Leprosy and Migration in India

Secondary Research Report-2022

NOVARTIS

ACKNOWLEDGEMENTS

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EXECUTIVE SUMMARY

India has made significant strides in reducing the burden of leprosy. It has reduced the prevalence rate from 57.8/10,000 in 1983 to its "elimination as a public health problem" of less than 1/10,000 in 2005 (Sengupta, 2018). Besides achieving the national elimination target, India, as per findings from a mid-term evaluation, achieved elimination at the state level in 34 states/Union Territories (UTs) out of the total 36 states/UTs. Despite this success, India continues to account for 60% of the new cases of leprosy reported globally each year. The annual reports of the last four years of the National Leprosy Eradication Programme (NLEP) have consistently observed that four states/UTs viz. Orissa, Chandigarh, Delhi, and Lakshadweep, which had achieved elimination earlier in 2011–2012, have shown a prevalence of >1 per 10,000 population. At the district level, by March 31, 2019, 588 districts out of 708 districts in India had achieved a prevalence rate of less than 1/10,000 with the balance districts being highly endemic (Ministry of Health and Family Welfare [MoHFW], Government of India [GOI], 2019-20).

This secondary research study has examined the linkages between migration and leprosy patients in India. It has examined the policy framework and paucity of disaggregated data pertaining to migration and the resurgence of leprosy cases in the erstwhile leprosy free areas and districts, which concerns the public health initiatives.

The study informs areas in which primary research need to be initiated to completely eradicate leprosy and prevent any recurrence. Practical policy responses that can be adapted from two successful health programme initiatives, viz., HIV/AIDS programme and tuberculosis initiatives have been examined and described in the study. Further, the trends of migration, especially seasonal and circular migration from the source states to states, needs to be examined.

In 1983, India launched the National Leprosy Eradication Programme(NLEP) for early detection of leprosy and free of cost treatment to prevent occurrence of Grade 2 disability; stop the transmission of the disease; spread awareness and reduce the stigma associated with leprosy.

In 1983, India launched the National Leprosy Eradication Programme (NLEP). Being implemented under the National Health Mission (NHM), the primary goal of NLEP is early detection of leprosy and provision of complete treatment free of cost, to prevent occurrence of Grade 2 disability, stop the transmission of the disease at the community level, spread awareness about leprosy, and reduce the stigma associated with it (MoHFW, GOI, 2020).

Independent surveys have revealed that there are a number of hidden, undiagnosed cases in the community. In 2017, the Indian Council of Medical Research (ICMR) conducted a survey to assess the new leprosy case burden (Katoch, et. al., 2017). The survey estimated the prevalence rate to be 2.7/10,000, and that disability was also on the rise.

At the state level, Bihar (16,595), Maharashtra (16,572) and Uttar Pradesh (15,484) have reported the highest number of new leprosy cases. Delhi (1,824) and Chandigarh (134) reported relatively lower number of new cases, though they showed a prevalence of over 1 per 10,000 of population and a higher percentage of Multibacillary (MB) cases.

The findings from the ICMR survey and rising prevalence led NLEP to start a programme in 2020 for Active Case Detection (ACD) and Regular Surveillance (RS)[5] . Under this programme, screening, contact screening and tracing, and maintenance of records for ACD is carried out by ASHA/Trained Frontline Worker (FLW) deployed by the District Leprosy Officer (DLO). The diagnosis of leprosy is done through a physical examination. Whenever a new Paucibacillary (PB) or Multibacillary (MB) case of Leprosy is detected, the treatment begins immediately. However, emerging drug resistance, albeit low at present, is a matter of concern (Mahajan, et. al., 2020).

Some challenges in implementing the NLEP include lack of early case detection, lack of providing a continuum of health care, inadequate human resources, and the stigma

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associated with the disease, including 114 Laws in India which discriminate against Leprosy (The Leprosy Mission Trust India, n.d.). While efforts to address these challenges are underway, migration of people affected withleprosy is a reality. It has not been factored appropriately in NLEP.

Migration facilitates movement of disease between endemic and non-endemic areas. It has been considered a factor in continued leprosy incidence. This is facilitated by the latent nature of leprosy, and clinically non-symptomatic presentation.

Migration and Leprosy

An analytical review of published studies in PubMed (Rathod, et. al., 2019) and news articles related to migrationin leprosy identified migration as one of the important obstacles in achieving elimination ofleprosy. Migration can lead to default in treatment of already diagnosed cases. In suchcases, the disease will progress and the person may develop serious disabilities and deformities. Also, affected individuals could become a source of infection in the community (World Health Organization [WHO], n.d.); and may spread the disease unknowingly. This highlights the importance of monitoringpopulation movement at the municipality level to establish early warning systems. Since the migrants are mainly circular, it would be essential to increase disease surveillance in states/districts with high migration coupled with endemicity.

In the context of migration and public health management, a distinction can be made between permanent migrants and seasonal or circular migrants. Permanent migrants are those who no longer have a strong link with the areas from which they migrated; while circular migrants retain strong links with their areas of origin. Importantly, circular migrants both short term and long term, especially from endemic districts, are more likely to exhibitthe health indicators of their areas of origin, and could play a strong role in driving the continued transmission of leprosy.

Circular migrants migrate for temporary periods, either moving from place to place or to a fixed destination, and return to their place of origin after brief periods/few months. Most are recruited through contractors and work mostly in the areas of construction, brick-kilns, manufacturing, etc. Being semi-permanent or long-term circular migrants, they remain in precarious employment, mostly as wage workers, and are vulnerable during periods of shock to the economy. They are away from their home on an average of about 7.5 monthsin a year (Nayar & Kim, 2018). Most seasonal migrants are more likely to be from households that are alreadypoor, socially disadvantaged, less educated and employed in agriculture. Public health policy needs to consider the socio-economic characteristics of circular migrants.

In India, a majority of the circular migrants come from the states of Uttar Pradesh and Bihar, who move to Delhi, Maharashtra, Punjab and Haryana. Almost all the districts of the states reporting a high migrant outflow are also high endemic districts. *Delhi, Chandigarh and Maharashtra, which had eliminated leprosy as a public health hazard, are now exhibiting higher rates of transmission of leprosy* (DownToEarth, n.d.). Both in Delhi and Chandigarh, the increase in the transmission rate is significant. Hence, seasonal migrant labour or circular migrants are the highest risk group within migrants for whom

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A challenge to eliminate leprosy in the context of migration stems from the relationship between poverty and leprosy. There is a consistent relationship between leprosy and unfavorable socio-economic circumstances. A systemic review of literature - of original articles, investigating socio-economic risk-markers of leprosy in countries with over 1,000 cases annually, for five years between 2006 and 2016, found links between poverty and living in crowded urban slums, and the risk of contracting and developing leprosy.

Examination of the migratory trends helps to gain insights into the continued spread and transmission of the disease. This study report focuses on population migrating for economic reasons or for employment. Employment is an important pathway out of poverty and such migrants often live in hard conditions to save and repatriate their earnings to families back home.

No precise estimates exist on the number of migrant workers in India. Although the Census provides a satisfactory measure of permanent migration, it fails to measure long-term semi-permanent circular migration, since it is not designed to measure short-term circular

No precise estimates exist on the number of migrant workers in India. Census data shows that the poorer states in India like Uttar Pradesh and Bihar are the major source of migrants - both long-term as well as short-term circular migrants. Maharashtra, Delhi, also Chandigarh attracts the larger number of migrants from these states.

migration (Srivastava, 2020). Similarly, the National Sample Survey Organisation (NSSO) is unable to capture properly the short-term seasonal streams longer than 6 months. Circular migrants[1] are estimated at a total of 14 crore (140 million) of which 12 crore (120 million) are largely employed in low skilled precarious employment. Thus, whenever there is a shock to the economy, they are the worst impacted in terms of employment, eroding their savings and/or their nutritional status that often pushes them back to poverty.

An analysis of Census data shows that the poorer states in India are the major source of migrants - both long-term as well as short-term circular migrants. **Uttar Pradesh** (UP) and **Bihar** are the largest source of migrants and **Maharashtra** and **Delhi** attract the largest number of migrants. Data suggests that distance matters in determining the destination state, with the northern states being the most preferred for the migrants from UP and Bihar. Delhi is the most preferred choice. About, 43% of Delhi's population[2] are migrants with over half coming from UP and Bihar. Another important urban destination is **Chandigarh** with over 60% of its population comprising migrants (2011 Census) with a majority migrating for work. The largest numbers of migrants to Chandigarh are from UP (17.4%) and Bihar (5%).

To understand the impact of migration on leprosy, it is important to understand the extent of overlap between high-endemic/high-prevalence states/districts and their migration landscape. The Report of the Working Group on Migration (Ministry of Housing and Urban Poverty Alleviation [MoHUA], GOI, 2017) based on the 2001 Census identified the top 17 districts, which accounted for 25% of inter-state all-male out-migrants. These 17 districts are concentrated in Eastern UP and Bihar, except for Ganjam in Odisha.[3] About 60% of the outmigration from the six districts of Bihar- Madhubani, Darbhanga, Samastipur, Patna, Saran and Siwan (which form a contiguous arc) are to Delhi (28%), Maharashtra (17%) and West Bengal (14%). Another 36 districts accounted for an additional 25% of inter-state out-migrants. In all, 53 districts in India account for half the male inter-state out-migrants in the country.

Detailed policy interventions in the destination states - as health is a state subject, must profile-scrutinise and monitor migratory cycle. Effective steps need to be taken at destination points to diagnose leprosy patients, and to provide them with treatment.

COVID-19 impacted the migration landscape drastically. Lockdowns imposed mid-April 2020 onwards, led to a large urban exodus. By May 2020, migrants returned to urban areas in search of employment. The coming of the second wave from February-March 2021 led to another slowdown which again impacted the informal wage workers. The circular work-force was negatively impacted by the lockdowns imposed. It is critical that, at least in the short-term, the circular migrants are identified and monitored closely for leprosy, and preventive steps taken.

Analysing the trends of immigration is also pertinent to India. Being the largest and

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1   Includes long-term circular and short-term circular employment

2   As per NSS 64th round (July, 2007 to June, 2008).

3   A comparison between the top migratory districts in Uttar Pradesh and Bihar tend to belong to leprosy endemic districts. The report of working group has provided several annexes detailing the migratory trends, and top migratory districts and their endemicity status.

economically stronger country in the Indian sub-continent, it attracts a large number of immigrants from its neighboring countries. While the borders with Pakistan and Myanmar are largely closed; immigration from Sri Lanka substantially reduced with the end of the civil war; the focus is on the immigration from Nepal and Bangladesh. Nepal has a high leprosyrate, though lower than India's. Their national leprosy PR and district-wise leprosy burdenhave been rising in the last five years, and leprosy endemic districts increased from 17 to 21 from 2017 to 2018. In the last decade, an estimated 8 lakh people migrated to Indiafrom Nepal. An immigrant from Nepal tends to be illiterate/lowly literate, and unskilled. Uttar Pradesh, Bihar, West Bengal and Assam are the major hubs of Nepali immigration. The undocumented circularity of population flow across the border complicates monitoring the health parameters of the high-risk migrant worker. This increases risk of greater spread of leprosy across the borders.

India shares a long and porous border with Bangladesh. A task force on border management in 2001 estimated that India was home to 1.5 crore Bangladeshi migrants with a majority being in West Bengal and Assam. Illegal immigration to India from Bangladesh continues. Bangladesh detects about 4000 leprosy cases every year, even though its prevalence rate is lower than India's. The Bangladeshi migrants show characteristics similar to the circular migrant labour, and carry the same risk profile.

Lessons from Tuberculosis and HIV/AIDS Control Programmes

Two important communicable diseases - Tuberculosis and HIV-AIDS, in which prolonged treatment and follow up is necessary as in leprosy, have evolved systems for close monitoring and follow up which can be adopted by the NLEP. Lessons from these two programmes have been articulated in the present report to inform policy and tools to strengthen the NLEP. While, the current policy landscape of leprosy management does not include factors related to migration directly, this report

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seeks to recommend important programme implementation examples and initiatives that can be adopted under NLEP.

The HIV programme was the first one in India to define migrants. It was observed that migration fuelled the rise in previously low HIV incidence areas. It is a comprehensive definition that gives importance to source and destination, household migration, and gender. *An adaptation of the definition of HIV programme is recommended for adoption to NLEP.*

RECOMMENDED DEFINITION OF MIGRANTS FOR NLEP

– People (men and women) who move from their place of origin (source) to another location (destination) – irrespective of district/state/country
– Return to their place of origin at least once in 6-12 months
– Move frequently between districts for work purpose
– Move directly between the places (or) via the transit locations
– Move either alone or with their partners and/or other Household Members
– Those returned to places of origin (at source areas)
– Household members of migrants (at source areas)

The HIV programme's rights-based, gender responsive framework, developed to provide a continuum of prevention and treatment could easily be replicated by NLEP. Two other strategic aspects of the HIV programme viz. (i) Information Monitoring System that registers all patients with a unique ID to monitor the treatment, enabling the patient to migrate, and take treatment in another city / district hospital; and (ii) its successful addressing of the issue of community participation and mobilisation for migrant interventions could be adopted in NLEP. Further, the on-ground experience of engaging the community structures at the source and destination districts under the HIV programme can be emulated for leprosy as well.

Similar to HIV and leprosy, TB Control Programme faces the challenge of migrants, and an additional challenge of patients migrating between doctors, especially in the private sector. The challenge of completing treatment is more in TB, since untreated disease proves fatal and there is the challenge of increasing drug resistance. To address migration, the programme highlights high risk populations first; then from among them, highlights those who have limited access to health care, including migrants. Such in-depth understanding can lend some support to NLEP. Additionally, the TB programme has progressed in the use of rapid diagnostic tests, artificial intelligence, digital adherence tools that help on quick diagnosis, initiation of treatment, and monitoring adherence. Lastly, the TB control programme has a case based, web-based surveillance system, NIKSHAY, adapted and customised from the use of ICT in the HIV/AIDS Control Programme.

Patient support systems have evolved in the programmes that are holistic and implemented from the time of diagnosis till completion of treatment. A similar approach and adaptation has to be done with NIKUSTH[4]. Digital health is gaining ground since the COVID19 Pandemic. NLEP too must forge ahead with the use of ICT.

Policy response to management of leprosy

It is recommended that NLEP should address the persistent rhetoric of India having eliminated leprosy; admit that the disease persists; and applying appropriate epidemiology, define what 'Zero Leprosy' would actually mean in prevalence rates for the nation. In view of the size and diversity of India, targets for prevalence rates by 2030 need to be defined for each state. Importantly, the response needs to be phased and spread out across years, comprehensively incorporating other social and medical issues.

Considering that the disease is endemic and complex in its medico-social manifestations, the suggested policy response has been phased out into: Immediate Policy Response (over the next 1 year), medium term policy response (over 2-5 years) and long-term policy response (over 10 years).

Under the immediate response, NLEP should consider interventions that start building human resources in terms of number of people and high-quality skills through capacity-building; sustain and intensify active case detection and regular surveillance; and address stigma by abolishing discriminatory laws. Under the mid-term policy response, NLEP should intervene to strengthen monitoring, especially monitoring treatment among migrants; start community participation and enable empowerment efforts. The long-term policy response calls for continued research in medical areas such as exploring rapid tests, improved drug regimens; and in social areas such as the phenomenon of migration amongst leprosy patients, methods of behaviour change communication for patients, and communities to address stigma.

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4   A real time leprosy reporting software implemented across India

Key areas of primary research on migration and leprosy

Research has emerged as an important aspect to address leprosy elimination. This report highlights key areas of primary research including the need to conduct sociological studies on migration and leprosy, medical studies on the pattern of the disease, and operational research on modified health systems. It identifies specific areas of research within these subsets for consideration, especially, given the dwindling investment in research on leprosy in India, and the urgent felt need to bring in advanced research methodologies in this domain. Towards this end, FAIRMED India is undertaking a 3-year pilot study in four locations of the country i.e. source states: Bihar and Uttar Pradesh; and destination state/UT: Delhi and Chandigarh, to gain an understanding of the issues faced by migrant leprosy patients.

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ABBREVIATIONS

ACD	Active Case Detection
ADB	Asian Development Bank
ASHA	Accredited Social Health Activist
BSF	Border Security Force
CSW	Communication Support Worker
DDS	Diamino Diphenyl Sulfone
DLO	District Leprosy Officer
EDPAL	The Elimination of Discrimination against Persons affected with Leprosy
FLWs	Front Line Workers
G2D	Grade 2 Disability
ICMR	Indian Council of Medical Research
ICT	Information and Communications Technology
ID	Identity
IEC	Information, Education and Communication
IHR	International Health Regulations
LCDC	Leprosy Case Detection Campaigns
LGBTQ	Lesbian, gay, bisexual, and transgender
MB	Multibacillary Leprosy
MDT	Multi-Drug Therapy
MO	Medical Officer
NACO	National AIDS Control Organisation
NGO	Non-Governmental organisation
NLCP	National Leprosy Control Programme
NHM	National Health Mission
NLEP	National Leprosy Eradication Programme
NPCB	National Programme for Control of Blindness
NSDP	National State Domestic Product
NSSO	National Sample Survey Office
NTCP	National Tobacco Control Programme
NTD	Neglected Tropical Diseases
PB	Paucibacillary
PDS	Public Distribution System
PHCs	Public Health Centres
PR	Prevalence Rate
PEP	Post Exposure Chemoprophylaxis
RS	Regular Surveillance
SDR	Single Dose Rifampicin
SLO	State Leprosy Officer
TB	Tuberculosis
TMU	Tropical Medicine Unit
UP	Uttar Pradesh
UPR	Usual Place of Residence
VFR	Visiting Friends and Relatives
WHO	World Health Organization

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CHAPTER 1: GLOBAL SITUATION OF LEPROSY

Hansen's Disease (also known as leprosy) is caused by an infection with Mycobacterium Leprae, usually acquired through contact with an infected person (Fine, 1982). Based on both archaeological records and studies of the modern genome of the bacillus (Monot et.al. 2005), Leprosy is said to be one of the oldest diseases known to humankind. It predominantly affects the peripheral nerves, skin, and leads to impairment and disability, with consequences of considerable stigma and social segregation.

In present day, early diagnosis and treatment will prevent damage to the soft tissues and bones of hands, feet and face. It was in the 1940s, that Diamino Diphenyl Sulfone (DDS)/ Dapsone, a bactericidal drug, was found to be effective against the disease. However, since the 1980s, with the introduction of multi-drug therapy with Rifampicin, Ofloxacin and Clofazimine, the incidence and prevalence of the disease has remarkably decreased.

Leprosy predominantly affects the peripheral nerves, skin, and leads to impairment and disability, with consequences of considerable stigma and social segregation.

The remarkable decline in the leprosy cases is evident from the fact that in 2019, the WHO reported just over 200,000 cases globally (WHO, 2021). Of these, nearly 80% came from three nations namely, India, Indonesia, and Brazil. Around 5% had visible deformities at the time of diagnosis, a 40% reduction since 2014; the new child case detection rate was 7.9 per million children, a significant improvement over the 2014 rate of 10.1.

The global strategy adopted in early 2000s was to eliminate leprosy as a public health problem, defined as <1 case on treatment per 10,000 population. Today, the world is working towards Zero Leprosy by 2030, defined as zero infection and disease, zero disability, zero stigma and discrimination (WHO, 2021).

The Zero Leprosy by 2030, reflects epidemiological changes, focuses on interrupting transmission and achieving zero autochthonous cases. High burden countries need to accelerate activities and low burden countries need to complete tasks to make leprosy history.

The new strategy is in sync with global health trends, including the move towards multi-disease service integration and digitization, developing human resources, surveillance and addressing anti-microbial resistance. Also, the burden of disease includes not only people needing physical treatment and socio-economic rehabilitation, but also those in need of mental health support.

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Leprosy is now one of 20 Neglected Tropical Diseases (WHO, n.d.). The overall global decline has shown that a world free of leprosy and related disability, and free of leprosy-related stigma is possible and worth aspiring for.

1.1 Leprosy in India

Leprosy is endemic in India. As with the rest of the world, there was no specific treatment till the 1940s. The National Leprosy Control Programme (NLCP) was launched in 1955. Multi Drug Therapy (MDT) came into wide use from 1982; and since 1983, the National Leprosy Eradication Programme (NLEP) is being implemented as a centrally sponsored scheme (MOHFW, GOI, 2020). The NLEP strategy is based on controlling the disease through early case detection, reduction in the quantum of infection in the population and reduction in infective source,thus breaking the chain of disease transmission.

India has made significant strides in reducing the burden of leprosy. It has succeeded in reducing the prevalence rate from 57.8/10,000 in 1983 to its "elimination as a public health problem" of less than 1/10,000 in 2005 (Sengupta, 2018). In addition to achieving the national elimination target by the end of 2005, India by March 2011–2012 succeeded in achieving elimination at the state level in 34 states/UTs out of the total of 36 states/UTs. By 31st March 2019, 588 districts out of 708 districts in India had achieved a prevalence rate of less than 1/10,000 (MOHFW, GOI, 2019-20). The remaining districts are those where the disease is highly endemic.

India has made significant strides in reducing the burden of leprosy by reducing the prevalence rate to its "elimination as a public health problem" of less than 1/10,000 in 2005. By March 2011-2012, it succeeded in achieving elimination at the state level in 34 states/Union Territories (UTs). And, by 31st March 2019, 588 districts out of 708 districts in India had achieved a prevalence rate of less than 1/10,000. Despite this success, India continues to account for 60% of the new cases reported globally each year.

Despite this success, the fact remains that India continues to account for 60% of the new cases reported globally each year. Also, there appears to be stagnation in the number of new cases detected i.e. the number of new cases detected in 2007 (137,685 cases) remained at almost the same level at 135,485 in 2016; reducing marginally to 120,334 new cases in 2018-19 the NLEP's last four years' annual reports have consistently observed that four states/UTs viz. Orissa, Chandigarh, Delhi, and Lakshadweep, which had achieved elimination earlier in 2011–2012, have shown a prevalence of >1 per 10,000 population (MOHFW, GOI, 2019-20). This is a matter of concern. In addition, the child leprosy rate exhibited was higher than the national average of 9% andranged from 14% to 23% in 6 states (Tamil Nadu, Punjab, Dadra & Nagar Haveli, Bihar, Mizoram, and Arunachal Pradesh) showing continued transmission of the disease (Rao & Suneetha, 2018).

In 2019-20, the state-wise report of NLEP noted that the target areas of Uttar Pradesh and Bihar were among the states reporting the highest number of new leprosy cases at 15,484 and 16,595 respectively. However, Delhi and Chandigarh reported relatively lower number of fresh cases i.e. 1824 and 134 respectively, though they showed prevalence of/nearing 1 per 10,000 of population and higher percentage of MB cases. The following table (Table 1) discusses the other indicators of Leprosy in these 4 states, and a few select states having high prevalence per 10,000 population.[1]

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[1]   Refer to Annexure I for data for all states.

Table 1: Key Indicators for the Spread of Leprosy in Selected States (NLEP, 2019-20)

Indicators	Uttar Pradesh	Bihar	Delhi	Chandigarh	Maharashtra	Odisha	Chhattisgarh	Madhya Pradesh	All India
New Cases	15,484	16,595	1,824	134	16,572	10,077	8,905	8,020	114,451
PR/10000 pop'ln	0.43	0.77	0.99	1.03	0.79	1.45	2.08	0.8	0.57
% Of MB cases	45.61	45.08	87.45	81.34	54.95	48.8	54.13	62.61	54.29
No. of child cases	528	1694	58	12	1358	681	479	292	7,859
No. of new cases with G2D	158	458	256	6	258	200	309	287	2,761

As will be discussed later, a possible cause for the high prevalence rates – Uttar Pradesh, Bihar, Maharashtra, Odisha, Chhattisgarh and Madhya Pradesh – is the high incidence of migration, often between these States.[2] For further details, please refer to the National Leprosy Eradication Program (https://nhm.gov.in).

With the implementation of NLEP India has made significant strides in reducing the burden of leprosy. The program however needs to address existing gaps in the management of leprosy in order to move towards Zero Leprosy. The key gaps identified include the following.

- There are four alarming trends (Rao & Suneetha, 2018) and these can be summarised as:
  – There are pockets of high endemicity, which need to be closely monitored.
  – There are many hidden cases in the community, for which early diagnosis is important.
  – There is a stagnation in new cases detection rate, and
  – The disability rates in new cases are on the rise.
- Complacency set in when the target of < 1/10,000 was realized in large tracts of the nation. Doing away with skin smear services, rapid merging of leprosy services into the general medical health services, efforts towards further reducing the duration of therapy, and reduced attention to research and funding of leprosy programme - are some of the direct results of such skewed interpretation.
- Migration of patients is a reality that has not been factored in appropriately in NLEP. This is unlike other national programmes such as National Tuberculosis Control Program (NTCP) and control of HIV-AIDS.
- Drug resistance is limited but is a reality. India is yet to develop protocols for treatment failures and drug resistant cases.
- Research in leprosy has drastically come down in India. The continuing epidemiologicaland societal changes are not being studied and documented adequately.

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[2] For instance, Maharashtra is a state with a high prevalence of migrants. This may explain the high prevalence of the disease in other states, but not necessarily in Odisha - the reasons there need to be studied. Chapters 2 and 3 discuss and explore migration and leprosy in greater detail.

The Covid-19 pandemic accentuated the challenges faced in managing leprosy. The medical professionals working on Leprosy were mostly distracted and the restriction of movement made it even more difficult to cater to the detection and treatment of the same. Shutdowns and advocated social distancing also limited the access to MDT.

During the pandemic all the non-urgent hospital consultations and admissions were being discouraged in health facilities because of concerns of responding to increasing COVID-19 cases. This situation created a gap in health service needs for leprosy patients. Not only the access to hospitals has been an issue for leprosy affected persons but maintaining personal hygiene on their own is another major challenge. For instance, frequent hand washing being one of the essential ways of preventing COVID-19 transmission, is likely to be one of the biggest challenges for leprosy patients with deformities, cracked and dry skin making them unable to maintain the personal hygiene.

Covid-19 observed one of the greatest migration crises in the country. Migrants were faced with an undue share of challenges leading to a lot of reverse migration; some struggled to receive food and housing. The restrictions in the movement also led to delay in the screening and treatment (Guillermo et.al. 2021) for leprosy amongst migrants.

In the current Leprosy program, technology-based tracking is one of the most important policy steps. The reports shared by the stakeholders at all the levels are used for calculating monitoring indicators, including targets, etc. Better technology will be a major added advantage enabling rendering and receiving accurate, quicker data and make the system of analysis even more efficient. An efficient database will help tracking leprosy patients who are migrating for livelihoods, ensure their access to treatment, and ensure they complete the drug regimen prescribed. It will help easier tracking and checking of family members.

1.2 Lessons from other Disease Management

The need to monitor and follow up with patients till they complete the treatment is paramount in leprosy. Patients can migrate to another area, within /outside the State; they may migrate to the private sector; or they may simply be lost to do a follow up. In case of migration, they may inform the Medical Officer and proceed, or they may leave without information. A number of scenarios are possible.

Two important communicable diseases in which prolonged treatment and follow up is necessary – as in leprosy – are Tuberculosis and HIV-AIDS. Both are being addressed in India through national programmes, under the National Health Mission. Both the Programmes have evolved systems for close monitoring and follow up, which can be emulated by the NLEP.

There are lessons to be learnt from the elimination of another Neglected Tropical Disease, Dracunculiasis, and from the National Programme for Control of Blindness. India has successfully eliminated other Neglected Tropical Diseases: Endemic Treponematoses, Disabilities due to Trachoma; and has decreased the incidence of Lymphatic Filariasis and Leishmaniasis. There is every reason to believe that India can make leprosy history. Chapter 4 details out the learning from other programmes which can be adapted by NLEP.

CHAPTER 2: MIGRATION MOBILITY AND THE SPREAD OF DISEASES
INCLUDING LEPROSY

Disease has frequently followed those pulled to new destinations by opportunity, better conditions or pushed from their homes by events, calamity or chaos. Epidemics of plague, cholera, leprosy and syphilis have followed the interaction of local populations with mobile populations or migrants and traders. In more recent times, HIV/AIDS, swine influenza, H1N1 and Covid-19 have followed mobile populations.

This chapter explores the intimate relationship that exists between human mobility, the introduction and spread of an infectious disease like Leprosy, and the policy decisions required to control and mitigate adverse health outcomes.

2.1 Role of Migration in the spread of Disease and Development of Public Health Protocols

Human mobility patterns have influenced public health since time immemorial. Human migration, or human mobility, is the result of search for better living conditions. In present economic environment, search for employment and/or better wages work as "pull factors" in determining flows in human migration; also the search for profits in trade and commerce. Similarly, "push factors" like the occurrence of a major drought and famine or war in the places of origin of migrants play a major role in determining patterns of human migration.

Migrants and other mobile populations reflect the health characteristics of their place and environment of origin and carry several of these with them when they move.

Migrants and other mobile populations reflect the health characteristics of their place and environment of origin and carry several of these with them when they move. In addition, migrants are subject to other specific influences that may adversely affect their health. These factors result from the process of migration itself, for example, during the travel phase between origin and destination. This is frequently observed in disadvantaged or poor migrant populations and refugees. After arrival, a migrants' health may be impacted due to poverty, their search for earning a livelihood, and/or occupational risks, besides differences in language and culture. Further, access to health care facilities maybe limited (Gushulak & MacPherson, 2006) becauseof reasons such as language or access barriers. The dynamic interaction between the migrant and host population generally leads to a greater spread of diseases carried by mobile populations to the host population and vice-versa. Increase in size of the mobile population is likely to result in greater spread of previously rare or uncommon infections.

As migrants carry with them the health indicators of their origin, it is important to look at the place of origin of migrants and the interaction between the migrant and the host state or district, considering the socio-economic environment both at the originating and host area/ district. Evaluating migration and mobile history of populations supports consideration of diseases with a long latency period like that of *leprosy*. This will help diagnostic services to become more attuned to disease epidemiology prevalent in the migrant's place of origin. Migrant populations returning to their places of origin at frequent intervals may carry with them the health indicators of their host state leading to an increased risk to diseases prevalent at the place of origin especially to the children born at new destinations.

Migration-associated influences on the epidemiology of disease have both immediate and long-term effects on host country/state health indicators due to differentials in disease prevalence.

The continued arrival of new residents from high prevalence areas is likely to lead to transmission of the disease to the host state or country and require changes in the public health interventions required to control transmission of the various diseases. Some of these public health interventions are mentioned below (Gushulak & MacPherson, op.cit.)

Immediate Term: Response to Imported/Introduced Illness
Continued/Enhanced need for Clinical/Laboratory Capacities for imported diseases
• Sustained laboratory capacity for imported diseases   • Maintenance of competency in imported health issues   • Contingency planning and exercise testing of plans   • Development of specialized reference centres
Long Term: Response to Growing Migrant Population Component
Increasing Demands for Service/Access and Provision of appropriate diagnostic and treatment services
• Modification of training programs for health providers   • Translation and interpretation services   • Cultural awareness and sensitivity programs and training

These issues play out in all mobile or migrant populations either within or across nations. Within a country there exists endemic districts for particular diseases which then spread to districts/areas with a lower endemicity through mobile populations. Thus, the long-term consequences of movement of populations between locations with different socio-economic and health environments need to be taken into account for deciding public health interventions.

Role of Migration in the Development of Public Health Protocols
Historically, disease control strategies have developed in response to the relationships existing between human mobility and disease. Nations have frequently responded to human mobility by implementing disease control policies and practices to control the spread of disease, which today are recognised as public health interventions. Some such health protocols are discussed below:

— Medieval Europe had made extensive efforts to mitigate the impact of leprosy. Leprosy control efforts focused on the practices of inspection and isolation of the patients. These were enforced by either religious and/or municipal bodies. Special facilities and institutions called Leprosaria were constructed at the town outskirts for the stay of the patients. In addition, the patients were required to wear special clothes and, in some instances, also carry a bell to identify themselves. This is probably the origin of the stigma associated with leprosy.

— In the renaissance period, the increasing importance of trade and commerce led to frequent outbreaks of plague - in ships carrying people who were sick or became sick shortly after docking of the ship. This led to the introduction of the practice of quarantine. It was imposed on passengers, crew and the cargo to prevent disease introduction. The quarantine period was equivalent to sufficient time to allow incubating disease to present with clinical illnesses. Over time quarantine became the cornerstone of public health systems to deal with mobile populations and disease control (Gushulak & MacPherson, op.cit.)

- — The process of quarantine however fails to identify latent or sub-clinical illnesses like leprosy, tuberculosis, hepatitis, etc. The nature of latent or chronic infections is such that the presentation occurs long after the period of travel that brought a carrier infected migrant to the new destination (Gushulak and MacPherson, 2010). The consideration of latent or sub-clinical diseases would instead require evaluation of mobile history of migrants or mobile populations Gushulak and MacPherson, 2006).
- — The development of vaccines against some of the major diseases like smallpox, tuberculosis, Yellow Fever etc. changed the need for screening against someof the diseases like small pox. Instead, it became essential to certify vaccination against these diseases.
- — In the twenty-first century, the current global epidemic of Covid-19 has led to the imposing of quarantine on travellers and/or carrying a certificate certifying that they are disease free. Bans on travellers from certain areas have been imposed. This scenario has played out both internationally and for travel across various states within a nation.

While the focus of screening for diseases being checked may change over time, the basic principles of screening processes and quarantine are universally applied to mobile populations especially in migrations across countries. The standardization of quarantine and international disease control practices began in Paris in 1851, with a series of 14 international conferences to examine international agreements on these issues. Following World War II, these efforts eventually merged into activities in the World Health Organization (WHO) and were adopted as the International Sanitary Regulations in 1951 and renamed the International Health Regulations (IHR) in 1969. The IHR provides an overarching legal framework that defines countries' rights and obligations in handling public health events and emergencies that have the potential to cross borders. The IHR is legally binding on 196 countries, including India. The Regulations outline the criteria to determine whether or not a particular event constitutes a "public health emergency of international concern and the requirement to report public health events". WHO plays the coordinating role in IHR implementation.

Role of Migration in Transmission of Leprosy
Migration as referred in this section includes internal migration: both within the country i.e. either inter-state m or intra-state migration and immigration across countries. Migration has been considered a possible factor in continued leprosy incidence. Latent nature of leprosy and its clinically non-symptomatic presentation could facilitate its transmission when no symptoms are present, or when mild symptoms are overlooked. Historically, migration has been a major influencing factor in the facilitation of disease transmission between endemic and non-endemic areas.

2.2 Migration and Leprosy: A Historical Perspective

The oldest remains of leprosy have been found in Rajasthan (India) dating back to the Indus Valley civilisation (2000 BC). Textual references to the disease have been found in the Atharvaveda, an ancient Sanskrit text, and the Sushruta-samhita, a medical work from India that dates to about 600 BC, and also in a Chinese medical text from 400 BC. Geneticists have traced the origins and worldwide distribution of leprosy from East Africa or southwestern Asia from where it migrated along human migration routes eastward and westward, developing a distinct subtype in Asia, another subtype in Europe and North Africa. In fact, Leprosy was brought to the Americas by the Europeans (Mark, 2017). Thus, migration or human mobility has been instrumental in the spread of Leprosy across the world.

Numerous references exist to the rise of leprosy in Europe and the middle-east including Jerusalem in the Middle Ages, along the trade routes and with the return of people from the Crusades. Extensive and coordinated attempts were made to mitigate the impact of leprosy in medieval Europe. Leprosy control efforts were associated with the development of policies of inspection and isolation enforced by religious and municipal authorities. Facilities and institutions were constructed - lazarettes or leprosaria to house those believed to have the disease. The disease started waning abruptly in Europe in the 13th and 14th century shortly before TB became the region's most significant epidemic disease.

In the nineteenth and twentieth centuries, Leprosy was probably endemic in India, especially as the pre-modern treatments against leprosy were not very effective. In 1881, around 120,000 leprosy patients were documented, while the 1921 census estimated the total number of leprosy patients at 102,000. However, these figures underestimate the actual number of people as throughout the colonial period the vast majority of people affected by leprosy remained outside institutional support and treatment (Medical History of British India, n.d.). The discovery that leprosy was caused by a bacillus, raised the issue of its containment through the segregation ofleprosy patients. The central government passed the Lepers Act of 1898, which providedlegal provision for forcible confinement of people affected by leprosy in India. Implementationof measures restraining the employment of people affected by leprosy and their use of public transport and water facilities were left to the discretion of provincial governments.Separate Asylums were set up for the housing of leprosy patients. By 1921, there were 94asylums in India including 73 under direct British rule and mainly supported by Christian Missions (Kakar, 1996).

In 1983, India had a prevalence rate of 57.8/10,000. With the introduction of the Multi-Drug Therapy by WHO in 1985, India succeeded in bringing the national prevalence rate down to less than 1/10,000 by December 2005. By 2016, the prevalence rate declined even further to 0.66/10,000.

Leprosy continues to exist in parts of the world, even though it has been eliminated as a public health problem.

Leprosy continues to exist in parts of the world, even though it has been eliminated as a public health problem. A large number of leprosy cases continue to be identified mainly in large parts of South-East Asia namely India, Indonesia and in Brazil. Migration facilitates movement of disease between endemic and non-endemic areas, and has been considered a possible factor in continued leprosy incidence. The spread of leprosy is facilitated by its latent nature and clinically non-symptomatic presentation. However, greater research is required to establish how leprosy is transmitted. Thus, for elimination of leprosy, it is important that trends and patterns in the mobility of populations be taken into account for deciding public health policy responses at the national and subnational levels.

Studies on the Role of Migration in Leprosy Transmission

Several studies have been conducted both internationally (refer to Annexure II) and at the national level related to migration in leprosy, which have identified migration as one of the important obstacles in achieving elimination of leprosy. Some studies at the national level include:

i. A 5-year retrospective study (April 2007-March 2012) at a tertiary level hospital in Delhi (Chhabra et.al., 2015) - Leprosy Clinic of Guru Teg Bahadur Hospital - covering 849 registered patients revealed over fifty percent of the patients were migrants from neighbouring states of Uttar Pradesh (40%) and Bihar (12%) with a male preponderance. It may be noted that Delhi has a large number of migrants from Bihar and Uttar Pradesh. A cause for concern was that 87% of the patients were diagnosed with MB leprosy and 37% cases presented with reactions (i.e. Type-I 30% cases; type-II - 7% cases). WHO grade II deformities were also present in nearly 40% of patients. This indicates late diagnosis of leprosy probably because of presence of large number of infected migrants. It highlights the need for continuation of targeted leprosy control activities, and active case detection.

ii. Another retrospective study at a tertiary care hospital in Mumbai - Vimala Dermatological Centre, from 2008-2015, covering 578 cases indicated similar results i.e. majority of patients were migrants mainly from Uttar Pradesh (38%) and Bihar (8%), a key source of migrants coming to Mumbai. The study exhibited a high proportion of MB cases (47%) and Grade-I deformity (14%) and Grade-II deformities (9%); and an increase in the proportion of children in the newly registered cases (from 3% in 2008 to 18% in 2015). These are indicative of active community transmission and delayed diagnosis. This highlights the need for targeted intervention on children, and migrant populations.

iii. A 10 year retrospective study conducted at the urban leprosy centre in Jammu analysed 743 cases over the period 2005-2014. The study revealed that 8.6% were childhood cases, 52.5% patients were migrants, and 56.4% were farmers and laborers with a male preponderance. An important observation was that while majority of the cases were migrants, a five yearly analysis revealed that proportion of locals increased in the period 2010-14 over the period 2005 -09. Smear positivity was seen in 29.6% of cases and showed an increasing trend. An important observation was the increase in multibacillary cases. World Health Organization (WHO) grade 2 disability also showed an increasing trend over the past decade pointing to delayed diagnosis. The consistent reporting of pediatric cases and the increasing trend in smear positive cases is an indicator of ongoing community transmission of the disease in the community (Mushtaq, et.al., 2020).

The above studies indicate that migration facilitates transmission of leprosy from endemic to non-endemic areas and is a factor in its continued incidence. Several international studies have showed that migration facilitates transmission of leprosy. Historical accounts also substantiate this.

2.3 Impact of Migration on Control of Leprosy

In an increasingly integrated world, migration is an important factor impacting policy decisions in areas of public health. Owing to the sheer volume of migrants, it is important to examine different kinds of migration that occur so as to take into account this granularity while deciding public health policy.

Migration in search of livelihood is facilitated through social networks and the movement is between specific areas. This highlights the importance of monitoring population movement at the municipality level to establish early warning systems. Migration can lead to default in treatment of already diagnosed cases that leads to risks in population mobility. While it is not possible to restrict population, it would be necessary to increase disease surveillance in states'/districts with high endemicity to control its spread. It would be important to emphasize that there are some challenges in the diagnosis of leprosy, as no rapid diagnostic kits are available for a quick diagnosis. Thus, the need is to strengthen community awareness on leprosy. It will have a positive impact and facilitate self-reporting of cases.

2.4 Socio-economic Risk Markers for Leprosy

Food shortage and poverty have significantly been associated with Leprosy. A study in a leprosy endemic area of Bangladesh indicated a strong association of leprosy with quality of nutrition and diet related factors. The Body Mass Index (BMI) and food expenditure per capita was found to have a strong association with leprosy. Further, the study found that household food stock and diet diversity were important factors associated with the development of Leprosy (Wagenaar et.al., 2015).

A systemic review of literature, between 2006 and 2016, including original articles investigating socio-economic risk-markers of leprosy in countries with more than 1000 cases annually for five years found links between poverty and living in crowded urban slums and the risk of contracting and developing leprosy (Pescarini, et.al., 2018). The countries covered in the study were mostly Brazil, India and Bangladesh. The literature review pointed to a consistent relationship between leprosy and unfavourable socio-economic circumstances. There was evidence for increased risks of leprosy in individuals who are male, share homes with leprosy cases, live in crowded conditions, and have experienced food shortages in the past. Food shortage, an indicator of extreme poverty and undernourishment appeared to be a risk marker for leprosy. The studies, also pointed to associations between leprosy and socio-demographic risk markers of crowding, sanitation, and poverty[1] across different geographic settings. In most studies, literacy and high levels of education were associated with lower leprosy rates probably due to better health knowledge and access to better work conditions. Person-to-person contact inside the household is one of the most likely sources for leprosy transmission.

The socio-economic or demographic characteristics (i.e. crowding, sanitation, and poverty) and leprosy in both individualized and ecological studies suggest an association between these risk markers and leprosy.

This study report underscores the many ways that poverty can create conditions that perpetuate leprosy risk. In addition, these findings call attention to persistent gaps in knowledge of the associations between leprosy and socioeconomic risk markers, and highlight a lack of studies conducted in low-income countries.

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1 An important risk indicator for higher rates transmission of leprosy is poverty. Poverty and the associated search for employment is one of the important factors that push migrants from their places of origin. Recent studies indicate migrants as a high-risk group in the spread of leprosy coming largely from the states of Uttar Pradesh and Bihar. One of the main challenges in the elimination of leprosy will be targeting this higher risk group within endemic communities.

2.5 Conclusion

Disease has generally followed mobile populations across countries and continents. This has resulted in concerted efforts to develop health protocols to mitigate the spread of disease. These protocols are the forerunners of the public health protocols that have been developed or are under development. Leprosy is one of the ancient diseases that has followed mobile populations across the world. The migration of populations has played a major role in the spread of the disease from endemic to non-endemic areas.

As discussed (refer to section 2.1.1), an important health protocol of quarantine developed to mitigate the spread of diseases spread through mobile populations is not effective in controlling the spread of latent or sub-clinical diseases like leprosy. Instead the need is to analyse the health history of mobile populations. Due to migration, local disease events are more likely to play out on a much bigger scale on the national or global scene. Thus, national and sub-national health policies will need to reflect the dynamics, between public health policies, population migration and the health environment.

2.6 Policy Response

1. It is essential that public health protocols for eliminating the spread of leprosy include an analysis of the health history of migrants within their jurisdictions and across different phases of population mobility. There is a need for close coordination between the governments of states from where migrants originate, and the destination states to ensure closer surveillance and tracking of leprosy patients. Also, there is a need to ensure prophylactic treatment to family members and contacts to prevent the spread of leprosy. The prophylactic treatment is generally a single dose rifampicin (SDR). As SDR-PEP implementation is still at an early stage in India, a lot more planning is needed for successful nationwide implementation of this strategy (Rao, 2021).To ensure prophylactic treatment of family members and contacts it may be important that NLEP procures its own stock of SDR.

2. Research on risk factors on the spread of leprosy underscore the importance of monitoring or disease surveillance in states with relatively lower per capita incomes as populations tend to migrate from the lower income states to those with higher incomes. States/districts with a high proportion of migrants need to be identified along with their source districts to closely monitor both: identification of new cases; and continued treatment of old cases to prevent default in treatment.

CHAPTER 3: TRENDS IN MIGRATION

Chapter 2 brought to the fore the role of migration in the spread of diseases from endemic to non-endemic areas which has contributed to the spread of leprosy, and prevented its elimination. Historical evidence has pointed to the clear role of migration as an important instrument for the spread of leprosy. Similarly, recent studies indicate a predominant proportion of leprosy patients being migrants, in the destination areas. Seasonal or circular migrants are a high-risk group within migrants for the continued transmission of leprosy. Thus, an examination of the migratory trends becomes important to gain insights into the spread of the disease. Chapter 3 examines the trends in migration of populations across the country, and the international migratory trends to the extent that they have an impact on the transmission of leprosy within the country.

A majority of migration in India is internal migration i.e. migrants move from one part of the state/country to another – whether intra-state or inter-state migration. At the same time, a large number of people emigrate from India. India also receives immigrants generally through its land borders, mainly from Nepal and Bangladesh.

People migrate for varying reasons viz. marriage, join families, acquire a better education and for employment. In India, most people migrate for marriage, and to join their families. Employment as a reason for migration is limited. According to Census 2001, the total internal migrants stood at 315 million; of this, around two-thirds were women migrating primarily for marriage. Census 2011 showed similar trends. The total number of internal migrants stood at 456 million and women accounted for 68 percent. Among women, the primary reason for moving was marriage (66%) and moving with household (11%). Overall, forty six percent of total migrants moved because of marriage, and of these 97% were women. Migration for economic reasons is less important but it has increased over time. It is more male dominated. From 16 million people migrating for economic reasons (Census 2001), it rose to 45 million (Census 2011).

This section explores the trends in migration - both internal migration and trends in immigration flow into the country, with a focus on the population migrating for economic reasons or for employment. This population is generally working and living in difficult conditions with limited access to affordable health care. An attempt will be made to identify the main states/districts of origin of the migrant labourer, and their migratory corridors. The risk indicators associated with different types of migration (permanent or circular migration) for transmission of leprosy will be examined. This will help to understand the interaction between migration and leprosy in India so that effective public health initiatives can be taken to fight leprosy transmission.

3.1   Internal Migration

Types of migration
Employment, as a driver of migration, is an important pathway out of poverty, a means to improve access to basic necessities such as education and healthcare. It is also an adaptive strategy to escape the negative impacts of climate change and environmental disasters on livelihood. "Migrants fuel the Indian economy by carrying human capital to regions where it is needed, and enabling the acquisition of new skills and a better standard of living" (MOHUA, 2017).

Migration can result in the permanent relocation of an individual or household, referred to as permanent migration. Permanent migrants have identity papers of the place of stay, and are generally in a position to access the social protection system. Studies show that permanent migrants are more likely to be concentrated in higher consumption quintiles than non-migrants. They also tend to be better educated than non-migrants.

Permanent migration is akin to the classical one-way rural–urban migration. However, unlike this classical one-way rural–urban movement, a large percentage of rural–urban migrants leave behind their families and property in their area of origin. These migrants are drawn from the lower consumption quintiles and are mostly male. They retain their links with the rural hinterland, returning occasionally during spells of unemployment, for holidays, or when work in rural areas peaks. Some of them may stay on permanently in urban areas, while others may eventually return to their rural homes. These migrants can be classified as *circular migrants* (Srivastava, 2020). Circular migrants, include migrants who have acquired a tenuous foothold in the urban job market, and may not have identity papers at their area of destination. They participate in the labour market in less favourable ways than non-migrants because of debt-interlocking, involvement in subcontracting chains, greater isolation, fragmentation, and segmentation of the labour market.

Some of these circular migrants acquire a more permanent status in the urban areas. Referred to as *semi-permanent circular migrants*, this segment of migrants remains in precarious employment and are vulnerable during periods of shock to the economy. These migrants continue to retain a link with their area of origin.

A majority of the *circular migrants or seasonal short-duration migrants*, migrate for temporary periods, either moving from place to place or to a fixed destination, returning to their place of origin after brief periods, at the most, after a few months. Most are recruited through contractors and work mostly in the areas of construction, brick-kilns, manufacture etc. These migrants are generally away from their home on an average of about 7.5 months in a year (Nayyar & Kim, 2018). Most reside at work-sites or in the open, while a small percentage live in crowded tenanted places.

Most of the seasonal short duration migrants are more likely to be from households that are poor, socially disadvantaged, less educated (Nayar & Kim, op.cit.), and employed in agriculture (Azim Premji University, 2021).[2] These migrants work in temporary and seasonal precarious jobs mostly in wage employment. They can also be called "*push-migration*" i.e. people leaving because of lack of local options – for example, to earn a living.

Seasonal migrants are the most vulnerable and their conditions of work and living (two thirds of seasonal migrants live on worksites) severely constrain their ability to establish their bonafides and identity in the destination areas. Their entitlements and claims even in their areas of origin are relatively weaker. Studies show that the identification proof is not important for circular migrants who move across states. This is perhaps indicative of the fact that circular migrants, by definition, are looking to return home; they often move without their family, and have no portable access - across state borders, to social welfare benefits in view of inadequate identification documents (Nayyar & Kim, 2018).

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2   Circular migrants are more likely to be illiterate or have not completed their primary education. Seasonal migrants usually belong to poorer and landless groups as compared to long term circular migrants. Households classified as Scheduled Tribe or Scheduled Caste are more likely to have short-duration out-mi- grants.

A survey conducted on migrant labour over 7 districts in rural Bihar in 2016 revealed their main characteristics as follows (ibid.):

- About a fifth of all migrants were employed in the agricultural sector. A substantial majority were employed in the construction and brick-making sectors followed by a variety of non-agricultural occupations, both, in the services and manufacturing, predominantly in prosperous urban destinations
- Most migrants had long-term linkages with their destination, also a well-defined migration trajectories to long-standing destinations (for example: Rohtas-Gujarat; Madhubani-Delhi; Madhubani-Mumbai; Purnia/Araria-Punjab; Araria-Himachal Pradesh; Madhubani-Bangalore)
- Migrant workers were most likely to be casual wage labour having only verbal/oral contracts, working in the informal sector, and working long hours. Majority of them earned less than the statutory minimum wages at their destination. Their migratory cycle was about 10 months or more in a year. *They could be characterised as long-term circular migrants*.
- They lived in harsh conditions at their destination and shared cramped housing. A very small proportion had any identity documents at destination such as ration card, voter card, Aadhar card, or bank account.

Permanent long terms migrants are least likely to retain the characteristics of the place of origin, especially if they have settled in their destination area for a couple of years. They are likely to acquire the characteristics of their place of destination over time. Circular migrants will be depicting the health indicators of their place of origin, especially if they are returning to their place of origin on an annual basis. Thus, circular migrants -both short-term and long-term, are the highest risk category for the transmission of leprosy. Amongst them, the short-term circular migrants or seasonal migrants carry the highest risk as they return to their native place on an annual basis, and are driven by poverty to migrate and earn their living.

3.2 Trends in Migration

Both Census data and NSSO data provide trends in migration. Both also show limitations. **No precise estimates exist on the number of migrant workers in India.**

Estimating migrant population
In India, the Census defines a migrant "as one residing in a place other than his or her place of birth or one who has changed his or her usual place of residence, to another place".
The Census provides a satisfactory measure of permanent migration, and imperfectly measures long-term semi-permanent circular migration; it is not designed to measure short-term circular migration (Srivastava, 2020).

Data for migrant labour is available from specific rounds of the National Sample Survey Organisation (NSSO) household data which counts short-term migrants as those who have not stayed at their "usual place of last residence" for a period between one to six months. This however, misses short-term migrants whose migratory cycle is longer than 6 months. As discussed in the previous section, the short-term circular migrant has on average a migratory cycle of about 7.5 months or even more (Nayyar & Kim, 2018).

The NSSO is unable to capture properly the short-term seasonal streams. Further, labour mobility is not a primary area of the Census and the NSSO. (MoHUA, 2017)

Studies have indicated that the Indian workforce has steadily increased, matching the decline in the agricultural workforce. Migrant workers estimated on the basis of the Census data of 2011 and NSS data of 2007-08 and 2011-12, and projected for 2017-18, are given below (Source: Srivastava [2020])

Table 2: Projection of Migrant Workers

Migrant Category	No. of Migrants (in million)			Precarious Employment	Likely Job Type
	Total Migrants	Inter-state	Intra-state		
Permanent Migrants	160				Generally skilled
Long-Term Circular Migrants	85	(30% interstate) 25	(70% intrastate) 60 million	(75% of total) 65 million	Services, Manufacture. 50% low skilled
Short-Term Circular Migrants	55	(50% interstate) 27	(50% intrastate) 27	(100% of total) 55 million	Construction, Manufacture, Services, Agriculture 80% low skilled

From the above it is seen that the short-term circular migrants are generally employed in low skilled precarious employment, and three-fourth of long-term circular migrants are in precarious employment. Thus, whenever there is a shock to the economy, this category of labour is the worst impacted in terms of employment, and consequently erode their savings and /or their nutritional status. In case the shock to the economy persists for long periods, the long-term circular migrants are also likely to be adversely impacted and consequentially the nutritional status of a larger proportion of migrant labour will be adversely impacted. The precariously employed amongst the circular migrants carry the highest risk in the transmission of leprosy.

Migration path
Migrants are part of India's invisible workforce. No accurate estimates exist of the extent of circular migration in India. Census and NSSO data give a more accurate estimation of long-term migrants and short-term migrants of less than 6 months. The data does not cover seasonal migrants, who have a cycle of more than 6 months and form the largest part of India's labour workforce.

An analysis of census data indicates that the poorer states in India are the major source of migrants -both long-term and short-term. The richer in the village may migrate "pulled" by better prospects and the poor are "pushed" by poverty (MOHUA, 2017). Based on the 2011 Census, the top 50 inter-state migration corridors (India Migration Now, n.d.) have been identified and are included as Annexure III. The six top source states of migrants, and the top six destination states are listed below (India Migration Now, op.cit.)

Table 3: Top six source and destination states

S. no.	Major source states of migrants	Number	Major destination states of migrants	Number
1	Uttar Pradesh	1,11,66,265	Maharashtra	7848274
2	Bihar	62,92,324	NCT Of Delhi	5237199
3	Rajasthan	27,44,557	Madhya Pradesh	3176555
4	Karnataka	21,55,844	Gujarat	3009841
5	Maharashtra	20,53,151	Uttar Pradesh	2701026
6	Madhya Pradesh	20,47,219	Karnataka	2548563

The above table shows that Uttar Pradesh and Bihar are the largest source of out-migrants in the country. The states of Maharashtra and Delhi attract the largest number of migrants. In fact, proportionate to its size, Delhi attracts the maximum number of migrants.[3]

Out-migration from Uttar Pradesh and Bihar
Uttar Pradesh and Bihar provide the largest number of migrants across India. Both these states are among the poorer states and have large populations with low human development indicators. High levels of unemployment results in the two states having high levels of out-migration. According to the Centre for Monitoring Indian Economy (CMIE) data, in December 2021, the unemployment rate in Bihar was 16%; while in Uttar Pradesh it was 4.9%. The migratory path of the migrants i.e. the important destination states for migrants from these two states have been identified in the table below on the basis of census data (India Migration Now, op.cit.).

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3   The top 50 state to districts migration corridors in the country based on the 2011 Census data have also been identified and enclosed as Annexure IV.

Table 4: Important destination states for migrants from Uttar Pradesh and Bihar

Source State	Destination State	Number	% of Migrants from UP	Source State	Destination State	Number	% of Migrants from Bihar
UP	Delhi	2,854,297	25.56	Bihar	Jharkhand	1,336,048	21.23
UP	Maharashtra	2,754,706	24.67	Bihar	Delhi	1,106,629	17.59
UP	Madhya Pradesh	2,181,762	19.54	Bihar	West Bengal	1103757	17.54
UP	Gujarat	929,411	8.32	Bihar	Uttar Pradesh	1072739	17.05
UP	Uttarakhand	890,663	7.98	Bihar	Maharashtra	568667	9.04
UP	Punjab	649,557	5.82	Bihar	Haryana	390937	6.21
UP	Rajasthan	585,982	5.25	Bihar	Gujarat	361010	5.74
UP	Bihar	319,887	2.86	Bihar	Punjab	352537	5.60
UP	Total	11,166,265	100	Bihar	Total	6292324	100

The above table is indicative that the northern states are the preferred destination states for the migrants from UP and Bihar. Delhi is the most preferred choice of the migrants from UP and Bihar. According to the NSS 64th round, 43% of Delhi's population are migrants with over half coming from UP and Bihar. While all migrants in Delhi are inter-state, there is a difference between migrants who come from urban and rural areas. Typically, migrants from rural areas tend to be employed in manufacturing, trade, transportation etc. those from the urban areas are employed in areas like health, education, financial intermediation IT etc. (MOHUA, op.cit.).

Another important urban destination is Chandigarh which can also be described as a city of migrants. More than 60% of its population comprises of migrants (Census 2011) with a majority migrating for work. The largest number of migrants to Chandigarh are from Uttar Pradesh (17.4%) and Bihar (5%). In fact, over time the migration from Uttar Pradesh have increased replacing Punjab as the largest source of migrants. Most of the male migrants from UP came to the city for work and employment, followed by Punjab and Bihar. While being significant sources of out-migrants, both UP and Bihar also attract a lot of in-migrants.

Patterns in migration
The decision to migrate for economic reasons is typically driven by the spatial earnings gap. It can be seen that out-migration from a state is dominated by states with the lowest per capita National State Domestic Product.

Also, the share of migrants moving within states is much higher than that of migrants moving across states. Trends based on census data shows that inter-state migrants comprised only 13.31 % of total migrants in 2001. The literature suggests that state borders remain an important impediment to migration. It has been estimated that migration between neighbouring districts in the same state is around 50 percent larger than migration between districts that are on different sides of a state border. Three key inhibitors of interstate migration: inadequate portability of social welfare benefits as well as a significant home bias in access to education and public employment, which is, in part, attributable to reservations for scheduled castes and scheduled tribes (Nayyar & Kim, 2018).

3.3 Leprosy Endemic Districts and Migration

A large number of leprosy endemic districts have been identified by the government. It is important to analyse whether these endemic districts in any way coincide with the important out-migrant districts so as to increase the health surveillance of migrants from these districts.

The Report of the Working Group on Migration on the basis of Census (2001), identified the top 17 districts which accounted for 25% of all male out-migrants across state boundaries. All these districts are practically contiguous and concentrated in eastern Uttar Pradesh and Bihar, with the exception of Ganjam district in Odisha. About 60% of the outmigration from the six districts of Bihar- Madhubani, Darbhanga, Samastipur, Patna, Saran and Siwan (which form a contiguous arc) are to the states of Delhi (28%), Maharashtra (17%) and West Bengal (14%) (MOHUA, op.cit.). Another 36 districts accounted for an additional 25% of inter-state out-migrants. Thus 53 districts in India account for half the male inter-state out-migrants in the country. These districts again lie mostly in eastern Uttar Pradesh and Bihar.[4]

As the top source districts for migrants lie mostly in Bihar and eastern Uttar Pradesh, we have looked at the endemic districts in Bihar and Uttar Pradesh. Further, both Uttar Pradesh and Bihar report the maximum number of new leprosy cases annually. In fact, these states also include the largest number of high endemic and endemic districts of leprosy. In fact, all the districts of Bihar are either high endemic or endemic.[5]

A comparison between the top migratory districts in Uttar Pradesh and Bihar and the endemic leprosy districts is given in the table below (Source: MOHUA, 2017; Customised tables from the Registrar General of India, based on Census 2001)

Table 5: Top Migratory Districts in Bihar and UP and their Endemicity Status

Top 25% of total male out-migration					Next 25% of total male out-migration			
S. No.	District	State	Leprosy Endemic		S. No.	District	State	Leprosy Endemic
1	Gonda	UP			1	Bijnor	UP	
2	Basti	UP			2	Muzaffarnagar	UP	
3.	Gorakhpur	UP			3.	Meerut	UP	
4.	Deoria	UP			4.	Bulandshar	UP	
5.	Sultanpur	UP			5.	Aligarh	UP	
6.	Madhubani	Bihar			6.	Etah	UP	
7.	Azamgarh	UP			7.	Siddharthanagar	UP	

4   A list of these districts is enclosed as annexure IV.
5   Refer to Annexure V for list of high endemic, endemic and low endemic districts for Bihar, Delhi and Uttar Pradesh.

Top 25% of total male out-migration							
S. No.	District	State	Leprosy Endemic	S. No.	District	State	Leprosy Endemic
8.	Darbhanga	Bihar	High Endemic (Red)	8.	Agra	UP	Endemic (Yellow)
9.	Siwan	Bihar	High Endemic (Red)	9.	Kushinagar	UP	Endemic (Yellow)
10.	Saran	Bihar	High Endemic (Red)	10.	PurbaChamparan	Bihar	High Endemic (Red)
11.	Jaunpur	UP	Endemic (Yellow)	11.	Etawah	UP	Low Endemic (Green)
12.	Pratapgarh	UP	Low Endemic (Green)	12.	Sitamarhi	Bihar	High Endemic (Red)
13.	Samastipur	Bihar	Endemic (Yellow)	13.	Faizabad/Ayodhya	UP	Endemic (Yellow)
14.	Allahabad	UP	Endemic (Yellow)	14.	Gopalganj	Bihar	Endemic (Yellow)
15.	Patna	Bihar	High Endemic (Red)	15.	Rae Barelli	UP	Endemic (Yellow)
16	Varanasi	UP	Endemic (Yellow)	16.	Muzaffarpur	Bihar	Endemic (Yellow)
				17.	Balia	UP	High Endemic (Red)
				18.	Vaishali	Bihar	Endemic (Yellow)
				19.	Ghazipur	UP	High Endemic (Red)
				20.	Begusarai	Bihar	Endemic (Yellow)
				21.	Bhojpur	Bihar	Endemic (Yellow)
				22.	Bhagalpur	Bihar	High Endemic (Red)
				23.	Munger	Bihar	Endemic (Yellow)
				24.	Nalanda	Bihar	High Endemic (Red)
				25.	Rohtas	Bihar	High Endemic (Red)
				26.	Aurangabad	Bihar	High Endemic (Red)
				27.	Nawada	Bihar	High Endemic (Red)
				28.	Gaya	Bihar	High Endemic (Red)

Colour Code	Category
Red	High Endemic
Yellow	Endemic
Green	Low Endemic

As can be seen from the above table, most of the migrants belong to leprosy endemic districts. It is therefore essential that the health profile of these migrants and their interaction with the health environment over their migratory cycle is scrutinised and monitored as circular migrants closely reflect the health profile of their area of origin. Effective steps need to be taken at their destination points to identify leprosy patients and to provide them with treatment.

3.4 Impact of Covid-19 on Migration

The lockdowns imposed in the wake of Covid-19 pandemic in 2020 and 2021 exposed a large majority of the vulnerable circular migrants to a loss in jobs and incomes. From mid-April 2020 onwards, there was a large urban exodus, with millions of migrants attempting to move back to their home villages on foot, bicycles, cycle carts, and hired vehicles. By the beginning of June, the government estimated that it had been able to facilitate the interstate movement of about a crore (i.e. ten million) of migrants, but several times that number moved on their own (Srivastava, 2020). This reverse migration to their states of origin, accompanied by large losses in income and wages, would have also adversely impacted the migrant labours' nutritional status. By May 2020, as economic activity recovered, employment levels started recovering. The coming of the second wave (February-March 2021 onwards) led to another slowdown which again impacted the informal wage workers.

Circularity is strengthened in times of uncertainty and crisis. The circular work-force working in predominantly informal sector were negatively impacted by the lockdowns. Even after the immediate impacts of the nationwide lockdown were over, employment levels remained slightly below pre-pandemic levels for several months. More importantly, there was a significant drop in earnings and rise in precarity (Azim Premji University, 2021). In addition to increased joblessness, there was also a significant shift towards more informal work. Salaried workers returned to the labour market and had to be content with self-employment or temporary wage work (Azim Premji University, op.cit.). Women and younger workers were hit particularly hard both in terms of loss of work and ability to re-enter the labour market. Workers crowded into fallback arrangements i.e. self-employment in agriculture and retail. All these impacts have obvious implications for household finances, food security and other welfare indicators (Azim Premji University, op.cit.).[7]

Covid-19 pandemic provided a severe shock to the economy and forced the long-term circular migrants to lose their jobs, also suffer nutritional deprivation which is indicative of a higher leprosy risk. A majority of these migrants are coming from the highly endemic leprosy districts (i.e. from the states of Uttar Pradesh and Bihar), which compounds this risk.

The total vulnerable migrant workforce is estimated at 111 million in 2017-18 (Pandey, 2017). These workers were the most impacted by the Covid-19 pandemic. It would be essential that at least in the short-term the circular migrants are identified and are monitored closely for leprosy and preventive steps taken.

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6   The employment ratio or the workforce participation rate (WPR) took a sharp dive in April 2020, due to the lockdown but recovered to around 90 per cent of its pre-pandemic value by June. Between July and December 2020 it stagnated.

7   The short-term circular and vulnerable long-term circular migrants in the urban workforce have been estimated as 44 million and 67 million respectively (2017-18)

Being the largest and economically stronger country in the Indian sub-continent, India has always attracted a large number of immigrants from its neighbouring countries. India shares a long land border with Pakistan, Nepal, Bangladesh and Myanmar and Sri Lanka, India's closest neighbour, is a mere 36 Km away by sea. The borders with Pakistan are more or less sealed; with Myanmar, the border is more or less closed. Hence, the focus is on immigration from India's other neighbours and its impact on spread of leprosy. Immigration from Sri Lanka had spiked in the 1980's due to civil war there. With the end of the war in 2009, refugees coming from Sri Lanka to India declined substantially. Further, most of the migration was to the states of Tamil Nadu where the prevalence rate of leprosy is low.

Immigration from Nepal
Nepal is a landlocked country with a majority of population living on subsistence agriculture. Substantial migration across the border has existed since pre-independence, and continues till today. India and Nepal share an open border. Most of the immigration across the Indo-Nepal border is undocumented. Hence, there is limited data on the number of immigrants from Nepal.

The 2001 census of Nepal recorded that absentee population from Nepal towards India constituted 89.2 per cent of the total migrants. It further estimated that about 8 lakh people migrated to India in the last 10 years. The immigrant from Nepal generally tends to be largely illiterate/lowly literate, unskilled and from rural Nepal. The states of Uttar Pradesh, Bihar, West Bengal and Assam are the major hubs of immigration. It is estimated that about 5 to 7 million Nepalese are currently in India and 3 to 5 lakhs in Delhi alone.

Nepal, like India suffers from a high leprosy rate, though it is much lower than India, and reports less than 10,000 new leprosy cases per annum. However, the national leprosy PR and district-wise leprosy burden have been rising in the last five years. Leprosy endemic districts increased from 17 to 21 from 2017 to 2018 and reported a PR of 0.99/10,000 in 2018/19 (Singh, 2020).

The Nepali immigrants, predominantly male, migrate from the poorer districts. Though mostly not studied beyond secondary levels, they are in the economically active age group, and work in the informal sector, which makes their jobs more precarious. Their migration path is based on their social network. The Nepali worker is similar to the migrant circular workers in India. They face greater vulnerability of employment and can be categorised as high risk as the Indian circular migrant worker.

The circularity of population flow across the border being undocumented complicates monitoring the health parameters of the high-risk migrant worker. This increases risk of a greater spread of leprosy across the borders.

Immigration from Bangladesh
India shares a long and porous border with Bangladesh spanning about 4,000 Km which includes hills, rivers, and jungle tracks. Migration from Bangladesh into Assam, Tripura and West Bengal in search of economic opportunities existed before India's independence. This trend accelerated with the independence of Bangladesh in 1971.

A taskforce on Border Management in 2001 estimated the number as 15 million with a majority being in West Bengaland Assam (Das, 2016). This migration is undocumented and illegal; hence, no authenticestimations exist. As the migrants are mainly illegal, and unskilled, they work in low payingjobs like agricultural labourers, construction workers, rickshaw pullers, hawkers, weavers, domestic helpers, rag pickers and scavengers. From the 1980's onwards, Bangladeshi migrants have moved also into the hinterland to Uttar Pradesh, Bihar, Delhi and as far west as Maharashtra and to Gujarat, Karnataka, Tamil Nadu and Kerala. The Bangladeshi migranthas characteristics similar to the circular migrant labour, and carries the same risk profile.

In the recent past, there appears to be a change in flow of migrants into India. As per data available with the BSF, in the past four years, more immigrants have been caught returning to Bangladesh than entering India illegally (Singh, 2020). This is perhaps due to the fact that Bangladesh has made significant improvements in its social development indicators. It hasalso witnessed a steady improvement in its economy. As per an ADB report, Bangladeshhas surpassed India as the fastest-growing South Asian economy (BBC News, 2020).

Bangladesh detects about 4,000 leprosy cases each year, even though its PR is lower than India's. However, the continuous illegal immigration across the border is a risk factor in the continuance of leprosy in the subcontinent.

3.6   Conclusion

Leprosy was eliminated in India as a public health hazard in 2005 (Rao & Suneetha, 2018). However, there has been an upsurge in the spread of leprosy to areas/districts which are destinations of a large number of migrants.[8]

Delhi and Chandigarh which had earlier reported elimination of Leprosy as a public health hazard are now exhibiting a PR/10,000 of about 1 or greater (MOHFW, 2020). The share of migrants to Delhi from Uttar Pradesh, Bihar, Jharkhand and Uttarakhand increased consistently between 1991 and 2011 (Kawoosa, 2020). Chandigarh receives migrants from Uttar Pradesh, Haryana, HimachalPradesh and Bihar. Delhi and Chandigarh also have a large number of migrants from bothNepal and Bangladesh.

India's economy is serviced by a large migrant circular workforce which comes predominantly from the states of Uttar Pradesh and Bihar. Their destination states are largely the northern states of Delhi, Maharashtra, Punjab, Haryana and Chandigarh. They work predominantly in the informal sector with a large number working in the construction sector and reside in congested small urban dwellings/work-sites. Access to social benefit schemes like MGNREGA, PDS, etc. is important as circular migrants are predominantly poor and likely to suffer from poor nutrition.

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8   A recent upsurge in the main destination states of Maharashtra, Delhi and Chandigarh reported. Both Maharash-
       tra and Delhi reported a very high number of MB cases – 46% and 87% respectively in 2019-2021 indicating
       late identification of leprosy. A number of case studies in hospitals in Maharashtra and Delhi have identified that
       migrants from Uttar Pradesh and Bihar were the largest sub-group among the leprosy patients.

Leprosy transmission rates tend to be higher, lower the nutritionalstatus of the person. In addition, a large number (especially the short-term circular migrants) do not possess identification papers like Aadhar card etc. which limits their access to thesocial welfare system.

During periods of high economic stress, the long-term circular migrants become vulnerable and are likely to suffer economic loss through loss of employment. This high-risk migrant workforce, is likely to move back to their places of origin as circularity increases at times of stress and increases vulnerability. This is what happened during the lockdowns imposed during the pandemic of Covid-19. It is thus important to monitor the health profile of circular migrants throughout their migration cycle.

The characteristics of the immigrant work-force from Nepal and Bangladesh are akin to that of circular migrants in that they are employed mostly in the informal unskilled sector. They also reside in crowded urban tenements with low-income levels and are more susceptible to leprosy transmission.

Both Nepal and Bangladesh suffer from high levels of leprosy. With the continuous flow of migrants across the borders, it is likely that infections are following the migrant in their back-and-forth movement across the border. Leprosy among foreign-born is a new indicator introduced by WHO, and collected since the last three years. This indicator provides proxy information on imported disease. Nepal reported 784 foreign-born cases, all of them cross-border patients residing in a neighbouring country. With India reporting a higher number of leprosy cases than Nepal, it is likely that the migrant labour has been instrumental in spreading the disease in Nepal.

3.7 Policy Response

- There is need of greater health surveillance and monitoring of circular migrants at both their districts of origin, and at their destination areas. Important areas of focus could be major construction sites and urban slums in destination areas such as Delhi, Maharashtra and Chandigarh.
- An improved accessibility and screening to health care facilities at the migrants' place of origin is important for early diagnosis of the disease to prevent further transmission.
- The health status of family members of migrants needs to be closely scrutinised and monitored. It would be essential to provide them with prophylactic leprosy treatment.
- Systems need to be developed to ensure access to food security to improve migrants' nutritional status.
- Immigrants from both Nepal and Bangladesh are a high risk for the continued spread of leprosy; closer scrutiny of their health status needs to be maintained.

CHAPTER 4: POLICY RESPONSE TO MANAGE MIGRATION RELATED CHALLENGES

Leprosy is an ancient endemic disease in India. Its rapid decline since the early 2000s is encouraging for the National Leprosy Eradication Programme (NLEP). The Programme has the necessary tools – survey and surveillance protocols, and an effective range of drugs – to realize the Goal of Zero Leprosy by 2030.

However, there is learning to be gained from two other National Programmes – the National Tuberculosis Control Programme (NTCP) and the National Programme for the Control of HIV/AIDS. These Programmes have treatment regimens lasting several months / years; they also face the challenge of migration amongst patients. Hence, prior to discussing how NLEP can address migration related challenges, here is briefly a look at how the other programmes addressed it.

4.1 Management of migration related challenges by the National Programmes for Control of HIV/AIDS and Tuberculosis (TB)

The National Programmes for Control of HIV/AIDS and Tuberculosis can be studied by NLEP for Learning, and adaptation. There are similarities between leprosy, TB and HIV/AIDS, worth pondering upon.

Table 6: Similarities between TB, HIV/AIDS and Leprosy

Issues	Tuberculosis	HIV/AIDS	Leprosy
Long latent period	✓	✓	✓
Disease kills if untreated	✓	✓	X
Marked stigma and ostracism	X	✓	✓
Long duration of treatment	✓	✓	✓
Challenge of migration and dropouts	✓	✓	✓
Private sector involved in treatment	✓	✓	X
Online system for registration and treatment	✓	✓	On paper[1]
Migrants monitored and supported	✓	✓	On paper

A. Learning from the National Programme for Prevention and Control of HIV/AIDS
Key learnings are in the area of monitoring treatment, especially amongst migrants, and how the programme addressed stigma comprehensively.

The programme was the first one in India to define migrants, because of the realisation that migration fuelled the rise in previously low incidence areas. The need for close monitoring and follow up of patients arose when Anti-Retroviral Treatment was initiated under the National Programme in 2006-07. The initial definition of migrants was adopted from the Census of India. The phenomenon of migration was then studied in greater detail, and

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1   The Leprosy Programme does have Nikusth for online registration and treatment. Presently though, Nikusth is not functional. Besides, ACD requires patients to be counselled about continuing treatment during migration, and States are supposed to inform each other; however, the system does not function at the field level.

the following definition was adopted (Source: National AIDS Control [NACO] Program Phase IV):
- People (Both male and female) who move from their place of origin in rural areas (source) to a town / city (destination) – irrespective of district/state/country
- Return to their place of origin at least once in 6-12 months
- Move frequently between districts for work purpose
- Move directly between the places (or) via the transit locations
- Move either alone or with their partners
- Those returned to places of origin (at source areas)
- Female spouses of migrants (at source areas)

This is a comprehensive definition and considers patterns of migration (discussed in Chapters 2 and 3). It gives importance to both source and destination, considers household migration, and gives importance to gender. This definition is recommended for adoption to NLEP as well.

A recommended definition of migrants for NLEP

- People (men and women) who move from their place of origin (source) to another location (destination) – irrespective of district/state/country
- Return to their place of origin at least once in 6-12 months
- Move frequently between districts for work purpose
- Move directly between the places (or) via the transit locations
- Move either alone or with their partners and/or other Household Members
- Those returned to places of origin (at source areas)
- Household members of migrants (at source areas)

Migration in leprosy may be different because of the stigma associated with the disease.

- The communities which are highly affected may be migrating for reasons of livelihood and food security to avoid stigma and possibly for purposes of treatment
- A feature peculiar to leprosy is that people affected often go to different hospitals across districts and states, either seeking treatment in different places to avoid stigma, or they believe in some hospitals because of positive reviews from others.

All these features peculiar to migration, peculiar to leprosy, needs further exploration.

The HIV/AIDS programme recommended studying the evidence on migration and HIV/AIDS in greater detail, design structural interventions to address the disease amongst migrants, and design strategies to ensure treatment for all migrants. A rights-based, gender responsive framework was then developed to provide a continuum of prevention and treatment.

Likewise, NLEP must study migration in greater detail, and develop its own definition, taking the broad framework of the HIV/AIDS programme.

The other issue of interest in the HIV/AIDS Programme is how it assists migrants in seeking treatment. The Information Monitoring System registered all patients with a unique ID and monitored the treatment. In case the patient missed the monthly doses for 3 consecutive times, the counsellors would get into action to trace the patient. Using the unique ID, the patient could migrate; also take treatment from another city / district hospital, where treatment would be continued. All that was needed was a letter from the parent hospital addressed to the other hospital. Since 2020, the system has been upgraded to automatically transfer the patient to the next hospital online, using the unique ID number.

Finally, the HIV/AIDS programme has successfully addressed the issue of community participation and mobilization. Involving patients and the LGBTQ Community has helped in addressing legal and social barriers, also helped in ensuring prevention and treatment. Community mobilization was a core strategy for migrant interventions. The programs on the ground have generated extensive experience of engaging the community structures in both source and destination districts. At the destination migrant interventions, the migrant community associations have been mobilized to expand coverage and in generating demand for services. In order for the migrant interventions to be community led and owned, the migrant associations and migrant community were involved in all stages of migrant interventions including planning, implementation, monitoring and evaluation (Rao, 2017).

B. Learning from the National Tuberculosis Control Programme (NTCP)
The TB Control Programme also faces the challenge of migrants, and an additional challenge of patients migrating between doctors, especially in the private sector. Unlike HIV/AIDS, the challenge of completing treatment is more in TB, since untreated disease increases fatality along with increasing the challenge of drug resistance.

The National Strategic Plan for Tuberculosis Elimination 2017-2025 approaches the challenge of migrants comprehensively and in its own unique way:

- It highlights high risk populations first, and then from among them, highlights those who have limited access to health care including migrants, especially undocumented migrants like illegal miners (as in Jharkhand and Meghalaya), beggars, and internally displaced populations.
- It highlights the challenge of patients going to private doctors /religious healers and shift between doctors.

This is an important learning, for it shows that the NTCP has studied the challenge of migration in detail. Such research is necessary for NLEP.

The next set of learning lies in the manner TB Control, also the recent COVID-19 control measures, have moved with rapid diagnostic tests, use of artificial intelligence, and the use of digital adherence tools. All this helps quick diagnosis for initiation of treatment, and closer monitoring of treatment. Digital health care needs to be adapted for leprosy control as well.

Yet another learning is the way health systems and patient support systems have evolved in TB Control. This is implemented as follows:

1. Flexible DOTS has been implemented; it is necessary to also explore Flexible MDT
2. Initial and frequent follow-up counselling of the patient and family members
3. Supervision of treatment by a trained treatment supporter (a health worker or community volunteer)
4. Locally managed additional nutritional support
5. Retrieval of treatment interrupters
6. Screening for adverse reactions
7. Appropriate social support scheme
8. Psycho-social support
9. Co-morbidity management, and
10. Follow-up laboratory investigations.

NLEP may be doing several of these interventions. However, a closer look at how the patient centered approach of the TB programme does it, improving the NLEP protocols is needed.

Of special interest is the manner in which TB patients are linked to *Pradhan Mantri Jan Dhan Yojana* (PMJDY) and Aadhar, so that cash benefits and other benefits directly reach the patient's bank account.

Finally, NTCP has a case based, web-based surveillance system, *NIKSHAY*, which was developed by the Central TB Division in partnership with National Informatics Centre (NIC). Launched in 2012, it has evolved over time as e-NIKSHAY or enhanced Nikshay, and is now a nation- wide data base.[2] All the patients are registered in this system by their certified providers as beneficiaries based on their demographic details, mobile number, and a bank account number. An alpha-numeric beneficiary ID is generated for patients, which is used by her/him to avail the services at every point. TB diagnostic test reports (Digital X-ray and GeneXpert test) and monthly prescriptions are updated in this MIS, which assists TB case management system in maintaining an end-to-end diagnostic and treatment trail of the patient. It is available to the private sector so that they can register patients they treat, and patients can benefit from the free drugs available.

Digital health is gaining ground since the COVID19 Pandemic. NLEP must also forge ahead with the use of ICT.

In India, TB is a notifiable disease, but Leprosy is notifiable only in some States (Rao, et.al., 2020). A study byRao et. al. (.ibid) among 201 private sector dermatologists estimated that 40% of leprosy patients are diagnosed and managed outside of the Public Sector, and since they are notuniformly notifiable across India, an accurate epidemiological picture and tracking becomes challenging.

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2   *e-NIKSHAY* has been adapted from the use of ICT in the HIV/AIDS Control Programme. But it has been modified and the scale adapted to meet the expanded needs of the TB Control Programme. A similar approach of study and adaptation has to be done with *NIKUSHTH*.

4.2   NLEP Policy Response for Management of Migration related Challenges

Migration for a number of reasons is on the rise in an increasingly globalized and inter-connected world. The COVID-19 pandemic and the response in the form of lockdowns have especially highlighted the plight of the migrants. The Government of India is now planning to launch a programme to collect data on migrants, and an online system will enable migrants to benefit from government services wherever they migrate to (Haq, 2021).

While a specific policy response to migration related challenges is definitely needed, such a response cannot be planned in isolation. There needs to be a series of policy responses addressing different facets of NLEP. This is because of the complexity of the disease, society's behaviour and the socio-economic needs of those affected by leprosy.

The following sections outlines the overall policy responses for management of Leprosy while highlighting the responses required to address the challenges of migration.

With an objective of realising the Goal of Zero Leprosy by 2030, it is recommended that NLEP should first address the persistent rhetoric of India having eliminated leprosy, and admit that the disease persists.[3] Also, considering the spread and diversity of nation, targets for prevalence rates by 2030 need to be defined for each state, since, as discussed in Chapter 1, prevalence rates vary between states.

An overall policy response is necessary to convey that leprosy is given due priority in India. Leprosy is a Neglected Tropical Disease (NTD), but it should not be neglected in the sense of a forgotten disease. The nation is working towards universal health coverage, and the health needs of the poor and the disadvantaged, who are the most affected by the disease, will especially need to be met.

4.3   Phasing of the Policy Responses

Considering that the disease is endemic and complex in its medico-social manifestations, the response needs to be phased and spread out across years. The response needs to be all encompassing.

The proposed phasing of the policy responses is:

– Immediate policy response: over the next 1 year
– Mid-term policy response: over the coming 2-5 years
– Long-term policy response: over the coming 10 years

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3   Elimination was defined in the early 2000s as prevalence rate of < 1/10,000 population. Now WHO is recommending Zero Leprosy, which is Zero Infection and Disease, Zero Disability, Zero Stigma and Zero Discrimination.

Figure 1 . Recommended Policy Responses and their Phasing
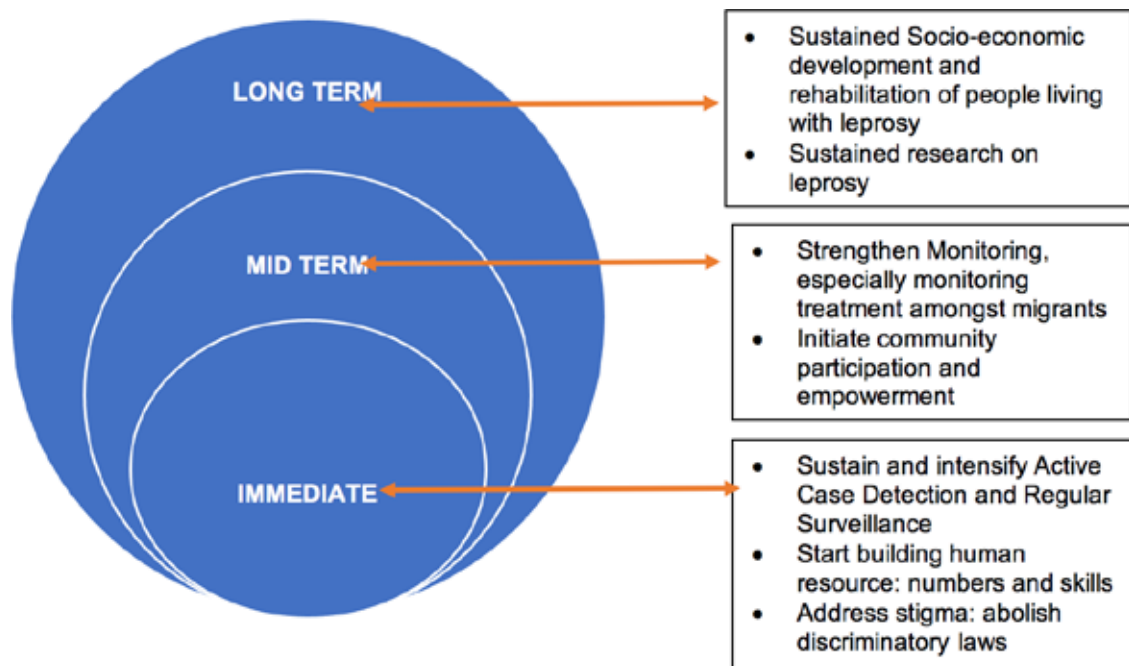
The Challenge: Active Case Detection (ACD) and Regular Surveillance (RS) have detailed and well-designed protocols to incentivise early case detection and treatment by frontline workers and prevent resultant stigma& deformity. However, these were designed in 2020, and the COVID19 pandemic prevented further implementation. These need to be re-started once the lockdown restrictions are lifted in their entirety.

The following sections details out the recommended policy responses

4.3.1 Immediate policy response

Sustain and intensify Active Case Detection and Regular Surveillance

NLEP has done well to map endemic districts and initiate Active Case Detection (ACD) and Regular Surveillance (RS). This has led to an increased enumeration of patients and numbers of patients starting treatment.

The focus needs to be on early diagnosis, and prevention of deformities. This will help patients in completing treatment with minimal stigma. As for those with deformities, reconstructive surgery is now available to address the problem and minimize infirmity. The number of patients eligible for such surgery and those who consent to undergo the procedure – since it is voluntary – will dwindle over time with continued focus on early diagnosis and treatment.

This initiative needs to be sustained and intensified in the following manner:[4]

- ACD needs to be implemented throughout the year
- This needs to be sustained and intensified in the present districts, and expanded steadily to other districts in the same state
- Where patients migrate from the endemic districts, NLEP must initiate ACD in the corresponding state and districts.

ACD must progress from established areas where people live that is cities and villages, to areas where circular migrants live and work, for example, in sugarcane fields/ wheat fields, and in areas of brick kilns.[5]

While regular surveillance is advocated for high prevalence districts, even in districts where the prevalence rate is much lower than the elimination rate of 1/10,000 population, regular active surveillance needs to be initiated. Passive surveillance in Outpatient Departments needs to be stopped for now.

ACD and RS need to be combined with counselling. Detection and treatment of patients will succeed only if the patient, her/his family, and the community understands the disease, and how it can be easily and successfully treated. This will help address all myths and barriers and eventually remove stigma. In addition, there should be single dose rifampicin, contact examination, disability management and scale up of MDT, with a special focus on women and children.

Start building human resources, both numbers and skills

> The Challenge: The realization in 2005 that India has achieved the goal of elimination of PR <1/10,000 led to merging of the NLEP under the National Health Mission, and diversion of the human resources to other health programmes. Early detection of leprosy is a skill and now that the decision is for ACD and RS, NLEP needs more numbers of skilled frontline workers.

ACD and RS need skills, and NLEP has suffered on this front. Skilled workers are needed to identify the early signs of the disease, and skilled laboratory technicians are needed to correctly take the slit skin smears and identify the bacteria.[6] As highlighted in Chapter 1, the skilled human resources were diverted to other national programmes once NLEP felt that the goal of elimination of PR <1/10,000 population was realized.

NLEP must take immediate steps to either bring back the trained human resources, or train more frontline workers in early diagnosis and management. Simultaneously, it must train more laboratory technicians in the art of taking slit skin smears and diagnosing infection.

A mapping of present-day deployment of human resources – numbers available and location – will assist NLEP to plan, train and deploy skilled human resources in a rational manner. Learning can be adapted from the National Programme for Control of Blindness (NPCB), for example, which worked systematically to eliminate avoidable blindness as a

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4   This also addresses the gaps highlighted in Chapter 1.

5   The patterns of such migration have been outlined in Chapter 3.

6   Slit skin smear technology is a special skill and is not routinely taught to all technicians. Hence, the need to specially train more. This will help in initiation of early and correct treatment.

significant public health challenge[12] . NPCB developed the skills of frontline workers all over India to detect cataract, vitamin deficiencies and trachoma. This helped in early detection and rapid treatment. Such skilled workers are needed in NLEP too, in both districts / states of origin as well as in districts/states they migrate to.

NLEP's initiative to involve dermatologists in the programme was a welcome step. The help - especially of private dermatologists, is critically needed for early diagnosis and initiation of treatment and ensuring that treatment is completed well in time through close monitoring. The learning from the National TB Control Programme on the involvement of private practitioners needs to be adapted by NLEP. (MOHFW, 2017)

A learning from the eradication of *Dracunculiasis* in India is the need to provide cash incentives for the reporting of cases (National Centre for Disease Control, n.d.). The programme handsomely rewarded any person/hospital which diagnosed and reported cases of dracunculiasis. Apart from the ASHAs getting incentives, districts can be compensated handsomely for diagnosing, reporting, andcuring patients.

Abolish discriminatory laws that perpetuate stigma

> The Challenge: Stigma and ostracism around leprosy has been part of Indian society since ancient times. These have led to over 700 colonies of leprosy patients and has pre-vented their mainstreaming. MDT cures leprosy rapidly; there is a need to treat leprosy as any other skin disease. Laws discriminating against leprosy have no place in today's times.

In 2016, the Government of India repealed the Indian Lepers Act of 1898 (Jyoti, 2016). In 2019, it passedthe Personal Laws (Amendment) Bill, which sought to remove Leprosy as a ground for divorce in five personal laws (The Print, 2019).

There are several more – 3 Union and 105 State Level laws, which need to be repealed. This was identified by the Law Commission of India in its Report No 256, "Eliminating Discrimination against Persons Affected by Leprosy" (The Leprosy Mission Trust India, n.d.). This Report recommended repealingof numerous laws and acts which discriminate against people living with leprosy. It also recommended steps towards affirmative action and mainstreaming them under the rangeof socio-economic development schemes of the Government of India.[7]

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[7] The Report was submitted to the Ministry of Law and Justice, Government of India in 2015. However, even as late as August 2019, the former Minister of Health and Family Welfare, had to remind his counterparts in the Ministry of Law and Justice, and the Minister for Social Justice and Empowerment, that the recommendations of the Law Commission need to be expedited, and that the relevant discriminatory laws / acts need to be repealed /suitably amended. ("Harshvardhan writes to Ministers", 2019)

The recommendations of the Law Commission need to be expedited. The COVID-19 pandemic may have delayed the process. Possibly, the relevant law / act is never to be implemented – for example, the Life Insurance Corporation of India charges extra premium for people with leprosy; the railways have an act to segregate patients with leprosy. However, repealing / amending them will be a big morale booster for people with leprosy and prove that the state and the community does care for them. The stigma associated with the disease makes a patient to hide the symptoms / avoid treatment and migrate to other places. Such positive steps to remove the stigma will generate more confidence amongst the patients and their families.

4.3.2 Mid-term policy response

A two- pronged policy response, mutually supporting each other, and implemented over the coming five years, through a robust programme design and implementation, is recommended to realize the goal of Zero Leprosy by 2030. Both are important and necessary to address the challenge of migration amongst patients with leprosy.

Figure 2. Mid Term Policy Response
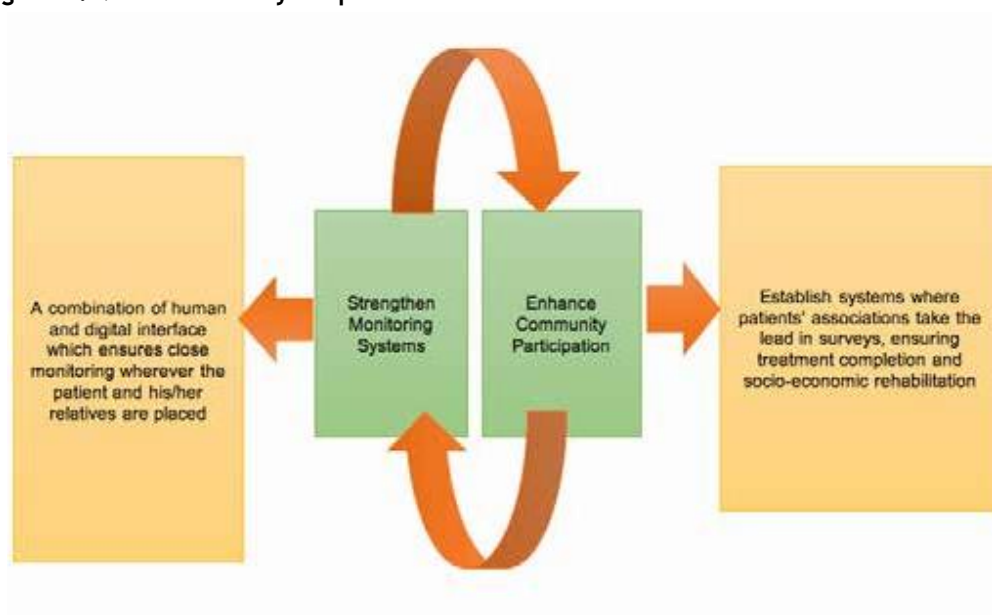
Strengthen monitoring systems

> *The Challenge:* NLEP must move away from paper registers to online reporting, monitoring, and tracking systems. NIKUSTH was started with this intention but is presently not operational. NLEP can explore how other digital technologies can be suitably adapted for its programmes.

Health programmes in India had been experimenting with digital recording and monitoring systems. COVID-19 pandemic contributed to firming up this approach. A number of senior public health professionals are now working to provide affordable health care through digital technologies.[8]

What is needed is a combination of a human and digital interface. Patients need to be diagnosed early by frontline workers, and, immediately examined by a physician. Registration should be online, and each patient can be provided with a unique ID number, which can be used to monitor treatment anywhere in the nation. Technology can thus track and treat patients wherever they go.

A simplified flow diagram recommending such an application is shown in the following figure.

Figure 3: Combination of Human and Digital Interface
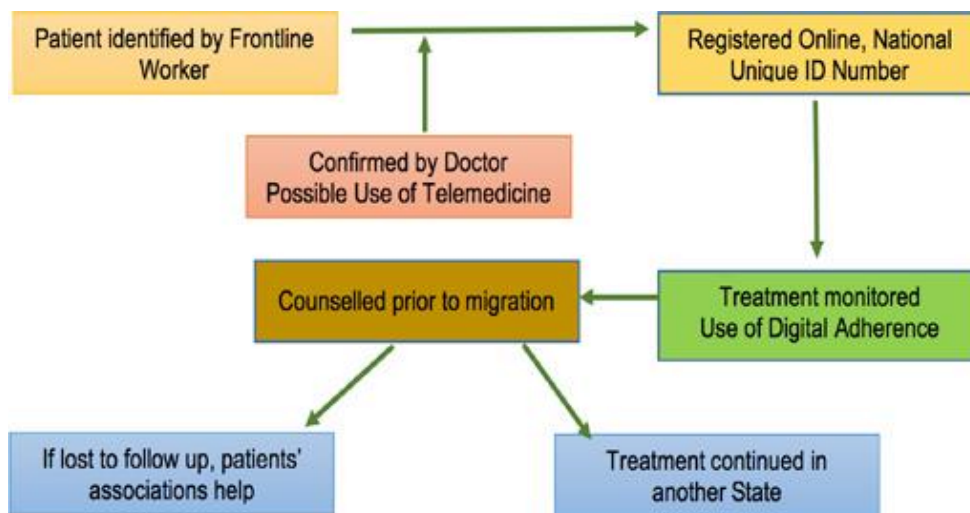
Close monitoring of patients, and their relatives for onset of symptoms, is made easier through the proper application of digital tools. The National AIDS Control Organization (NACO) first used such tools for monitoring of Anti-Retroviral Treatment. The National TB Control Programme adopted this to develop its own tool for the monitoring of treatment.

NLEP has a tool in the form of *Nikushth*. This has been rejuvenated, and expanded in scope, to ensure that each patient gets a Unique ID, which can be monitored by treatment providers anywhere in India. This system needs to be provided to private dermatologists so that their patients can also be registered on a single portal. This ID can be expanded to include the patients' relatives, too, who develop the disease.

Telemedicine is one possibility for diagnosis by a clinician in case the area being surveyed is remote and there are fewer experts. Other digital tools can be adapted from the National TB Control Programme:
–   Digital Adherence Tools: monitors whether patients are taking their daily medicines. In case of a missed dose, the counsellor contacts the patient and enquires about any challenge faced.
–   Artificial Intelligence: can be used to rapidly scan the skin and nerve lesions and arrive at a diagnosis. This will assist the work of frontline workers.

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8   The Swasth Alliance (https://www.swasth.app/home) of over 150+ healthcare organizations, including hospitals, rural health NGOS, insurers, health tech, med tech and others, aims to increase the adoption of technology in order to drive healthcare inclusion and outcomes.

Technologies will succeed if the patients are counselled well about the disease, its rapid cure, and all myths are addressed. The stigma around the disease needs to be dispelled firmly by the counsellors. Only then will patients be confident and comfortable about completing their treatment schedule on time and will not hesitate to seek treatment in case of migration.

For this to succeed, the need is for active community participation.

Enhance community participation

> *The Challenge*: Ignorance, stigma and ostracism around leprosy have often prevented patients from seeking early treatment, and completing treatment in time. The situation complicates when patients migrate, for they often miss out on treatment, apart from hiding their disease. Community participation is needed to address the ignorance and stigma, as well as ensure that the patients get their dues from the Government schemes.

Enhanced community participation is needed for:

– Addressing the challenge of stigma and ostracism around leprosy, and
– Ensuring early diagnosis, completion of treatment and ensuring necessary socio-economic rehabilitation.

It is ignorance of the disease, as well as stigma around the disease that prevents patients from seeking early treatment; even completing treatment on time. Migration complicates the issue, for patients may not know where to seek treatment. Once the disease is advanced, patients are discriminated against and often ostracised, and they often miss out on benefits from the government under food supplies, housing, and education. To address the ignorance, stigma and myths, a robust community participation is needed.

The key stakeholders are:

– Patients affected with Leprosy,
– Non-Government Organizations working for Leprosy, and
– Corporates willing to support leprosy elimination programmes.

Leprosy has witnessed a number of community centred initiatives. The *Hind Kusth Nivaran Sangh* and Baba Amte's *Anandwan* are excellent examples, where patients with leprosy managed their own affairs and supported each other. These institutions worked to address the challenge around stigma and ostracism. These initiatives were excellent when treatment was a prolonged affair, and the need was predominantly for the socio-economic rehabilitation of the disabled.

Now the need is for early diagnosis, rapid initiation of treatment and completion of course, wherever the patient may be. Here the need is for a robust civil society initiative by 'Patients' Associations' - as a leadership initiative, separate from the present NGOs.

Such associations could deploy members to be counsellors, surveyors and even laboratory technicians. Theycould be those who enumerate families to ensure they receive whatever is due in the formof food, education and housing subsidies. The associations could be a monitor for services being provided by the government, also work to ensure regularity of drug supplies.

A nationwide civil society movement along these lines was undertaken by NACO (Rao, 2017). Patients with HIV/AIDS, and other key stakeholders like CSWs, were involved inthe control of the disease and dispelling stigma and myths. They helped in addressing thechallenges of the LGBTQ Community. This eventually resulted in their formal recognition andrealization of their rights. Such a community led initiative will complement the monitoring andreporting system as well as provide an important human interface to digital technologies.

There are a limited number of NGOs working for Leprosy, and their numbers are dwindlingwith its decline. This trend needs to be reversed, as India gears up for moving towards ZeroLeprosy. NGOs are best placed to initiate a nationwide civil society movement; their workneeds to be encouraged and supported.

Corporates have supported disability limitation and rehabilitation in India. Their support can be directed effectively for those patients requiring such support. Supporters for the *JaipurFoot* are an example. Likewise, *Operation Smile* does an excellent job with patients sufferingfrom cleft palate. Similarly, with the assistance of NGOs and Patients' Associations, a framework can be designed for disability limitation and rehabilitation. It must be emphasised that early diagnosis and rapid initiation of treatment are critical, so as to limit the need forreconstructive surgeries to the minimal.

4.3.3 Long-term policy response

These need to be planned for a period up to 2030, by which the nation should aim to realisethe goal of *Zero Leprosy.*

Overall socio-economic development, and especially of the migrants
Leprosy thrives amongst the poor and marginalized, in crowded settlements. Research hasshown that poor diet quality can predispose the disease. Even as India works for overallsocio-economic development, affirmative action can be planned for patients affected by leprosy. This is a recommendation of the EDPAL (2015) - that patients need to be rehabilitatedsocio-economically as well as medically.

Patients need to be enrolled in Aadhar, and benefit equally from the subsidies on
  – Food, through the Public Distribution System (PDS)
  – Housing, through the PM Awaas Yojana (PMAY)
  – Opening of bank Accounts
  – Insurance schemes
  – Loans for microenterprises, through the Mudra Yojana, and
  – Education support for children.

Patient cards generated from a nationwide online registration system can help in ensuringtreatment anywhere in the country and help in accruing benefits under different Governmentschemes. *Aadhar* must not be a barrier in accessing treatment. The moment a case is detected, treatment needs to be started, irrespective of where the patient is staying andwhich state s/he comes from.

The COVID-19 pandemic has highlighted the need to strengthen the country's health systems. There is renewed focus on adequate and skilled person power, equipment anddrugs, digital health, and on community mobilization. The challenge with migrants has been noted, and realization has set in to document their numbers in detail; see how their healthand development needs can be met adequately and affordably.

These are positive developments for NLEP too. A recognition that the disease persists, followed by a robust policy response will be galvanizing for the patients and their families. *An ancient disease can finally be eliminated in the present decade.*

CHAPTER 5: PRIMARY RESEARCH AREAS

Although leprosy is on a decline, and science has provided us with powerful drugs, the disease continues to be persistent, and because of the long latency period, it is often an enigma. The phenomenon of migration amongst leprosy patients has been recently recognized and needs to be understood clearly.[1] This chapter highlights the need for primary research and identifies some in areas of leprosy and migration.

Migration has emerged as one of the key concerns contributing to the spread of leprosy and preventing its elimination. More primary research is needed to gain insights into the issues surrounding migrant leprosy patients, and their households. The results would help design strategies to meet existing gaps and challenges in the leprosy program management. The objective of the primary research will be to populate an agreed upon framework with data, thus allowing NLEP to roll it out, and study its success in the nation-wide endeavour towards Zero Leprosy.

More primary research is needed to gain insights into the issues surrounding migrant leprosy patients, and their households; and help design strategies to meet existing gaps and challenges in the leprosy programme management.

The World Health Organization (WHO) has proposed a framework for addressing the challenge of migration and tuberculosis. It is recommended that NLEP discuss and debate this framework and develop one for its own use.
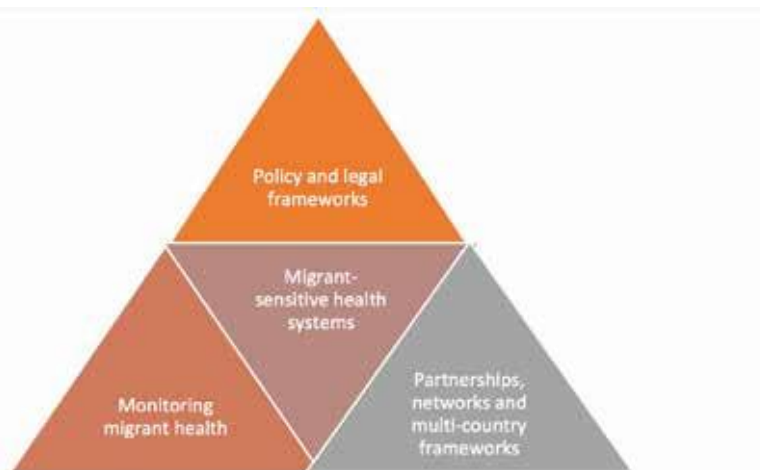
Figure 4. WHO Framework to address challenges of Migration and Tuberculosis

The central pillar of the WHO framework is the development and implementation of a Migration Sensitive Health System. The three pillars supporting the central pillar are: (i) Policy and Legal Frameworks; (ii) Monitoring Migrant Health; and (iii) Partnerships.

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1   Continued research is needed in both medical field covering areas such as improved drugs and drug regime as well as in the social field covering areas such as behaviour change communication for patients and communities, with an overall aim to bust myths and overcome stigma. In the medical field, other research areas identified include genomic studies on the bacteria; rapid tests for diagnosis since the slit skin smears often pose a challenge; epidemiological studies with cohorts of parents and their close contacts to gauge possible changing patterns of the disease. Also, the reason for emerging drug resistance needs to be studied in detail. There are no accurate estimates of drug resistance, a few cases have been documented. The 2nd line drugs are not widely available, and these need to be identified.

5.1 Recommended areas for primary research

The need for primary research around migration and leprosy emerging from the existing gaps can be categorised under the following three heads:

- Sociological studies around migration and leprosy;
- Medical studies around patterns of disease; and
- Operational research on modified health systems.

Sociological studies around migration and leprosy

Migration is now an established way of life.[2] There is especially a paucity of data on the migration patterns of patients with leprosy, which need to be studied in detail in order to gain insights into the persistence of the disease.

There may be several scenarios regarding migration of people affected by leprosy; some key information required across each of these scenarios is highlighted below:

- **Patient is unaware of the disease and moves from the place of origin (source):** The disease is diagnosed at the destination place. Does the person return forthwith, or go elsewhere for treatment? Does the diagnosis impact patients' employment opportunities?
- **Patient is aware of the disease while leaving the place of origin (source):** Does the person continue with her/his plans, or go elsewhere?
- **Patient and other household members have the disease at source:** Do they migrate to escape discrimination?
- **Patient diagnosed with disease as s/he returns from destination:** Does the migration pattern change?

There is recognition that stigma and social ostracism influence the decision to migrate, and possibly re-locate to another place. *The extent to which this leads to people affected with leprosy migrating to leprosy colonies needs to be studied.* The presence of over 700 leprosy colonies attracting patients regularly needs to be researched upon.

Further, issues around access, availability and affordability of health care for migrants need to be studied in detail, especially those who approach health centres at the destination for continuing treatment, and those who approach a centre at destination point for the first time. The challenges faced by migrants affected by leprosy in accessing health care facilities and getting regular treatment at the destination needs examination.

During periods of high economic stress, the long-term circular migrants become vulnerable and are likely to suffer economic loss through loss of employment. This high-risk migrant workforce, is likely to move back to their places of origin as circularity increases at times of stress and increases vulnerability.

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2   The COVID-19 pandemic and subsequent lockdowns highlighted the extensive level of inter-state migration and the absence of robust updated information on migratory patterns.

The challenge of portability with Public Distribution System (PDS) entitlements may limit food and nutrition security amongst migrant populations.[3] Although only suspected, and not been proven, poor nutrition maylead to lower levels of cell mediated immunity, leading to higher levels of leprosy transmission rates (Anantharam et.al., 2021; Rao & Annamma, 2012) Moreover, migrants are more likely to be illiterate or have not completed their primary education which further makes it challenging.

Documenting migration patterns will help to set up systems to ensure that all benefits from health and nutrition programmes, as well as other subsidies are provided to the marginalized migrant population. Primary research needs to focus on the inter-linkages between access to health, quality of nutrition programmes, subsidies to migrant population, and the goal of leprosy eradication and management.

In addition, g*ender studies amongst migrants with leprosy will help understand if women suffer more*; whether the challenges faced by women affected with leprosy, and who are migrating, are more severe than men. Also, women may not be migrating but may become infected when the spouse returns. Subsequent challenges faced at the family and community level need to be understood as well.

A detailed mapping and understanding of the migratory pattern of people affected by leprosy will help NLEP to (a) plan its ACD Campaigns, at both the source and possible destinations; and (b) time the campaigns so as to ensure maximum coverage. The process and data will help in planning necessary counselling programmes, and behaviour change campaigns.

Besides, a detailed MIS is suggested for tracking migrants at source, in transit and at the destination to enable uninterrupted continued treatment despite migration. MIS can be developed as an extension of *Nikushth*.

Medical studies around patterns of disease amongst migrants
Medical studies around patterns of leprosy amongst the migrants are needed. Some are outlined below:
- A key concern is Multibacillary Leprosy; it is considered as the primary reason for the spread. Intensified ACD and regular MDT helps control MB Leprosy, but it would be worthwhile studying if other forms of leprosy increase, especially the indeterminate and pure neuritis types (by following up on a cohort of migrants and their families)
- One reason for the elimination of leprosy from Europe is hypothesised as an increase in Tuberculosis. It is also hypothesised that BCG provides protection against leprosy. These factors need to be studied over a period of time amongst families of migrants
- Post Exposure Prophylaxis (PEP) is being implemented amongst those exposed to the primary patient. Follow up needs to be done and over a period of time data generated to understand the efficacy and effectiveness of PEP
- Drug resistance is on the rise; most probable reason is dropouts due to migration. The extent of the challenge amongst migrants needs to be documented
- Finally, mental health challenges may be coming up in new patients, especially among those who return with the disease. Documentation of these challenges will guide strategies to address them.

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3   The Government of India subsidizes food grain and pulses for the poor and vulnerable populations. These are available through Public Distribution System shops.

Operational studies on modified health systems

The modified approach of ACD and RS need to be studied for their efficiency and effectiveness, especially around timing, to ensure that there is maximum coverage of migrants, both at source and destination. Currently, ACD is being planned and implemented in the high endemic districts. In case a migrant with leprosy goes to an area with no ACD, s/he should be subjected to an immediate physical examination.

The leprosy endemic districts in India are often those with endemicity of other neglected tropical diseases: leishmaniasis, lymphatic filariasis, nematode infections, in particular. There are campaigns for detection and treatment being planned and implemented for them on an annual basis. An operational framework needs to be researched upon and implemented to ensure that campaigns are synchronized and timed along with the migration patterns.

Partnerships between the health systems of source and destination states, and between the Government and private healthcare providers, are important in the treatment of the disease amongst migrants. While there is a system to inform other states about diagnosed patients, and the private sector is being involved, operational research is needed to understand the barriers to the success of the systems, with recommendations to address them.

Systematic steps need to be taken to remove the stigma around leprosy, and make it a notifiable disease.

There is a case for leprosy being made a notifiable disease. If it were to be so, private practitioners would have to report a case, leading to improved data; also enabling checkups of contacts. The stigma around leprosy is possibly a deterrent; but then, HIV/AIDS is notifiable and yet confidentiality is maintained. Systematic steps need to be taken to remove the stigma around leprosy, and make it a notifiable disease.

Operational research is also needed on how health systems can improve counselling of patients and their families, on how community behaviour towards the disease needs to be influenced, and how patients with leprosy can be involved in community mobilisation campaigns.

5.2 Promoting an environment of research

The current investment towards research on leprosy in India is dwindling. However, the need to incorporate advanced research methodologies is urgent to promote an environment of research with the goal of addressing resurgence and spread of leprosy.

More needs to be done, and make the research database substantial. Medical colleges and social science colleges need to be funded well in order to conduct pioneering research and support the health systems to address the disease comprehensively.

India did well prior to the stated national commitment to eliminate leprosy by 2005. Earlier research thrust was on (i) documenting patterns of leprosy and identifying the pure neuritis pattern as exclusive; (ii) studying ways to help the disabled; and, (iii) trying out a vaccine against the disease. The realisation that the disease persists led to mapping of the endemic districts, and designing of campaigns for early detection and treatment.

More needs to be done and make the research database substantial. Medical colleges and social science colleges with an important role to play need to be funded well in orderto conduct pioneering research and support the health systems to address the disease comprehensively.

Further, India has limited studies on cohorts. Migrating patients offer this opportunity. Marketing agencies use different methods to study how communities can be influenced, and accordingly design their communication campaigns. Health systems need to bring in such expertise. Operational research on studying health systems frameworks is another expertise that needs to be included.

In conclusion, the tools for the rapid identification and elimination are available. Well planned research can help target these tools effectively and efficiently. Migration amongst leprosy patients is a subject which demands such research, and hence the research agenda needs to be comprehensive and supported. Towards this end, FAIRMED India is undertaking a 3-year pilot study in four locations of the country i.e. *source states*: Bihar and Uttar Pradesh; and *destination State*/UT: Chandigarh and Delhi, to gain an understanding of the issues faced by migrant leprosy patients.

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CHAPTER 6: CONCLUSION

"There is no shortage of ugliness in the world, but by closing our eyes on ugliness, we will intensify it"
— The House of Black (1962), a documentary classic, filmed in a leprosy colony in Tebriz, Iran

India declared successfully eliminating leprosy in 2005. The spread and diversity of the nation not being considered, it led to endemic areas, where the disease persisted. By 31st March 2019, 588 districts out of 708 districts in India had achieved elimination viz. a rate of less than 1/10,000 (MoHFW, 2020). The disease was highly endemic in the remaining districts. Since thedeclaration of elimination in 2005, the number of new cases each year has remained more or less constant, ranging from 1.2 to 1.37 lakhs per annum, with a few states with relatively high grade 2 disability. Any case of preventable disability due to leprosy is a failure of the health system.

Any case of preventable disability due to leprosy is a failure of the health system.

Although late, recognition of persistence of leprosy led some states like Maharashtra (with a relatively high PR rate: 0.79 per 10,000 in 2019-20) starting their own surveys. Witha view to widen the coverage of population screening for early case detection, and to strengthen the active surveillance NLEP launched the Active Case Detection (ACD) and Regular Surveillance (RS) in 2020. The COVID19 pandemic has slowed down these efforts even before it gathered momentum. They need to be re-started and intensified.

The unique challenge in leprosy is the associated stigma and ostracism. Any effort to control the rise in prevalence rates, will need to contend with them. The persistence of over 700 odd leprosy colonies and the lethargy around steps being taken to eliminate discriminatory acts is a reminder of the uphill tasks before NLEP as it sets course towards a Zero Leprosy India by 2030.

A Zero Leprosy India is very much possible. Even in the most infected patients, potent drugs available can kill nearly all the bacteria with the first dose itself. This, and the tools available for case detection, will enable the health system to overcome the disease. Early detection and treatment, with associated confidentiality, will help overcome stigma as well.

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This, and the tools available for case detection, will enable the health system to overcome the disease.

Humankind has always migrated. Migrants reflect the health characteristics of their place and environment of origin and carry several of these with them when they move resulting in the spread of diseases. Globalization has increased the pace and the magnitude of migration as well as spread of disease, exemplified by the COVID19 pandemic. An unfortunate, and possibly unforeseen, collateral damage of the response to control the spread of COVID19 has been increased migration. One trend is individuals and families returning home, possibly temporarily; and the other trend is distress migration as a result of weakened sources of livelihood. Be as it may, the trends lead to spread of diseases, including leprosy.

A clarion call to realize Zero Leprosy has come at an opportune moment. Apart from the tools already available with NLEP:

- India is working to strengthen health systems, including work on increasing skills and capabilities of human resources, especially frontline workers;
- Digital health technologies are increasingly being adopted;
- Disease control programmes for HIV/AIDS and Tuberculosis have tested models to address the challenge of migrants;
- Communities are becoming aware of their health needs, and community mobilization is on the rise; and,
- The nation is working to document the extent and patterns of migration in detail; also working on systems designed to ensure that migrants receive support extended by the state in food and shelter, access to affordable health care, and education.

NLEP needs to build on these opportunities based on relevant data from the field. Indian researchers have done extremely well to contribute to the elimination of a number of health and nutrition diseases, using a combination of epidemiological and sociological research. Its surveillance skills have helped control emerging diseases such as the *Nipah* Virus. A similar scientific and data driven approach will help strengthen NLEP to realize a nation with Zero Leprosy.

Data is especially needed around migration and leprosy. There is a stark paucity of research in this area.[1] The complexity of the Indian health system is that health is a state subject and ensuring health services availability and access to migrant population requires the cooperation and coordination of multi state actors. The complexity increases when treatment is prolonged, as in leprosy, and is further complicated by the stigma associated with it.

A robust policy response, spread over the coming decade, is needed. With all available tools of early detection, treatment and prophylaxis, and digital technology, leprosy can be controlled and eliminated.

As India contemplates Universal Health Coverage (UHC) and moves towards strengthening health systems and making health care more available, accessible, and affordable, this decade can witness the last of an ancient and dreaded scourge.

A robust policy response, spread over the coming decade, is needed. With all available tools of early detection, treatment and prophylaxis, and digital technology, leprosy can be controlled and eliminated.

Let migration not be an excuse for incomplete treatment and dropouts. Mother Teresa famously said, *"The biggest disease today is not leprosy or tuberculosis, but rather the feeling of being unwanted."* For too long have people with leprosy been isolated. We need to give them their rightful placed in society, and let them contribute towards the nation's development.

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1   Although there are a number of research studies in other endemic countries such as Brazil.

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Annexure I: Key Indicators for the Spread of Leprosy
Source: *State-wise Report 2019-2020, NLEP*

S. No.	State/UT	New Cases	PR/10000 pop'ln	% Of MB cases	No. of child cases	No. of new cases with G2D
1	Andhra Pradesh	4685	0.55	48.45	355	129
2	Arunachal Pradesh	30	0.19	76.67	1	3
3	Assam	850	0.25	83.76	67	92
4	Bihar	16595	0.77	45.08	1694	458
5	Chhattisgarh	8905	2.08	54.13	479	309
6	Goa	79	0.56	96.20	8	1
7	Gujarat	4081	0.36	57.12	209	40
8	Haryana	398	0.13	85.43	8	6
9	Himachal Pradesh	141	0.18	90.78	1	13
10	Jharkhand	6160	0.98	49.87	440	113
11	Jammu & Kashmir	110	0.11	77.27	0	1
12	Karnataka	2724	0.30	71.40	121	68
13	Kerala	675	0.23	70.67	52	52
14	Madhya Pradesh	8020	0.80	62.61	292	287
15	Maharashtra	16572	0.79	54.95	1358	258
16	Manipur	21	0.09	61.90	0	4
17	Meghalaya	17	0.05	88.24	1	11
18	Mizoram	5	0.04	80.00	0	0
19	Nagaland	36	0.16	80.56	1	1
20	Odisha	10077	1.45	48.80	681	200
21	Punjab	531	0.17	91.34	28	18

S. No.	State/UT	New Cases	PR/10000 pop'ln	% Of MB cases	No. of child cases	No. of new cases with G2D
22	Rajasthan	1124	0.14	96.35	19	18
23	Sikkim	19	0.22	73.68	2	0
24	Tamil Nadu	4252	0.37	44.17	651	106
25	Telangana	4001	0.60	55.61	230	36
26	Tripura	73	0.05	84.93	1	44
27	Uttar Pradesh	15484	0.43	45.61	528	158
28	Uttarakhand	320	0.22	72.81	12	0
29	West Bengal	6208	0.58	71.12	517	65
30	A & N Islands	20	0.42	65.00	0	0
31	Chandigarh	134	1.03	81.34	12	6
32	D & N Haveli	200	2.61	21.00	24	0
33	Daman & Diu	29	0.43	41.38	0	1
34	Delhi	1824	0.99	87.45	58	256
35	Lakshadweep	0	0.00	0.00	0	0
36	Ladakh	2	0.64	100.00	1	0
37	Puducherry	49	0.22	44.90	8	7
	Total	114,451	0.57	54.28	7859	2,761

Annexure - II: List of published Studies in PubMed along with their findings which identified migration as one of the important obstacles in elimination of leprosy
Source: Rathod, S, Jagati, A, AgarwaI, P (2019). Impact of Migration on Epidemiology and Control of Leprosy. Review Article, *Indian J Lepr 2019*, 91: 139-152.
https://www.ijl.org.in/published-articles/14092021165214/6_S_Rathod_et_al_(139-152)_(1).pdf

STUDY TITLE	TYPE OF STUDY	REMARKS: IMPACT OF MIGRATION
Patterns of Migration and Risks Associated with Leprosy among Migrants in Maranha˜o,Brazil. (Murto et al 2013)	This case control study compared individuals newly diagnosed with leprosy in 2009-2010 (n=340) and a clinically unapparent control group in same time period (n=340) without any clinical signs of leprosy and were matched for age, sex and location in the four endemic municipalities in the state of Maranha˜o, north-easternBrazil.	Past five-year migration was foundto be significantly associated with leprosy, and remained significant after controlling for household and familial contact as potential confounders. Factors associated with leprosy among past 5-year migrants included alcohol consumption, poverty, and household, family and other leprosy contact. Patterns of migration identified mainly rural-urban flow of migrants generally undertaken to reduce poverty. This often placed migrants at higher risk or disease morbidity due to poor living conditions in urban slums. Further, population movement was clearly facilitated through strong destination based social networks as a precursor to migration. On a community level, social networks facilitating migration can lead to, highly localized movement between specific neighbourhoods in sending and receiving communities.
Imported Infectious Diseases in Mobile Populations, Spain (Monge-Maillo et al 2009)	This retrospective, Cohortstudy was carried out at The Tropical Medicine Unit (TMU) which is a referral center at theInfectious Diseases Department of the Ramón y Cajal Hospital in Madrid, Spain. In parallel with clinical work, data was collected regarding the Latin American and sub-Saharan African immigrants seeking health care at TMU from April 1989 through June 2008 for this epidemiologic and clinical study.	Of total 2,198 immigrants referred to the Tropical Medicine Unit of Ramón y Cajal Hospital over a 20-year period, 8 (0.4) had Leprosy. Increased population mobility has led to the disappearance of existing barriers for the spread of certain diseases.

STUDY TITLE	TYPE OF STUDY	REMARKS: IMPACT OF MIGRATION
Neglected Tropical Diseasesoutside the Tropics (Norman et al 2010)	There were 6168 patients (2634 immigrants, 3277 travelers and 257 visiting friends and relatives(VFR) travelers) in this cohort study conducted in Spain. Neglected tropical diseases (NTD) occurred more frequentlyin immigrants, followed by VFR travelers and then by other travelers (p,0.001 for trend).	Out of the total 10 cases of leprosy detected, 9 are immigrants and 1 wastraveler. Immigrants are potential source of disease in non-endemic region for leprosy.
WHO Multidrug Therapy forLeprosy: Epidemiology of Default in Treatment in Agra District,Uttar Pradesh, India (Kumar et al2015)	Analysis of the data collected in active surveys in Agra was done. Patients were given treatment after medical confirmation and were followed up. The treatmentdefault and other clinical outcomes were recorded. Therewere 94 defaulters.	Migration was the most common causeof defaulting treatment in both MB andPB leprosy cases (9.6% and 15.5% respectively) The group of ' lost to treatment' was due to either migrationto the other areas or job related non availability.
Leprosy in Toronto: an analysis of 184 imported cases (Boggild et al 2004).	A review of the clinical records of 184 leprosy patients referredto the Tropical Disease Unit at Toronto General Hospital	Patients were more likely to be male (122 or 66.3%) and of Indian (44 or 23.9%), Filipino (49 or 26.6%) or Vietnamese (37 or 20.1%) origin. Patients experienced symptoms for a mean of 4.8 years before referral tothe Tropical Disease Unit. Most had no family history of leprosy (152/172 or 88.4%). Immigration from endemicareas has resulted in the importation of leprosy into countries.
Epidemiology of Leprosyin Spain: The Role of the International Migration (Ramos et al 2016)	Observational, retrospectivestudy on leprosy cases reported through the National System of Compulsory Disease Notification, from 2003 to 2013. Of the 168 leprosy cases registered during the period, 40 (24.6%) were Spanish patients,while 128 (76.2%) were detectedin legally resident immigrants.	The increased migration of people fromendemic areas into Europe has impacted the incidence of leprosyin these countries where leprosy has been considered to be eradicated or controlled for decades.
Factors Associated with Migration in Individuals Affected by Leprosy,	This Population-based cross-sectional Study included 394 newly diagnosed leprosy cases and 391 individuals from a clinically unapparent population.	Of those with leprosy, 258 (65.5%) were birth migrants, 105 (26.6%) were past five-year migrants, and 43 (10.9%) were circular migrants. Three independent factors were found to be significantly associated with migration among those with leprosy: (1) alcohol consumption, (2) separation from family /friends, and (3) difficulty reaching the healthcare facility. Separation from family/friends was also associated with migration in the clinically unapparent population. The health sector may consider adapting services to meet the needs of migrating populations. Research is needed to explore risks associated with leprosy susceptibility from life stressors, such as separation from family and friends, access to healthcare facilities, and alcohol consumption to establish causal relationships.

Annexure III : Top 50 Inter-State Migration Corridors
Source: India Immigration Now, (n.d.), Analysis of 2011 Census Data.

SOURCE: STATE	DESTINATION: STATE	TOTAL
Uttar Pradesh	Nct Of Delhi	2854297
Uttar Pradesh	Maharashtra	2754706
Karnataka	Maharashtra	1399591
Bihar	Jharkhand	1336048
Uttar Pradesh	Madhya Pradesh	1090881
Bihar	Nct Of Delhi	1106629
Bihar	West Bengal	1103757
Uttar Pradesh	Madhya Pradesh	1090881
Bihar	Uttar Pradesh	1072739
Gujarat	Maharashtra	983653
Maharashtra	Gujarat	971975
Uttar Pradesh	Gujarat	929411
Andhra Pradesh	Karnataka	890697
Uttar Pradesh	Uttarakhand	890663
Madhya Pradesh	Maharashtra	824624
Rajasthan	Gujarat	747445
Tamil Nadu	Karnataka	736821
Madhya Pradesh	Uttar Pradesh	668537
Haryana	Nct Of Delhi	666331
Uttar Pradesh	Punjab	649557
Rajasthan	Haryana	611160
Maharashtra	Karnataka	586864
Utter Pradesh	Rajasthan	585982

SOURCE: STATE	DESTINATION: STATE	TOTAL
Rajasthan	Maharashtra	570233
Bihar	Maharashtra	568667
NCT of Delhi	Uttar Pradesh	566210
Madhya Pradesh	Rajasthan	554058
Haryana	Punjab	545584
Punjab	Haryana	538328
Haryana	Rajasthan	533963
Rajasthan	Madhya Pradesh	500481
West Bengal	Jharkhand	494609
Maharashtra	Madhya Pradesh	494312
NCT of Delhi	Haryana	468298
Karnataka	Andhra Pradesh	466951
Jharkhand	West Bengal	459436
Kerala	Tamil Nadu	447701
Andhra Pradesh	Maharashtra	437034
Jharkhand	Bihar	433696
Uttarakhand	Uttar Pradesh	393540
Bihar	Haryana	390937
Bihar	Gujarat	361010
Bihar	Punjab	352537
Kerala	Karnataka	334181
Uttar Pradesh	Bihar	319887
Rajasthan	Nct Of Delhi	315238
Tamil Nadu	Kerala	311347
West Bengal	Maharashtra	309766
Uttarakhand	Nct Of Delhi	294704
Karnataka	Tamil Nadu	289302

Annexure IV: Top 50 State to District Migrant Corridors
Source: India Immigration Now, (n.d.) Analysis of 2011
Census Data. Retrieved from:
https://indiamigrationnow.org/

Source: State	Destination: District	Destination: State	Total
Uttar Pradesh	Mumbai Suburban	Maharashtra	11,09,176
Uttar Pradesh	Thane	Maharashtra	8,96,712
Uttar Pradesh	North East Delhi	Delhi	6,18,973
Tamil Nadu	Bangalore	Karnataka	5,83,467
Uttar Pradesh	North West Delhi	Delhi	5,66,267
Uttar Pradesh	South Delhi	Delhi	5,03,897
Maharashtra	Surat	Gujarat	4,58,423
Uttar Pradesh	Surat	Gujarat	4,36,786
Gujarat	Mumbai Suburban	Maharashtra	4,16,174
Andhra Pradesh	Bangalore	Karnataka	3,94,293
Uttar Pradesh	West Delhi	Delhi	3,36,600
Uttar Pradesh	South West Delhi	Delhi	3,33,242
NCT of Delhi	Ghaziabad	Uttar Pradesh	3,27,580
Uttar Pradesh	East Delhi	Delhi	3,10,047
Uttar Pradesh	Udham Singh Nagar	Uttarakhand	3,03,181
Uttar Pradesh	Mumbai	Maharashtra	2,96,593
Karnataka	Kolhapur	Maharashtra	2,93,869
Uttar Pradesh	Faridabad	Haryana	2,91,484
Bihar	North West Delhi	Delhi	2,64,298
Maharashtra	Belgaum	Karnataka	2,58,428
Uttar Pradesh	Hardwar	Uttarakhand	2,56,199
Bihar	Dhanbad	Jharkhand	2,37,294
Haryana	Northwest	Delhi	2,25,572

Source: State	Destination: District	Destination: State	Total
Rajasthan	Ahmadabad	Gujarat	2,23,351
Bihar	South	Delhi	2,23,293
Madhya Pradesh	Nagpur	Maharashtra	2,21,198
Tamil Nadu	Puducherry	Puducherry	2,21,165
Karnataka	Mumbai Suburban	Maharashtra	2,19,398
Bihar	South West	Delhi	2,13,251
Uttar Pradesh	Ludhiana	Punjab	2,12,482
Bihar	Kolkata	West Bengal	2,11,174
Rajasthan	Surat	Gujarat	2,10,952
Karnataka	Pune	Maharashtra	2,02,137
Uttar Pradesh	Ahmadabad	Gujarat	1,98,298
Gujarat	Thane	Maharashtra	1,96,005
Bihar	Ranchi	Jharkhand	1,94,630
Bihar	Surat	Gujarat	192045
Bihar	Barddhaman	West Bengal	182441
Uttar Pradesh	Dehradun	Uttrakhand	182247
Uttar Pradesh	Chandigarh	Chandigarh	179574
Kerala	Bangalore	Karnataka	179404
Bihar	West	Delhi	179006
Haryana	Alwar	Rajasthan	174177
Rajasthan	Mumbai Suburban	Maharashtra	174067
Bihar	Thane	Maharashtra	173388
Bihar	Bokaro	Jharkhand	170397
Uttar Pradesh	Pune	Maharashtra	167727
Haryana	South West	Delhi	165258
Bihar	PurbiSinghbhum	Jharkhand	157052
Karnataka	Sangli	Maharashtra	156832

Annexure V: High Endemic/Endemic Districts: Bihar, Uttar Pradesh, Delhi, and Chandigarh
Source: NLEP, Central Leprosy Division, 2019

The endemicity of a district is calculated based on 4 indicators (NCDR, PR, G2D and New child case). Different weightage is assigned to each of the indicator ((NCDR-40%, PR-20%, G2D-20% and New child case-20%) and finally a composite index is calculated as the sum of these four weightages.

- Further, the districts are classified in three categories (High endemic, endemic and low endemic) as mentioned below:
- **High Endemic:** A district is defined as a High Endemic District when its composite index is above 16.00%.
- **Endemic:** A district is defined as an Endemic District when its composite index is between 06.00% and 15.00%.
- **Low Endemic**: A district is defined as a Low Endemic District when its composite index is between 0.00% and 5.99%.

Colour code	Category
3	High Endemic
2	Endemic
1	Low Endemic

BIHAR

Category	N
High Endemic	23
Endemic	15
Low Endemic	0

S. No.	Name of District	Category of the district		S. No.	Name of District	Category of the district
1	Araria	3		20	Madhepura	3
2	Arwal	2		21	Madhubani	3
3	Aurangabad	3		22	Munger	2
4	Banka	3		23	Muzaffarpur	2
5	Begusarai	2		24	Nalanda	3
6	Bhagalpur	3		25	Nawada	3
7	Bhojpur	2		26	Patna	3
8	Buxar	2		27	Purnea	3
9	Darbhanga	3		28	Rohtas	3
10	E. Champaran	3		29	Saharsa	2
11	Gaya	3		30	Samastipur	2
12	Gopalganj	2		31	Saran	3
13	Jamui	2		32	Sheikhpura	2
14	Jehanabad	3		33	Sheohar	2
15	Kaimur	3		34	Sitamarhi	3
16	Katihar	2		35	Siwan	3
17	Khagaria	2		36	Supaul	3
18	Kishanganj	3		37	Vaishali	2
19	Lakhi Sarai	3		38	W. Champaran	3

UTTAR PRADESH

Category	N
High Endemic	14
Endemic	42
Low Endemic	19

S. No.	Name of District	Category of the district		S. No.	Name of District	Category of the district
1	Agra	2		39	Jaunpur	2
2	Aligarh	2		40	Jhansi	2
3	Allahabad Prayagraj	2		41	Kannauj	2
4	Ambedkarnagar	2		42	Kanpur Dehat	2
5	Amethi	2		43	Kanpur Nagar	2
6	Amroha(JBP.Nagar)	3		44	Kanshganj	1
7	Auraiya	2		45	Kaushambi	2
8	Ayodhya	2		46	Kheri	3
9	Azamgarh	2		47	Kushinagar	2
10	Badaun	3		48	Lalitpur	2
11	Bagpat	1		49	Lucknow	2
12	Bahraich	3		50	Maharajganj	2
13	Ballia	3		51	Mahoba	1
14	Balrampur	1		52	Mainpuri	2
15	Banda	1		53	Mathura	1
16	Barabanki	3		54	Mau	2
17	Bareilly	3		55	Meerut	2
18	Basti	2		56	Mirzapur	2
19	Bijnor	3		57	Moradabad	3
20	Bulandshahr	2		58	Muzaffamagar	1
21	Chandauli	2		59	Pilibhit	3
22	Chitrakoot	1		60	Pratapgarh UP	1
23	Deoria	2		61	Raebarely	2
24	Etah	1		62	Rampur	2
25	Etawah	1		63	Saharanpur	1
26	Farrukhabad	1		64	Sambhal	3
27	Fatehpur	2		65	Sant Kabir Nagar	2
28	Firozabad	1		66	Shahjahanpur	2
29	Gautam Buddha Ng.	1		67	Shamli	1
30	Ghaziabad	1		68	Shravasti	2
31	Ghazipur	3		69	Siddharth Nagar	2
32	Gonda	2		70	Sitapur	3
33	Gorakhpur	2		71	Sonbhadra	2
34	Hamirpur UP	1		72	St. Ravidas Nagar	2
35	Hapur	2		73	Sultanpur	2
36	Hardoi	3		74	Unnao	2
37	Hathras	1		75	Varanasi	2
38	Jalaun	2				

DELHI

Category	N
High Endemic	2
Endemic	4
Low Endemic	5

S. No.	Name of District	Category of the district
1	Central Delhi	2
2	East	1
3	New Delhi	3
4	North	1
5	North East	1
6	North West Delhi	2
7	Shahdara	3
8	South Delhi	2
9	South East	1
10	South West	1
11	West Delhi	2

CHANDIGARH

Category	N
High Endemic	0
Endemic	1
Low Endemic	0

S. No.	Name of District	Category of the district
1	Chandigarh	2

**The Research Study is carried out
by**

**Swiss Emmaus Leprosy Relief Work India
in collaboration with
Changescape Consulting**

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