB Strategy.*”

The three level of indicators and related targets are set for this strategy (for 2030 – linked to the SDGs, and for 2035) and milestones (for 2020 and 2025). The three indicators are: 1. the number of TB deaths per year; 2. the TB incidence rate (new cases per 100 000 population per year); and 3. the percentage of TB patients and their households experiencing catastrophic costs due to TB disease.



**Table 4.4: End TB Strategy Milestone and Targets**

	Milestone		Targets	
			SDG	END TB
	2020	2025	2030	2035
Reduction in no. of TB deaths* <i>compared with 2015 (%)</i>	35%	75%	90%	95%
Reduction in TB in incidence rate <i>* compared with 2015 (%)</i>	20%	50%	80%	90%
TB affected families facing catastrophic costs due to TB (%)	0%	0%	0%	0%
* The United Nations Sustainable Development Goals (SDGs) include ending the TB epidemic by 2030 under goal 3.				

Source: WHO, End TB Strategy, 2015

#### **4.6.1 Pillars and Principles of End Tb Strategy**

The End TB Strategy is basically designed with the pillars and principles in order to reach the target. The main focus of strategy is embedded upon to provide a unified response to ending TB deaths, disease, and suffering. The strategy is built on three pillars underpinned by four key principles and are as follows;

Pillars: Brings together critical interventions to ensure that all people with TB have equitable access to high-quality diagnosis, treatment, care and prevention, without facing catastrophic expenditure or social repercussions.

*Pillar 1: integrated, patient centred TB care and prevention.*

*Pillar 2: Bold policies and Supportive system.*

*Pillar 3: Intensified research and innovation.*

Principles: The success of the strategy in driving down TB deaths and illness will depend on countries respecting the key principles as they implement the interventions outlined in each pillar.

*Principle 1: Government stewardship and accountability, with monitoring and evaluation.*

*Principle 2: Building a strong coalition with civil society and communities.*

*Principle 3: Protecting and promoting human rights, ethics and equity.*

*Principle 4: Adaptation of the strategy and targets at country level with global collaboration.*

Since 1997, every year WHO has been publishing a global TB report. To deliver a wide-ranging and conversant assessment of the TB epidemic and of improvement in prevention, diagnosis and treatment of the disease, at every level be it global, country or regional is the main purposes this report. The report is basically prepared in the framework of recommended global TB strategies and targets authorized by WHO's Member States, wider development goals set up by the United Nations (UN). (WHO, End TB Strategy, 2015)

The global TB report 2019 was published on October 17, 2019 with the addition of targets which was set as per the first UN high level meeting on TB (held in September 2018).

To get the successful result of targets of the End TB, the implementation of this strategy has been decided to accelerate with the Global Ministerial Conference which aims in “*Ending TB in the Sustainable Development Era: A Multisectoral Response*” (ibid).

The data of this Strategy however is not showing positive result. As per the Global Tb report 2019, since 2010, annual declines in incidence have been much slower in the WHO regions of the Eastern Mediterranean (0.9% per year), South-East Asia (2.2% per year) and the Western Pacific (1.6% per year), with cumulative reductions of 2.8%, 6.6% and 3.8%, respectively, for the period 2015–2018. Similarly, annual declines in TB mortality rate have also seen much slower in the WHO Region of the Americas (2.2% per year), Eastern Mediterranean Region (3.6% per year), South East Asia Region (2.2% per year) and Western Pacific Region (3.6% per year), with cumulative reductions of 6.6%, 9.8%, 6.8% and 10.0%, respectively, in the period 2015–2018. This shows that these regions are not on way to reach the 2020 milestone (WHO Global TB Report, 2019).

Therefore, as it is clearly seen from the recent data the South-east Asia Region of World Health Organisation is way more back from the targeted eradication of TB disease. Where India also come under the 30 high TB as well as MDR TB burden countries. The geographical distribution of cases of MDR/RR-TB show that 50% of cases were in India (27%), China (14%) and the Russian Federation (9%). The strategy of WHO’s End TB is somehow lacking in all these above-mentioned regions (WHO Global TB Report, 2019).

In case of Sikkim with the high number of DR-TB cases, the strategy of WHO is implemented through RNTCP, however the result is somehow slow or stagnant. For the

fast and positive result, the acceleration of strategies is important with effective implementation from the very root.

## Chapter V

### **Findings and Conclusion**

The study has attempted to analyse the socio-economic environment and its relation with tuberculosis in Sikkim, particularly in north and east districts. The study was conducted with the following objectives (i) To examine the spatial variations in the incidence of tuberculosis. (ii) To study the socio-economic factors that are responsible for the cause and spread of tuberculosis. (iii) To review the health policies and health care services of tuberculosis. Likewise, the research questions proposed for the study was (a) Are there any spatial variations in the incidence of tuberculosis? (b) What are the socio-economic factors that can be responsible for the cause and spread of tuberculosis? Is there any role of other factors such as consumption pattern, micro-environment, overcrowding, occupation, etc. in the incidence of tuberculosis in Sikkim? (c) What are the socio-economic profiles of tuberculosis patients in Sikkim? (d) Is the general definition of tuberculosis as ‘poor man disease’ applicable in Sikkim? (e) How is the health care policies and services in Sikkim and does it have any influence in the Tuberculosis in Sikkim?

After understanding and meticulously analysing the available materials, data and samples for pursuance of this study, the findings and conclusions are thematised as per the objectives. As according to the first objective, the study has attempted to examine the spatial variation in the incidence of tuberculosis. The global spatial pattern of tuberculosis indicates that the incidence and prevalence of tuberculosis is densely distributed mainly in the developing countries for e.g. (China and India) or are still underdeveloped (Bangladesh and Central African Republic). As according to the WHO global TB Report, 2019 among the sis WHO Regions, most of the regions which have

high TB burden are South East Asia, African Region etc. and the lowest being the European Region.

Among all India as a country accounts for one of the high-ranking TB burden Country in incidences and prevalence of tuberculosis. It is estimated from the global TB report that 10 million people had TB in 2018 where India accounted for 27% of the world total with 130,000 drug resistant cases.

Sikkim as a region is also facing numbers of TB or more importantly MDR-TB cases. The spatial pattern of TB in Sikkim is little opposite as compare to the global spatial pattern of tuberculosis. Among the four districts of Sikkim, East district which is more developed yet highly as well as densely populated has the highest rate of incidence and prevalence of tuberculosis. Contrast to that north district in Sikkim is less developed or urbanised than east Sikkim and also less populated as well as less densely populated or sparsely distributed.

As in the case of Sikkim and particularly from the North and East district, East district of Sikkim has the high number of incidences of tuberculosis/ prevalence as pre the data given by Central TB Division (2018), 536+295 cases were recorded out of the population of 2.01(Gangtok) and 1.01(Singtam) lakhs and north district accounts for 110 tuberculosis cases out of the population of 0.46 lakhs. The total TB cases in Sikkim as a whole is 1476 out of the population of 6.49 lakh. East district alone contributes 36% (Gangtok) and 20% (Singtam) to total tuberculosis Cases and north as only 7%. However, here it is important to notice that if the percentage TB cases in each district with its own total population then the ratio does not vary that high as east has 0.28 percentage and north has 0.24 percentage. It has also been important to highlight that most of the case from north district has been diagnosed in the hospitals of East District

which explains that most of the cases in North district has its actual infection root in East District.

As per the policy of RNTCP, the diagnosed TB patients should get treatment from its respective place or permanent address, it makes easier to analyse that exact data of the infected people however the root of the infection should also analyse in order to examine the spread of the incidence and prevalence of the tuberculosis. According to one of the public health care providers (PHCP 3), some of tuberculosis patient are not the permanent resident of the Sikkim however they are residing here from a long period of time so in such cases they are registering them in their respective postal address. Therefore, while counting the Tuberculosis cases they are also registered in the respective places.

The factor contributing to such spatial pattern in global, national as well as state are many. The medical, social, economic, environmental, political, etc. does plays an important role in the designing of spatial variation of tuberculosis.

The spatial pattern and distribution of TB have lot more to say and can explain the dynamics of TB. The spatial pattern of TB in global level, national level and local level does not always have similar pattern and distribution. The impacts and causes of TB cases with such spatial pattern and variations are to be analysed intensively and was attempted to analyse through the perspective of socio-economic aspect in the second chapter of the study.

The second objective of the study deals with the socio-economic analysis of tuberculosis. The scientific fact about the tuberculosis is not challenged by this study instead is trying to incorporate the socio-economical aspect to further analysis of tuberculosis in Sikkim. The Socio-economic factors are directly or indirectly

responsible for the cause and spread of TB in Sikkim. Socio economic factors such as material deprivation, employment, income inequality, cultural, age, gender, education, knowledge of the disease, etc. are analysed in the study and it is found that even other factors such as consumption pattern, micro-environment, carelessness of the patients are the cause and impact of the tuberculosis in Sikkim.

Talking about the Socio-economic profile of the tuberculosis patients in Sikkim, most of the people belongs to low income rate family. Out of 10 interviewed patients the all of them belonged to low income families. However, only the economy does not have its major role, other factors does have its influence on TB and the general definition of tuberculosis as a poor man disease is true in some measure but only as it has a high risk among economically deprived people with poor living condition, lack of nutritious food, inaccessibility to healthy drinking water, etc. The incidence and prevalence of TB cases has the high risk among the economically weak people so as economy is one of the main causes of tuberculosis and the consequences of which is showing its impact on the social life of people. On the other side sometimes the social interaction of people may cause tuberculosis which can impact the economy of the individual, household, state and even country. Therefore, the analysis of socio-economic condition of the people while studying the case of tuberculosis is important.

As per the findings of the study and as according to the narratives embedded in the study the socio-economic conditions or the socio-economic factors has played a major role in overall health care and the prevalence and incidences of tuberculosis in Sikkim. Therefore, in case of east district, the socioeconomic factors have played a crucial role in controlling the incidents of TB as economy status plays of the infected person, plays an important role in accessing the overall health care facilities, especially in case of tuberculosis. The social fact and the economic conditions are directly related to each



other as one's economic condition decide the social position, and the capability to access various facilities to sustain everyday life. As mentioned in previous chapters the economic conditions of respondents were not stable therefore, the socio-economic condition had played an important role in fighting the disease in their respected lives, the cost of medication, the accessibility to healthcare facilities or be it the nutritional expenses in case of infected persons was high.

Though the government has been providing basic healthcare facilities and medicines to the infected persons along with the nutritional expenses, still the cost of treatment is not covered fully. Therefore, looking at the cases examine for the study the findings indicate that in case of tuberculosis socio-economic condition of the patient or of the infected persons becomes equally important in fighting the disease.

The social stigma to tuberculosis is sincerely beyond the imagination. Even if the patient is fully recovered and cured from any type of TB, the patient can never recover fully from the social stigma that one's goes through. Once infected with tuberculosis is never cured is what society think. The acceptance of society is important regarding TB and society should approach TB as curable disease. Both medicines and society (stakeholders) have an equal role and importance while a TB diseased patient goes through treatment procedures. Social support is what has its immense contribution in helping the recovery of a TB diseased patient as TB is not acceptable in society.

Likewise, tuberculosis which was once discussed to be a poor man's disease has transformed with time to become a social disease. The, social stigma attached with disease also becomes a prime factor for fighting the disease. Social stigma is basically attached with the economy. The economically weak people are the one who are experiencing the social exclusion in the society. The record of the economically

wellbeing people are very less and the reason behind it is one that they are financially rich and with that they usually go to private medical institution for their treatment so their high chance that their TB cases are not registered with that they are at low risk to experience social exclusion due to tuberculosis. It is a social fact that economically weaker section is at high risk of tuberculosis.

The third objective of the study is more focused on the healthcare facilities and services in Sikkim particularly TB. With the analysis of the healthcare services it has been noticed that the healthcare services and facilities for tuberculosis is in all possible way provided in global, national and state level. In global level WHO has come up with number of strategies such as End TB by 2020, Stop Tb etc. and in national level the RNTCP take cares of the policies, programmes and services related to tuberculosis. In Sikkim, there is no particular or its own health policies for tuberculosis, and it has been following policies of the RNTCP. However, Sikkim government has come up with the policy to provide Rs 2500 each month to each and every TB patient with certificate of Identification (COI) or Sikkim Subject (SS) holder in order to help them with financial support.

As mention earlier Sikkim does not have its own tuberculosis programme and is following the programme of RNTCP and the result of the programmes related to eradicate the incidence and prevalence of TB cases is very slow or quite stagnant in Sikkim with increasing number of MDR TB cases which over the span of time has become an alarming issue in Sikkim. Therefore, the policies and programmes of RNTCP in Sikkim should be further examine, accordingly keeping the geographical location, social and cultural tradition of Sikkim in mind. Further so it would be even better if Sikkim could come up with its own policies complementing RNTCP as it is not enough.

The decentralisation of the planning is also important in order to eradicate the causes from its root. Till now the plans and aims to eradicate TB is centralised WHO to at the top planning in a global scale and RNTCP to be in India. So that the decentralised planning is important to make the End TB Programme successful. It has been critically analysed by number of scholar that RNTCP has number of shortcoming and gaps in the process of eliminating TB in India. Pai, et al. (2017), has highlighted detailed shortcomings of RNTCP, major being the lack of investment in health-related projects, unnotified TB cases, involvement of private sectors, investment in research and surveillance, and the involvement of civil society.

In the cases like Sikkim and also other the government should really focus on the bottom to top approach plays and important role for any successful planning than the top to bottom approach. Due to lack of bottom to top approach in the planning and policies of TB, the essential awareness and counselling has been seen as a major gap in the planning. Each and every one be aware of basic knowledge about DSTB, MDR TB, XDR TB, pulmonary TB, extrapulmonary TB, Zoonotic TB, etc and its risk factors, precautions, prevention measures etc.

With only being able to a proper knowledge about any disease could save some lives (especially suicidal). Even in 21<sup>st</sup> century TB is still a vast issue all around the world and specially in economically weak countries where even small State of India, Sikkim comes to contribute its huge number with MDR TB cases and the participation of each individuals will make a huge contribution and immense help in eradicating and controlling TB disease. In order to eradicate and control Tb in Sikkim it is important to understand the physical, economic, social and cultural setting of Sikkim. Not only the technical issues however the ethical issue related to Tb prevention, treatment and care plays an important role in controlling such plague. The approaches to TB care need to

address ethical issues for winning the confidence and cooperation of patients as well as care providers.

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## Appendix I

### Glossary of Terms Related to Tuberculosis (TB)

**TB disease** – An illness in which TB bacteria are multiplying and attacking a part of the body, usually the lungs. The symptoms of TB disease include weakness, weight loss, fever, no appetite, chills, and sweating at night. Other symptoms of TB disease depend on where in the body the bacteria are growing. If TB disease is in the lungs (pulmonary TB), the symptoms may include a bad cough, pain in the chest, or coughing up blood. A person with TB disease may be infectious and spread TB bacteria to others.

**BCG** – A vaccine for TB named after the French scientists who developed it, Calmette and Guérin. BCG is rarely used in the United States, but it is often given to infants and small children in other countries where TB is common.

**Chest x-ray** – A picture of the inside of your chest. A chest x-ray is made by exposing a film to x-rays that pass through the chest. A doctor can look at this film to see whether TB bacteria have damaged the lungs.

**Contact** – A person who has spent time with a person with infectious TB.

**Culture** – A test to see whether there are TB bacteria in your phlegm or other body fluids. This test can take 2 to 4 weeks in most laboratories.

**Directly observed therapy (DOT)** – A way of helping patients take their medicines for TB. If you get DOT, you will meet with a health care worker every day or several times a week. You will meet at a place you both agree on. This can be the TB clinic, your home or work, or any other convenient location. You will take your medicines while the health care worker watches.

**Extensively drug-resistant TB (XDR TB)**- XDR TB is a rare type of TB disease that is resistant to nearly all medicines used to treat TB.

**Extrapulmonary TB** – TB disease in any part of the body other than the lungs (for example, the kidney, spine, brain, or lymph nodes).

**HIV infection** – Infection with the human immunodeficiency virus, the virus that causes

AIDS (acquired immunodeficiency syndrome). A person with both latent TB infection and HIV infection is at very high risk for developing TB disease.

**Isoniazid (INH)** – A medicine used to prevent TB disease in people who have latent TB infection. INH is also one of the four medicines often used to treat TB disease.

**Latent TB infection**– a condition in which TB bacteria are alive, but inactive in the body. People with latent TB infection have no symptoms, don't feel sick, can't spread TB bacteria to others, and usually have a positive TB test. But they may develop TB disease if they do not receive treatment for latent TB infection.

**Multidrug-resistant TB (MDR TB)** – TB disease caused by bacteria resistant to two or more of the most important medicines: INH and RIF. *Mycobacterium tuberculosis* – bacteria that cause latent TB infection and TB disease.

**Negative**– Usually refers to a test result. If you have a negative TB skin test reaction or TB blood test, you probably do not have TB infection.

**Positive** – Usually refers to a test result. If you have a positive TB skin test reaction or TB blood test, you probably have TB infection.

**Pulmonary TB**– TB disease that occurs in the lungs, usually producing a cough that lasts 3 weeks or longer. Most TB disease is pulmonary.

**Resistant bacteria** – Bacteria that can no longer be killed by a certain medicine.

**Rifampin (RIF)**– One of the four medicines often used to treat TB disease.

**Rifapentine (RPT)**– One of two medicines used to treat latent TB infection.

**Smear**– A test to see whether there are TB bacteria in your phlegm (sputum). To do this test, lab workers smear the sputum on a glass slide, stain the slide with a special dye, and look for any TB bacteria on the slide. This test usually takes 1 day to get the results.

**Sputum** – Phlegm coughed up from deep inside the lungs. Sputum is examined for TB bacteria using a smear; part of the sputum can also be used to do a culture.

**TB skin test**– A test that is often used to find out if you are infected with TB bacteria. A liquid called tuberculin is injected into the skin on the lower part of your arm. If you have a positive reaction to this test, you probably have TB infection. Other tests will be needed to find out if you have latent TB infection or TB disease.

**TB blood test**– A test that uses a blood sample to find out if you are infected with TB bacteria. The test measures the response to TB proteins when they are mixed with a small amount of blood. Examples of these TB blood tests include QuantiFERON®-TB Gold In-Tube test (QFT-GIT) and T-Spot ®. TB test.

**Tuberculin or PPD** – A liquid that is injected into the skin on the lower part of your arm during a TB skin test. If you have TB infection, you will probably have a positive reaction to the tuberculin.

Source: Questions and Answers about Tuberculosis (TB), 2014, CDCP (Centre for Disease Control and Prevention)

**Incidence of Tuberculosis (TB):** the number of TB cases in one year per 100,000 population.

**Prevalence of Tuberculosis (TB):** the number of TB cases in a population at a given point in time per 100, 000 population.

**Death rate associated with TB:** Death rate associated with TB are defined as the estimated number of deaths due to TB in one year per 100, 000 population.

### **Other Important Terms**

**Medical Geography:** An important “new” area of health research that is a hybrid between the geography and medicine dealing with the geographic aspects of health and health care. Medical geography studies the effects of locale and climate upon health.

**Health Geography:** The study of health geography has been influenced by repositioning medical geography within the field of social geography due to a shift towards a social model in health care, rather than a medical model.

## Appendix II

### Interviewing one of the Public healthcare Provider



Source: Fieldwork, 2019.

### CBNAAT (Cartridge Based Nucleic Acid Amplification Test), An equipment for testing the Sputum



Source: Fieldwork, 2019.



**District Hospital, Mangan, North Sikkim**



Source: Fieldwork, 2019.

**District Tuberculosis Centre (DTC), Mangan, North Sikkim**



Source: Fieldwork, 2019.

STNM Multi-speciality Hospital, Gangtok



Source: Fieldwork, 2019.

District Tuberculosis Centre (DTC), Gangtok, East Sikkim



Source: Fieldwork, 2019.

## Tuberculosis Patients



Source: While visiting Hospitals during fieldwork, 2019.

*Disclaimer: Pictures were taken with the consent of the patients and are blurred to maintain their privacy.*