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# Tuberculosis in the Elderly

## Rapid Assessment Report

### India (2023)



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## Message from NTEP



सत्यमेव जयते



**Dr. Rajendra P. Joshi**  
Deputy Director General  
Central TB Division

भारत सरकार  
GOVERNMENT OF INDIA  
स्वास्थ्य और परिवार कल्याण मंत्रालय  
MINISTRY OF HEALTH & FAMILY WELFARE  
ROOM NO. G2 (GROUND FLOOR),  
JEEVAN VIHAR BUILDING, 3, SANSAD MARG,  
CONNAUGHT PLACE  
NEW DELHI - 110001  
ddgtb@rntcp.org  
ddgtb-mohfw@gov.in  
011-21400941

### Message from Central TB Division

In March 2023, the Honourable Prime Minister of India reiterated the nation's commitment to achieving a TB-free India, launching several new initiatives to build on our successes and achievements to date. The TB response in India has been swift to recover from the impact of the COVID-19 pandemic, with an annual case notification of over 24 lakhs, higher than the pre-pandemic high in 2019.

To achieve our ambitious goal, the Central TB Division is working in mission mode through a multi-pronged approach. We have rolled out new strategies, adopted new tools and introduced new regimens, all intended to achieve our vision of providing high-quality, person-centred services. This includes a focus on those most vulnerable and at risk, including the elderly, who need clinical and social support to seek timely care and be cured of TB. In fact, the findings of the recent National Prevalence Survey showed a high prevalence of TB in the elderly, at 588 per 100,000 as compared to the national average of 316.

The elderly population in India is steadily growing in size; advances in health care and improvement in health services has led to a longer life span. This means that we must pay greater attention to the health of the elderly and develop new strategies for their continued longevity, improved quality of life and better health outcomes.

I am very pleased that REACH, with support from USAID, has undertaken this important rapid assessment of TB in the elderly, the first such in India. This report presents an epidemiological profile of TB in the elderly, identifies their physical and socio-economic needs and presents recommendations for our collective action. India's National Strategic Plan for TB Elimination (2020-25) recognises the need for a comprehensive TB-Geriatrics framework and this report is an important first step in this direction.

On behalf of the Central TB Division, I congratulate and thank all those who have provided their valuable inputs to this assessment. We look forward to working together to develop and implement robust strategies to focus on tuberculosis among the elderly population in India.

(Dr. Rajendra P Joshi)

## Message from USAID/India

For several decades, the United States and India have worked together to combat tuberculosis (TB) by improving patient-centered diagnosis, treatment, and prevention. The United States Agency for International Development (USAID) is proud to work with the National TB Elimination Programme (NTEP) in India, supporting the Government of India's goal to end TB, while enhancing global health security.

Towards this goal, USAID is actively implementing the ALLIES (Accountability Leadership by Local Communities for Inclusive, Enabling Services) project to assist the NTEP in India. Our approach encompasses community-led actions, including the implementation of the Community Accountability Framework, and focuses on TB in the elderly and individuals with disabilities.

This report presents USAID's findings of a groundbreaking rapid assessment, focusing on the intersection of TB in the elderly — a first-of-its-kind study in India. With India's rapidly growing elderly population, it is crucial to prioritize the health of this demographic, considering their distinct physical, social, and emotional needs. To minimize diagnostic delays, enhance treatment outcomes, and tackle subconscious age-related biases, it is essential to strengthen both clinical care and supportive systems for elderly individuals affected by TB.

USAID is confident that this collaborative rapid assessment on TB in the elderly, with inputs from various stakeholders, will significantly raise awareness on this critical issue. The findings will support collective knowledge and understanding of geriatric TB, leading to more inclusive and accessible TB services for the elderly.

Aligned with our commitment to diversity, equity, inclusion and accessibility, USAID proudly supports this assessment and commends REACH for raising awareness on the complex intersections of TB in the elderly. USAID remains committed to supporting the Government of India in their nationwide efforts to eliminate TB, striving for a future where everyone, regardless of background or abilities, can live free from the burden of TB.

*Sangita Patel*  
**Ms. Sangita Patel**  
Director, Health Office  
USAID/India

## Message from REACH

As we continue our tireless efforts to combat tuberculosis (TB) in India, we see first-hand the full extent of the impact of this disease on individuals, families, and communities across the country. Over the last few decades, we have made remarkable strides in raising awareness, expanding access to diagnosis and treatment, providing nutritional support and reducing TB incidence and mortality – all while ensuring high standards of TB care. But certain demographics, such as the elderly, need our greater attention we cannot overlook the unique challenges they face.

The elderly population, with their co-existing health conditions, is at a higher risk of contracting TB. In addition, they often face barriers that hinder their access to proper healthcare, including limited awareness, financial constraints, lack of mobility, and difficulties in seeking timely medical attention.

As the country celebrates longer life expectancy and improved healthcare, we also face the urgent task of ensuring that our senior citizens are not left behind in our fight against TB. Currently, there are no elderly-specific guidelines in place, at the global or national levels. We, therefore, undertook this national-level rapid assessment, the first of its kind, to identify the specific vulnerabilities faced by elderly people with TB, review existing guidelines, and share recommendations to address gaps in knowledge and care delivery systems.

We are delighted to present this rapid assessment and thank all senior officials, technical experts, NTEP teams, TB Champions, TB survivors, people on treatment for TB and their family members who shared their experiences and insights for this research. The findings in this report present specific areas for our intervention to identify and respond to the unique physical, social and emotional needs of elderly people affected by TB.

We are grateful to USAID for their constant support to undertake this rapid assessment, as part of the Accountability Leadership by Local Communities for Inclusive, Enabling Services (ALLIES) project.

Finally, we are grateful to the Central TB Division team for their steadfast leadership and guidance. We are deeply committed to continuing to work together to achieve our collective dream of a TB-free India.



**Dr. Ramya Ananthakrishnan**

Director, REACH

## Acknowledgements

This rapid assessment was conceptualised by Dr. Ramya Ananthakrishnan, Director, REACH and Ms. Anupama Srinivasan, Asst. Director, REACH; authored by Dr. Manjot Kaur, Consultant, REACH; with support and inputs from Mr. Subrat Mohanty, Sr. Advisor and Project Lead, REACH and Dr. Sripriya Pandurangan, Deputy Project Lead, REACH.

We thank all senior officials, programme implementers and technical experts who accepted our request to be interviewed for this rapid assessment and provided their valuable time and inputs, including Dr Nishant Kumar, Joint Director (TB), Central TB Division, Ministry of Health and Family Welfare, Govt. of India; State TB Officers of Chhattisgarh, Uttar Pradesh and Sikkim; District TB Officers, District PPM Coordinators and other NTEP staff. We are very grateful to the following technical experts for their participation in this rapid assessment: Dr Rohit Sarin, Principal Consultant and former Director, National Institute of Tuberculosis and Respiratory Diseases; Dr Reuben Swamickan, Chief, Infectious Diseases Division, USAID/India; Dr. Kiran Rade, NPO, TB Epidemiology, World Health Organisation (WHO); Dr. Ashish Goyal, Geriatric Specialist

and President, Indian Academy of Geriatrics; Dr. Thangam D, Geriatric specialist and General Secretary, Indian Academy of Geriatrics; Dr. Kshitij Khaparde, Regional TB Lead, WHO; Dr. Dina Nair, Scientist, NIRT; and other WHO Consultants who provided critical inputs.

We are deeply grateful to all the TB Champions, TB survivors, people on treatment for TB and their family members who shared their experiences and insights for this assessment.

We express our sincere gratitude to the USAID/India team, including Ms. Sangita Patel, Director, Health Office; Dr Reuben Swamickan; and Ms. Amrita Goswami, Development Assistance Specialist for their support, technical guidance and the opportunity to undertake this rapid assessment, as part of the Accountability Leadership by Local Communities for Inclusive, Enabling Services (ALLIES) project.

Finally, we gratefully acknowledge the continued support and guidance of the Central TB Division and senior officials at the Ministry of Health and Family Welfare, Govt. of India.

## Contents

<b>Executive Summary</b>	<b>12</b>
<b>1. Introduction</b>	<b>13</b>
<b>2. Epidemiology</b>	<b>17</b>
<b>3. Access to care: needs and experiences</b>	<b>24</b>
<b>4. Policies and guidelines for TB in the elderly</b>	<b>33</b>
<b>5. Summary: Recommendations for the future</b>	<b>36</b>
<b>6. Conclusion</b>	<b>40</b>
<b>7. Appendices</b>	<b>40</b>

### List of figures

Figure 1: Age-disaggregated TB incidence [Global TB report 2020]	18
Figure 2: The proportion of notified TB cases aged $\geq 65$ in Japan, the Republic of Korea, Singapore, China, the Western Pacific region, and globally 2013-2020 [Global TB report 2021]	19
Figure 3: Wide ranging opinions on stigma experienced by the elderly people with TB	27
Figure 4: Results from a facility-based screening project in four districts in Tamil Nadu	29
Figure 5: Key Affected Populations [National Strategic Plan]	35
Figure 6: Summary of interviews with representatives of affected communities -1	40
Figure 7: Summary of interviews with representatives of affected communities -2	41

### List of tables

Table 1: Retrospective studies in India examining treatment outcomes in the elderly	21
Table 2: Key documents with missing guidance on the TB in the elderly	35

### List of boxes

Box 1: Defining "the elderly"	14
Box 2: Findings from a Facility-based screening project in Tamil Nadu	29
Box 3: Responsiveness towards the elderly in public vs private healthcare sectors	31
Box 4: Regional variations in attitudes towards the elderly	33
Box 5: Timeline of geriatric policy development in India	34

## Executive Summary

There are at least three powerful reasons to develop a better understanding of Tuberculosis (TB) among the elderly. Firstly, the elderly are a large (and rapidly growing) cohort: in India, people over the age of 60 are projected to increase from 9% of the total population in 2011 to 13% of the total population in 2026. Secondly, this population has a higher susceptibility to all infectious as well as non-infectious diseases. As such, they are not only an important group to focus on in terms of access to health but are also significant from an epidemiological perspective. Thirdly, there are large gaps in our knowledge and understanding at multiple levels for this age group – policy, epidemiological understanding clinical guidelines to name a few.

This national-level rapid assessment on Tuberculosis in the elderly, the first of its kind in India, was undertaken by REACH in 2022-23, with support from USAID. The rapid assessment was carried out through a combination of desk research and qualitative research focusing on interviews with affected communities, TB programme implementers, technical and policy experts. The assessment included a review of existing epidemiological data and research to understand the TB burden in this cohort, an examination of existing guidelines and current practices and identification of some specific areas for interventions to strengthen India's response to TB in the elderly.

There is increasing evidence, from studies in India and other high-burden countries, that older people are more vulnerable to develop TB. India's recent National TB Prevalence Survey, completed in 2021, revealed that the prevalence of TB in people aged 55+ is 588, considerably higher than the overall national prevalence of 316. Further, there is a significant burden of undiagnosed TB among older adults in low and middle-income countries, and the health service disruptions due to COVID-19 have affected this population disproportionately to a higher degree. Other epidemiological insights from this rapid assessment are that the rates of adherence for successful treatment outcomes are lower among elderly people with TB, and that mortality rates are higher.

In the context of lived experiences of elderly people with TB, the assessment showed that factors which most impact a person with TB's journey through the care cascade include physical vulnerabilities due to age and loss of economic independence worsened by poor linkages to financial support mechanisms. Other factors which influence individual experiences are challenges around access to information, nutrition, societal and individual behavior patterns around age, mental health and stigma.

The assessment identified gaps at the level of policy (global and national-levels) as well as programmatic implementation when it comes to TB in the elderly. The first of the gaps is in data reporting itself - TB data is not often disaggregated by age and gender while analysing and reporting (global and national reports primarily use the distinction of children and adults when describing TB landscapes). At the health system level, there are challenges at all levels of implementation - targeted case finding, access to facilities for diagnosis and treatment, service provider capacity and support systems. These challenges point to a need for re-examination of our systems through a lens of responsiveness towards the elderly.

## 1. Introduction

Older people are a valuable societal resource – a resource that is admittedly associated with many challenges, but also has the potential to realise many opportunities. Understanding these challenges and opportunities is an essential task in humanity's progress towards health and well-being for all. As a result of interconnected factors like improved health care services, decreasing fertility rates and increased life expectancy, the cohort of elderly people is increasing in size across the world - it is estimated that by 2030 there will be 34 nations where over 20% of the population is above 65 years of age<sup>1</sup>. India, according to the last census (Census 2011), has 104 million people over the age of 60 years, i.e., 8.6% of the total population; this is projected to be at 12.6% of the total population by 2026<sup>2</sup>.

In addition to the size of the cohort, there are two further reasons why an increased attention on the health of the elderly is necessary. First, due to age-related changes in all systems of the body – from the cardiovascular to the immune system - this population is more vulnerable to both communicable and non-communicable diseases. Second, the health needs of the elderly population are understood to a much lower degree compared to any other population, creating a significant knowledge gap. Even the definition of 'elderly' is not straightforward (see box 1). Clinical practice guidelines also do not adequately define 'elderly' persons and provide limited guidance on how to apply treatment recommendations to older persons<sup>3</sup>.

The three above-mentioned factors – large and rapidly increasing size, greater vulnerability to diseases and large gaps in understanding – make a strong case for a greater focus on senior health, to prevent and mitigate poor

health, catastrophic health expenditures and poor quality of life in this population.

### 1.1 Purpose of the document

This rapid assessment has examined Tuberculosis from the perspective of geriatric health, covering aspects such as the scale of the challenge, age-specific vulnerabilities, current understanding and systems and recommendations for addressing gaps in knowledge and care delivery systems.

TB is an apt lens through which elderly health can be focused on – it infects over 10 million and kills over 500,000 people across the world every year. Before COVID-19, it was the leading cause of death among all infectious diseases. It is also the disease that shines the harshest spotlight on injustice and inequity: in spite of the sheer scale of the TB burden, it continues to be a blind spot in public awareness because unlike COVID-19, it primarily affects the poorest and the most vulnerable people in the world.

Even within the populations affected by TB, there are sub-groups that are more at-risk than the others. There have been some movements to recognise that diagnostic and therapeutic approaches need to be adjusted according to affected populations rather than a 'one size fit all' approach. Population specific approaches have led to customised guidelines for children, people living with HIV (PLHIVs), tribal populations and other vulnerable groups. Further, gender-sensitive and specific approaches have been outlined. In fact, India is one of the first countries to utilize the Communities, Rights and Gender tools developed by the Stop TB Partnership.

1. <https://www.who.int/india/health-topics/ageing>; accessed on 15 Aug 2022
2. Government of India. Elderly in India: 2016. New Delhi: Central statistics Office, Ministry of Statistics & Programme Implementation, Government of India; 2016.
3. Singh S, Bajorek B. Defining 'elderly' in clinical practice guidelines for pharmacotherapy. Pharm Pract (Granada). 2014 Oct;12(4):489. doi: 10.4321/s1886-36552014000400007. Epub 2014 Mar 15. PMID: 25580172; PMCID: PMC4282767.

## Who are 'the elderly'?

The less-than-ideal state of understanding around the needs of the elderly is underscored by the absence of a clear definition of the cohort. WHO factsheets refer to populations above the age of 65 as the elderly, whereas the Government of India uses the term for people over the age of 60 in all policy documents. The National TB Prevalence Survey highlights the unique challenges of older people with TB by examining people over the age of 55 (the survey uses two sub-categories for this cohort – 55 to 64, and 65 and above).

This question of definition was included in the interviews in this rapid assessment. While all representatives of affected communities (people with TB, survivors, caregivers) believed that people over the age of 60 should be classified as the elderly (likely to be a reflection of their experiences of existing government policies, especially policies around pensions and other benefits), technical experts had three additional observations on this aspect:

- **Defining ageing as a continuum:** Just like gender, age can be seen as a continuum rather than a clear cut-off. Ageing increasingly adds physical and mental health challenges to the experience of life, and the extent of these challenges is determined by other factors like socio-economic status and gender. An awareness of these factors and the role they play is an essential component of elderly care. **However, for the purpose of care delivery, a cut-off age of 60 can continue to be a useful marker to identify and care for people vulnerable to age-related health issues.**
- **Defining ageing in the light of a country's progress:** As countries improve their overall health and socio-economic conditions, elderly health improves too, a trend that is reflected in policies around increasing the age of retirement from government positions (the retirement age in India has increased from 58 in 1998 to 60 in 2004; in the US, the age of retirement is 65 as of 2010). It is possible that, in future, policymakers focusing on geriatric health in India will define the elderly as people over the age of 65.
- **Intersectionality of age and socio-economic factors:** There are many contextual factors which play a role in the health experiences of the elderly. These can include gender, geography, ethnicity, education, employment status, income levels, sexual orientation, disability status and so on. It is easy to envision that the experiences of an 80-year-old male in a high-income household may be different (and better) in comparison to a 60-year woman in a low-income home. Therefore, while age-responsive policies can use a pre-defined age cut-off to provide targeted support, it is important to consider the possibility of building adaptable, people-centric care systems that recognise the intersectionality of socioeconomic factors with age, and can respond to the unique needs of individuals.

Box 1: Defining "the elderly"

In spite of these encouraging developments, the elderly age group continues to remain, comparatively speaking, under the radar of TB elimination strategies. There are no elderly-specific guidelines in place at the global or national levels even though there is increasing evidence that the geriatric population is highly vulnerable to TB, with increased risk due to multiple comorbidities, higher death rates and more unfavourable treatment outcomes.

Contemporary India has seen many societal changes that have made it necessary to examine the rights of elderly people in India, especially rights related to health. Factors such as urban development, regional variations in development and urban migration have adversely impacted elderly people's health and vulnerability. There is evidence that older people regularly experience the ill effects of senior maltreatment, and that elderly persons are excluded from health programmes, either deliberately or unwittingly. This is especially true for elder women, indigenous elder persons, elder migrants and older persons from the LGBTQI+ community<sup>4</sup>. The absence of age-responsive considerations in all healthcare programmes in the country needs urgent attention.

An equitable approach to ending TB, which requires that health policy and programmes prioritise the needs of those often left behind, begins with an understanding of all barriers to accessing TB services, and this includes barriers related to age. There are plenty of data-backed studies (many of which are referenced in this report) as well as anecdotes which indicate that the elderly disproportionately experience access-related challenges, exclusion, stigma and poor treatment outcomes, making them

one of the most vulnerable groups for TB. In addition, there are at least two additional, epidemiologically significant reasons why the current lack of attention towards TB in the elderly needs to urgently shift:

- Persistence of TB in this large and rapidly increasing age group may become an important source of transmission and perpetuate the pool of infection in the community.
- The clinical presentation of the disease onset and progress of illness may be different in the elderly from the rest of the population, making diagnosis as well as treatment more challenging.

**India's National Strategic Plan for TB (NSP 2020-25) does identify TB-Geriatrics as an important area for strategic intervention. The NSP describes the need to develop a framework to address TB among the elderly and their specific needs, and establish a collaborative approach to improving screening for TB in specific settings with vulnerable elderly populations. No such frameworks are in place as yet, and although there are some examples of focused interventions (screening in old age homes, creation of geriatric OPDs), these are not routine, and far from systemic.**

4. Right to Health as Human Right for the Elderly Persons in India. International Journal of Law Management & Humanities. Volume 4 Issue 1. Available at: <https://www.ijlmh.com/wp-content/uploads/Right-to-Health-as-Human-Right-for-the-Elderly-Persons-in-India.pdf>. Accessed on 5 April 2023.



## 1.2 Objectives

Through this assessment, REACH proposes to initiate discussions to address gaps in the knowledge around TB in the elderly, and to strengthen our collective understanding of the unique challenges that this age group faces in the TB context. The goal is to build a pathway through which India can arrive at clear strategies to identify and respond to the unique physical, social and emotional needs of elderly people affected by TB. As such, there were three objectives for the rapid assessment:

1. To review existing epidemiological data and research to understand the TB burden among people over the age of 60, as well as challenges unique to this age group
2. To review existing guidelines and current practices
3. To identify specific areas for interventions and to make recommendations to strengthen the response to TB in the elderly in India

## 1.3 Methodology

This rapid assessment of the current state of challenges and opportunities in TB service delivery for elderly people in India is not intended to be a research study. As such, it is not based on statistically significant data sampling methods. The assessment is intended to provide a high-level overview and perspective into an important dimension of the TB response.

**Desk review:** The desk review focused on the current state of understanding on three key areas in relation to TB in the elderly:

1. Epidemiology – risk factors, incidence, prevalence, diagnosis, treatment
2. Access to care: needs, experiences and challenges in the TB care cascade
3. Policies, guidance and recommendations to influence health system practices

For each of these areas, the desk review makes an attempt to first summarise the existing

knowledge, and then to build a picture of gaps in knowledge.

**Qualitative research:** Knowledge gaps that emerged from the desk review were used as inputs for designing questions for qualitative research to gather insights from people across three key categories:

- a. Affected communities** – elderly people with TB and their families/caregivers, TB survivors and TB Champions. This included 25 people, of which 9 were elderly TB survivors or people with TB, 2 were family members of TB survivors, and 14 were TB survivor-Champions.
- b. TB programme implementers** - care delivery personnel in public and private health systems. This included 11 people from seven states (Assam, Chhattisgarh, Delhi, Maharashtra, Sikkim, Uttar Pradesh and West Bengal)
- c. TB technical experts and policy experts** connected working closely with the NTEP. This included a total of 9 people who were representatives of WHO, USAID, NIRT, NITRD as well as private practitioners.

Gathering experiences and views from each of these three categories of people was helpful in crafting a comprehensive picture of the unique needs of elderly people with TB, and also led to a list of recommendations for improvements in the care delivery ecosystem.

### Areas not in scope

The following areas are not covered in this rapid assessment:

- Pathophysiology of TB in the elderly
- Diagnostic recommendations
- Treatment recommendations

## 2. Epidemiology

Broadly speaking, in comparison to younger populations, the elderly experience a higher predisposition to infection, a decreased capacity to mount a response to diseases, and a decreased response to treatment. Specifically for TB, the disease may have a very different epidemiological profile in the elderly, with variations observable across the entire length of the care cascade – including risk factors, trends in incidence and prevalence, diagnostic challenges and treatment outcomes.

### 2.1 Risk factors

There is increasing evidence that older people are vulnerable to develop TB, and increasing understanding that cases of TB in the elderly may be linked to the reactivation of lesions that have remained dormant for several decades. The vulnerability is attributable to changes in the immune system related to senescence, notably the decline in the ability to reactivate previously acquired immunity, and additional factors that can include comorbidities, use of immunosuppressive drugs, malnutrition, chronic alcohol use, and underlying malignant conditions<sup>5,6,7</sup>. Diabetes can triple the risk for active TB. With rates of diabetes rapidly rising in many high burden TB countries, and becoming a common comorbid condition for

older people, this vulnerability is a strong contributing factor<sup>8</sup>.

*“An important geriatric syndrome that should be more widely known is the frailty syndrome – this is a multisystem dysregulation, leading to decreased physiological reserve, decreased immunity and increased vulnerability for all kinds of adverse health outcomes”*

– Geriatric Specialist

In India, there is recent evidence that risk factors contributing to vulnerability among the elderly can include socio-economic factors: a 2021 cohort study conducted under the RePORT India consortium revealed that poor education, unemployment, OBC caste, marriage, alcohol consumption and unemployment were found to be significantly associated with an increased prevalence of elderly TB<sup>9</sup>. The experts interviewed for this needs assessment identified the following risk factors that need to be understood better: lower immunity due to age and malnutrition caused by socioeconomic factors and mental health vulnerabilities.

5. Caraux-Paz, P.; Diamantis, S.; deWazières, B.; Gallien, S. Tuberculosis in the Elderly. *J. Clin. Med.* 2021, 10, 5888. <https://doi.org/10.3390/jcm10245888>
6. Stead WW. The pathogenesis of pulmonary tuberculosis among older persons. *Am Rev Respir Dis.* 1965; 91:811–822. doi: 10.1164/arrd.1965.91.6.811
7. Schaaf HS, Collins A, Bekker A, Davies PD. Tuberculosis at extremes of age. *Respirol.* 2010; 15(5):747–763 doi: 10.1111/j.1440-1843.2010.01784.x
8. A.L. Riza, F. Pearson, C. Ugarte-Gil, B. Alisjahbana, S. van de Vijver, N.M. Panduru, et al. Clinical management of concurrent diabetes and tuberculosis and the implications for patient services. *The Lancet. Diabetes & endocrinology.*, 2 (9) (2014 Sep), pp. 740-753
9. Murali, Sharan et al. “Comparison of profile and treatment outcomes between elderly and non-elderly tuberculosis patients in Puducherry and Tamil Nadu, South India.” *PloS one* vol. 16,8 e0256773. 27 Aug. 2021, doi:10.1371/journal.pone.0256773

## 2.2 Incidence and prevalence trends

### Global trends related to TB in the elderly

The age-disaggregated data in the Global TB Report 2021 (Figure 1) demonstrates that, at the global level, the highest incidence TB cases is estimated to be in age range of 25 to 54 years, and that there is a progressive decline in estimated incidence by age. It is noteworthy, however, that the estimates of TB incidence among people over the age of 65 are at least three times more than those among children in all WHO regions. Further, in the WHO regions of the Eastern Mediterranean and the Western Pacific, the TB incidence is the highest among the elderly compared to all other age groups.

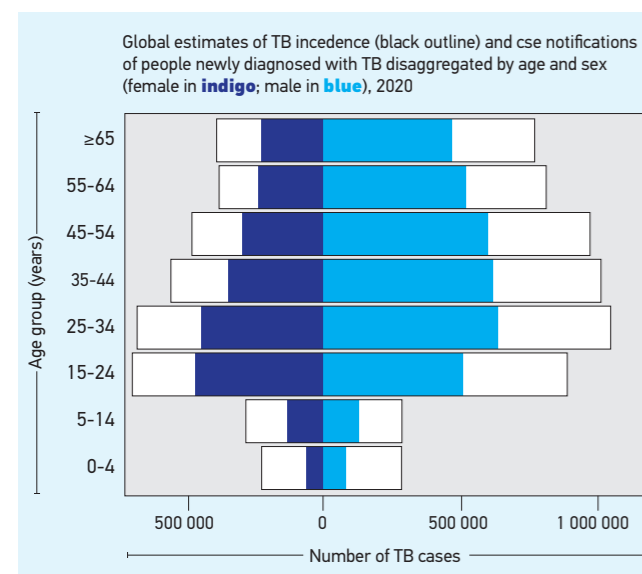


Figure 1: Age-disaggregated TB incidence [Global TB Report 2021]

Regional studies provide additional clarity on prevalence trends in the elderly. Data from Hunan Province in China showed that the prevalence of TB was more than twice as high in people aged 65 years and above. The country's National Tuberculosis Prevalence Survey in 2010 revealed relatively stable and low TB prevalence rates up to age 40 after which prevalence more than quadruples to age 75; this age-associated increase in TB incidence was most pronounced in Chinese men. The PLATINO study which examined TB rates in Brazil, Uruguay, Mexico, Chile and Venezuela found that adults over 60 were particularly vulnerable to develop active TB; according to the study, 2.3% of 50 to 59-year-olds and 3.4% of people over 60 had a TB diagnosis, twice as high as disease rates recorded in adults between 40-49 years of age. Similar findings have been reported in Central American countries and the United States.

A 2023 summary report puts the spotlight on the Western Pacific Region which has one of the fastest-growing populations of older adults ( $\geq 65$  years) globally, and provides country case studies from China, Japan, the Republic of Korea, and Singapore<sup>14</sup>. In these countries, TB case notifications and estimated disease incidence rates were found to be the highest among older adults (Figure 2). In China, 19% of all people notified with TB are over this age group. In Japan, the proportion of older adults among new cases has increased from 48% in 2000 to 59% in 2010 and 69% in 2020, even as the total number and rate of TB cases have decreased in the last decade. In the Republic of Korea, 49% of the people notified with TB (23,500) in 2020 were aged 65 and above. In Singapore, older age groups ( $\geq 60$ ) made up a significant proportion of the TB notifications

in 2020, both among Singaporean-born (58%) and foreign-born (46%) individuals. The report identifies age-specific challenges around underutilisation and variable implementation

of active case finding, TB infection testing and the provision of TB preventive treatment (TPT) in all four countries.

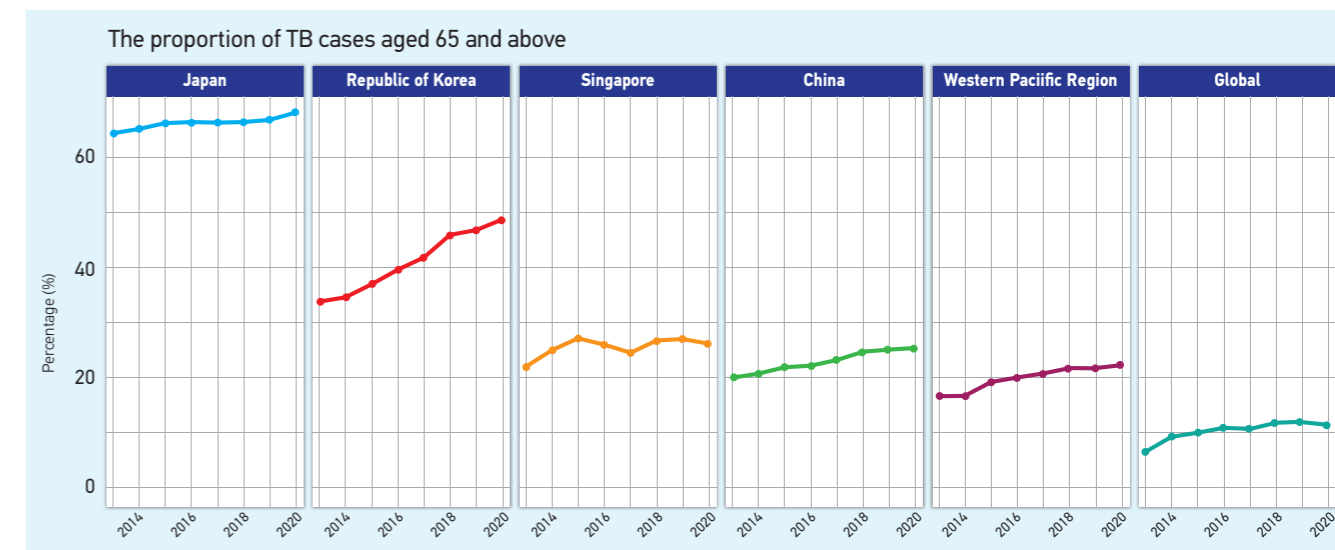


Figure 2: The proportion of notified TB cases aged  $\geq 65$  in Japan, the Republic of Korea, Singapore, China, the Western Pacific region, and globally 2013–2020 [Global TB report 2021]

### India-specific incidence and prevalence trends:

#### National Strategic Plan (NSP) 2020-2025:

According to India's NSP for TB Elimination (2020-2025), the geriatric age group constitutes about 12% of the TB notification in the country<sup>15</sup>. As previously mentioned, this age group makes up about 8.6% of the country's total population, implying a higher prevalence of TB in older people compared to people under 60 years of age. A 2013 retrospective cohort study which reviewed three-month records in 12 selected districts of Tamil Nadu revealed that older TB patients (over the age of 60) accounted for 14% of all people with TB<sup>16</sup>.

#### National TB Prevalence Survey (NATBPS) 2019-2021:

India's recent National TB Prevalence Survey, carried out in the country from 2019 to 2021, collected and analysed age-disaggregated data at each step of the survey. The survey revealed that the prevalence of TB

in people aged 55+ is 588, considerably higher than the overall national prevalence of 316<sup>17</sup>. Other relevant insights from the survey are listed below:

- The symptoms of TB (cough, chest pain, expectoration, loss of appetite) are seen to progressively increase by age; the over-65 age group reported the highest percentage of symptoms across all symptoms, followed by the 55-64 age group.
- Over 60% of people with symptoms of TB in this age group did not seek medical care.
- There was a progressive increase by age in the past history of TB; 65+ had the highest number of people with a history of TB.
- Among the survey participants, the highest treatment coverage rates were seen among the 55-64 age group (with males accessing treatment significantly more than females), with a sharp decline in the proportion of people above 65. The survey recognises that this data point indicates a gap in

10. Global Tuberculosis Report 2021. Available online: <https://www.who.int/publications/i/item/9789240037021> (accessed on 24 August 2022).

11. B. Abuaku, H. Tan, X. Li, M. Chen, X. Huang Treatment default and death among tuberculosis patients in Hunan, China Scandinavian journal of infectious diseases., 42 (4) (2010 Apr), pp. 281-287

12. Y. Xia, S. Jiang Control CCfD (Ed.), The 5th Nationwide TB Prevalence Survey in China, Lille, France (2011)

13. A.M. Menezes, P.C. Hallal, R. Perez-Padilla, J.R. Jardim, A. Muino, M.V. Lopez, et al. Tuberculosis and airflow obstruction: evidence from the PLATINO study in Latin America The European respiratory journal., 30 (6) (2007 Dec), pp. 1180-1185

14. India TB report 2023. Available at: <https://tbcindia.gov.in/showfile.php?lid=3680> (accessed 31 Mar 2023)

15. India TB report 2023. Available at: <https://tbcindia.gov.in/showfile.php?lid=3680> (accessed 31 Mar 2023)

16. Ananthakrishnan R et al. The profile and treatment outcomes of the older (aged 60 years and above) tuberculosis patients in Tamilnadu, South India. PLoS One. 2013 Jul 8;8(7):e67288. doi: 10.1371/journal.pone.0067288.

17. National TB Prevalence Survey in India (2019-2021). Available online: <https://tbcindia.gov.in/showfile.php?lid=3659> (accessed on 24 August 2022)

treatment coverage for the older age group, especially since the survey also revealed that the positivity on all the microbiological tests used in the survey (CBNAAT, AFB and culture) increased by age, with the highest rates of positivity in people over 65.

**India TB Report 2023:** India's annual TB report, released on World TB Day 2023, reveals significant facts about geriatric TB. Among the people notified with TB in 2022, 23.6% were older than 55 years. The report also states that there has been a gradual increase in the proportion of notified TB cases who were in older (>54 years) age groups with a simultaneous decrease in the proportion among younger (<25 years) age groups, and that these characteristics have largely remained uniform over the years from 2019 to 2022<sup>18</sup>.

### 2.3 Delays in diagnosis and treatment initiation

There is a strong possibility that there is a considerable burden of undiagnosed tuberculosis among older adults in low and middle-income countries, caused by a wide range of factors. According to clinical experts, diagnosis of TB among the elderly is a complex issue because many of the symptoms of TB are either mistaken for other diseases or missed as "signs of old age". For example:

- Loss of weight in an older person can lead to a diagnostic protocol to rule out carcinomas which are common in this age group.
- Persistent cough can lead to a diagnosis of COPD or simply, "cough due to old age".
- Fatigue and loss of appetite are also believed to be signs of old age.

It is possible that symptoms of TB may show up in innocuous forms in older people or not

show up at all. Given these challenges, it is easy for healthcare providers to make a late diagnosis of TB, or even miss it altogether. A related challenge is that older adults are more likely to develop extra-pulmonary TB or forms of disease with atypical symptoms that are harder to diagnose than conventional sputum smear-positive pulmonary TB<sup>19</sup>.

The disruptions in TB services caused by COVID-19 have led to a widespread decrease in TB diagnosis and notification across the world, but these disruptions have not been equally distributed. The consequences of disruptions have been greater for some groups than others, with children and the elderly in particular being disproportionately affected in the majority of countries. Based on trend analysis carried out in 45 high burden countries, there is strong evidence from 24 countries, including India, that the risk of having diagnosis missed or delayed was higher for the elderly than adults<sup>20</sup>.

Delays in diagnosis in elderly people can also be caused by a wide range of factors related to access to care issues (these were explored in detail through interviews and focus group discussions, and are described further in section 3).

### 2.4 Treatment completion and outcomes

Among the elderly, TB and other comorbidities (especially diabetes) often need to be treated simultaneously; this is a challenge both in terms of a higher pill burden that the person with TB needs to tolerate, but also in terms of the careful dosage titration that the provider needs to ensure. Further, adverse drug reactions (ADRs) are more common and more severe in older people with TB. A combination

of these factors along with other psycho-social challenges discussed ahead may contribute to lower rates of adherence among the elderly, lower rates of successful treatment, and higher mortality.

According to the 2010 Global Burden of Disease estimates, the majority of TB-related deaths (57%) occurred among people older than 50; over a half of these were in those aged 65 and above. Older people also contribute a large proportion of Disability-Adjusted Life Years (DALYs); 51% of TB DALYs occurred in those aged 50 years and older in East Asia. Older people also experience more frequent

drug-related adverse events and increased co-morbidity<sup>21</sup>.

*"In my experience, elderly people with TB seem to have a very short timeline between diagnosis and death"*

*- TB Programme implementer*

Various studies undertaken in India provide evidence that people over the age of 60 have a higher risk of unfavourable treatment outcomes as compared to all others with TB. Some of these studies are listed in the table below:

Table 1: Retrospective studies in India examining treatment outcomes in the elderly

Location   Period	Study type and size	Observations
Tamil Nadu 2021	Retrospective cohort study on 1259 people with TB, of which 197 (16%) were elderly <sup>22</sup>	<ul style="list-style-type: none"> <li>• Adherence to medication was better among the elderly people with TB but the treatment outcomes at the end of intensive and continuation phase were better among non-elderly people with TB</li> </ul>
Tamil Nadu 2014	Retrospective cohort study on 5,208 people with TB, of which 865 (16%) were elderly <sup>23</sup>	<p>Older people with TB:</p> <ul style="list-style-type: none"> <li>• Were more likely to be male (84% vs. 71%), smokers (46% vs. 37%) and illiterate (63% vs. 45%)</li> <li>• More likely to have pulmonary TB and initial smear negative disease</li> <li>• Had a higher loss to follow-up (15% vs. 11%) and death rates (9% vs. 4%)</li> <li>• Had a larger proportion of people reporting side effects related to anti-TB drugs (63% vs. 54%)</li> </ul>
Tamil Nadu 2013	Retrospective cohort study on 10,477 people with TB, of which 14% were elderly <sup>24</sup>	<ul style="list-style-type: none"> <li>• People over 60 were found to have 38% higher risk of unfavourable treatment outcomes with higher death and loss to follow-up rates</li> <li>• The risk for unfavourable treatment outcomes was higher for those aged 70 years and more, males, re-treatment patients and those who received community-based directly observed treatment</li> </ul>
Rural West Bengal 2005	Retrospective cohort study on 3676 total cases, of which 808 were elderly (22%) <sup>25</sup>	<ul style="list-style-type: none"> <li>• New smear positive and extrapulmonary cases were significantly more in the young while new smear negative and retreatment cases were significantly more in geriatric population</li> <li>• Cure and treatment completed cases were significantly lower and death and loss-to-follow-up were significantly higher in the geriatric population</li> <li>• Sputum conversion rate at end of 2 months was also significantly lower in the geriatric group</li> </ul>

21. ibid

22. Murali, Sharan et al. "Comparison of profile and treatment outcomes between elderly and non-elderly tuberculosis patients in Puducherry and Tamil Nadu, South India." PLoS one vol. 16,8 e0256773. 27 Aug. 2021, doi:10.1371/journal.pone.0256773

23. Velayutham BRV, Nair D, Chandrasekaran V, Raman B, Sekar G, et al. (2014) Profile and Response to Anti-Tuberculosis Treatment among Elderly Tuberculosis Patients Treated under the TB Control Programme in South India. PLOS ONE 9(3): e88045. <https://doi.org/10.1371/journal.pone.0088045>

24. Ananthakrishnan R et al. The profile and treatment outcomes of the older (aged 60 years and above) tuberculosis patients in Tamilnadu, South India. PLoS One. 2013 Jul 8;8(7):e67288. doi: 10.1371/journal.pone.0067288.

25. Mukherjee, Abhijit. (2008). Tuberculosis in Patients Below and Above 60 years and Their Treatment Outcome Under RNTCP -A study in Rural West Bengal, India. Journal of the Indian Academy of Geriatrics. 4. 60-3.

18. India TB Report 2023. Available at: <https://tbcindia.gov.in/showfile.php?lid=3680> Accessed on 31 Mar 2023

19. Joel Negin, Seye Abimbola, Ben J. Marais, Tuberculosis among older adults – time to take notice, International Journal of Infectious Diseases, Volume 32, 2015 <https://doi.org/10.1016/j.ijid.2014.11.018>.

20. McQuaid, C.F., Henrion, M.Y.R., Burke, R.M. et al. Inequalities in the impact of COVID-19-associated disruptions on tuberculosis diagnosis by age and sex in 45 high TB burden countries. BMC Med 20, 432 (2022). <https://doi.org/10.1186/s12916-022-02624-6>

Location   Period	Study type and size	Observations
Yavatmal, Maharashtra 2005	Retrospective cohort study on 3,441 people with TB, of which 367 were elderly (11%) <sup>26</sup>	<ul style="list-style-type: none"> <li>The treatment completion rate was significantly lower in the elderly</li> <li>The death rate was significantly higher in the elderly</li> </ul>
Delhi 2001	Retrospective study of 7,439 people with TB, of which 315 were elderly (4%) <sup>27</sup>	<p>Older people with TB:</p> <ul style="list-style-type: none"> <li>Had higher occurrence of pulmonary TB than extra-pulmonary TB (16:1) compared to the younger age group (4:1)</li> <li>Showed lower sputum conversion (75.3%) compared to younger age groups (85.7%)</li> <li>Had lower cure rates (69.2% vs 80.7%) and relatively higher loss-to-follow-up and treatment failure rates</li> </ul>

Interviews with caregivers underscored the treatment adherence challenges faced by elderly people with TB and identified a few recurrent themes as the causes:

- Pill-burden
- Side effects
- Mental health vulnerabilities
- Systemic issues (see section 3.4)

*“Older people with TB are often disheartened by the medicine side-effects. They say – what is the point of taking these medicines if they make me feel worse? I’m so old I’m going to die anyway”*

*– TB Champion who supports elderly people with TB*

## 2.5 Impact of gender on TB in the elderly

It is well-known that a higher prevalence of TB is reported among men as compared to women, as well as higher rates of notification. This difference in prevalence is likely to be exaggerated with age, i.e., older men are likely to have significantly higher rates of prevalence than older women. The 2001 retrospective study described previously - with 7,439 people

with TB (of which 315 or 4% were elderly) - revealed that male: female ratio of 315 geriatric people with TB enrolled under DOTS was observed to be 3:1 as against the 1.4:1 in younger people with TB. This is clearly an area where more investigation is necessary, but there were many relevant viewpoints that emerged from the qualitative research:

- In the homes and societies where pre-existing gender discrimination is present, it gets intensified when the person becomes older and frailer, and less likely to be perceived as “useful”
- Older women, in comparison to older men, are more likely to be dependent on caregivers for their healthcare needs, for e.g., for needing companionship for facility visits for follow-up testing or drug refills.

The disproportionately higher dependence experienced by older women was demonstrated even in the process of qualitative research for this assessment - of the nine people with TB/TB survivors who agreed to be interviewed, only two were women, in spite of multiple attempts to have a more balanced ratio in the interviews. The first woman (on treatment) was interviewed telephonically, over a phone that belonged to her son, at a time that was convenient for

the son. The second woman (TB survivor) participated in an in-person focus group discussion along with her husband who answered the majority of the questions that were posed to her.

## 2.6 Gaps in epidemiological comprehension and reporting

In most countries, it is now a routine practice to collect data on gender and age when TB data is collected, leading to the possibility of useful insights on epidemiological differences across age and gender categories. However, the data is not often disaggregated by age and gender while reporting and analysing. In describing current TB landscapes, global and national reports only use the distinction of children and adults.

The Global TB Report 2021 highlights that the highest burden is in adult men, who accounted for 56% of all TB cases in 2020, and compares the data point with adult women and children (who accounted for 33% and 11% of all the TB cases respectively). There is no reference in the text of the report to any epidemiological data specific to the elderly, even when data and charts exhibit high burdens of estimated TB incidence in this cohort. Insights related to diagnosis, treatment, prevention, drug resistance and mortality are disaggregated and described in the report by gender, and by distinction between adults and children. For example, there is no mention of mortality trends among elderly people with TB - the report mentions that “among the deaths among HIV-negative people with TB, 53% were men, 32% were women and 16% were children (aged <15 years). Of the TB deaths among HIV-positive people, 50% were men, 40% were women and 9.8% were children”. The Global TB report is an important document, which forms the basis of national-level planning in most high-burden countries. A lack of focus on the elderly in such a document is a lost opportunity to influence national-level plans.

A similar trend can be seen in national-level documents in India. Three important national data sources are especially relevant: the India TB Report, the National Family Health Survey (NFHS) and the Sample Registration System (SRS).

**India TB Reports 2022 and 2023:** None of the ~50+ tables which provide information across multiple points on the care cascade are disaggregated by age; approximately 10 charts/tables are disaggregated by gender. Geriatric TB is not mentioned at all in the 2023 report, and it is mentioned once in the 2022 report (to share that the “Jubilant Bhartiya Foundation started a screening and nutrition support project among the elderly population in one block of Gajraula in Uttar Pradesh”). In comparison, paediatric TB is mentioned 49 times and 41 times respectively.

Some of the states interviewed for this rapid assessment are carrying out the occasional analysis of age-disaggregated data from Ni-Kshay for elderly populations; however, this is not done systematically. Insights from the analysis are not shared widely or nationally at this time. In comparison, all states do carry out age-analysis to understand trends in pediatric TB in their geographies (possibly due to reporting requirements).

**The National Family Health Survey 2019-21 (NFHS-5)** - the fifth document in the NFHS series - provides data on many important indicators for population, health and nutrition. The survey has been built from information gathered from 636,699 households, 724,115 women, and 101,839 men. There are 131 key indicators (described at the level of country, state/UT and districts), and there is a surprising absence of data related to the elderly in significant areas, for e.g. -

- Education indicators (on literacy, years of schooling and usage of internet) only cover people from age 15 to 49
- Women’s empowerment indicators (measurement through metrics such as participation in household decision-making

26. Pardeshi G, Deshmukh D (2007) Disease characteristics and treatment outcome in elderly tuberculosis patients on DOTS. Indian Journal of Community Medicine 32: 292.

27. Arora, Vijay & Singla, Neeta & Sarin, Rohit. (2002). Profile of geriatric patients under DOTS in Revised National Tuberculosis Control Programme. The Indian journal of chest diseases & allied sciences. 45. 231-5.

and ownership of land) only surveyed women aged 15 to 49

- Gender-based violence indicators only surveyed women aged 18 to 49
- Nutritional status (measured through BMI and waist-hip ratios) surveys people from 15 to 49
- Anemia is measured for children or adults up to age 49
- Cancer screening carried out for people between ages 15 and 49
- Knowledge about HIV surveyed among people from 15 to 49 years of age

For all of the indicators mentioned above – from education to cancer screening – people over 50 years of age are not included in data collection, which seems like a major missed opportunity given the large (and rapidly increasing) size of the older population in the country.

There are three exceptions to this lack of interest in the elderly – indicators related to tobacco and alcohol usage, hypertension and blood sugar measurements cover age

groups 15 and above. However, these are not disaggregated for specific age groups, and therefore substance use in the country is understood for the entire population from age 15 and above, with no way of comprehending which age groups are more vulnerable.

**Sample Registration System (SRS)** - provides reliable annual estimates of Infant mortality rate, birth rate, death rate and other fertility & mortality indicators at the national and sub-national levels. It is a large-scale demographic survey conducted every year by Office of the Registrar General, India in all States/Union territories. The latest SRS bulletin (2020) provides death rate information by location (by state, and by urban vs rural), and by gender (men vs women). The latest edition of Cause of Death statistics (2017) disaggregates the causes of death by age and uses very broad age categories, for e.g., 15-29, 30-69, 70 and above, thereby missing the opportunity to understand the specific health threats for the elderly.

### 3. Access to care: needs and experiences

#### PHYSICAL VULNERABILITIES:

- Need for companions and special modes of transport
- Difficulty in navigating healthcare facilities
- Loss of work and wages

#### SOCIO-ECONOMIC FACTORS:

- Loss of economic independence
- Nutrition challenges
- Poor linkages to financial support schemes

#### PSYCHOLOGICAL AND SOCIETAL FACTORS:

- Behaviour patterns
- Access to Information
- Stigma
- Other mental health vulnerabilities

#### HEALTH SYSTEM ELEMENTS

- Access to diagnostics and treatment
- Health system capacity
- Other health-system factors

This section, which attempts to build a picture of how responsive the current systems (health systems and socioeconomic systems) are to the needs of older people with TB, has been developed entirely based on interviews with people with TB, caregivers, programme partners and technical experts. This points to a key gap area in the current evidence base: there is clearly an urgent need for population-level studies that attempt to document and understand the experiences of elderly people with TB.

#### 3.1 Physical vulnerabilities

Age-related physical decline, complicated by physical weakness due to comorbidities and due to TB (or its treatment) was the most prominent theme to emerge in the discussions with affected communities. Physical frailty impacts the lives and care-seeking behavior for people with TB in at least three distinct ways:

- **Need for companions and special modes of transport:** Many elderly people are unable to travel to health facilities without an attendant due to fear of falling or general physical frailty. If the older person lives alone or with family members unable or unwilling to care for them, the inability to travel alone to facilities contributes to delayed diagnosis. Further, a large number of people with TB, especially those in rural areas, travel long distances on foot or using motorcycles, neither of which is ideal for an elderly person. The challenge of traveling through hilly terrains is believed to be the most critical cause of diagnostic delays among the elderly in the north-eastern states of the country. More appropriate alternatives like decentralised services as well as comfortable transport options (with subsidised fares for the elderly) are an essential requirement to reduce delays in diagnosis of TB among the elderly.
- **Difficulty in navigating healthcare facilities:** Many healthcare facilities have accessibility issues which make them daunting for elderly people with TB. Examples shared

*“My state’s number one challenge for the elderly is transport. The terrain is so difficult, roads are so poor, transport options are so limited that people just don’t come to health facilities until it is too late. This is probably true in all rural areas in the country, but hilly terrains like ours are especially challenging”*

*– TB Programme implementer*

by affected communities include multiple stairs, cramped waiting areas with limited seating and unclear signboards.

- **Loss of work and wages:** Physical weakness can result in an inability to work outside or inside the home, which in turn, has economic or mental health consequences – loss of sources of income, social connections, sense of purpose and motivation for self-care.

*“For six months, I was not able to work on my farm. I was so tired all the time. It was a bad time. I am able to work now”*

*– 64-year-old TB survivor, Chhattisgarh*

#### 3.2 Socio-economic factors

In interviews with affected communities, the second most prominent theme to emerge (after physical vulnerability) was socio-economic challenges. These can be understood under three themes, which in many ways, influence each other.

##### Loss of economic independence

Due to physical frailty or government policies around retirement age, most people over the age of 60 are likely to be unemployed. According to the 2017 Longitudinal Aging Study in India (LASI)<sup>28</sup>, which is based on interviews with 73,000 respondents, only 36% of people over the age of 60 years are engaged in income-generating activities (50% if they are men). Of these, only 5% have full-time jobs, and only

25% have documentary evidence of their current work, indicating a predominance of the informal sector in the Indian economy. This points to a high likelihood that the elderly are economically dependent on family members, which was borne out in all our interviews with affected communities. Only one out of the nine elderly PwTB/TB survivors interviewed was actively engaged in work (he worked on his farm). Economic dependence impacts healthcare seeking behavior to a great degree – if an elderly person has symptoms of TB, they are likely to visit a healthcare facility for diagnosis only when they receive the required financial support (for transport, fees in the case of private care, and for any incidental out-of-pocket expenses) from family members.

### Nutrition challenges

In an estimation of population attributable fractions (PAF) for the major risk factors of TB, the Global TB Report 2020 indicates that undernourishment<sup>29</sup> is the leading risk factor accounting for 19% of the cases<sup>30</sup>. When the data was re-examined in the light of more recent evidence, it was found that there was 65% increase in number of cases attributable to undernutrition in Asian countries. In India, between one-third and half of incident TB could be attributable to undernutrition<sup>31</sup>. It would be pertinent to examine the data in a gender and age-disaggregated manner to understand if the attributability varies by age group and if certain groups of people have a higher degree of vulnerability to the effects of undernutrition.

*“Sometimes, when I visit an elderly person with TB, I find they have not taken their medicine and I ask why. And they say, oh there was no food for me so I did not want to eat the medicine on an empty stomach. It makes me so sad. Some families just don’t care for their aged relatives. I carry some peanuts and biscuits in my bag, I sit with them, make them eat and then ensure they take the medicine”*

– TB Champion, New Delhi

Interview respondents shared that in low-income households, older people (and girl children) are most likely to experience nutritional challenges – lower quantity (and quality) of food, infrequent meals etc. In the context of TB care, where people with TB need focused nutritional support, this becomes a major contributor to poor treatment adherence and outcomes. Technical experts believe that elderly women with TB are likely to be worse off in comparison to elderly men.

### Poor linkages to financial support schemes

In addition to elderly pension schemes under the central government, every state has provisions for pension schemes for the elderly. However, these are fairly narrow in scope – available to people who have retired from government employment, widows or to people living below defined poverty lines – and thus not available to a large majority of elderly people. Among those interviewed for this assessment, only one out of the nine people with TB or TB survivors had received their full Nikshay Poshan Yojana payments, six had received part payments, and two had not received any payment at all.

## 3.3 Psychological and societal factors

### Behaviour patterns

Symptoms suggestive of TB are more likely to be ignored in an older person. This is partly because many symptoms, like persistent cough, fatigue and loss of appetite can be dismissed (by the individual themselves as well as by their families) as “signs of old age”. Further, linked to the previous points about economic dependence, the elderly often experience neglect and isolation from their families, leading to poor care-seeking behavior. Interviewees shared many anecdotes of older people with symptoms not being tested for TB until the disease had significantly progressed. This is borne out by the National TB Prevalence Survey which revealed that over 60% of people with symptoms of TB in this age group did not seek medical care for their symptoms. Further, there is a tendency to first visit the nearest private provider, which, by virtue of being in the vicinity is both convenient and less daunting. More often than not, this adds to diagnostic delays.

### Access to Information

Multiple factors can make it more difficult for older individuals to access health information compared to younger individuals: they are less likely to have a well-informed social network that can guide them to appropriate healthcare facilities; they are less likely to have

internet access or to be comfortable using technology to find health information online. Additionally, the mobility and transportation issues previously discussed might also make it more difficult for older people to participate in information and awareness events.

*“Young people go out to work, to socialise, so they can find out where to go for diagnosis and treatment. Older people stay at home. When they have symptoms, they don’t know where to go for testing and they don’t have anyone they can ask”*

– TB Champion, Raipur, Chhattisgarh

### Stigma

The question of stigma led to a wide range of responses and contradictory opinions (see figure 3). On one hand, five out of the nine technical experts interviewed for the paper were of the opinion that the stigma experienced by older people with TB would be lower in comparison to younger people because the latter tend to spend more time outside of the home for work and social activities. Further, it was hypothesised that younger people with TB encounter challenges in various life milestones (like marriage and job-seeking), which may not be relevant for older people. Eight out of the 25 representatives from affected communities agreed - their experiences aligned with the view that older

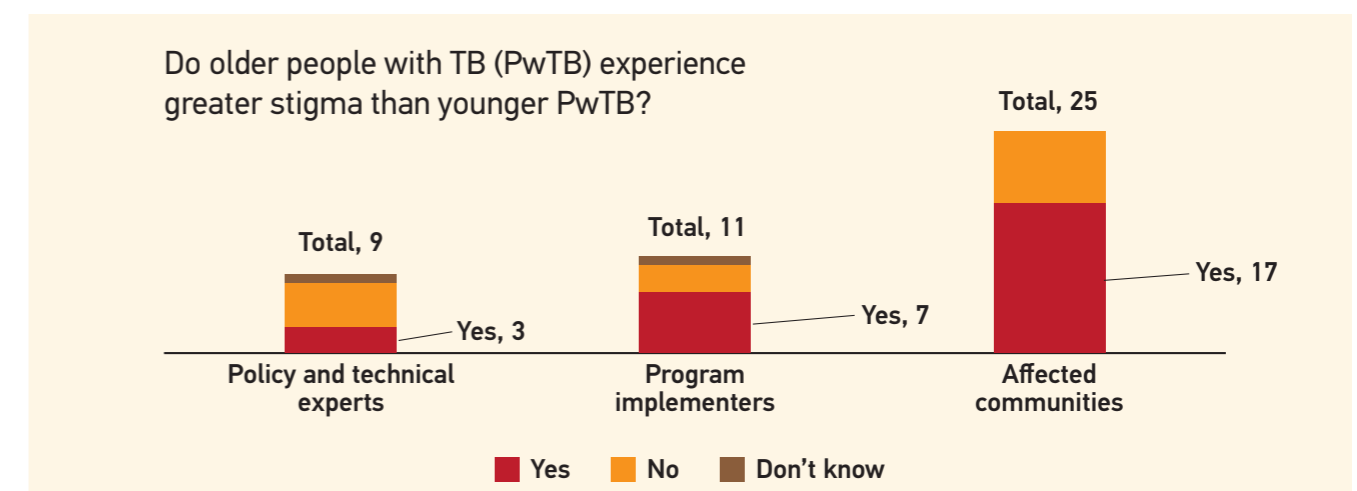


Figure 3: Wide ranging opinions on stigma experienced by elderly people with TB

28. International Union for the Scientific Study of Population. Link accessed 14 Jan 2022: <https://www.niussp.org/education-work-economy/labour-force-participation-among-older-adults-in-india/#:~:text=For%20instance%2C%20only%20some%2036,%25%20if%20they%20are%20women>

29. As per Dr. Anurag Bhargava, undernourishment is an indirect model derived estimate of decreased per capita energy availability, while undernutrition is defined by direct anthropometric measurements of nutritional status. The two terms are used interchangeably in the Global TB Report 2020. When the data was re-examined, the attributability was measured specifically for undernutrition (rather than undernourishment).

30. Global Tuberculosis Report 2020. Geneva: World Health Organization; 2020.

31. Bhargava, Anurag et al. “Attributable is preventable: Corrected and revised estimates of population attributable fraction of TB related to undernutrition in 30 high TB burden countries.” Journal of clinical tuberculosis and other mycobacterial diseases vol. 27 100309. 8 Mar. 2022, doi:10.1016/j.jctube.2022.100309

people were protected from stigma due to their reduced social mobility.

*“No one among the neighbours even knew that I had TB. I did not go out of the house for six months. My son told the neighbours that I was not well and resting. No, I was not lonely. My grandchildren would wear a mask to come and sit with me and talk to me”*

*– 61-year-old male TB survivor, Jharkhand*

On the other hand, it is possible that TB-related stigma may worsen the social isolation which is already experienced by senior citizens. Some experts and affected communities interviewed opined that older people in many Indian families experience disrespect from their families due to their economic dependence. A disability or an illness like TB can add to the challenge. Examples were shared of instances where the older person with TB was confined to one part of the house, forbidden from communicating with other family members, or worse, turned out of the house altogether. Further, older people may have a greater need for social interaction, and therefore, isolation may be harder to manage.

A few experts pointed out that the experience of stigma in the elderly, like other experiences, is likely to be strongly influenced by their socio-economic setting. The elderly in low-income households, it was hypothesised, would likely experience a greater degree of isolation and stigma.

There is also a possibility that the TB-related stigma experienced by the elderly is complicated by “ageism”, which is defined by WHO as the stereotypes, prejudice and discrimination based on age<sup>32</sup>. Ageism has been recognised as a global challenge and as a cause of poorer health, social isolation

and earlier deaths. As a recent WHO paper points out, age-related discrimination can seep into many institutions and sectors of society including those providing health and social care, the workplace, media and the legal system<sup>33</sup>.

Given the divergent set of opinions and experiences, there is a clear need for more research into the question for stigma experienced by the elderly. Also, there is a need to understand how gender impacts the experience of stigma – women, with a greater likelihood of dependence on their families are very likely to have worse experiences around stigma, isolation and neglect.

#### Other mental health vulnerabilities

In addition to stigma, other challenges that can impact mental health were identified during interviews and group discussions:

- The anxiety of being “not useful” or irrelevant in the family or community
- The loss of purpose and connection with work (outside or inside the home)
- Loneliness (some people in this age group are likely to have lost a spouse which adds to the loneliness)
- Dependence (Economic or physical)
- Cognitive decline and related inability to manage health needs
- Fear of TB and a sense of “self-stigmatisation”
- Increase in use of tobacco, alcohol and other substances (this was mentioned as being relevant primarily for men, and may have some regional variations)

Older people, especially if living alone or with family members who are unable to care for them, are very likely to miss appointments for follow-up or drug refills. TB Champions shared multiple instances of older people not taking the medicines because of forgetfulness or other mental health issues. Compassionate, comprehensive psychosocial counseling

and frequent reminders were extremely important elements in ensuring compliance with treatment protocols.

### 3.4 Health system elements

#### Targeted active case finding

In all the seven states that were interviewed as part of this rapid assessment, targeted case finding at facility-based settings was being carried out; facilities in this case primarily include specialised residential settings for the elderly – known as elderly homes, old-age homes, senior living or assisted living facilities. In Sikkim this also includes monasteries where a large numbers of monks over the age of 60 reside. States either carry out targeted screening annually or 6-monthly, but results from the exercise are not always disaggregated and analysed by age.

All programme implementers shared that elderly people are more likely to be home when door-to-door screening is going on, and therefore likely to be included in the data. However, there seems to no specific focus on data related to the elderly in community-based screening activities. Again, the exception was Sikkim where NTEP programme leadership shared that they have consistently been examining age-disaggregated data and find that 10-15% of people newly diagnosed with TB are over 60 years of age.

Another missed opportunity that was identified by technical experts was facility-based screening at the level of OPD clinics for other disease areas, especially Non-Communicable Diseases. Similarly, health and wellness centers (HWCs) are ideal spots where all elderly walk-in patients should be screened for TB.

### Findings from a Facility-based screening project in Tamil Nadu

REACH implemented a two-year project called “Mentors for Community Health” from Jan 2020 to Dec 2021. One of the two key arms of the project, which was supported by a TB REACH Wave 7 grant from the Stop TB Partnership, was facility-based screening at public health facilities and out-patient departments in four districts in Tamil Nadu (Salem, Thirunelveli, Vellore, and Villupuram). The project revealed startling and useful insights around the prevalence of TB in the people over the age of 60, who constituted nearly 40% of the people with symptoms suggestive of TB, and nearly 30% of people identified with TB (see figure 4)

Box 2 Findings from a Facility-based screening project in Tamil Nadu

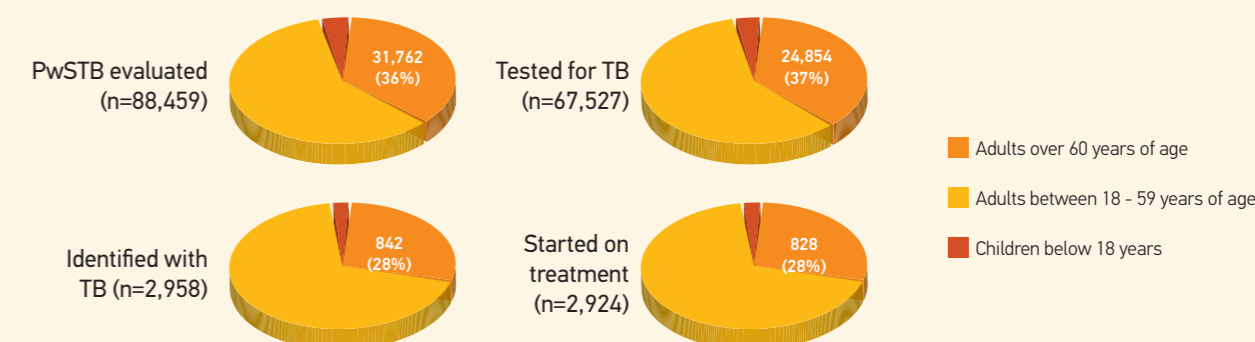


Figure 4: Results from a facility-based screening project in four districts in Tamil Nadu

32. Ageing: Ageism. WHO paper available on this link. Accessed on 20 Jan 2023.

33. Ageism is a global challenge: UN. WHO paper available on this link. Accessed on 20 Jan 2023

## Access to diagnostics and treatment

- Lack of decentralisation in treatment and diagnostics:** TB service delivery is often not offered in person-centric ways, and it is not uncommon to see a person with symptoms of TB having to visit multiple facilities over multiple days for sample collection, X-rays, pre-treatment evaluation and treatment initiation. This is especially challenging for elderly people who may be dependent on others for facility visits due to mobility issues or due to any other cause. One of the experts interviewed pointed out that as the NTEP transitions from microscopy to molecular diagnostics as the first line of testing, there is decreasing decentralisation of diagnostics. Therefore, access to diagnostic facilities is becoming more even more challenging for vulnerable populations, such as the elderly.
- Distance to facilities:** All representatives of the affected community spoke about difficulties around travel to facilities for diagnostics, follow-up and drug refills. When asked to imagine a responsive healthcare system, the first suggestion was always support for travel to healthcare facilities – examples for the type of support included bus-passes, travel reimbursements, and volunteer companions. As an example of the latter, TB Champions were recognised as valuable members of the community support system, frequently ferrying people with TB to facilities.

*“This bhaiya (brother) used to come to my home and take me to the hospital for my check up every month”*

*– 62-year-old male TB survivor in Chhattisgarh speaking about the local TB Champion*

## Health system capacity

- Diagnostic capacity and utilisation:** As mentioned before, diagnosing TB in the elderly needs a higher index of suspicion. There needs to be a higher utilisation of chest X-rays and molecular methods for diagnosis rather than microscopy. Interviewed experts

stressed that:

- X-ray utilisation is low for older people with symptoms of TB.
- X-rays are not available in convenient, decentralised locations.
- Sample collection for molecular testing is often challenging for elderly people.

Although all the interviewed people with TB and TB survivors reported that their CXRs had been done, they also reported that this had required multiple facility visits and travel time.

*“We have training on how to take pediatric samples. Then we have pediatric drug formulations like syrups and dispersible tablets in weight-adjusted dosages. It is high time we had similar things for geriatric patients”*

*– Technical expert*

## Service provider capacity

As mentioned previously, older people with TB may present with comparatively “vague” or atypical symptoms. One geriatric specialist clinician shared her experience of diagnosing TB in many older people where their only symptom was dyspepsia. To diagnose TB in the light of such less than obvious signs requires a certain degree of alertness among healthcare providers, which is often missing in programmatic settings, and which can lead to TB getting diagnosed only in advanced stages of the disease. In addition to diagnostic acumen, technical experts pointed out other areas where provider capacity is often missing or limited, for example:

- Collecting samples
- Adjusting drug dosages based on nutrition and other medication for comorbidity treatment
- Continuously monitoring health and follow up, especially KFTs and LFTs
- Managing adverse drug reactions (more frequent and more severe in the elderly)
- Psychosocial counseling for treatment compliance
- Comorbidity management

## Public sector vs private sector: is there a difference in responsiveness towards the elderly?

In the context of health system capacity, it may be useful to examine the private sector separately given its large scale and proportional contribution to TB service delivery in India: in 2021, about a third of the 2.1 million people notified with TB were from the private sector, underscoring the importance of this sector in India’s TB elimination goals. There are no studies that do a comparative analysis of age-responsiveness in care delivery in public vs the private sectors. When this question was explored in the group discussions and key-informant interviews, it revealed the following:

- A large proportion of the respondents shared the belief that there may be lesser age-related discrimination (as shown through generally more respectful behavior) in the private sector. This may be reflective of a socio-economic hierarchy– people visiting the private sector are assumed to be of a higher socio-economic class, and are therefore treated better.
- Many respondents who had been to both private (in the early stages of the care cascade) and public sector shared that the latter was easier to navigate because there was lesser pressure to spend money and to undergo multiple rounds of testing (one person with TB had undergone four CT scans in the private sector before finally getting diagnosed and starting treatment in the nearest district TB center).

Like other issues raised through this rapid assessment, the issue of the private sector’s capacity to respond to the needs of elderly people with TB is a nuanced one, and merits additional investigation.

*Box 3 Responsiveness towards the elderly in public vs private healthcare sectors*

## Other health-system factors

### Lack of holistic care models

Healthcare in India continues to be run under compartmentalised vertical programmes which makes service delivery disease-centric rather than person-centric. In such a system, when an elderly person has both TB and diabetes (which they often do), they are required to have their samples drawn at different clinics (often located far from each other) and to be managed by different healthcare providers who are unable to treat the person as a whole. While this aspect of care is challenging for all people with TB, it is especially true for elderly people with TB with reduced mobility. More than half of the interviewees from affected communities

spoke about the difficulties of having to go to different facilities for Chest X-rays, blood tests, NAAT tests or CT scans.

### Limited implementation of geriatric OPDs

There are a few instances where National Programme for the Health Care of the Elderly (NPHCE) recommendations for separate geriatric OPDs at healthcare facilities have been implemented, for e.g., at the National Institute of TB and Respiratory Diseases in Delhi and at all healthcare facilities in Sikkim. However, this is far from a general trend, and crowded waiting rooms and long queues continue to daunt elderly people with TB. This is truer for urban settings like Delhi and Mumbai.



### Healthcare worker attitudes

As mentioned under the discussion on stigma, it is important to consider the possibility of ageism or age-related discrimination being practised by healthcare personnel. One technical expert pointed out that although inappropriate, it is easy to see how there may be a tendency (on the part of healthcare workers) to prioritise children and young adults as “the future of the nation”, and how this prioritisation might come at the cost of older people. That ageism is present in India’s healthcare institutions was confirmed by another of the interviewed experts, who has a large clinical practice, and who shared that discrimination towards senior citizens can take many forms; for example, shorter doctor-patient interactions, condescending attitude and downright disrespectful behaviour. It must be noted that five out of the nine TB survivors and people with TB interviewed shared that healthcare facility staff was supportive towards their needs, practising kindness in a variety of ways – seeing them out of turn rather than making them wait in queue, accompanying them for X-rays and blood tests, visiting them at home and providing drug refills at home. In response to this, all the technical experts agreed that while this was heart-warming to hear, responsive care needs to be systemic rather than individual dependent.

*“During my treatment period when I went to the market, people who knew me used to tell others that I had TB. Some of them avoided me. I had the same experience when I went to my native place by bus. All this made me very sad. Even in the hospital, the way they collect sputum for testing is very bad. They tell the patient to keep the sputum in the window and stand away. This was also painful for me”*

*– 62-year-old male TB survivor, Tamil Nadu*

### Limited support systems

The NTEP offers many different kinds of treatment support systems to people registered for TB treatment, regardless of whether they access care in public or private sectors. Based on the location, timing and convenience, people with TB can opt for treatment with a community treatment supporter. However, challenges remain in implementation as well as in measuring the impact of these support structures. In fact, the Tamil Nadu-based retrospective cohort study (2013) mentioned previously found that older people with TB who received their treatment through a community-based volunteer/health care worker had a higher loss to follow-up<sup>34</sup>. It was hypothesised that the reason for this could be that providers might have limited capacity to manage adverse reactions which are quite likely to be common in this age group. There is a clear need to understand, supervise and improve decentralised support services.

### No focus on prevention

As testing and treatment for TB infection is currently being rolled out across the country, there is an urgent need to focus on and understand the needs of the elderly in terms of TB prevention.

## Regional variations in societal patterns and health systems

It can be conjectured, based on anecdotes gathered during this rapid assessment, that there might be regional variations in the service delivery elements described above. For example, the north-eastern parts of the country (represented by Assam and Sikkim in this paper) may have societal structures aimed at caring for the elderly. NTEP representatives from both the states spoke not only about government policies focused on elderly welfare (e.g., a wide coverage of old age pensions, prioritization for TB prevention therapy) but also about social attitudes of responsibility for the elderly. This, however, needs a deeper look to confirm whether the policies and attitudes translate into better TB services, and whether there are applicable lessons for the rest of the country.

*“For us, older people are like children. As in, they are the community’s responsibility. There is no pressure on them to work and earn their living. If they want to work, fine. If they don’t want to work, the society will take care of them, whether they are rich or poor”*

*– TB Programme implementer, Sikkim*

*“We prioritise older people here. Our government has a ‘Matri Pitri Vandana’ portal where we can apply for casual leave online to spend festivals time with parents”*

*– TB Programme implementer, Assam*

*Box 4 Regional variations in attitudes towards the elderly*

## 4. Policies and guidelines for TB in the elderly

According to experts, it is fair to say that current diagnostic tools, treatment models and support systems have been developed with a focus on the economically productive age group, i.e., people of ages 19 to 60, and, to a lesser extent, the paediatric age group. This is in line with the historical progression of most infectious diseases: as populations shift, so does the epidemic. In other words, increasing longevity leads to a higher incidence and prevalence among older people. Such a shift might even be seen as an indication that the epidemic is on a decline. More importantly, the shift is an indicator that there is need

for increased focus on building systems and policies for older people.

*“It’s not so much that the elderly people with TB in India are being missed per se. It’s more that they are not being prioritised. There is a tendency to prioritise the needs of children with TB or young people with TB, and in the process, the elderly are marginalised. But as this population increases, priorities will need to shift”*

*– Clinician and key opinion leader*

34. Ananthkrishnan R et al. The profile and treatment outcomes of the older (aged 60 years and above) tuberculosis patients in Tamilnadu, South India. PLoS One. 2013 Jul 8;8(7):e67288. doi: 10.1371/journal.pone.0067288.

## 4.1 Current set of guidance and recommendations

### General policies and guidance for the elderly

Box 5 lists Government of India policies for the elderly in a broader context.

#### Geriatric care systems in India: a timeline

- **1999:** National Policy on Older Persons announced by the Government of India, soon after the UN General Assembly Resolution to observe 1999 as International Year of Older Persons
- **2007:** The Ministry of Social Justice and Empowerment passes a legislation on "Maintenance and Welfare of Parents and Senior Citizens Act 2007"
- **2011:** Revision of National Policy on Older Persons to "National Policy on Senior Citizens 2011" or NPSC 2011 which stresses that older women and older individuals in rural communities need additional focus, mentions new pension schemes and recommends intersectoral collaboration between the Ministries of Home Affairs, Health & Family Welfare, Rural Development, Panchayati Raj and others for implementation of the policy.
- **2011:** The Ministry of Health & Family Welfare launched the "National Programme for the Health Care of Elderly" (NPHCE), which made recommendations for service delivery via the three-tier system of NHM.
- **2016:** NPHCE rolls out tertiary care for the elderly under the "Rashtriya Varisth Jan Swasthya Yojana" through which services are being provided through Regional Geriatric Centres (RGCs) located at 19 Medical colleges in 18 states of India and two National Centres of Aging (NCAs) - one in AIIMS, Ansari Nagar, New Delhi and another in Madras Medical College, Chennai.

Box 5: Timeline of geriatric policy development in India

### TB-specific policies and guidance for the elderly

TB reports and publications that call out the need for attention on the elderly age group are listed below, along with specific recommendations:

**India's national TB prevalence survey 2019-2021:** The survey makes strong recommendations to focus on the elderly and urges the NTEP to "prioritise interventions in high prevalent states with focus on screening of elderly, malnourished, diabetics, and implement strategies to reduce the Prevalence to Notification gap." However, there are no suggestions on methodology and specific actions to be implemented.

**India's NSP 2020-2025:** The NSP mentions elderly in a few important instances:

- Services available at health and wellness centres (HWCs) - *"The wide range of services provided at these Health and Wellness Centres will encompass maternal and child health services, communicable and non-communicable diseases, services for the elderly and palliative care including free essential drugs and diagnostic services."*
- Stigma - *"Stigma is an important social determinant of TB. Stigma and discrimination are major impediments to treatment adherence, mainly among unmarried women, newly married women and the elderly."*

Recommendation number 4.3.11

TB-Geriatrics outlines specific needs:

- Develop framework to address TB among geriatric population and address special needs among the population
- Institute effective screening for TB in Old age homes and other settings and ensuring continuity of care
- Establish collaboration with National Programme for Healthcare of the Elderly (MoHFW) and Integrated Programme for senior citizens (Ministry of Social Justice and Empowerment)

- Engage with Geriatric Society of India/ Indian Academy of Geriatrics/Association of Gerontology in increasing awareness on TB burden and information on availability of services
- Partner with NGOs already working with the geriatric population - HelpAge India, Manavlok, Abhoy Mission, Asha Kiran, Shraddhanand Mahilashram etc. in screening of TB and linkage to appropriate care

## 4.2 Gaps in existing guidance and recommendations

The table below mentions a few critical documents which might have been ideal places for mentioning guidance for prioritising, identifying and treating TB in the elderly, but where such any such guidance is conspicuous by its absence.

Document	Published by   Year	Significant points and gaps related to TB in the elderly
The Global Plan to End TB 2023-30	Stop TB Partnership   2022	<ul style="list-style-type: none"> <li>■ The term elderly is mentioned only once: in the list of people who have limited access to quality TB services</li> <li>■ In comparison, children are mentioned 80 times</li> </ul>
Guidelines for Programmatic Management of Drug Resistant TB (PMDT)	National TB Elimination Programme (NTEP)   2021	<ul style="list-style-type: none"> <li>■ There are exactly four references to the treatment of DR-TB in the elderly; these include suggestions to watch for a few specific side effects like hepatotoxicity (in case of BDQ containing regimens) and 8th nerve toxicity (in case of fluoroquinolone-containing regimens)</li> <li>■ In comparison, there are 137 instances where MDR-TB in paediatric age group is mentioned</li> </ul>
Free Diagnostics services initiative	National Health Mission (NHM)   2019	<ul style="list-style-type: none"> <li>■ Detailed discussion on training phlebotomists on how to take samples in children. No mention of challenges in sample collection for the elderly</li> <li>■ The data collection is disaggregated by OPD/IPD/gender/state/district/facility/ children; no disaggregation by age</li> </ul>

Table 2: Key documents with missing guidance on the TB in the elderly

Another significant area where a mention of the elderly is marked by its absence is the table in India's National Strategic Plan that lists key affected populations (see figure 5). It describes three broad groups which are populations at risk of TB infection and illness.

The third category - "people at increased risk of TB because of biological or behavioural factors that compromise immune function" - is clearly one where elderly people can and must be considered.

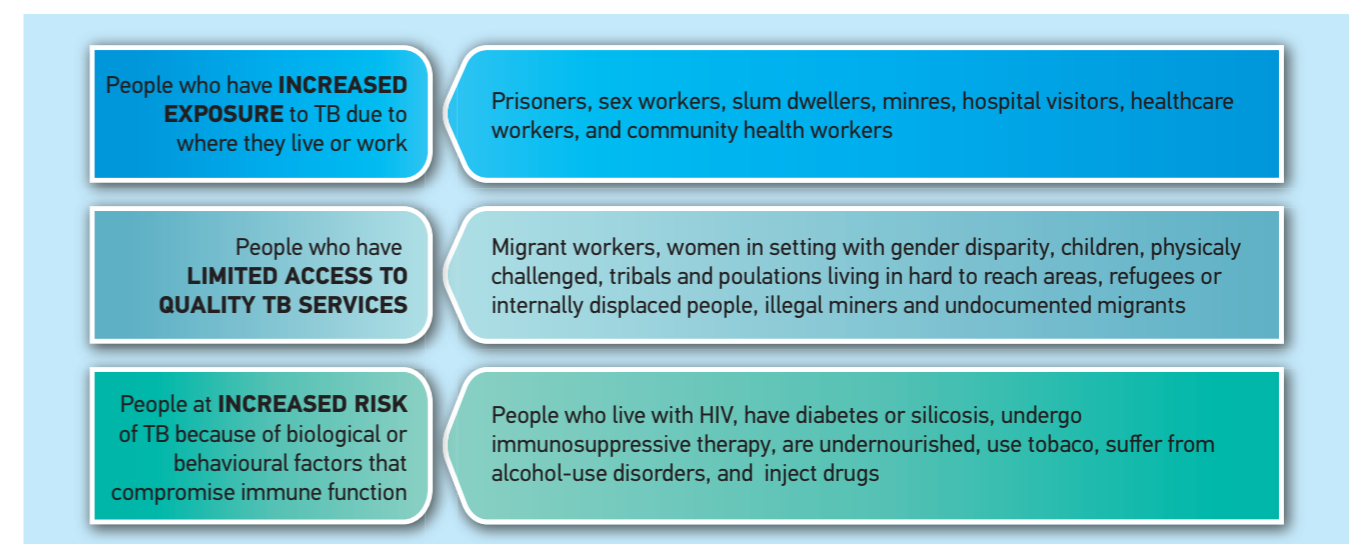


Figure 5: Key Affected Populations [National Strategic Plan]

## 5. Summary: Recommendations for the future

It is evident that older populations continue to be the recipient of the most challenging experiences in the TB care cascade – delayed and missed diagnoses, unfavourable treatment outcomes, difficulty in accessing care and support systems. Further, the service disruptions due to the pandemic have disproportionately impacted older people. It is important to recognise these inequities and the cultural and social issues that have contributed to them. As India continues to respond to TB in mission mode to achieve TB elimination, this sub-group of people with TB need increased attention from the NTEP. There is also an urgent need for increased research, advocacy and intersectoral coordination specific to the elderly. This section describes the recommendations that emerged from interviews and FGDs.

### 5.1 Systemic recommendations

#### Systematic targeted screening and active case finding among people over the age of 60

Many states are implementing TB screening in assisted living facilities/ old age homes, but these are not being done in a systematic manner, and data from targeted screening is not being analysed or shared widely. Further there are many missed opportunities around screening of elderly people visiting OPDs at HWCs, PHCs, CHCs, NCD clinics. To achieve better coverage in screening of the elderly, the following are recommended:

- Development of SOPs for facility-based and community-based screening of the elderly
- Monitoring the performance of periodic screening activities in congregate settings (like elderly care homes) as an indicator in

district performance reviews

- Documenting and sharing of best practices in targeted screening – lessons learned, challenges, opportunities
- Developing dashboards to aggregate and comparing results of targeted screening among the elderly across different states and districts
- Expanding elder-focused screening to community-based settings through community-based assessment checklists (CBAC)

#### Technical and operational guidelines for diagnosis and treatment of the elderly

There is a requirement for clear technical guidance around how diagnostic and treatment approaches for TB among the elderly needs to be different from existing algorithms. Such guidance needs to be rooted in evidence and updated clinical understanding, and needs to combine clinical recommendations and programmatic guidance. The following are recommended, as potential additions to existing technical and operational guidelines:

- Developing diagnostic protocols for atypical signs and symptoms (e.g., sample extraction protocols)
- Developing guidelines for comprehensive assessments of co-morbidities and drug dosage adjustments and SOPs for identification and management of ADRs in the elderly
- Developing and rolling out scoring system to predict risk of disease and unfavourable outcomes based on risk assessment including age as a factor (there are examples of a few states like Tamil Nadu already doing this in a sporadic manner; those models need to be considered for customisation and scale-up)

- Developing and making available guidelines for drug-resistant TB in the elderly
- Undertaking assessment and capacity-building among selected service providers, especially CHOs and MOs, to identify TB in the elderly, with training on elderly focused diagnostic algorithms

#### Support protocols

A combination of interconnected contextual factors (physical, social, economic) contribute to suboptimal treatment experiences among the elderly; well-considered support protocols need to be built in response to these factors. The following are recommended:

- Setting up special help desks for the elderly at key facilities
- Building community support systems for treatment support: an elderly-focused “community care model” could include a mapping of existing support structures at the village or block levels, identification and assignment of volunteer attendants and supporters to the elderly. In this regard, the recently published “Guidelines on Engaging Family Caregivers for Supporting Persons with Tuberculosis in India” by the NTEP are an important resource and should be implemented in a strategic manner with a focus on periodic outcome measurement.
- Deploying mobile vans to provide follow-up diagnostic testing and FDC refills for elderly people with TB
- Providing special transport (and travel concessions) for visits to health facilities for diagnosis, treatment and follow up for elderly people with TB
- Deploying models for remote treatment monitoring (through video calls/other telemedicine approaches) for the elderly
- Prioritising elderly people with TB for DBT payments using decentralised funding/block level funds
- Building systems to connect elderly people with TB to relevant pension schemes or other social schemes; providing volunteers to help with paper work

#### Prioritisation for TB prevention therapy (TPT)

People over the age of 60 represent an important source of infection in the community, and at the same time, a group amenable to receiving preventive therapy (not likely to migrate, more open to counseling). The following are recommended:

- Including elderly people in priority groups for TPT
- Including TPT for the elderly in contracts to patient-provider support agencies (PPSAs)

#### Data collection, analysis and monitoring

Studies indicate that treatment outcomes are poorer in older people with TB, but there hasn't been any population-level analysis in this area. Even though age-disaggregated data is collected via Ni-Kshay, there is little to no routine analysis and reporting of treatment outcomes in people over the age of 60 (there are a few local exceptions with districts carrying out district level analysis of elderly TB but the findings are not widely disseminated). Given the robustness of Ni-Kshay and the data-rich NTEP ecosystem, the following are recommended to strengthen this aspect:

- Publishing age-disaggregated NTEP data at national, state and districts levels. This is achievable with Ni-kshay.
- Including, in the annual TB report and district TB profiles, sections on geriatric TB, with sub-sections on diagnosis, treatment initiation, co-morbidities and outcomes
- Building a knowledge base of epidemiology, presentation and outcomes of TB among the elderly.
- Analysing historical age disaggregated NTEP data to understand the time-trends in epidemiology.
- Carrying out a “Vulnerability mapping” of states to identify areas with higher proportion of elderly population (can be prioritised for ACF campaigns and support systems)

## 5.2 Intersectoral coordination

Intersectoral collaborations focused on care for elderly people with TB need to be organised and implemented across two dimensions: public health dimension and social dimension. The goal should be to create an institutionalised, responsive care delivery at multiple systems. A few examples of each type of collaboration are described below.

### Collaboration with National Health Mission (NHM) and National NCD Programme

- Implementing bidirectional diabetes-mellitus and TB screening protocols (routinely testing every elderly person with TB for Diabetes mellitus and linking them to appropriate diabetes care services; routine testing of all people with diabetes for TB and linking them to TB care services)
- Developing and implementing protocols for large scale TB and heart health bidirectional screening among older populations
- Utilising (with appropriate modifications if needed) Ni-kshay to record and report comorbidity data for people above the age of 60.
- Training Community health officers (CHOs) at Health and Wellness centers (HWC) to carry out TB screening for all people over the age of 60 visiting the HWC

### Collaboration with National Programme for Health Care of the Elderly (NPHCE)

- Implementation of NPHCE policy in HWCs, PHCs and CHCs, including mechanisms such as geriatric OPD-days, special queues for the elderly etc.
- Co-creating protocols on holistic care models for the elderly

### Other collaborations

Collaboration with Department of Social Justice and Empowerment, Panchayati Raj Institutions (PRIs), Ministry of Women and Child Development (WCD):

- Supporting enrolment on pension schemes, transport allowances (or free transport passes) to all elderly people with TB, supplementary nutrition support, prioritising elderly for Nikshay Mitras etc.
- Developing protocols on implementation of targeted welfare schemes, including focused interventions for women elderly people with TB
- Vocational training and/or linkages with home-based local industries

## 5.3 Research recommendations

The following emerged as key questions around which further research would be useful to better understand TB in the elderly in India:

- Vulnerability mapping – Are there specific geographic areas with higher concentration of the elderly (relation with migration patterns)?
- Clarity on disease burden at state levels with research questions like:
  - What is the proportion of elderly people among people newly diagnosed with TB and DR-TB?
  - What are recurrence rates among elderly people with TB?
  - What are mortality rates among elderly people with TB?
- Predictors for unfavourable outcomes among the elderly TB group, with a focus on:
  - What is the prevalence of substance use (especially alcohol and tobacco) in people over the age of 60 and impact on outcomes?
  - What is the impact of gender on treatment outcomes among elderly people with TB?
  - How do co-morbidities among the elderly impact treatment outcomes?
  - What are treatment completion rates among elderly people with TB?

- Is there any correlation between specific genetic profiles and treatment success among elderly people with TB?
- How do outcomes of DR-TB among elderly people with TB differ from outcomes of DR-TB among other adults?
- Mental health challenges among the elderly:
  - What is the burden of mental health challenges among elderly people with TB?
  - What is the potential impact of mitigation strategies (like counseling or providing opportunities for volunteering activities) on the mental health of elderly people with TB and on treatment outcomes?
  - Do elderly people with TB experience stigma differently?
- Implementation of support schemes –
  - What proportion of elderly people with TB have access to bank accounts and are able to access direct benefit transfers?
  - What is the current coverage of pension schemes in India?
- Impact of TB Prevention – To what extent does TPT or revaccination prevent TB among elderly people?

## 5.4 Advocacy recommendations

TB in the elderly needs greater attention at all levels. Some recommendations are:

- Including issues around elderly people with TB in the district TB forum meetings; invite elderly people with TB and survivors to share perspectives
- Designing campaigns aimed at engaging the youth into elder care
- Acknowledging at a global/country level: The World TB Day focused on children in 2012; similar acknowledgement of older adults is essential to raise awareness and pave the way for action.
- Contracting private sector partners (PPSAs for example) for engaging with geriatric societies and designing solutions for elderly people with TB.

*“For us, tribal health is a priority. We’ve recognised that people living in tribal areas have unique problems and needs. Maybe we need to start seeing the elderly in the same way, start prioritizing them too”*

*– State TB Officer*

## 6. Conclusion

Older people represent a storehouse of wisdom for current and future generations. Respect for older people's rights benefits society as a whole. Humans are rapidly moving towards a future where people over the age of 60 will make up large and significant proportions of our societies. However, healthcare systems are not undergoing a parallel movement towards becoming systems that can care for such a society but instead continuing to function in ways that are largely unresponsive to the needs of the elderly.

These trends are starkly visible in TB, which remains a significant public health concern among older adults, particularly in low and middle-income countries. To address these challenges, national governments, health care providers, civil society organisations and global technical partners like WHO need to work together to scale up efforts to prevent, detect, and treat TB in older adults. This includes providing technical support and guidance, training health care workers, and advocating for increased funding and resources for TB control.

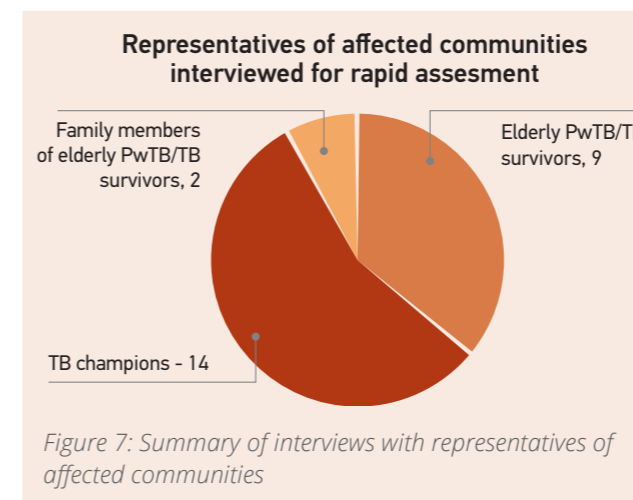
It is essential to prioritise TB prevention and control among the elderly in order to reduce the burden of this disease and improve the health and well-being of this vulnerable population. Developing and implementing age-responsive TB recommendations is an important next step in India's mission to end TB. Age-responsive healthcare systems, built for TB care delivery today, can become foundations for holistic care systems for all health areas in the future.

## 7. Appendices

### 7.1 Community interviewees

S. No.	Discussions with affected communities	Date
1	1-1 conversation (telephonic) with 70 year old PwTB (female) based in Muzzaffarpur	22 Dec 22
2	1-1 conversation (telephonic) with 60 year old PwTB (male) based in Patna	22 Dec 22
3	Focus group (over zoom) with 12 TB Champions based in Delhi	28 Dec 22
4	1-1 conversation (in-person) with 62 year old PwTB (male) based in Trichy	09 Jan 23
5	1-1 conversation (in-person) with 74 year old PwTB (male) based in Coimbatore	08 Jan 23
6	1-1 conversation (in-person) with 62 year old PwTB (male) based in Cuddalore	09 Jan 23
7	Focus group (in-person) with 4 PwTB (one female and three male), 2 family members and 2 TB champions in Chhattisgarh	24 Jan 23

Figure 6: Summary of interviews with representatives of affected communities



### 7.2 Questionnaire 1

**Purpose:** This questionnaire is aimed at FGDs and IDIs with affected communities, i.e.:

- Elderly people with TB, or elderly TB survivors - i.e., people who are experiencing/have experienced the healthcare system as a patient, and
- People who are close family members/caregivers of elderly people with TB or elderly TB survivors.

#### A. Questions to understand current state of policy landscape around geriatric TB

- How do you define 'elderly'? Is there an official definition that you're aware of?
- In your view, are there any country/state-level policies (may or may not be related to health) for the protection of the elderly? Are there any policies for the health of the elderly?
- In your view, are there any government institutions at the level of the centre/state which are tasked with the policies and practices related to the elderly?
- In your view, is there any policy to collect and use age related data (for people with TB)? Why or why not?
- In your view, is there any policy to provide special care and treatment to the elderly when it comes to:

- TB screening,
- TB diagnosis
- TB treatment and support
- TB prevention

- Should there be such policies? Why? Why not?

#### B. Questions to understand the needs of the population:

- Based on your experience/observations, what are some needs (or vulnerabilities or challenges) that are unique to the elderly cohort, when it comes to -
  - Stigma related to TB
  - Access to care - mention examples like structural issues in the healthcare facilities, distance, signage
  - Screening
  - Services related to diagnosis and treatment
  - Services around contact investigation
  - Services around prevention therapy
  - Services related to treatment support, including socioeconomic support
  - Experiences around treatment adherence
  - Any other part of the patient cascade/experience
- What socio-cultural norms and practices may play a role in shaping the experiences of an older person with TB?
- Are there any other considerations like religion, caste and geographic location that contribute to the experiences of the elderly people with TB?
- Are there any gender differences in terms of needs of this cohort for each of the points mentioned above?
- Are there other factors of vulnerability (HIV, co-morbidities, alcohol dependence) that play a role in shaping the experiences of an older person with TB?
- Have you experienced or observed any age-related discrimination in TB care delivery services in the public or private care systems?

13. Is there a difference between the public and private care systems in terms of the experience of older people with TB?

**Questions to explore opportunities for process improvements and collaboration**

14. Please answer from your observation/experience - for each of the points in the patient cascade - screening to diagnosis to treatment - is the existing healthcare system responsive to the needs of the elderly people who have TB or who are at risk of getting TB? Can you share some instances of when the system was responsive/not responsive?
15. What are the process improvements that would make the system age-responsive?
16. Please mention if there have been any interactions with the healthcare delivery system (staff, TB champions, medical officers) which have stood out - both pleasant and unpleasant.
17. What kind of organizations should be participating in strengthening care delivery systems for older people with TB?
18. Can you think of any other departments/organizations which care for the elderly, and which should work closely with the TB care system?

## 7.3 Questionnaire 2

**Purpose: This questionnaire is aimed at healthcare personnel, or people who influence the healthcare system in different capacities:**

- Leaders connected with and influencing the NTEP (e.g., CTD staff)
- TB technical experts and policy experts (e.g., NIRT experts)
- TB program implementers - care delivery personnel in public and private health system (e.g., doctors, medical officers, STSs)

### A. Questions to understand current state of policy landscape around geriatric TB

*Questions in this section focus on building an understanding of existing policies/guidelines/practices around*

- General focus on the elderly
- Screening, diagnosis, treatment and prevention
- Age-disaggregated data collection and analysis

#### General focus on the elderly -

- How do you define 'elderly'? Is there an official definition that you're aware of?
- Are there any country/state-level policies (may or may not be related to health) for the protection of the elderly? Are there any policies for the health of the elderly?
- Which government institutions at the level of the centre/state are tasked with the policies and practices related to the elderly?

#### Regarding policies/guidelines to collect and analyse age-disaggregated data for people with TB -

- Is age-disaggregated data (for people with TB) collected and analysed at any level? National-level? State-level? District-level?
- Are there any policies/guidelines in place?
- Is there a variation in terms of state and national-level policies (or practices)?
- As far as you know, have there been any discussions to initiate/refine such policies?
- What are the possible steps that you foresee in building/implementing such a policy? Are there any challenges that you foresee?

#### Regarding policies around implementing age-sensitive practices at different levels in the patient cascade - screening, diagnosis, treatment, support and prevention -

Same questions as question numbers 4-8 above.

### B. Questions to understand the needs of the population:

*What are the special needs of this cohort, i.e., people over the age of 60 who have TB or are at risk of TB?*

- Based on your experience/observations, what are some needs (or vulnerabilities or challenges) unique to the elderly, when it comes to -
  - Stigma related to TB
  - Access to care - mention examples like structural issues in the healthcare facilities, distance, signage
  - Screening
  - Services related to diagnosis and treatment
  - Services around contact investigation
  - Services around prevention therapy
  - Services related to treatment support, including socioeconomic support
  - Experiences around treatment adherence
  - Any other part of the patient cascade/experience
- What socio-cultural norms and practices may play a role in shaping the experiences of an older person with TB?
- Are there any other considerations like religion, caste and geographic location that contribute to the experiences of the elderly people with TB?
- Are there any gender differences in terms of needs of this cohort for each of the points mentioned above? The number of elderly women is increasing faster than elderly men, with a sex ratio of 1065 women per 1000 men as per recent estimates - what does this mean for TB care delivery?

13. Are there other factors of vulnerability (HIV, co-morbidities, alcohol dependence) that play a role in shaping the experiences of an older person with TB?

14. Have you observed any age-related discrimination in TB care delivery services in the public or private care systems?

15. Is there a difference between the public and private care systems in terms of the experience of older people with TB?

### C. Questions to explore opportunities for process improvements and collaboration

16. For each of the points (in the patient cascade) mentioned above - is the existing healthcare system responsive to the needs of the elderly people who have TB or who are at risk of getting TB? Can you share some instances of when the system was responsive/not responsive?

17. What are the process improvements that would make the system age-responsive?

18. What are some possible intersectoral collaborations that can contribute to improvements in patient experience and healthcare processes?

19. What kind of organizations should be participating in strengthening care delivery systems for older people with TB?

20. Are there any existing examples of partnerships focused on geriatric TB?











**Resource Group for Education and Advocacy for Community Health (REACH)**

**Chennai Office:** 194, 1st Floor, Avvai Shanmugam Salai Lane, Off Lloyds Road, Royapettah, Chennai – 600014, **Phone:** 044-4 5565445 / 044-28132099

**Delhi Office:** BB-5, 1st Floor, Greater Kailash Enclave Part II, New Delhi – 110048. **Phone:** 011- 49055686

 [support@reachindia.org.in](mailto:support@reachindia.org.in)

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