



Impact Assessment of Law, Human Rights, Gender, Key and Vulnerable Populations-related Barriers in Nepal's TB Response

2022



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FOREWORD

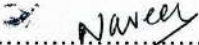
It is my pleasure to introduce this report on the "Community, Rights, and Gender Assessment of Tuberculosis in Nepal." Tuberculosis is a serious public health issue in Nepal, and it continues to pose a significant burden on the health and well-being of our population. Throughout the years, we have expanded access to diagnosis and treatment, improved the quality of care, and collaborated with partners to address the challenges of tuberculosis control in Nepal, and we are proud of the significant progress we have made in recent years in controlling this disease.

TB is not only a medical problem but also a social and economic one, affecting the most vulnerable populations and causing a significant burden on the health system and the economy. It is evident that the widespread existence of vulnerability, marginalization, stigma, and discrimination in our society makes the lives of people living with TB further complicated.

This assessment has given us an opportunity to assess the community, rights, and gender situation in the country regarding the National TB Program. It has covered seven themes adapted from the right-to-health framework and assessed the significance of human rights, law, and gender perspective. It also reflects the situation of TB affected and survivors status of community engagement and has highlighted the areas where we need to work more on a policy level to holistically promote community engagement through the National Tuberculosis Control Program.

We are moving forward with the findings and recommendations in the coming years, and I hope that this report will be an equally valuable resource for healthcare professionals, policymakers, and researchers who are working to combat tuberculosis in Nepal. I also hope that it will raise awareness about the importance of community engagement and inspire continued commitment and action to combat this disease.

My sincere thanks to all the government bodies, partner organizations, and individuals who worked on this assessment. To conclude, I congratulate everyone involved in the assessment, and publication of this report.


.....
Dr. Naveen Prakash Shah
Act. Director, NTCC

Message from Stop TB Partnership

To All Our Nepali Friends,

I could not be happier to share some reflections regarding the finalized Nepal TB CRG Assessment. Its completion speaks high to the hard work and commitment of the National TB Program in Nepal, the passion of TB affected community and civil society partners in country- including Trishuli Plus - and the strong partnerships from stakeholders in country.

The Global Plan to End TB 2023-2030 provides a road map for ending TB by 2030 and several interventions are listed to support countries to implement this roadmap. TB communities, rights, and gender features in an unprecedented manner. The Global Plan clearly calls on countries to complete a TB CRG Assessment, to develop a national TB CRG Costed Action Plan, to integrate it into the broader TB National Strategic Plan and then to ensure it is fully implemented. This is consistent with the United Nations High Level Meeting on TB (UNHLM) Political Declaration commitments, the End TB Strategy, the Global Fund Strategy and, ultimately, with the UN Sustainable Development Goals. Nepal is on track to achieve this, moving closer to achieving national commitments made during the UNHLM on TB. Congratulations!

The increased focus and presence on TB CRG reflect the awareness that to end TB we must promote and protect the human rights of people affected by TB. Central to achieving this, we must identify, monitor, mitigate and overcome the human rights and gender related barriers that inhibit people from accessing the TB services they need. Given there are so many missing people with TB, this enhanced focus on TB CRG is timely.

Nepal joins over 20 other countries that Stop TB Partnership has supported to complete TB CRG Assessments. Those assessments have all found that despite our efforts, barriers in accessibility, availability, acceptability, and quality of TB services remain. That stigma, discrimination, privacy, and confidentiality continue to be barriers that require attention. The nuances of gender related barriers must be further addressed. That participation of people affected by TB must be further strengthened. And, that we need to have renewed focus on the vulnerabilities and barriers experienced by TB key and vulnerable populations in our countries to ensure they too can access the TB services they need.

Stop TB stands ready to support the National TB Program and TB affected communities to turn this assessment into Actions towards the next steps to finalize a costed TB CRG Action Plan to address the identified barriers. Working closely with Global Fund, USAID and through Challenge Facility for Civil Society, we hope to see significant progress in this important area of the TB response.

2023 will be the year of the second United Nations High Level Meeting on TB. I look forward to the continued leadership of Nepal in supporting an ambitious Political Declaration. Yes! Together we can End TB.



Dr Lucica Ditiu, Executive Director, Stop TB Partnership



Message from APCASO

APCASO is a regional civil society network organization that supports and promotes advocacy and community systems strengthening to advance health, social justice and human rights for key, vulnerable and marginalized communities in Asia-Pacific. We are the host and convener of the Activists' Coalition on TB Asia-Pacific (ACT! AP). As such, we believe that bio-medical approaches to TB responses, alone, will not achieve country goals and targets on TB. CRG interventions – i.e., community systems strengthening (CSS) and community engagement, addressing human rights barriers, and gender transformation, need to be center pieces of TB plans, policies, programs, budgeting, and resource allocation.

APCASO hence extends its warmest congratulations to Trishuli Plus and broader Nepal TB key stakeholder partners for the development of this country TB CRG assessment report. This report is valuable in pinpointing CRG areas in the country's TB scenario that need attention and action. The report takes stock of and highlights key CRG issues in the context of TB for the country. The ball is now in the court of country duty-bearers, including from the National TB program and other TB program implementers, policymakers, and donors, to consider and act upon the report findings and recommendations. APCASO remains committed to support Trishuli Plus and other TB community and civil society partners in Nepal, as they work and engage with government and other country stakeholders in having CRG-responsive TB country plans and actions.

RD Marte,
Executive Director, APCASO



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ACKNOWLEDGEMENT

I would like to express my deepest gratitude to everyone who has contributed to the first ever comprehensive community, rights and gender assessment for tuberculosis program in Nepal. First of all, I want to thank all the participants who participated in the focus group discussions and the health care providers who have generously shared their time and experience with us. My sincere thanks to all the organization representatives who have shared their experiences and insights for key informant interviews. Their information was critical to the evaluation.

I sincerely appreciate the support provided by the National Tuberculosis Control Center for their guidance throughout the assessment. I would also like to thank Save the Children International for its support in assisting us in conducting focus group discussions and key informant interviews in several provinces. My sincere gratitude to the Chitwan Sakriya Women's Foundation, Human Conscious Society, JANTRA and Bagmati Welfare Society Nepal for their coordination and support.

My special thanks to Dr. Naveen Prakash Shah, Act. Director NTCC, Ms. Rita Bhandari Joshi, Former Director, NTCC, and Dr. Sarad Kumar Sharma, Chief, Planning, Monitoring, Evaluation, and Research Section, NTCC, for their valuable input and guidance for the assessment. I would also like to thank Ms. Khin Pa Pa, Team Leader, WHO, and Ivana Lohar, USAID Nepal, for their valuable time and insights.

I am grateful to the consultants and colleagues who oversaw the assessment. I extend my thanks to consultants Mr. Sanjeev Raj Neupane and Mr. Rup Narayan Shrestha. I would also like to thank Ms. Reecha Puri, CRG officer and Mr. Sadhuram Sapkota, Finance Director and all other colleagues at Trishuli Plus Community Action Group for their hard work and expertise in driving this assessment forward.

I also want to thank the partners who have supported this effort. The NTCC, STOP TB Partnership, The Global Fund/Save the Children International, APCASO, USAID and many other organizations have provided technical assistance, funding, and other resources to help us strengthen the assessment. We are grateful for their ongoing support.

Once again, many thanks to everyone who was involved in the assessment. Your contributions have been invaluable, and I am deeply grateful for your dedication to improving the lives of those affected by this disease.

Sincerely,

Achut Sitaula



Executive Director, Trishuli Plus Community Action Group

"STOP AIDS KEEP THE PROMISE"

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List of Acronyms

| | |
|--------|--|
| CCM | Country Coordinating Mechanism |
| CNR | Case Notification Rate |
| CRG | Community Rights and Gender |
| DOTS | Directly Observed Treatment Short-course |
| DR-TB | Drug Resistant TB |
| FGD | Focus Group Discussion |
| HDI | Human Development Index |
| HLM | High Level Meeting |
| JMM | Joint Monitoring Mission |
| KII | Key Informant Interview |
| KVP | Key and Vulnerable Population |
| NATA | Nepal Anti-Tuberculosis Association |
| NTC | National Tuberculosis Centre |
| NTP | National Tuberculosis Programme |
| SDG | Sustainable Development Goals |
| STP | Stop TB Partnership |
| UN HLM | United Nations High Level Meeting |
| WHO | World Health Organisation |

Executive Summary

Introduction

The TB Community, Rights, and Gender (CRG) Assessment is a qualitative process that prioritizes the experiences and participation of communities affected by TB, including key and vulnerable populations. It is a process that seeks to identify and address barriers to TB prevention, diagnosis, and treatment, as well as promote community participation and human rights in TB programs. It also assesses the significance of human rights, law, and gender in the TB response in partnership with the national TB program and other stakeholders. This assessment also focuses on ensuring that people affected by TB have equal access to quality health services and are not discriminated against based on their gender, ethnicity, or socioeconomic status. In general, the TB CRG assessment is an essential tool to ensure that TB services in Nepal are delivered in a way that meets the needs and rights of all people affected by TB, including every gender, children, key populations, and vulnerable populations.

The CRG assessment was conducted in Nepal for the first time, and the findings from this assessment will help in developing policies, strategies, and interventions to improve TB prevention and control in Nepal. The assessment is focused on the seven themes adapted from the right to health framework. These are accessibility, availability, acceptability, quality, stigma, and discrimination; health-related freedoms (e.g., privacy and confidentiality); barriers among prioritized KVPs; gender-related barriers in the TB response, participation of TB survivors and KVPs; and legal and administrative remedies. Based on these themes, the present situation, gaps, and recommendations are discussed in the report.

Methods

This assessment was completed with a series of desk reviews of relevant documents, several focus group discussions with TB-affected/infected/survivors, and key informant interviews with the health service provider at the community and district levels. Nine key informant interviews and 10 focus group discussions were conducted with a total of 79 participants (male: 33; female: 34; and others: 12) in 3 districts (Kailali, Chitwan, and Dhanusha). The guidelines for discussions and interviews were developed based on the CRG tools developed by the STOP TB Partnership and the CRG reports of different countries that had already completed assessments. In addition to this, stakeholder meetings were held with officials from NTCC, SCI, WHO, and other stakeholders working in TB to further explore the scenario of the National TB Program based on the preliminary findings of an assessment from the policy and national levels.

The assessment report was prepared with technical guidance from the STOP TB Partnership, Global Fund, Save The Children and NTCC. The first draft of the assessment was prepared and shared with the relevant stakeholders involved in the assessment, for which it underwent numerous revisions before being finalized.

Results

1. Accessibility, availability, acceptability, and quality of TB services:

In Nepal, the closest community health center offers DOTS TB therapy, and there were no issues regarding it. However, the two diagnostic methods that are most frequently used (microscopy and GeneXpert) are scarce and only accessible in a few ground-level medical institutions. Furthermore, regarding the gender identity of TB affected, there were no issues reported with accessibility / regular availability of medication from the closest DOTS facility, but the majority had issues with prompt diagnosis.

2. Stigma and discrimination

The severity of discrimination at the individual and communal levels based on TB status has lessened over time, but it persists. The subjects' experiences with discrimination and stigma varied. Based on our findings, participants were divided into two groups: those who experienced no discrimination and those who did. But everyone continued to experience self-stigma and discrimination, which in and of itself is a threat to the national tuberculosis program.

3. Health-related freedoms (e.g., privacy and confidentiality)

The right to health, the right to control one's health and body, the right to be free from interference (such as the freedom from torture and non-consensual medical treatment and experimentation), and the proper protection of patient privacy and confidentiality are all included under the category of health-related freedoms. In our study, no gender-based unfair practices in medical settings when people have accessed TB treatments were reported. However, protective behavior from health service providers was noted as instances of personally inappropriate behavior toward TB-affected individuals in healthcare.

4. Barriers among Key Vulnerable Populations

Transgenders identified their communities at numerous risks for infection and disease. Due to the discrimination and fear of social rejection they experience, they often hesitate to openly disclose their status in society. They feel it is emotionally safer to leave their community, and there are a number of homeless transgenders living in poor environmental conditions. Furthermore, a large number of people in the community consume alcohol and smoke cigarettes, increasing their risk of developing tuberculosis. Given how deeply ingrained the stigma against transgender people is, contracting any other disease would exacerbate the situation.

5. Gender-related barriers in the TB response.

A huge disparity exists in the Nepalese community regarding the TB response from a gender perspective. In Nepal, males are two times more infected with TB in comparison to females. However, their enrollment in treatment and adherence are comparatively low. However, even if women are diagnosed later than men, their adherence to treatment is higher.

6. Participation of TB survivors and KVPs

Meaningful community engagement is critical to improve the reach and sustainability of TB services and accelerate progress toward ending TB by 2030. It is essential to bring the voices of affected communities: TB survivors and Key-populations into decision-making, developing policy, programs, and activities at global, regional, and country levels. Among the total number of participants, we interacted with during FGDs, there were only a few people who had a previous history of participation in those activities.

7. Legal and Administrative remedies

Tuberculosis like other infectious diseases, has also been issue of stigma and discrimination. Different efforts have been done to increase access to the treatment as well as protect the rights of individuals infected and affected with TB. In Nepal, there has been provision of free diagnosis and treatment for individuals infected with TB. Nepal has also worked a lot in the implementation of documents ratified by various international forum to increase the access to

diagnosis & treatment and reduce stigma and discrimination associated with tuberculosis.

Recommendations

Theme-based recommendations have been included in an assessment report to provide a clear and structured approach to addressing the challenges and barriers related to TB prevention and control identified during the assessment. A few of the major recommendations include:

- Roll out the TB stigma assessment using the STP TB stigma assessment tool—the “Implementation Handbook and Data Collection Instruments”-and conduct policymakers' TB CRG dialogues to advocate for increased collaboration between the TB and HIV national response using existing governing structures.
- Mobilize parliamentarians, medical professional associations, TB survivors, and celebrities for stigma reduction and social media platforms (like Facebook, Twitter, Instagram, TikTok, etc.)
- Organize trainings of journalists and media professionals on TB, stigma elimination, and health-related community, rights, and gender issues, and organize a workshop to develop communication materials to reduce the stigma of TB in the community.
- Conduct mapping of TB-related CSOs/CBO and use the results to develop a community engagement strategy that includes TB survivors’ engagement and strengthens TB Champions interventions in hard-to-reach areas.
- Engage communities, community-led organizations, and TB-affected people in advocacy and community-led outreach campaigns to address harmful gender norms and stereotypes and other gender and human rights-related barriers, including stigma reduction and human rights literacy.
- Strengthen the linkage of One Impact community-led monitoring (CLM) to legal counseling and support.

1. Introduction:

Tuberculosis (TB) is a public health problem in Nepal. TB is caused by the bacillus *mycobacterium tuberculosis*, and is spread when people who are infected with TB expel bacteria into the air; for example, by coughing. The disease primarily affects the lungs (pulmonary TB) but can also affect any parts of the body (extra pulmonary TB). The problem is further complicated by poverty which results in a vicious intergenerational cycle of malnutrition, tuberculosis and poverty. TB is a disease of poverty, and economic distress. And the widespread existences of vulnerability, marginalization, stigma & discrimination in our society make the life of people living with TB further complicated, contributing to barriers to accessing TB prevention, diagnosis, treatment, care and support services while providing opportunities to further strengthening current approaches to planning, implementation, monitoring, review and governance.

According to the Global TB Report published by WHO in Oct 2022, an estimated 10.6 million people were infected with TB in 2021, which is an escalation by 4.5% in comparison to 2020 and was the first time in nearly twenty years that the number of people infected with TB has increased globally. The deaths related to TB also increased from 1.6 million in 2020 to 1.7 million in 2021. The burden of drug-resistant TB also increased in 2022 by 3% in comparison to 2021¹.

The TB program in every country in the world suffered backlash after COVID-19 just like other regular health programs mainly due to the lockdowns, disruption of global supply chain mechanism and shifting of the health resources to COVID-19 response which ultimately resulted in fewer people diagnosed and enrolled on TB treatment, fewer people continuing the treatment and fewer people having access to preventive treatment that can stop disease from spreading. In 2020 and 2021, four million people infected with TB were missed by the TB program as a result they were undiagnosed and untreated, which led to increased transmission, and deaths. Timely TB diagnosis and treatment is important because the treatment regimen has a success rate of 85%. In 2020, the 15% decline in the number of people enrolled on treatment for drug-resistant TB is attributed to the COVID-19¹.

Another area, which suffered backlash after the COVID-19 pandemic is funding for TB programs. The funding in TB program was already below the targeted fund required for TB elimination and the situation was further deteriorated by the pandemic. The funding on TB program was already below the 2022 goal of \$13 billion and amidst this the global annual spending on essential TB services fell from \$6 billion in 2019 to \$5.4 billion in 2021¹.

The United Nations High Level Meeting on TB Political Declaration from 2018², includes a number of commitments directly relevant to TB communities, rights and gender (CRG). These including advancing an equitable, rights-based TB response, meaningful engagement of TB key and vulnerable populations (KVP), ending TB stigma, removing discriminatory laws and policy, fostering gender equity and social inclusion, access to medicines and psychosocial support. The Global Plan to End TB 2023-2030 provides a road map to realizing these commitments, and calls on countries to conduct a TB CRG Assessment, develop a costed TB CRG Action Plan, integrate that plan into the National Strategic Plan (NSP) and fund and implement that plan³. Stop TB Partnership (STP) has developed tools to support the TB CRG Assessment and Action Plan and has now supported over 20 countries to commence these processes.

1.1 Country Profile

In 2015, with the promulgation of new constitution Nepal moved to federalized structure from the unitary government system. Under the federal system of government, the country is divided into 7 provinces, 77 districts, and 293 urban & 460 rural municipalities (in total 753 local levels). The national census conducted in 2021 has estimated the total population in Nepal to be 29.3 million⁴.

¹ Global Tuberculosis Report 2022, WHO

² <https://www.stoptb.org/advocate-to-endtb/united-nations-high-level-meeting-tb>

³ The Global Plan to End TB 2023-2030, Stop TB Partnership

⁴ Preliminary Report of National Census 2021, CBS

The Human Development Index (HDI) value for Nepal in 2018 was 0.579 and was ranked 147 out of 189 countries of the world. Life expectancy at birth has been increasing steadily and in 2018 was 70.5 years⁵.

Although Nepal has achieved tremendous progress in improving the life expectancy, child health, maternal health and control of many infectious disease the gains are uneven and much more needs to be done in terms of equality and quality of health services. Nepal continues to face a triple burden of health problems from Non-Communicable Diseases (NCDs), Communicable diseases and Natural disasters & climate change (like accidents, violence, antimicrobial resistance, and injuries). Out of around one hundred ninety thousand estimated deaths in Nepal in 2019, 71 percent were attributed to NCDs, 21 percent were attributed to communicable, maternal, neonatal and nutritional diseases, and the remaining 8 percent to injuries. Of the total Disability Adjusted Life Years (DALYs), 32 percent were due to behavioral risk factors, 22 percent were due to environmental and occupational risk factors, 14 percent were due to metabolic risk factors⁶.

Nepal is committed towards the End TB Strategy, TB-related targets of the Sustainable Development Goals (SDG) and the first United Nations High Level Meeting (UNHLM) on TB.

1.2 Demography

According the Census of 2021, the total population of Nepal is 29.3 million with 49% male and 51% female. Out of the total population of Nepal, 66% live in urban areas where as 34% live in rural areas. Province-wise, Madhesh province has the largest population where as Karnali Province has the least. There are 53,43945 households in Nepal and the population density is 198⁷.

The average annual population growth rate is 0.93%. The average annual population growth rate recorded in 2021 census is less in comparison the census of 2011 which recorded a population growth rate of 1.35%. The declining population growth rate is the result of several factors including decreasing fertility rate, increasing migration, public health, and urbanization. The fertility rate recorded in 2021 census is 1.85. The fertility rate has declined from 2.51 in 2011 to 1.85 in 2021⁸.

The Census of 2021 has shown increase in migration of Nepalese population to abroad. Since 2011, more and more Nepalese have migrated abroad in search of better opportunities which in turn is a critical factor for the lower population growth rate in Nepal. The number of women that migrated to foreign countries has increased by 71% in comparison to the previous census owing to the development of information and technology⁷.

The urban population is also increasing in Nepal. The rapid growth in population has led to mismanaged urbanization as more people are migrating to cities making them more populous. In 2021, the urban population reached 66.8%, which is an increase from what was reported in the 2011 report, where urban population was at 63.2%. In contrast to this, the rural population has decreased to 33.9% in 2021 in comparison to a 36.8% in 2011⁷. Increase in poverty, a lack of education, and employment opportunities in rural areas are key motivators for people to relocate from rural to urban areas. As more people migrate to urban areas in search of employment, income levels tend to rise as more jobs and opportunities are available due to the economic activity.

1.3 Health System

One of the vital changes in Nepal's health system over the past few years is the decentralization. With the promulgation of new constitution in 2015, Nepal moved to federalization. Along with the new constitution the health system in Nepal was also restructured and synchronized as per the motto of

⁵ Human Development Report 2021/2022, UNDP

⁶ Non-Communicable Disease (NCD) Policy Brief, 2019, Nepal Health Research Council (NHRC)

⁷ Preliminary Report of National Census, 2021, CBS

⁸ Preliminary Records of National Census 2021, CBS

the constitution. Nepal has three tiers of government- central, provincial and local level with the sub-national government having more authority and resources in planning and managing health services than before. The primary health care system in Nepal now comprises of more than 4000 peripheral primary health care facilities including Health Posts, Primary Health Care Centres and Hospitals which are managed by local government. The Ministry of Health and Population at the central level carries out functions related to regulation, outbreak control, quality assurance, research and managing specialized hospitals. Ministry of Social Development (Or Ministry of Health in some provinces) at the province level oversees provincial health offices, hospital, health functions of local government including managing logistics and drug supply. The three levels of government share authority and responsibility in catering health services to the citizens of Nepal as per the constitution.

Just like in many other sectors the decentralization also brought both opportunities and challenges in the Nepal's health system. The federalism has brought an opportunity to reform and restructure Nepal's health systems towards decentralised leadership and governance, evidence-based planning and widening of the collaborative structures. Linked to these opportunities, the various frameworks have defined power and normative positions of government in relation to health systems and population health, strategic leadership, inclusive and transparent governance, and interactions, cooperation, and collaboration across the three levels of government.

While the Nepal's health systems have successfully managed natural disasters such as the earthquake (2015), the COVID-19 pandemic and other public health emergencies, the health system in Nepal still need to be more resilient. The concept of resilient health system also need to be contextualised and tailored according to the federalization. While health sector reviews have been integral part to assess progress, gaps, and challenges, they need to be enhanced for evidence-based planning and budgeting through feedback loops. This demands for learning and adaptive approach towards strengthening health systems across the three tiers of government.

The National Tuberculosis Programme began in Nepal in 1965 AD with a tri-patriate agreement between the government of Nepal, WHO and UNICEF. The national TB programme adopted the DOTS strategy first in 1996 through four pilot sites. By 2001 the DOTS strategy was expanded throughout the country. The National Tuberculosis Program in Nepal has a network of 4,323 treatment centres, 96 urban health centres, 624 microscopy centres and 56 GeneXpert centres. The treatment of drug resistant TB is available through 21 treatment centres and 86 sub-centres which are decentralized up to the community level. There are 7 DR TB hostels throughout the country for DR-TB patients who need hospitalization and in-patient services. However, these hostels are inadequate and there are plans to incorporate these hostels into the hospitals. The culture and drug susceptibility testing are available only at the central level in NTC Bhaktapur and GENETUP (NATA).

1.4 Situation of TB in Nepal

The first-ever TB prevalence survey conducted in Nepal in 2018 showed that the burden of TB in Nepal is much higher than the estimates used previously that were based on proxy measures. The new estimated TB prevalence rate (TB of all forms) from prevalence survey of 2018 was 416 (314-518) per 100,000 population and TB incidence, was 245 per 100,000 population. With the new estimates from prevalence survey, it was found that the gap in TB program is more than previously estimated for example 54% (31,000) of people with TB are being missed by the National TB Programme (NTP)⁹.

The new estimates of TB incidence from the prevalence survey indicated an annual decline of TB incidence in Nepal by 3% which is better than the global annual decline of around 1.5%. This decline can be attributed to the efforts from the national TB program over the last decade. However, with this pace it is not possible to meet the End TB targets and the decline need to be accelerated.

⁹ National TB Prevalence Survey 2018/19 Fact Sheet, NTC

32,043 TB cases were notified to the national TB program in the Fiscal Year 2018/19¹⁰. Considering the new estimates of 68,000 from prevalence survey the notification gap is 52.8%. Among the new TB cases notified in 2018/19, majority (63%) were male whereas only 37% were female. There is also geographic disparity among the notified TB cases with the lowest number reported from the mountains and highest number reported from terai. Similarly, Karnali province has reported the lowest number of TB cases whereas the Lumbini province had the highest TB case notification rate (CNR). Notification rates in children have been stagnant for the last few years. It is reported that the 63% of the childhood TB cases are between the age of 5-14 years.

The treatment success rate in Nepal in 2018/19 was 91% with variation across provinces. The proportion of childhood TB cases among all notified TB cases remains around 5.5%. It is estimated that there could be around 2,800 TB cases among malnourished children in Nepal. The National TB Program needs to invest more to screen these pediatric cases for TB.

In 2018-2019, of the 1,400 estimated incident cases of RR/MDR-TB in Nepal, only 635 were notified to the NTP. Among those notified, only 62% (392) were enrolled in the treatment resulting in high initial loss to follow up (LTFU). One of the barriers to adequate access to treatment of DR-TB is that the network for the programmatic management of DR-TB (PMDT) is too centralized and also reliant on hospital-based models of care. At present, there are 21 DR-TB treatment centers and 81 DR-TB treatment sub-centers across the country. There is a need for further decentralization of services and expansion of ambulatory model of care to expand Referral center in each province.

1.5 National TB Strategic plan

The National Tuberculosis Control Centre (NTCC) is one of the centers within the organizational structure of the Ministry of Health and Population, and is the focal point of National TB program. It is responsible for formulating policies, strategies and plans and carrying out monitoring, evaluation and quality assurance of National TB Program. The National TB Program has been formulating short and long-term plans and has been implementing programs accordingly since 1994/95. The TB program in Nepal is implemented in line with the global and national guidance and updated regularly with the availability of new international guidelines. The National Tuberculosis Program has developed a *National Strategic Plan to End Tuberculosis in Nepal (2021/22-2025/26)*¹¹ with the following vision, goal, objectives and strategies.

Vision: TB free Nepal

Goal: to decrease incidence rate from 238 in 2020/21 to 181 per 100,000 population by 2025/26; decrease mortality rate from 58 in 2020/21 to 23 per 100,000 by 2025/26;

Objectives:

- To build and strengthen political commitment, sustainability and patient-friendly health system to end TB.
- To ensure the identification of TB, diagnosis, quality treatment and prevention.

Strategies:

- Improve the quality of TB services and strengthen the health system for universal access to TB services; effectuate the TB services and support by increasing the community engagement in TB management, and strengthen the digitalized case-based surveillance system in health care facilities.
- Strengthen laboratory services to further improve the management of TB diagnosis and treatment.
- Quality Improvement of the services for TB prevention, identification and treatment

¹⁰ Annual Report 2020/21, DoHS

¹¹ National Strategic Plan to End Tuberculosis 2021/22 – 2025/26, NTCC, MoHP

Community System Strengthening in the National Strategic Plan:

Although not explicitly mentioned, there are some policy actions and activities proposed for community system strengthening under the National TB strategic Plan 2021/22 - 2025/26. Under the first strategy of the strategic plan one of the policy action is to "**Strengthen Community Involvement and Ownership in TB free Nepal campaign**". Some of the activities proposed under this policy action are implementation of TB free campaign, formulation of micro-plan, implementation of multisectoral concept, mobilise different communities for active case finding of TB. Similarly another policy action in the strategy is "**Implementation of multi-sectoral approach**". Some of the activities proposed under this Policy Action are strengthening TB-HIV collaboration, Cooperation with Tobacco Control Program and NCD programs, Establishing collaboration between NTP & Diabetes program and strengthening case finding among malnourished populations. Similarly another policy action that slightly touches on the community system strengthening is "**Ensure meaningful participation of private and non government sector for effective management of TB services**". The activities proposed under this policy action are development of package for service expansion in different sectors, development of partnership with relevant stakeholders and formulation of supportive policy & legal framework. Although the "National Strategic Plan" has some activities proposed for community system strengthening for TB there are lots of rooms for improvement. The involvement of TB affected & infected communities in the TB response, addressing Stigma & discrimination on TB, Participation of Key Vulnerable Populations (KVPs), addressing gender related barriers and addressing legal barriers are some of the areas that need strengthening in the strategic plan.

2. TB CRG assessment in Nepal

2.1 Background:

The TB Community, Rights & Gender (CRG) assessment is a qualitative process that prioritizes the experiences and participation of communities affected by TB, including TB key and vulnerable populations. TB key and vulnerable populations are groups at higher risk for TB or that lack access to health services due to biological, behavioral, social, or structural factors. The CRG assessment also assesses the significance of human rights, law, and gender in the TB response in partnership with the national TB program and other stakeholders

TB CRG assessments have already been conducted in over 20 countries. The barriers that have been most frequently identified have been analysed around 7 themes adapted from the right to health framework. These are:

1. Accessibility, availability, acceptability and quality
2. Stigma and discrimination
3. Health related freedoms (e.g. privacy and confidentiality)
4. Barriers among prioritized KVPs
5. Gender related barriers in the TB response
6. Participation of TB survivors and KVPs
7. Legal and administrative remedies

The CRG assessment of Nepal is also focused around these seven themes.

2.2 Motivation:

Nepal has articulated five-year National Strategic Plan to end Tuberculosis 2021/22 -2025/26. This plan has been developed under the auspices of the constitution of Nepal, National Health Policy 2019, the public health service act 2018, the fifteenth five-year plan 2019/20-2023/24 and the Nepal Health Sector Strategic Plan 2015—2020. One of the main aims of this national TB strategic plan is to implement national tuberculosis programs effectively as per the spirit of federalism. Also, this national Strategic plan will remind the government of Nepal in fulfilling its commitments made in the global and regional forums toward meeting the end TB targets. Until 2018/19 Nepal was using proxy measures to estimate the burden of TB in Nepal and as per the proxy measure the annual number of new TB infections in 2018 were estimated to be around 42,000. However, the first ever National TB prevalence survey carried out in 2018/19 found that the burden of TB in Nepal is much higher than that the programmes had previously estimated. This is the first strategic plan after the prevalence survey so this new strategic plan will guide Nepal in effective mobilization of domestic and international resources and also coordination with the key population and communities in order to meet the goals of ending TB by 2030.

The national strategic plan has a vision of TB free Nepal and goal of ending TB epidemic by 2035, eliminate TB by 2050 and reduce the catastrophic cost to zero. Nepal is very progressive in terms of developing policies and formulation of goals and targets. The past experiences shows that the progress on the achievements of target is usually low. One of the missing components as of now in the TB programs is the assessment of community rights and gender. In Nepal also the national TB programs in the past hasn't given due consideration on these dimensions. This assessment has given an opportunity for the national TB program to assess the community, rights and gender situation in the country with regards to the TB program.

2.3 Assessment Objectives:

This assessment aimed to support an improved national TB response through:

- Providing qualitative insights into the ways that gender, belonging to certain key and vulnerable populations, human rights and legal barriers impact the national TB response including related to TB prevention, diagnosis, treatment care and support guided by the seven thematic areas of the adapted right to health framework (see
- Providing information on how the TB response can improve to be more gender-sensitive, equitable, rights based and more responsive to the needs of key and vulnerable populations.
- To undertake a TB KVP prioritization.
- Assessing and making recommendations for a strengthened legal and regulatory framework for improved access to TB diagnosis, treatment and care.

2.4. Assessment Questions:

2.4.1 Gender

- What gender related barriers impact the TB response, and how do human rights issues on accessibility, availability, acceptability and quality (including re stigma, confidentiality, privacy, financial independence, decision making norms) create gender related barriers?
- How does gender identity impact on the social dynamics of TB vulnerability, care access and treatment outcomes and how does this vary across TB KVPs?
- What law, policy and program delivery, design and monitoring changes could be made to improve gender-sensitivity and participation in the TB response?

2.4.2 Key populations

- What TB KVPs need to be prioritized in Nepal?
- How does belonging to one or more of the selected key populations impact on the social dynamics of TB vulnerability, care access and treatment outcomes?
- What particular human rights related barriers manifest for TB KVPs including relating to accessibility, availability, acceptability, quality, (e.g. stigma, distance, language, economics)
- What law, policy and program design, delivery, monitoring changes could be made to improve TB response for people belonging to the selected key populations?
- How are TB survivors and TB survivor networks engaged, capacitated and supported to be active participants in the TB response?

2.4.3 Legal environment

- How does the current legal environment impact on access to TB-related healthcare, or increase vulnerability and create barriers to access TB-related healthcare?
- What rights-based laws, policies and programmatic responses – including strengthening laws, policies and regulations; reducing stigma and discrimination; privacy and confidentiality; participation; increasing access to justice; and improving law and policy enforcement – could be put in place to improve the TB response?

2.5 Assessment Methodology

Following were the methodology for completing this assignment:

- A) Desk Review of available literature: The first task under this assignment was review of the global, national and local resources regarding TB programs, strategic plans of TB and other documents related to CRG – in particular those developed by Stop TB Partnership on the TB CRG Assessment, TB CRG Action Plan and related tools and materials. Some of the sources for getting these documents were websites of Global Fund, WHO, Stop TB partnership,

National TB Centre (NTC Nepal), Save the Children Nepal and MoHP Nepal. Also, the documents from United National High-Level Meeting on TB (UNHLM) and other international conventions were reviewed.

- B) Development of the protocol and tools for the assessment: After the review of available literatures a protocol for the assessment was developed. For the protocol the international documents and the guidelines from technical partners were reviewed and tailored to the national context. The protocol and tools were shared with Global Fund, Stop TB Partnership, Save the Children, National TB Program and Trishuli Plus and finalized as per their feedback and suggestions.
- C) Primary data collection through Focus Group Discussions and Key Informant Interview: Once the protocol and tools were finalized, focus group discussions with community stakeholders, people living with TB, community champions of TB and local partners implementing TB programs were conducted in different provinces. Similarly Key Informant interview were conducted with District Public Health Officers, Focal persons of TB programs, representatives of Save the Children and NTC focal persons.
- D) Analysis of the findings and drafting the report: After analysis of the findings from literature review and FGD/KII, a preliminary draft of the report was prepared. This was shared with the concerned stakeholders and revised as per their feedback and comments.
- E) Sharing of the key findings through National Sharing workshop: Once the report was finalized, key findings were shared through a national sharing workshop. The national sharing workshop was held on Jan 12, 2022 in Hotel Ambassador, Kathmandu. (The list of attendees is in the Annex.)
- F) Develop the Community System Strengthening Action Plan for TB: A community system strengthening action plan for TB was also be developed based on the findings. This was done based on the TB CRG Action Plan development guidance from Stop TB Partnership.
- G) Finalize the report and submit to Save the Children: The final version of the report was then shared to Save the Children.

3. Literature review for CRG assessment in Nepal

3.1 Legal environment assessment for TB in Nepal

Nepal is very progressive in terms of formulation of national level policies and procedures. There are various general health and TB specific policies and procedures that have been introduced and executed in Nepal. One of the focus in this assessment will be to review all those policies with their reference and policy guidance on the control and elimination of TB as a public health problem from Nepal. In general following were the national policies reviewed as a part of legal environment assessment;

- The Constitution of Nepal 2072 (2015)
- National Health Policy Nepal 2076 (2019)
- The Public Health Service Act 2075 (2018)
- National Infectious Disease Act 2020
- Nepal health sector strategy 2015-2020
- Fifteenth five-year plan (2076/77-2080/81),
- National Strategic Plan to end TB 2021/22 to 2025/26
- Nepal Tuberculosis Management Guideline 2019
- Basic health service package 2075
- National TB Laboratory Plan 2020
- The Social Security Act 2075 (2018)
- National Health Insurance Policy 2071
- The National Guideline for TB Free Initiative in Nepal 2078

This analysis looked at the promotion and protection of human rights in law, policies and remedies, and the presence of an enabling legal environment in support of a strong national TB response.

3.2 Gender and TB in Nepal

Gender is one of the vital aspects of the TB response. It is prime factor to provide guidance to the population who is at risk of infection and disease, the method and importance of diagnosis, underlying factors that determines access to treatment and the factors that influence adherence to the treatment. The evidence suggests TB has higher prevalence among men almost by two folds than women, even in settings with high HIV prevalence. Similarly, case notification rates which is vital to case identification and treatment were higher for men, but the ratio of prevalent to notified cases of TB (an indication of how long patients take to be diagnosed), on average was 1.5 times less among men than women, suggesting that men are less likely than women to achieve a timely diagnosis¹². Despite timely diagnosis, women are reported to experience additional barriers to care access and greater stigma and psychosocial consequences of TB disease.

The National Tuberculosis Prevalence Survey Report 2020 in Nepal reported higher proportion of TB cases among men even though prevalence/notification rate was same for both genders. No further detail evidence is available in the context of Nepal with regards to TB from gender perspective that addresses the underlying causes. The key populations need special attention on subject as they often must go through range of social, economic, cultural, and other barriers such as fear of disclosure of status.

The World Health Organization's End TB Strategy has emphasized the importance of equity in access to diagnosis and treatment. Thus, it is impossible to meet the goal of ending the global tuberculosis epidemic until and unless the key populations are incorporated together and the underlying

¹² Global TB Report 2022, WHO.

perspective such as gender are studied, understood, and addressed holistically. This comprehensive study, thus for the first time in Nepal, will understand the complex forces of underlying factors related to gender that determines case notification, diagnosis, and treatment among key populations.

TB can affect anyone regardless of sex. However, the burden of TB is higher in men in comparison to women. Among the TB cases reported globally in 2021, 56.5% were adult men, 32.5% were adult women and 11% were children¹¹.

The higher share of TB cases among men is consistent with evidence from national TB prevalence surveys, which show that TB affects men more than women, and that gaps in case detection and reporting are higher among men. A randomized household prevalence survey of >260 000 individuals in Bangladesh found a male bias (male-to-female ratio, 3:1), despite equal participation of women¹³. The national TB prevalence survey of Nepal has also shown that male had significantly higher prevalence than female (male/female ratio 2.25)¹⁴. While two thirds of TB cases globally are in men, women generally face additional barriers to care, access and greater stigma and psychosocial consequences of TB disease. Women also face numerous additional challenges related to TB.

A cross-sectional institution-based study conducted between March and August 2018 in six ART sites of Nepal has shown that male PLHIVs were at greater risk of TB infection than female¹⁵. Among 28,677 TB cases reported in 2020/21 in Nepal, 38% were female and 62% were male¹⁶. Studies conducted in different settings around the globe has shown higher incidence of TB among male than female. One of the reasons for this might be the higher mobility of male than female due to socio-cultural dynamics resulting in high chance of exposure to TB bacilli. Also, the health seeking behavior is lower in female in comparison to male in Nepal¹⁷ and it might be another reason for lower diagnosis of TB among female than male. There might be various reasons for gender differences in TB case notification which include various factors from symptoms recognition to accessing health care services and obtaining correct diagnosis. Most of these factors are linked to gender and gender norms in our society which in turn influence exposure, govern behavior and create structural health system differential that impact people's health.

3.3 Prioritization of Key and vulnerable Population & Participation of TB Survivors

People living with HIV are twenty-one times more likely to develop TB than those without HIV. The combination of TB and HIV is a deadly combination. TB is still the leading cause of death among people living with HIV. As per WHO's Global TB Report (2020), out of the ten million cases of TB worldwide, an estimated 8.2 percent were co-infected with HIV. Although both TB and HIV diseases are under control in most of the developed world, they are not in the developing world. Through the course of the TB CRG Assessment, a prioritization exercise was undertaken to help further focus and developed nuanced interventions for TB KVPs.

One of the strategies of National TB strategic plan is to strengthen community involvement and ownership in TB free Nepal campaign. This can be achieved only through the strengthening of community to ensure necessary capacity and adequate resources for TB care and prevention; formulation of micro-plan; and implementation of multi-sectoral approach. However as of now we don't have much idea on how the key population perceive the national TB programs in Nepal. This assessment will help in understanding of the key populations (Prisoners, Migrants and people with diabetes) impact on the social dynamics of TB vulnerability, care access and treatment outcomes.

¹³ Gender differences in Tuberculosis: a prevalence survey done in Bangladesh, *Int J Tuberc Lung Dis*, 2004

¹⁴ National TB Prevalence Survey 2018, NTCC

¹⁵ Adhikari N, Bhattarai RB, Basnet R, Joshi LR, Tinkari BS, Thapa A, Joshi B. Prevalence and associated risk factors for tuberculosis among people living with HIV in Nepal. *PLoS One*. 2022 Jan 28;17(1):e0262720. doi: 10.1371/journal.pone.0262720. PMID: 35089953; PMCID: PMC8797228.

¹⁶ Annual Report DoHS 2077/78 (2020/21)

¹⁷ Nepal Demographic & Health Survey 2016, MoHP

Particular human rights related issues will also be explored relating to accessibility, availability, acceptability and quality of TB services, including with particular focus on stigma and discrimination, confidentiality, privacy, information, consent and legal remedies.

In addition, there was a review of the participation of TB survivors in the TB response. This included their participation in service delivery, through networks of TB survivors in advocacy, demand generations, monitoring, policy/interventions prioritization and review as well as governance.

4. FGD & KII for CRG assessment in Nepal

Nine Key informant interview and 10 Focus group discussions were conducted with total of 79 participants (Male: 33 Female: 34 and others: 12) in 3 districts (Kailali, Chitwan and Dhanusha). The field visits were conducted from 9th November to 25th November 2022. The sites for field visits were selected in coordination with Save the Children and Trishuli plus.

FGD Participants:

| Focus Group Discussion | Date & time of FGD | District | Sex disaggregation |
|-------------------------------|-------------------------------------|---------------------|---------------------------|
| FGD 1 | Nov 10, 2022 (11:00 AM to 12:30 PM) | Dhangadi, Kailali | Male: 5 Female: 1 |
| FGD 2 | Nov 10, 2022 (2:00 PM to 4:00 PM) | Godawari, Kailali | Male 2: Female: 2 |
| FGD 3 | Nov 16, 2022 (2:00 PM to 4:00 PM) | Bakhadimai, Chitwan | Male 3: Female: 5 |
| FGD 4 | Nov 17, 2022 (11:30 AM to 1:30 PM) | Bharatpur, Chitwan | Male 4: Female :4 |
| FGD 5 | Nov 17, 2022 (2:00 PM to 3:30 PM) | Bharatpur, Chitwan | Male 2: Female: 6 |
| FGD 6 | Nov 17, 2022 (4:00 PM to 5:00 PM) | Pulchowk, Chitwan | TG 1: MSM: 5 |
| FGD 7 | Nov 23, 2022 (11:00 AM to 12:30 PM) | Bateshwor, Dhanusa | Male 5: Female: 6 |
| FGD 8 | Nov 24, 2022 (10:00 AM to 11:30 AM) | Sinurjoda, Dhanusa | Male 6: Female: 4 |
| FGD 9 | Nov 24, 2022 (1:00 Pm to 2:30 PM) | Ghodgash, Dhanusa | Male 6: Female: 6 |
| FGD 10 | Nov 24, 2022 (11:00 AM to 12:30 PM) | Janakpur, Dhanusa | TG: 6 |

KII Participants:

| KII | Date | Position, Affiliation | Sex |
|------------|--------------|--|------------|
| KII 1 | Nov 11, 2022 | DOTS In-charge, Godawari Hospital | Male |
| KII 2 | Nov 11, 2022 | ART counsellor, Seti Zonal Hospital | Male |
| KII 3 | Nov 11, 2022 | DOTS service provider, Trishuli Plus, Kailali | Female |
| KII 4 | Nov 18, 2022 | ART Counselor, Bharatpur Hospital, Chitwan | Male |
| KII 5 | Nov 18, 2022 | TB District Project coordinator, Jantra, Chitwan | Male |
| KII 6 | Nov 18, 2022 | Outreach Workers, Jantra, Chitwan | Male |
| KII 7 | Nov 18, 2022 | DOTS service provider, Bharatpur Hospital | Female |
| KII 7 | Nov 23, 2022 | Project Coordinator, AHF NEPAL, Dhanusha | Male |
| KII 8 | Nov 23, 2022 | HP In-charge, Bateshwor Health Post | Male |
| KII 9 | Nov 23, 2022 | DOTS service provider, Health office, Dhanusha | Female |
| KII 10 | Dec 21, 2022 | Sr M&E Manager, NTCC, Bhaktapur | Male |
| KII 11 | Dec 23, 2022 | Team Leader, WHO | Female |
| KII 12 | Dec 25, 2022 | Program Director, Jantra, Kathmandu | Male |
| KII 13 | Dec 26, 2022 | Undersecretary, Statistics, NTCC, Kathmandu | Male |
| KII 14 | Dec 26, 2022 | NTCC Director, Kathmandu | Female |
| KII 15 | Dec 27, 2022 | Director, NATA, Kalimati | Female |

5. Findings from FGD and KII

5.1 Accessibility, availability, acceptability, and quality of TB services:

The DOTS TB treatment is available at nearest grass root health facility in Nepal. However, the mostly used diagnosis (microscopy and GeneXpert) is limited and is only available in some health facilities at ground level. TB affected individuals despite any gender identity in our assessment reported that there is no problem in accessibility and regular availability of medicine from nearest DOTS center but most faced difficulties on timely diagnosis. Apart from that, the medicines required for Isoniazid Preventive Therapy especially for PLHIV is sometimes out of stock at both national and local level. Key informants from ART center shared that there is no such issue such as shortage of medicines for DOTS treatment (both first line and second line). However, for the preventive approach of IPT, they face difficulties to arrange at times.

Majority of the patients neglect TB symptoms at the beginning and seek treatment from private pharmacies usually for a week to month. Majority of the respondents that we interacted in FGD had tendency to visit private pharmacies or medical when they have symptoms of TB and most pharmacies would refer to them for sputum test only after one or two weeks. It lengthens the duration of diagnosis and further worsens the symptoms. The report of the joint monitoring mission for TB in 2019 has also shared that more than 70% of patients with TB in Nepal first seek services from the private sector. The national TB prevalence survey 2018 has also identified that one TB patient is treated in private sector for three TB patient in NTP.

In addition, as mentioned by most of our key informants, limited functional diagnosis machine (mostly Gene Xpert) and shortage of cartridge at health facility acts as significant barrier to the timely diagnosis of infection. One of the key informants from Chitwan mentioned that the machines once are non-functional, usually takes at least 1-3 months for repairment or replacement. It prolongs the diagnosis duration on one hand, further elongates the severity among TB infected individuals, increases the probability of transmitting TB to others and increase the burden for sputum test on the lab.

“It took me almost 15 days to identify that I was infected with TB. At first, I went to private pharmacy for symptomatic treatment of prolonged cough. I was taking number of medicines, but cough persisted. I was suspected TB and finally after 2 weeks, I knew I was infected with TB”. (Male FGD participant, Chitwan)

“I had cough and fever for long time. I went to pharmacy and was taking medicines for thyroid and allergies as suggested. It took a long time to suspect that it could be TB. It was not even in my mind. So, it was already 2 months when I went for sputum test”. (Female FGD participant, Chitwan)

“I neglected symptoms of cough and cold for a long time. I tried all the home remedies and ayurvedic medicines, but it didn't make me feel well. I never suspected it could be TB and no one even told me either. It was already late, and the disease had progressed when I was finally diagnosed with TB”. (Female FGD participant, Dhanusa)

The acceptability of medicine in general is higher among females from gender perspectives. They are assured that the disease can be cured, and they need to take medicines not only for themselves but for their families too. Almost all FGD participants expressed their satisfaction with the availability of medicine and its quality, and the medicine was easily accepted by most TB patients.

“I even miss my work for days when I have to visit health centers for medicine. But I know that taking medicines can prevent transmission of infection to my children's”(Female FGD participant, Chitwan).

However, misleading information on medicines was also found among few participants such as not enough information on the use of medicine and dissatisfaction with health facilities for not having

the provision for confirmatory test to ensure complete cure of infection after DOTS treatment. Some of the beneficiaries mentioned not having enough counselling from the service providers. During the visit to the health facilities also we found that the service providers didn't provide enough counselling to the patients and due to the poor infrastructure of the service sites it was difficult to maintain confidentiality.

"I requested health workers for a confirmatory test after completing medication of my child, but they denied for test. How can I be ensured without the test that my child is healthy now" (Female FGD participant, Parents of childhood TB cases).

Recommendations:

- 1) Identify a CRG focal point at NTP, form a CRG working group at national level, conduct quarterly meetings of CRG working group and provide orientation to the NTP staffs and service providers on CRG.
- 2) Develop and integrate training curricula and materials on how to provide rights-based, gender-sensitive and people-centred services into pre- and in-service training of all health-care providers
- 3) Mobilise peer educators (TB survivors) to Support people who are receiving TB care to complete treatment
- 4) Conduct community-led supportive supervision
- 5) Use the One Impact approach to implement community led monitoring (CLM) in the monitoring of TB response and rights- based, gender-sensitive and people-centred services included patients' adherence to treatment in health-care facilities and at community level

5.2 Stigma and discrimination

The harshness of discrimination based on the TB status at individual and community level have lessened over the time, yet it exists. The participants had different experience of stigma and discrimination. There were two groups of participants: one who didn't feel any discrimination and the other groups who had harsh experiences. While one group of general participants whom we interacted during FGD shared that they didn't experience any stigma or discrimination just because they were male or female, another group of populations shared that they had/are still facing stigma and discrimination due to TB status. Self-stigma (Perceived stigma) exist among many cases. However as there has been no any stigma related study on TB we don't know the actual burden of stigma among TB cases. Globally the prevalence of perceived stigma among TB patient ranges from 21.3% to 56%.

"I don't think just being affected by TB; female face more stigma & discrimination than male. Its equal among both sexes" (Female FGD participant, Chitwan)

"My brother-in law restricted his children to come near around me for a long time when I was diagnosed TB". (Male FGD participant, Dhanusa)

"Most people here fear stigma. So, they prefer to take medicines from private clinic of India boarder so that people wouldn't know in their community that they are taking medicines." (Male FGD participant, Dhanusa)

It is no surprise that women have lower status in the Nepalese community. They still fear stigma and hesitate to disclose their status as they have responsibility of managing households, looking after children, and they think that disclosing their status might create problem for their family.

"There is already discrimination against women in far-west Nepal, disease further aggravate the situation for them." (Male FGD participant, Dhangadhi)

"I was asked to stay 10 days in a separate room, and I was not allowed to meet anyone. I was given separate utensils and people would just visit me from a distant. I couldn't even share I had TB with my friends because there is still stigma in our society." (Female FGD participant, Dhanusa)

"In our community, the discrimination still exists. When the surroundings find one has TB, then people wouldn't allow the infected to visit their homes." (Male FGD participant, Dhanusa)

While most of our key informants who were healthcare providers expressed that there is no gender biased or any type of discrimination against TB patients and they treat everyone equally. They believed that lack of gender friendly services could hardly create barrier to the program as it doesn't include interrogation of personal details related to sexual health.

"We health workers never discriminate our patients based on the disease status and there is no stigma towards TB patients from Health Providers level."(KII, DOTS Provider, Dhanusa)

"We do not discriminate any of our patients and as the infection doesn't include any information related to Sexual and reproductive health to be treated, I don't think the service has to be gender friendly." (KII, ART Counselor, Dhangadhi)

Recommendations:

- 1) Roll out the TB Stigma Assessment, using the STP TB Stigma Assessment tool–“Implementation Handbook and Data Collection Instruments”.
- 2) Conduct policy makers TB CRG dialogues to advocate for increased collaboration between TB and HIV national response using existing governing structures.
- 3) Mobilize parliamentarians, medical professional associations, TB survivors, and celebrities for stigma reduction.
- 4) Mobilize social media platforms (Use innovative approaches rather than the conventional media. Use Facebook, Twitter, Instagram, Tiktok etc)

5.3 Health related freedoms (e.g., privacy and confidentiality)

Health related freedoms include the right to health, right to control one's health and body and to be free from interference (for example, free from torture and non-consensual medical treatment and experimentation) along with proper safeguarding of patient's privacy and confidentiality. All the FGD participants across all the provinces had no issue regarding the disruption of their freedoms. They also agreed that there have been no discriminatory practices in health care settings while accessing TB services with regards to the gender. However there have been some instances reported by the patients where service providers have displayed personally inappropriate behaviors. In addition, most of the participants had no complaints regarding the maintenance of privacy and confidentiality, yet transgender's community infected with HIV and those with TB/HIV co-infection feared that their status will be disclosed if they went for TB medications. However, some of the beneficiaries mentioned not receiving enough counselling and instruction on use of medicines and management of side effects.

"I know I have TB and I must use mask and cover mouth and nose while sneezing. I also have responsibility not to spread TB to other. But sometimes the health provider behaves with me as if I am knowing spreading to other people" (Male FGD participant, Dhangadi)

"Even at times, if we forget to timely visit health center for medication, health workers call us to remind for medication." (Female FGD participant, Chitwan)

TB HIV co-infected individuals shared that they want to received TB medicines from the health facility farther away from their community because they are afraid that the community and health workers may disclose their HIV status and they may face stigma & discrimination. They also shared that although they receive ART from the ART centre for one (or sometimes two months), they have to go to the DOTS centre daily for their TB medication.

Recommendations

- 1) Organize trainings of journalists and media professionals on TB, Stigma elimination and health related Community, Rights, and Gender issues.
- 2) Organize a workshop to develop communication materials to reduce stigma of TB (translated in local and official languages) in health facilities and in the community.
- 3) Organize mass media and social media campaigns on TB, COVID-19 removing human right and gender barriers to TB services (SMS, radio, TV, social media, theatre, advertising spots etc.)
- 4) Strengthen mass awareness, both in the community and in community level, and schools, so that everyone knows about TB and how it is transmitted (which will help reduce stigma among TB patients)

5.4 Barriers among Key Vulnerable Populations

Prioritisation of KVPs

One of the key strategies identified in the national strategic planning for ending TB epidemic is the systematic screening of key and vulnerable populations of Nepal. The national strategic plan has identified following KVPs in Nepal; 1) household contacts of all index pulmonary TB cases including children 2) elderly 3) seasonal migrant workers 4) prisoners; 5) Slum dwellers 6) factory workers 7) refugees 8) PLHIVs 9) diabetics 10) children with malnutrition and ARI 11) smokers and 12) frontline health workers.

The top six prioritized key vulnerable populations through this assessment are:

Household contacts of all index pulmonary TB cases including children: Contacts of Pulmonary TB cases are one of the key vulnerable populations in Nepal. An active case finding project by BNMT in which household contacts of TB cases were screened using GeneXpert achieved 29% additionally in case notifications in the intervention districts¹⁸. Although the active case finding is currently ongoing in some districts it is not regular and need to be scaled up throughout the country. Also, during our key informant interview, health care workers mentioned some instances where the family members denied the household visit for screening of contact of index pulmonary TB cases due to the fear of stigma and discrimination from the community. The systematic screening of household contact of all index pulmonary TB cases has high potential of increasing the yield but is not implemented in systematic manner. So, household contacts of all pulmonary TB cases are identified as one of the most important KVPs.

People living with HIV: According to National Centre for AIDS & STD Control (NCASC) 30,000 people are estimated to be living with HIV in Nepal out of which 680 were new HIV infections in 2021 and the adult HIV prevalence is estimated to be 0.12%¹⁹. A cross-sectional institution-based study conducted among six ART centres in 2018 has shown 9.9% prevalence of TB among people living with HIV²⁰. In the year 2018/19 among the total registered TB cases, 69% were tested for HIV and 0.7% were found HIV positive²¹. Prevalence of TB among PLHIV is higher in Nepal and it is particularly high among male, dalit, with advanced HIV progression and with family history of TB. Targeted interventions are needed for prevention of TB among people living with HIV. Also, the

¹⁸ Gurung SC, Dixit K, Rai B, Dhital R, Paudel PR, Acharya S, Budhathoki G, Malla D, Levy JW, Lönnroth K, Ramsay A, Basnyat B, Thapa A, Mishra G, Subedi B, Shah MK, Shrestha A, Caws M. Comparative Yield of Tuberculosis during Active Case Finding Using GeneXpert or Smear Microscopy for Diagnostic Testing in Nepal: A Cross-Sectional Study. *Trop Med Infect Dis.* 2021 Apr 14;6(2):50. doi: 10.3390/tropicalmed6020050. PMID: 33919938; PMCID: PMC8167510.

¹⁹ Factsheet World AIDS Day 2022, NCASC

²⁰ Adhikari N, Bhattarai RB, Basnet R, Joshi LR, Tinkari BS, Thapa A, Joshi B. Prevalence and associated risk factors for tuberculosis among people living with HIV in Nepal. *PLoS One.* 2022 Jan 28;17(1):e0262720. doi: 10.1371/journal.pone.0262720. PMID: 35089953; PMCID: PMC8797228.

²¹ NTP Annual Report 2018/19

coordination between National TB Program and National HIV program needs to be strengthened for integrated and comprehensive HIV & TB diagnosis and management of TB-HIV co-infection. Considering the high prevalence of TB among people living with HIV and need of strengthening TB-HIV collaboration, people living with HIV are considered another priority KVPs in Nepal.

Children with malnutrition and ARI: Between Jan-Dec 2019, screening of 25,868 malnourished children, resulted in 4395 presumptive TB cases and among them 275(6.3%) were diagnosed with TB. In the same period among 29,745 children with ARI, 13,057 were presumptive TB and 689 (5.3%) were diagnosed as TB²⁰. The TB notification rate in children in Nepal has been stagnant for long. The proportion of childhood TB cases among all notified TB cases remain around 5.5%. The Joint Monitoring Mission Report of 2019 has also shared that malnutrition in children was a major health problem and there could be about 2,100 TB cases among malnourished children in Nepal. Considering the huge burden of malnutrition and acute respiratory infections in children (including pneumonia around 200,000 cases/year) children with malnutrition and ARI is another high priority KVP in Nepal.

Seasonal migrant workers: An estimated 667,417 migrants represent the ‘total absentee population’ in the country, out of which 509,228 are seasonal migrants working in India, these are considered to be at high risk of HIV and TB. Those who migrate to India mostly live in poor housing conditions, have poor access to quality health care and the cities of India where Nepalese migrate like Mumbai, Delhi, Punjab and Uttar Pradesh has high TB burden in India. So seasonal migrant workers are another high priority KVP in Nepal.

Prisoners: As of August 2021, there were 25,400 prison population in Nepal including pre-trial detainees and remand prisoners in 74 establishments/institutions across Nepal. The official capacity of prison system in Nepal is 15,466²². The occupancy based on the official capacity is 153.7%. This clearly shows that the prisons in Nepal are overcrowded. Besides this the prison rooms are not well ventilated and there are inadequate human resources along with absence of key focal persons to look after TB in prisons. There is no actual data measuring the burden of TB in prison settings in Nepal. Prison health is sadly neglected and under-addressed in Nepal just like in most parts of the world. Nepal in line with many countries does not have specific prison health policies. Periodic and timely screening, diagnosis and treatment of TB in prisons is very crucial. So, we have listed prisoners as one of the prioritized KVPs in Nepal.

People living in slums: Large number of population migrate from rural areas to urban areas in Nepal looking for better living conditions. Due to this, the proportion of urban population is increasing. In 2021, 66.7% of Nepal’s population was living in urban area in comparison to 17.07% just 10 years ago²³. According to World Bank, in 2020, 40% of urban population in Nepal live in slum areas²⁴. Slums have poor housing conditions, lack healthy living spaces, have poor sanitary conditions and lack access to basic health facilities putting slum dwellers at risk of infectious diseases including TB. Although microscopic camps are conducted sometimes in the urban slums as a part of active case finding these are not enough and regular. Considering the poor housing condition in slum that puts slum dwellers at risk of TB and lack of access the basic health services people living in slums are another KVP for TB in Nepal.

Transgenders identified their communities at numerous risks for infection and disease. Due to the discrimination and fear of social rejection they experience, they often hesitate to openly disclose their status in the society. They feel emotionally safer to leave their community and there are number of homeless transgenders living with in a poor environmental condition. Further, the community has huge number of peoples who drink alcohol and smoke cigarettes that increases risk to TB. Given the

²² World Prison Brief Data, Nepal, <https://www.prisonstudies.org/country/nepal>

²³ Preliminary Data from Census 2021, CBS

²⁴ <https://data.worldbank.org/indicator/EN.POP.SLUM.UR.ZS?locations=NP>

fact that the stigma for transgender people is deep-rooted, further getting infected with any other kind of disease worsen the situation.

"The behavior of people depends on the relationship we have with them. While near ones and close friends do not discriminate us for TB infection, others look with an eye of involvement in misdeed." (MSM FGD participant, Chitwan)

"I was severely ill due to TB infection and was admitted in Teku hospital. I had no money, and I was all alone. My parents rejected to visit me in the hospital as they were afraid, they will get infected too. I was already neglected from my family. My sister had to sell her jewelry to save my life." (Transgender FGD participant, Chitwan)

"The community perceives us as a different community and doesn't perceive us as normal human beings. In addition to the general perception, they have about us, the infection further increase hatred." (MSM FGD participant, Chitwan)

Tuberculosis is one of the opportunistic infections for People Living with HIV/AIDS. They are at high risk of getting infected with TB. Even though the discrimination against PLHIV have lessened over time, they are still stigmatized at different parts.

"Even the people from our same community shows discriminatory behavior if they find someone has TB." (TG FGD participant, PLHIV, Chitwan)

"The major issue with us is that most of us travel for a long time in festivals like dashain. While we visit places for programs, it is difficult for us to visit specific health center and intake medicine. So, this leads to negligence and discontinuation of medicine." (TG FGD participant, PLHIV, Dhanusha)

"If any of our friends is TB infected, then we do not involve them in our programs like orchestra until the person gets better due to risk of transmission." (TG FGD participant, PLHIV, Dhanusha)

The fear of disclosing status is very common among key-populations especially among PLHIV. This often prevent them from going to health Centre for DOTS treatment as they are concerned their HIV status will be disclosed.

"We must show our HIV report to health Centre if we decide to enroll for TB medication. As we don't want to disclose our status, there is problem for our community to enroll in TB medicine." (TG FGD participant, PLHIV, Dhanusha)

"Most people are not fully aware that there are two types of TB. So, whenever they hear someone has TB, they show discriminatory behavior. I think they should know that E-TB is not transmissible." (TG FGD participant, PLHIV, Dhanusha)

At present, even if the discrimination doesn't seem to exist from outside, it is still deeply rooted in the perceptions of people that their behavior shows.

"When I had TB few years ago, even though my family consoled me saying, I will be fine; their behavior such as refusing to stay nearby me or sharing towels distinctly made me feel discriminated." (Female FGD participant, PLHIV, Chitwan)

"One of my friends after getting infected with TB took DOTS from a distant health Centre as she feared discrimination." (Female FGD participant, PLHIV, Chitwan)

Recommendations:

- 1) Conduct mapping of TB related CSOs/CBO and use the results to develop a community engagement strategy including TB survivors' engagement.
- 2) Organize Know-Your Rights" and legal literacy trainings, for key and vulnerable populations.
- 3) Strengthen TB Champions interventions in hard- to-reach areas.

- 4) Recruit and train TB survivors to become Peer Counselors and involve in the implementation of Snowball Approaches for supporting TB case detection amongst hard-to-reach populations.

5.5 Gender related barriers in the TB response

A huge disparity exists in Nepalese community regarding the TB response from gender perspective. In Nepal, males are two times more infected with TB in comparison to female. However, their enrollment to treatment and adherence is comparatively low. One of the key informants from Chitwan shared that It's easier for female to enroll in treatment and mentioned that males are less likely to go for treatment. It is suggested that this is due to higher mobility among male population and their negligence that leads to low medicine compliance. Another key informant from Chitwan shared his experience where he had some alcoholic male clients who refused to enroll in TB treatment despite being diagnosed with TB. Even though enrollment and treatment compliance are better among women, they do not share their health problems until it gets worse as they are afraid of the response from family members. As mentioned by key informants of most districts, it is easy for health professionals to enroll them in treatment as women are more concerned about their families and children's health. Similarly, regarding the care from family members, male generally receives more care and attention while female must continue managing their household chores. Poor, marginalized and single women must face severe social and economic barriers to treatment as they often have responsibility of earning and taking care of children at the same time.

"In our community, if a male is infected with TB, then family members care about him and give food like egg, meat, and their nutritious food to eat. But, if a daughter in a law is infected, then, it usually takes a long time to take her to hospital until she expresses severity. While male is offered nutritious food, female on the other hand must cook herself and feed other family members." (Female FGD participant, PLHIV, Chitwan)

"I am a single woman and I have three children. My youngest daughter is one years old. I was diagnosed with TB few months ago and now that I have dual responsibility to earn every day to afford food for daily living and manage time to visit health Centre, I must often miss work once a week. Or else, my eldest son must skip his school to bring medicine for me from health center so that I can go to work." (Female FGD participant, Chitwan)

"I am a painter, and I should miss two day's work when I have to visit health center for medicine. And, for the days I miss work, I am not paid. This has reduced my income." (Male FGD participant, Chitwan)

"My older brother both was diagnosed with TB along with me almost at a same time. But my family gave more attention and care to him than me. They thought I could manage things on my own." (Female FGD participant, Dhanusa)

Recommendations:

- 1) Sensitize and engage community, religious and opinion leaders on gender and TB.
- 2) Create/ Strengthen CSO/CBO network for meaningful engagement and community-led advocacy and leadership of women in all their diversity against TB related stigma.
- 3) Engage communities and community-led organizations and TB affected people, in advocacy community-led outreach campaigns to address harmful gender norms and stereotypes and other gender and human rights-related barriers including stigma reduction and human rights literacy.
- 4) Develop and disseminate communication materials on patient rights and other human rights.

- 5) Support the inclusion of TB in national human rights commission operational guidelines and human rights observers' networks

5.6 Participation of TB survivors and KVPs

Meaningful community engagement is critical to improve the reach and sustainability of TB services and accelerate progress towards ending TB by 2030. It is essential to bring the voices of affected communities: TB survivors and Key-populations into decision making, developing policy, programmes, and activities at global, regional and country levels. Among the total number of participants, we interacted during FGDs, there were only few peoples who had previous history of participation in those activities.

"This is the first time I am participating in any discussion events. I was not aware about these kinds of activities before." (Male FGD participant, Chitwan)

"Everyone wants to be heard. If a platform of discussions is targeted to us, then maybe our problems and issues will be addressed. We are member of TB survivor group, and we help newly infected with the issues that they have." (Female FGD participant, PLHIV, Chitwan)

"I was once invited to such discussion by government health facility as my child had TB. We discussed about health status of children there." (Female FGD participant, Dhanusha)

Even though, it was the first discussion on TB that most participants were part of, they expressed their keen interest to be part of such activities in near future as it strengthens advocacy and their understanding on the subject.

"Frequent small community meetings and discussions can promote understanding of the people and can also contribute to regular medication." (TG FGD participant, Chitwan)

As per the rule of business of CCM Nepal, there is a provision of selecting one CCM member from "People living with or affected by TB". In addition to this, the CCM Nepal has one representative from "People living with or affected by HIV" and one representative from "People living with or affected by Malaria". As per the rule of business of CCM Nepal there is equal representation in CCM Nepal from the three constituencies -HIV, TB and Malaria. The CCM of Nepal is very inclusive in terms of representation from civil society. Out of total 17 members of CCM, 8 representatives are from civil society (2 from NGOs/CBOs, 3 from people living or affected by the disease and 3 from key populations). Of the remaining 9 members, 5 are from government, 2 from multilateral/bilateral, one from private sector and one from academia/research²⁵.

There are some opportunities for civil society's and communities' engagement in TB response but there are still rooms for improvement. Female Community Health Volunteers (FCHV) and Outreach Workers (OWs) are well engaged in TB service delivery. FGD participants expressed satisfaction and acknowledged the roles of FCHVs in helping people with TB. They also mentioned that FCHVs are often their first choice of contact for health issues.

Civil society activism for TB exists, but is not as strong like other programs such as HIV. The role of affected communities in service delivery monitoring has not been included or engaged in the TB response in Nepal. NGOs/CBOs have been consulted in the development of national policies and guidelines, but their engagement have not been thoroughly taken into consideration. Young people represent about half of the total population. Majority of the TB cases notified are from young age population. But young people's engagement in the TB programme is low.

Social Security for KVP

There are different measures of social security adopted by the government for the indigent population groups. The Constitution of Nepal itself ensures social security related rights for the indigent citizens

²⁵ Rule of Business, Country Coordinating Mechanism Nepal, Jan 2019

including incapacitated and helpless citizens, helpless single women, citizens with disabilities, children, citizens who cannot take care of themselves and citizens belonging to the tribes on the verge of extinction, in accordance with law. However, these social securities are general one and don't cover tuberculosis patient and KVPs specifically. The Government of Nepal has been providing monthly allowance for senior citizens and widows with conditions through annual policies and programs. However, there is no provision in the law for special social security for those infected and affected by tuberculosis or HIV. Government is providing financial support in lump sum and monthly basis for many kind of critical diseases under government budgetary program. National policy on drug-resistant tuberculosis management 2076 BS (2019 AD) has provided different types of support arrangements for patients those are involved under drug-resistant tuberculosis management. Similarly, there are some provision on social security act that provides child nutrition allowance but it has only provided social security allowance to the extremely poor/endangered and children below the age of five which should be specified by the Government of Nepal. However, due to complicated and cumbersome procedural arrangements in this system, not all the infected individuals have been able to get this support.

Recommendations:

- 1) Create, coordinate, and support a network of TB champions that includes Patient Clubs and representatives of TB key populations a National TB CSO and TB survivors Network or platform with regular meeting for meaningful engagement in TB response.
- 2) Create a linkage between communities and formal health systems in emergency settings, and support community health workers to provide rights-based and gender-responsive TB services to key and vulnerable populations.
- 3) Reinforce the capacities of the national Network of TB CBO and TB survivors to engage in governance structures and decision making.
- 4) Create a community CRG work group which can be a subgroup of the national Network of TB CBO and TB survivors with a monthly based meeting for oversight of the CRG Action plan and related issues.
- 5) Roll out training/capacity-building of TB survivors community health workers.
- 6) Develop TB survivor and TB affected community Communication materials based on TB responses and access to services.
- 7) Raise awareness on TB, human rights, and legal literacy in the communities through the TB Champions, Peer supporters, and community outreach workers.
- 8) Engage TB survivors as TB champions to demystify TB and serve as treatment counselors at the facility and community levels to improve case finding among vulnerable and hard-to-reach populations.
- 9) Review and implement advocacy communication and social mobilization (ACSM) strategy to include gender, stigma, discrimination, and human rights issues related to TB.
- 10) Conduct community-based capacity building sessions on the Community, Rights and Gender for KVP.

5.7 Administrative remedies

Most of the people still lack adequate awareness on TB. It is suggested that government has to re-focus on creating mass awareness through BCC/IEC materials and strengthen public private partnership to address huge gap in case finding. Moreover, Palika levels were suggested to be coordinated for National TB program.

"The mass awareness activities seem to be less prioritized. The loophole in public private partnership has resulted into great number of missing cases and timely diagnosis of infection. Thus, to envision a TB free society, PPM must be strengthened." (KII, ART counselor, Chitwan)

"National TB program needs to refine programs with the changing disease pattern. DOTS should be strengthened at palika level and there should be proper mechanisms to record and track patients under medications." (KII, ART counselor, Dhangadi)

It is undeniable that poor and marginalized are vulnerable to TB, and it is difficult for them to manage nutritious foods while infected thus, it has been recommended by most of our participants that the nutritional allowance would support them for speedy recovery.

"If government could provide few incentives for infected such as nutritional incentive, then poor and marginalized and the ones who do not have any source of income can consume nutritious food when they are infected." (Female FGD participant, Dhanusha)

While we have focused general populations for our interventions, key-populations mostly transgender who are one of the high-risk groups for TB has been overlooked. Their awareness level on TB is comparatively low followed by high probability of discontinuation of medicine among them due to frequent travel, thus, it needs to be seriously addressed.

"One of our key informants mentioned that "medicine compliance among transgender is a big issue as they travel frequently for their different programs." (KII, ART Counselor Chitwan)

"The major issue with us is that most of us travel for a long time in festivals like dashain. While we visit places for programs, it is difficult for us to visit specific health center and intake medicine. So, this leads to negligence and discontinuation of medicine." (TG FGD participant, PLHIV, Dhanusha)

"There are number of our friends who have left their home and are vulnerable to different health problems. We are often sensitized on HIV/AIDS and other issue, but TB is never prioritized. So, it is essential to consider us as target group." (TG FGD participant, Chitwan)

In addition to this, the most reported problem by all the Key informants were limited number of functioning diagnostic machine even at referral hospitals. The barrier at health system is one of the key barriers that needs immediate action. Nutritional or any type of financial support have been suggested to positively contribute continuation of medicine as suggested by FGD participants.

We often blame stigma and discrimination as the backlash, yet we fail to identify the policy gaps. "Health workers do not have adequate level of knowledge on sputum test at one hand, while on the other, we do not have adequate diagnostic tool and proper arrangements for MDR-TB. We have to focus on these aspects to strengthen the program." (KII, ART Counselor, Chitwan)

Frequent discussions and formation of survivor group were suggested by most participants to break the stigma and deliver their voices. They have confidence that such groups will motivate them to open about disease in the society without fear of discrimination.

"TB infected can be great source of motivation to break stigma and discrimination. They can share their story in a community to motivate people for complete medication and normalize the infection." (TG FGD participant, Dhanusha)

Regarding DOTS treatment, there were two schools of thoughts. While almost all key Informants stressed on the point that 'DOTS should actually be monitored daily', the other group of patients and survivors had a collective voice that it's not feasible to daily visit health center, thus should be adopted as per situation."

"Health facility provides medication for a week and have any no provisions to ensure if the person is taking medicine. Some people take medicines but might be even discarding medicines. So, it is essential to make people aware on tuberculosis." (Female FGD participant, PLHIV, Chitwan)

"To ensure regular intake of medicine, I think the medicines should be provided for long duration or else our community will miss medicines during their programs and travel." (TG FGD participant, Dhanusa)

"DOTS should not be taken lightly to meet TB targets. The irregular intake of medicine is one of the greatest threats to program." (KII Informant, ART Counselor, Chitwan)

Recommendations

- (1) Strengthen linkage of One Impact community-led monitoring (CLM) to legal counselling and support.
- (2) Develop a partnership with national associations of lawyers including young lawyers, women lawyers and support legal networks and related costs.
- (3) Develop Communication materials on the human right of people affected by TB.
- (4) Organize trainings of prison personal (both in prisons for women and men) on public health, access to TB services, human rights and gender related to TB and HIV/TB responses
- (5) Conduct/Update an Assessment of the legal and policy environment (LEA) for TB, TB/HIV and make recommendations.
- (6) Engagement of parliamentarians in laws and policies reforms, particularly decriminalization and in the role of protective legal framework in the TB response.
- (7) Review and integrate CRG approaches in key NTP policies and guidelines

6. Legal Review:

Tuberculosis like other infectious diseases, has also been issue of stigma and discrimination. In order to reduce stigma and discrimination associated with TB, States as well as in International organisations have made various attempts. Different efforts have been done to increase access to the treatment as well as protect the rights of individuals infected and affected with TB. In Nepal, there has been provision of free diagnosis and treatment for individuals infected with TB. Nepal has also worked a lot in the implementation of documents ratified by various international forum to increase the access to diagnosis & treatment and reduce stigma and discrimination associated with tuberculosis.

Nepal has been standing in forefront in the international forum in the prevention of tuberculosis and has been continuing this. The first-ever UN General Assembly high-level meeting on tuberculosis endorsed an ambitious and powerful political declaration.²⁶ While action plans have been formulated for elimination of TB by 2030 globally in the context of Sustainable Development Goal (SDG); Nepal has also been reviewing provisions in prevailing policies, laws, strategies for elimination of tuberculosis and in this regards to protect the human rights of infected and affected individuals.

6.1 International Instruments related to Human Rights

There are no international treaties directly related to tuberculosis, however provisions of Universal Declaration on Human Rights and other international treaties and agreements pertaining to human rights are applicable for the protection of human rights of individuals affected and infected by TB. There are many documents, which include issues related to HIV and Tuberculosis. Universal Declaration of Human Rights (UDHR) 1948, ensure that everyone has equal rights²⁷ and that everyone is entitled to all the freedoms²⁸ listed in the UDHR, “without distinction of any kind such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.” Further it also guarantees rights to personal freedom for each individual as well as right to equality before the law²⁹ and clearly states that everyone shall have equal protection of law without any discrimination³⁰. Further this declaration states that everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his/her control.³¹ Along with this, there are two covenants for the implementation of Universal Declaration. First of its, **International Covenant on Civil and Political Rights, ICCPR, 1966** ensures rights without any discrimination³². Article 6 guarantees that every human being has the inherent right to life and law shall protect that no one shall be arbitrarily deprived of his/her life³³. This covenant also includes there shall be no discrimination on the grounds of sex and Human Rights Council, during one decision, has also interpenetrate that word 'Sex' also denotes gender and hence discrimination on the ground of gender is also not allowed.³⁴ Another **International Covenant on Economic, Social and**

²⁶ The first-ever UN General Assembly high-level meeting on tuberculosis on 26 September 2018 endorsed an ambitious and powerful political declaration to accelerate progress towards End TB targets. This declaration was subsequently adopted by the General Assembly on 10 October 2018 (Resolution document A/RES/73/3).

²⁷ Universal Declaration of Human Rights (UDHR) 1948, Article 1.

²⁸ Universal Declaration of Human Rights (UDHR) 1948, Article 2.

²⁹ Universal Declaration of Human Rights (UDHR) 1948, Article 3.

³⁰ Universal Declaration of Human Rights (UDHR) 1948, Article 6 & 7.

³¹ Article 25 read as "(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

³² International Covenant on Economic, Social and Cultural Rights, 1966, Article 2.

³³ International Covenant on Economic, Social and Cultural Rights, 1966, Article 6.

³⁴ *Toonen v. Australia*, Communication No. 488/1992 31 March 1994, the Human Rights Committee.

Cultural Rights, 1966 is key for tuberculosis as well as its cover health related perspective also. Article 1 of ICESR has provided right to Self-determination to every person. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development. Article 2 guarantees there shall be no discrimination in the enjoyment of rights. Specially, provisions related to right to Health in Article 12 is important. It states that the States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and States Parties will take necessary step to achieve the full realization of this right.³⁵ During the interpretation of this Article, United Nations Committee on Economic, Social and Cultural Rights General Comment No. 14 related to Health³⁶ mentions that every state needs to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health.³⁷

Along with this, **United Nations General Assembly had appointed Special Rapporteur** to prepare detailed report on right of everyone to the enjoyment of the highest attainable standard of physical and mental health³⁸. Special Rapporteur highlighted key issues of develop monitoring and accountability mechanisms for realization of Right to Health and develop legal, judicial and administrative measures to protect from crime against it and develop education on Human Rights for Medical Practitioners along with creation of enabling environment for collective and participatory work with them.

For tuberculosis specific, various discussion have been carried out in this regard in international level but commitment has been made only recently. Specially, in absence of High-Level Political Commitment, tuberculosis is only considered as health-related issues because of which discrimination and stigma associated with it violation of human rights remains secondary. On 2014, World Health Organization adopted **Global strategy and targets for tuberculosis prevention, care and control after 2015**³⁹ which has objective to reduce tuberculosis gradually from the world. It also states that from 2015-2035, death due to tuberculosis will be reduced by 95% and infection of tuberculosis will be decreased up to 90% and has target to create condition where family need not borne financial burden due to tuberculosis. Along with this, there are also midterm target for 2020, 2025 and 2030. **Global Ministerial Conference** in Moscow in 2017⁴⁰ has issued new commitment to eliminate tuberculosis from world by 2030 AD through interrelated programs and increment of accountability. Along with this, it has also focused on new commitments from world summit in participation of head of Agencies.

United Nations had issued political commitment for fight against tuberculosis in the **High Level Meeting of General Assembly** in 2018. In this political commitment, principles by World Health Organization to End TB Strategy, Moscow Declaration to End TB and the 2030 Agenda for Sustainable Development were accepted specially to end inequality against TB. In fight against this, stress on

³⁵ Article 12 read as "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child; (b) The improvement of all aspects of environmental and industrial hygiene; (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases; (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

³⁶ Committee on Economic, Social and Cultural Rights on the right to the highest attainable standard of health (general comments) 2000 Aug 11; E/C.12/2000/4. Available at: [http://www.unhcr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En). [Ref list]

³⁷ Para 30. While the Covenant provides for progressive realization and acknowledges the constraints due to the limits of available resources, it also imposes on States parties various obligations which are of immediate effect. States parties have immediate obligations in relation to the right to health, such as the guarantee that the right will be exercised without discrimination of any kind (art. 2.2) and the obligation to take steps (art. 2.1) towards the full realization of article 12. Such steps must be deliberate, concrete and targeted towards the full realization of the right to health.

³⁸ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G10/131/18/PDF/G1013118.pdf?OpenElement>.

³⁹ Global strategy and targets for tuberculosis prevention, care and control after 2015, https://www.who.int/tb/post2015_strategy/en/#:~:text=The%20strategy%20aims%20to%20end,2020%2C%202025%2C%20and%202030.

⁴⁰ The Moscow Declaration to End TB, First WHO Global Ministerial Conference on Ending TB, November 16, 17 2017, https://www.unaids.org/en/resources/presscentre/featurestories/2017/november/20171123_end-tb#

multilateral and interagency involvement was of utmost importance for commitment to coordinate and support between programs of tuberculosis and HIV, Equality, Gender Equality, Protection and Promotion of Human Rights, Commitment to develop Health Services in the Community, commitment to strengthen public Health System which is one of the most important base for treatment of tuberculosis. Along with this, states need to build capacity of medical practitioners along with care from public and private sector and prepare base for strong partnership with community-based services.

High level Meeting for Renewed TB Response in WHO South-East Asia Region 2021AD also reaffirmed the commitment of 10 countries to end tuberculosis by 2030.⁴¹

Apart from this, *Sustainable Development Goal, SDG* that replaced Millennium Development Goal also has target to end the pandemics including tuberculosis by 2030.⁴² In order to achieve this, different targets and necessary strategy has been set. Like other countries, Nepal also need to work in legal and policy areas to achieve the target of Sustainable Development Goal and also need to make necessary legal and policy provisions to protect the rights of infected and affected. It is also easy for Nepal to implement the rights as Nepal is also party to many Human Right instruments that are helpful in achieving Sustainable Development Goals.

6.2 Declaration on the Rights of People Affected by Tuberculosis

This declaration was lunched in 2019 to protect and promote of every aspects of rights of the people affected by the tuberculosis. The declaration includes various 21 rights along with one wider definition section. This declaration guides countries to implement the commitments made at the United Nations High-Level Meeting on Tuberculosis 2018. It has included various affirmatives rights including right to life, right to dignity, right to get highest attainable physical and mental health, right to freedom for torture or other cruel, inhuman behaviors, right to confidentiality, right to information etc. The declaration codified key rights of people affected by TB that are enshrined in existing global and regional human rights laws. Aim of the declaration is to inform and empower people and communities affected by TB to be able to claim and protect their right to a life free from TB and when necessary to ensure equitable access to quality TB prevention, diagnosis and treatment, free from stigma and discrimination.⁴³

SAARC Level Commitment on Tuberculosis Control

On 1992 AD, South Asian Association for Regional Cooperation (SAARC) has established SAARC TB centre (STAC) as one of the regional cooperation organisation to work for prevention and control of TB (latter added HIV/AIDS) in the region by coordinating the efforts of the national TB programs (latter added National HIV/AIDS programs) of the SAARC member countries.⁴⁴ As per its objectives it is coordinating TB and HIV/AIDS related programs, however there are not any specific regional instruments on human rights related with TB.

Implementation of International Commitment

Nepal is accountable to various agencies for the implementation of commitment made in regard to the various agreements and documents ratified or signed by it, which includes:

⁴¹ Ministerial Statement of Commitment of High level Meeting for Renewed TB Response in WHO South-East Asia Region, Oct 26, 2021 AD,

⁴² Goal No. 3 of Sustainable Development Goal-SDG: By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases. **Indicator 3.3.1:** Number of new HIV infections per 1,000 uninfected population, by sex, age and key populations and **Indicator 3.3.2:** Tuberculosis incidence per 100,000 population. 2030 (80% reduction in incidence rate compared with the level of 2015) and 2035 (90% reduction in incidence rate).

⁴³ Text of Declaration: [Microsoft Word - FINAL Declaration on the Right of People Affected by TB 13.05.2019.docx \(stoptb.org\)](#)

⁴⁴ Source: website of SAARC Tuberculosis and HIV/AIDS Center (STAC) at <https://www.saarctb.org/saarc-tb-and-hivaids-centre>.

- a. Implementation of observations by various Human Rights Committees such as United Nations Committee for Child Rights Convention 1989, CEDAW Committee for Women Convention
- b. Observations of Universal Periodic Review of United Nations that is reviewed every 4 Years
- c. Commitments made in different international forums
- d. Decisions by International Court of Justice in the cases filed by individual or Group

Beside this, Government of Nepal also has obligation to implement decisions by International Court for the implementation of accountability under the international treaties and agreements. Considering this, the **Public Health Service Act, 2075(2018)** has formed an inter-ministerial committee named National Public Health Committee to be chaired by the Health Minister including specialist.⁴⁵ This committee is also responsible for implementation of commitments made by Nepal in international level in regard to different issues of public health and also work for coordination, collaboration and monitoring for implementing international policy, strategy and commitment in regard to public health in national interest of Nepal.⁴⁶

6.3 Domestic Laws on Tuberculosis control in Nepal

6.3.1 The Constitution of Nepal:

Constitution of Nepal has included different rights as fundamental rights and there are 17 different Act are already in place to ensure implementation of these rights by preparing separate laws.⁴⁷ Along with this, there is also provision for the protection of these laws through certain system in case of its violation. If laws do not protect these fundamental rights or if there are no laws in this regard, then constitution has provision for its protection through other special measures such as Supreme Court.

Constitution of Nepal has guaranteed many Natural and Human Rights ensured by international instruments for its citizens and other Nationals. On the other hand, it also has provision for effective compensation in case of violation or depriving one to use these rights. It has guaranteed right to live with dignity⁴⁸ as well as right to freedom of personal liberty which includes various rights related to freedom⁴⁹. This constitution also provides citizens equal before law and the equal protection of law. Further it also ensures principle of non-discrimination while application of general laws on grounds of origin, religion, race, caste, tribe, sex, physical condition, condition of health, marital status, pregnancy, economic condition, language or region, ideology or on similar other grounds. This constitution is very progressive in regards to tuberculosis or overall health issues because this includes fundamental rights of free basic health services to all citizens⁵⁰. Nepal has already enacted 17 laws for implementation of Fundamental Rights which includes Public Health Service Act 2075; Confidentiality Rights Act 2075. Article 46 of the Constitution also has right to obtain Constitutional remedies, which is known as extraordinary jurisdiction of Supreme Court. According to which, any individual or legal organization can file cases in the any courts including Supreme Court to protect and promote of fundamental rights those stated in the Constitution.⁵¹

⁴⁵ The Public Health Service Act, 2075, Section 50(1)

⁴⁶ The Public Health Service Act, 2075, Section 51 (e)

⁴⁷ Acts has been formulated and implemented for different rights under the Constitution of Nepal.

⁴⁸ Article 16 of the Constitution of Nepal,

⁴⁹ Article 17 includes a) Freedom of opinion and expression,(b) Freedom to assemble peaceably and without arms,(c) Freedom to form political parties,(d) Freedom to form unions and associations,(e) Freedom to move and reside in any part of Nepal,(f) Freedom to practice any profession, carry on any occupation, and establish and operate any industry, trade and business in any part of Nepal

⁵⁰ Article 35 provides following rights related to health: a) Every citizen shall have the right to free basic health services from the State, and no one shall be deprived of emergency health services. b) Every person shall have the right to get information about his or her medical treatment. c) Every citizen shall have equal access to health services. d) Every citizen shall have the right of access to clean drinking water and sanitation.

⁵¹ Constitution of Nepal, Article 133

6.3.2 Public Health Related Laws

Public Health Service Act enacted under the Constitution has opened avenues for the implementation of rights related to Health. Act clearly states that it shall be the duty of the concerned health worker to behave equally and respectfully towards all the service recipients and No health institution shall discriminate, or cause to be discriminated, anyone in the treatment on the basis of his or her origin, religion, race, caste, ethnicity, gender, occupation, sexual and gender identity, physical or health condition, disability, marital status, pregnancy, ideology or similar other basis as such.⁵² Country Civil Code, 2074 has also acknowledged this provision.⁵³

Though Constitution of Nepal for the first time has explicitly mentioned that there shall be No discrimination based on the health condition and has provision it under fundamental rights but some of the provisions in the prevailing laws have some provisions which can create discrimination towards tuberculosis infected persons in many instances. Act to control infectious disease has provided right to issue any directives on general public or group to control or prevent infectious disease as per the requirement.⁵⁴ Along with this, such people can be isolated in a particular place or place and also has provision to restrict the mobility or travel of such persons.⁵⁵ Prison Act has provision to keep sick prisoners or detainees separate from other detainee prisoners.⁵⁶ Along with this Hotel Management and sale and distribution of liquors (Control) Act has provision to provide hotel room to other than sick or infected.⁵⁷ Similarly, Juvenile Court can order to transfer the children to other places for certain period in recommendation of doctor if children in the Child Reform Centers suffer from chronic or strong diseases.⁵⁸

Most of these laws are unclear and not in use. For e.g. it is not clear which disease falls under infectious disease. Hence, on one hand it is not clear if tuberculosis infected people are kept separate and on the other hand, it is also not clear whether hotelier may refuse to provide hotel rooms for tuberculosis infected persons or not?

Immigration Act has provided rights to Director General of Immigration for regular, management and control of entry, arrival and departure of foreigners.⁵⁹ Under this, in case of failure to present international Health Certificate or in case of infectious disease or serious disease, director general has the right to cancel visa of foreigners.⁶⁰ On the same ground, department can also cancel the permit of the trekking route.⁶¹ In addition to this, if any Act is done against the Immigration Act or rules, then there is right to refuse to issue visa or grant permission to enter into Nepal. But under Infectious Disease Act 2020 in relation to COVID 19, not only foreigners but Nepalese National can also be stopped from

⁵² Section 12 of The Public Health Service Act, 207 (2018): To behave equally: (1) While carrying out treatment pursuant to this Act, it shall be the duty of the concerned health worker to behave equally and respectfully towards all the service recipients. (2) Notwithstanding anything contained in sub-section (1), a health institution may prioritize on the basis of the seriousness of the health of the patient while carrying out treatment. (3) No health institution shall discriminate, or cause to be discriminated, anyone in the treatment on the basis of his or her origin, religion, race, caste, ethnicity, gender, occupation, sexual and gender identity, physical or health condition, disability, marital status, pregnancy, ideology or similar other basis as such.

⁵³ Country Civil Code, 2074 Chapter 3 Section 17, 18 and 19

⁵⁴ Act to Control Infectious Disease, 2020, Section 2 (3)

⁵⁵ Act to Control Infectious Disease, 2020, Section 2 (3)

⁵⁶ Prisoners Act, 2019, Section 6(1) (e)

⁵⁷ Hotel Management and Alcohol Sale distribution Control Act, 2033, Section 5(1) (b)

⁵⁸ The Act relating to Children 2075 Section 44: To shift children suffering from chronic or serious disease to another place: (1) If any child kept in a child reform home needs continuous treatment because he or she has suffered from any chronic or serious disease or if the concerned doctor has recommended to shift any child somewhere else due to his or her physical or mental disability or his or her addiction to narcotics, the Juvenile Court may issue an order to shift such a child to another place for a certain period.(2) An institution or person who keeps the child as per the order issued pursuant to sub-section (1) shall submit a report related to the health of the child to the concerned Juvenile Court in every six months. (3) If the child is found to be healthy or free from addiction on the basis of the report referred to in sub-section (2), the Juvenile Court may issue an order to return that child to his or her previous condition.

⁵⁹ Immigration Act, 2049, Section 7

⁶⁰ Immigration rule, 051, rule 13

⁶¹ Immigration Rule, 051, Rule 37

entry into Nepal for prevention and regulation of the disease.⁶² In this way acts done for regulation and control of public health in lack of pre written laws not only can be arbitrary but there is also chance of violating or curtailing rights of individual and groups.

Major Steps taken by Government of Nepal in controlling COVID-19

Government of Nepal issued various directive and guideline to control infection of COVID 19 and related subject matters which include: Security Procedure required to follow during COVID 19 pandemic 2077 BS (2020 AD), Health protocol for isolation for COVID 19 infected individual 2077 BS (2020 AD), Health Standard for senior citizen during COVID 19 2077 BS (2020 AD), Health Sector Emergency Response Plan COVID 19 Pandemic. Here below are key issues or concerns of above-mentioned guidelines.

- Lockdown and Prohibition: Countrywide and in different part of the country
- Restriction and control in the mobility of travel through Public and Private Vehicle, Airplane and pedestrians
- Compulsory examination in areas of suspected infection through full or partial seizure
- Examination of suspected persons, treatment if infected and contact tracing of family members and others in contact with the persons
- Infected persons to be isolated in home or organizations and discharge only after one is free from infections
- Returnees from probable risk areas should be quarantined and examined
- In case of death of infected, deceased should be cremated as per the standards mentioned

While looking into the above facts, despite of the various provisions in the constitution, laws or policies; there are certain conditions in the public health or prevailing laws, which can discriminate or have different treatment towards tuberculosis infected. Hence, in order to protect infected and affected from public stigma and discrimination to prevent from curtailing rights; it is necessary to prepare and implement Infectious Acts, Regulations and Directives from Human Rights based Approach.

6.3.3 Treatment related provisions

Constitution of Nepal has guaranteed rights to Health for every Citizen.⁶³ According to this, every citizen shall have the right to free basic health services from the State, and no one shall be deprived of emergency health services. National Health Policy 2076 BS (2019 AD) has policies of carrying out effective programs for study, research, monitoring, prevention, control, alleviation and elimination of infected diseases including HIV and others and capacity building and institutional development at Federal, Province and Local Level for control, regulation, alleviation and elimination of infected diseases as per the International Health Regulation 2005.⁶⁴

Similarly, National Health Sector Program III (2015-2020) has also enshrined the Sustainable Development Goal and has included services related to HIV and AIDS as essential basic service⁶⁵ but there is no clear definition of essential Health Services and it is also not clear if it includes services related to TB. In the Annex I of this Program, under basic health services, Rapid HIV Treatment, ART from listed service centers (First line) and follow up treatment of the same and control of HIV infection

⁶² Directives and Notice issued by Government of Nepal on 2076/12/9
<https://www.moha.gov.np/public/upload/e66443e81e8cc9c4fa5c099a1fb1bb87/files:https://www.moha.gov.np/post/press-release-2035>

⁶³ Article 35 - Right relating to health: 1) Every citizen shall have the right to free basic health services from the State, and no one shall be deprived of emergency health services. 2) Every person shall have the right to get information about his or her medical treatment. 3) Every citizen shall have equal access to health services. 4) Every citizen shall have the right of access to clean drinking water and sanitation.

⁶⁴ National Health Policy 2076 Strategy 6.11

⁶⁵ National Health Sector Program III (2015 – 2020), Ministry of Health and Population

from mother to child has been mentioned in regard to HIV. ⁶⁶ Constitution of Nepal has guaranteed free basic health services from the State and no one shall be deprived of emergency health services on one hand and on the other hand, every citizen shall have the right to obtain free basic health services under the following headings, as prescribed in the Public Health Service Act are as follows⁶⁷

- (a) Vaccination service,
- (b) Motherhood, infant and pediatric health service such as integrated infant and pediatric disease management, nutrition service, pregnancy, labor and childbirth service, family planning, abortion and reproductive health,
- (c) Service relating to communicable disease,
- (d) Service relating to non-communicable disease and physical disability
- (e) Service relating to mental disease,
- (f) Service relating to elderly citizen's health,
- (g) Service of general emergency condition,
- (h) Health promotion service,
- (i) Ayurveda and other accredited alternative health service,
- (j) Other services prescribed by the Government of Nepal by a notification in the Nepal Gazette.

Along with this, there is also a provision where Province or Local Government can also add other services, as essential services as per the requirement and financial burden of such costs need to be borne by relevant Government.

National Health Policy 2076 BS (2019 AD) has policy to implement effective program for study, research, monitoring, prevention, control, alleviation and elimination of infectious diseases including HIV and Aids and Malaria.⁶⁸

National Strategic Plan to End Tuberculosis (2021/022- 2025-026) also planned its strategic intervention and action plan as per National Health Policy 2019, Fifteen National Plan and Public Health Service Act 2018.⁶⁹ Likewise Community System Strengthening Guidelines 2019 also under TB Free Guideline 2019 AD also identified that role of society to reduce stigma and discrimination to TB patient through community level. ⁷⁰ It has also an objective to reduce gender disparities, stigma, discrimination and other barrier to end Tuberculosis as well as improvement on excess to service.⁷¹

However, major problem facing by the TB control related authority is to case notification and continuation of treatment⁷². No laws or policy guidelines has provision of mandatory reporting of TB diagnosis and prevailing reporting system does not includes private health care setups like clinic or poly-clinic, pathology lab or pharmacy. TB related research also suggested that due to such gap on reporting of TB diagnosis is one of the root cause of gaps on estimation and treatment.⁷³ Therefore there should be some kind of reporting mechanism that make all kind of health care setups to report of TB diagnosis in their setups with maintaining confidentiality. Public Health Act has provision that health setup or health workers need information about infectious disease to concern agency immediately if

⁶⁶ National Health Sector Program III (2015 – 2020), Ministry of Health and Population Annex 1 Element of Basic Health Package. P 54.

⁶⁷ Section 4 of the Public Service Health Act 2075 (2018).

⁶⁸ National Health Policy 2076, Government of Nepal, Ministry of Health, Policy, 6.11.1 Page 3.

⁶⁹ National Strategic Plan to End Tuberculosis 2021/022-2025/026 AD) National Tuberculosis Control Center, P.1.

⁷⁰ Free Tuberculosis Guidelines, National Tuberculosis Center, P. 97.

⁷¹ Free Tuberculosis Guidelines, National Tuberculosis Center, P. 97.

⁷² KII with Dr. Sharad Sharma, Deputy-Director of NTB dated December 26, 2022 AD.

⁷³ KII with Dr. Bhavana Shrestha, Head of NATA, Kalimati dated December 28, 2022 AD.

any individual has been diagnosed with listed infectious disease.⁷⁴ As per the definition of the health setups, it also including non-governmental setup as well as private health setups however it does not cover pathology lab and pharmacy⁷⁵. Public Health Service Regulation 2077 BS (2020 AD) does not include any provision related to reporting of infectious diseases. Tuberculosis specific policies has few provisions for reporting of case notification. National Tuberculosis Management Guidelines 2019 has various provision to get report from national level, provincial level, district level, health worker level, DOTS center level and patient/community level.⁷⁶ This guideline make service providers responsible to report cases periodically. However, this could not make mandatory for private clinics for such reporting. Further Public Private Mix Guideline to End Tuberculosis 2019 AD (PPM Guideline) has made some effort to increase the coordination with private service providers to support in increasing case notification from private service providers. This PPM Guideline has various provisions focusing on identify the increasing rate of case notification which is one of the key barriers to get projected aim of TB free society by the national and international mandates. This PPM Guideline also detail plan to develop implementation tools to promote collaboration at national and provincial level. Further it also aims to develop appropriate method and procedure for mandatory case notification of tuberculosis under Public Health Service Act and Regulation. Due to lack of mandatory provision for reporting, there is still lapse in reporting of each and every case of TB that is diagnosed at different levels. Therefore, there should be provision in Public Health Regulation 2019 AD that describe mandatory reporting of TB diagnosis under Section 47 (4) of the Public Health Act 2018 AD.

Public Health Service Act 2075 BS (2018 AD) has provision for treatment of sick or infected. Section 9 of the Act states that if any family member, patron or any person, whose patronage has been accepted falls ill, the guardian, family member, patron and the person who has accepted patronage shall have the responsibility to take such a person to a health institution, get treated, bear treatment expenses and help and facilitate in the treatment.

6.3.4 Counseling

The Public Health Service Act has provision of taking informed consent of service recipient but health service may also be provided without informed consent of the service recipient in any of prescribed circumstances. If the service recipient is not in a condition to give consent or has not given anyone else permission or authority to give such consent, his or her wife or husband, father or mother, grandfather or grandmother, adult son or daughter, brother or sister so far as available respectively or available closest person of the service recipient who has given such consent, if the health service has been provided without consent under the prevailing law or by an order of the court, if there is a serious threat likely to occur upon public health if any person is not treated, If there is a possibility of death of the concerned patient or likely to occur irreparable damage to his or her health if it is delayed to provide health service, If the concerned person has not refused to obtain health service in an expressed or unexpressed manner or by conduct, In other cases as prescribed.⁷⁷

National Strategic Plan to End Tuberculosis 2021/022-025/026) has provision of psycho-social counselling services during treatment of tuberculosis for patient and family member if required.⁷⁸ However there should be awareness, advocacy related programs to patient and family members to make them realize the issue and inform them about access to medical treatment so that TB patient can track freely available treatment facilities.

6.3.5 Control and Prevention

National Health Policy 2019 has the provisions for the implementation of effective programs to execute including prevention, control and elimination of communication diseases, including tuberculosis. One

⁷⁴ The Public Health Service Act, 2075 (2018), Section 47 (4).

⁷⁵ Section 2 (q) define "health setups" means governmental health setups and this word also includes non-governmental or private or cooperative or non-profitable community based health setups established under prevailing law.

⁷⁶ National Tuberculosis Management Guidelines 2019, Page 5-8.

⁷⁷ The Public Health Service Act, 2075 (2018), Section 11

⁷⁸ Free Tuberculosis Guidelines 2019 AD,

of the key objectives of the National Strategic Plan to End Tuberculosis is to ensure the identification of TB, quality treatment and prevention.⁷⁹ It has various activities set for various level of government from federal to local level. National Blood Transfusion Policy issued by Ministry of Health, Government of Nepal 2071 has mandatory test including HIV, Hepatitis B before blood transfusion.⁸⁰ The Public Health Service Act also mentions while providing the service to the recipient, the institution providing blood transmission service pursuant to sub-section (1), shall only provide the blood having no infection of any kind of disease.⁸¹

6.3.6 Accessible and Affordable Medicine

Nepal has been providing tuberculosis treatment medicine free by procuring the medicines from foreign countries except few general medicines. Medicine especially for DRTB is very expensive⁸². Nepal is purchasing such medicine either through domestic resource or from support from donor agencies. However, there are some space to produce such medicine within country with affordable price. WTO Members adopted a special Ministerial Declaration at the WTO Ministerial Conference in Doha to clarify ambiguities between the need for governments to apply the principles of public health and the terms of the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). In particular, concerns had been growing that patent rules might restrict access to affordable medicines for populations in developing countries in their efforts to control diseases of public health importance, including tuberculosis, HIV and malaria. The Declaration responds to the concerns of developing countries about the obstacles they faced when seeking to implement measures to promote access to affordable medicines in the interest of public health in general, without limitation to certain diseases. While acknowledging the role of intellectual property protection "for the development of new medicines", the Declaration specifically recognizes concerns about its effects on prices.⁸³ Nepal however could not tap this opportunity for production of medicine.

There is also another fund source which can be mobilized in support of Tuberculosis related fund management. Government of Nepal is levying tax on each cigarette/tobacco that is imported or produced in Nepal and it has huge amount collected every year⁸⁴. However, it is never been given to tuberculosis sector despite being tobacco smoking as one of the leading cause of illness related to tuberculosis and smokers are one of the key vulnerable population for tuberculosis. Every year, Government of Nepal hike the tax on cigarettes, tobacco and liquors item and collect the tax.⁸⁵ This kind of tax is also used for administrative and some development work which is managed by the Inland Revenue Department. Earlier some of such tax were allocated to cancer treatment related health institutes. However, government has never allotted such fund to Tuberculosis related health program. If the government allocates certain percent of such tax heading, it will be an additional domestic resource on exiting resource pool for the management of tuberculosis.

6.3.7 Key and Vulnerable Population (KVP)

a) Women: Constitution of Nepal has same fundamental rights for men and women. Specially, under the Right to Equality, there is no discrimination between men and women. Along with that, there is also positive discrimination, which states special legal provisions can be made for women and other groups.⁸⁶ Nepal has ratified Convention on Elimination of All forms of Discrimination against Women (CEDAW), 1979 AD without any reservation and has eliminated most of the discriminatory laws

⁷⁹ National Strategic Plan to End Tuberculosis 2021/022-2025/026 AD) National Tuberculosis Control Center, P.1

⁸⁰ National Blood Transfusion Policy, 2014; objective-6, P10-11

⁸¹ The Public Health Service Act 2075 , Section 34(3)

⁸² National Strategic Plan to End Tuberculosis 2021/022-2025/026 AD) P. 18 Chapter 6.4. Financial Landscape.

⁸³ Declaration on the TRIPS Agreement and Public Health, Ministerial Conference, Fourth Session, Doha, 9- 14 November 2001, WT/MIN(01) / Dec/ W /2.

⁸⁴ Fiscal Act 2079 BS (2022 AD) Section 7 authorized to levy 30 paisa on each stick of cigarette, 60 paisa on each cigar, Rs. 60 per kg on tobacco, pan masala etc.

⁸⁵ Government's Budget Speech of FY 2079/80 BS (2022/023 AD), Schedule 2, [1595560286.pdf \(ird.gov.np\)](#).

⁸⁶ Article 18 of Constitution of Nepal

against women since last 30 years based on the provisions of temporary special measure⁸⁷ specified in the CEDAW.

Tuberculosis Specific Draft Law

A separate law also drafted to handle issues of Tuberculosis and related concerns namely "**Proposed Tuberculosis Control Bill 2073 BS (2016 AD)**". Key objectives of this Bill was to control TB, medication of TB patient and reintegrate in the social as well as prevent general public to get infected by the TB related infection and its consequence.

Proposed Bill has 4 chapters which dealt on diagnosis and prevention of TB, role and responsibility of medical doctors and TB patient for the control and preventive measures of TB infection. It also provides free diagnosis and treatment of TB including sputum. Further is also prohibits any kind of discrimination at health centers and health worker while providing service related to diagnosis, treatment and counseling. It has provision of support measures for TB patient that provides financial and material support during treatment period, special leave with or without remuneration for prescribed period. It also prohibit any institution and individual to bar any TB patient or suspected TB patient to get public facilities including enrolment at school, getting employment etc. Proposed Bill also has penal provision to those who defy legal provision which includes NRs.100/- to 1000/- fine to TB patient and NRs.1,000/- to 5,000/- fine to health workers.

Proposed bill had various round of discussion however it could not get success to enactment as Act. Public Health Service Act 2075 BS (2018 AD) has various general provision that proposed by this draft Bill, however there is not any specific provision on TB related aspect.

Constitution of Nepal has not only provided equal rights to women in property but also has provided right to lineage.⁸⁸ Country Civil Code, 2074 BS (2017 AD) also upholds the right to property by constitution and has provision which states that even married daughter is entitled to equal share of the property and property should be divided equally between other family members.⁸⁹ There shall be equal rights in property between husband and wife.⁹⁰ But if husband or wife removes or give physical or mental torture then there is provision according to which victim wife or husband can take one's property and separate from other.⁹¹ Similarly, it also has provision according to which widow can take property at any time and separate and need not return the property.⁹²

In regard to the law on identity, Constitution of Nepal has provided equal right to man and women in conferring Citizenship to their children⁹³ but in cases of children from Nepali mother married to foreign National, there is discriminatory provision.⁹⁴ This provision has been included in Citizenship Act 2063

⁸⁷ Article 2 of Convention on the Elimination of All forms of Discrimination against Women

⁸⁸ Constitution of Nepal, Article 38(1)

⁸⁹ Constitution of Nepal, Article 38(3)

⁹⁰ Country Civil Code Section 205 Consider anshiar (shareholder): For the purpose of other section of this chapter, in case of joint property, husband, wife, mother, father, daughter shall be considered shareholder and Section 206(1) each shareholder shall have equal part. (2) During the partition, if any woman is pregnant and if the child is shareholder then such child shall be considered equal shareholder and partition is made after separating equal part for the child. (3) If child born as Sub section (2) is not alive, then property separated for the child will be divided equally among other shareholders.

⁹¹ Section 213 of Country Civil Code

⁹² Section 214 of Country Civil Code: Widow can separate after taking property. (1) Whatever is written in this chapter, widow can separate any time after taking one's share of property. (2) In case of remarriage of a widow, property shall be transferred to son or daughter of ex-husband if any otherwise she herself will get it.

⁹³ Constitution of Nepal has 2 basis for conferring Citizenship. **On basis of descent** (a) a person who has obtained the citizenship of Nepal by descent prior to the commencement of this Constitution, (b) a person whose father or mother was a citizen of Nepal at his or her birth(c) Every minor who is found within Nepal and the whereabouts of whose father and mother are not known shall, until the father or the mother of the child is traced (d) A person who is born in Nepal from a woman who is a citizen of Nepal and has resided in Nepal and whose father is not traced (e) , in the case of a person born from a woman who is a citizen of Nepal and married to a foreign citizen, the person may acquire the citizenship of Nepal by descent if such person's mother and father both are citizens of Nepal at the time of acquisition of citizenship and **Naturalized Citizenship** a) a person born from a woman who is a citizen of Nepal and resides in Nepal and married to a foreign citizen b) person born from a woman who is a citizen of Nepal and married to a foreign citizen, if he or she has permanently resided in Nepal and has not acquired the citizenship of a foreign country.

⁹⁴ Article 11 and 12 of the Constitution of Nepal.

and Citizenship Regulation 2064.⁹⁵ Similarly Constitution of Nepal has established children's right to birth registration and name with identity as fundamental right according to which legal provision on birth registration has been implemented. But in many cases, members of tuberculosis or members of vulnerable group especially women have been facing administrative hurdles while making birth certificate or Citizenship or other identity documents.⁹⁶ Supreme Court has issued directive order to issue Citizenship from mother's name in those cases where all process as per the Constitution has been fulfilled⁹⁷ and to provide citizenship from mother's address in case of child of single mother.⁹⁸ There are many laws on violence against women, specially physical violence, beating, death, torture, sexual, mental violence such as accusation of witchcraft, provisions in relation to economic violence in prevailing laws i.e. Civil Code and Criminal Code. Separate laws on domestic violence⁹⁹ and Sexual Harassment in the Workplace has been formulated and implemented. Domestic Violence has not only included violence against women it has also incorporated violence against members of family and couple who are staying together as spouse or partner in live in relation.¹⁰⁰ Victim can file case in local level or National Women Commission beside Police or Court for getting Justice¹⁰¹ and it also has provisions of interim protection, medicine, compensation and locking perpetrator in their place.¹⁰²

b) Sex Worker:

There are some issues of sex worker women having tuberculosis and finding difficult to access the diagnosis and treatment services like other general populations. There are various activities being implemented under Global Fund program however this is only addressing HIV and TB co-infection. Sex workers do face different kinds of stigma and discrimination related to HIV and TB and violation of human rights which are enshrined in the Constitution of Nepal¹⁰³. Human Trafficking and Transportation (Control) Act, 2007 AD has defined act of going into prostitution as an offence of Human Trafficking¹⁰⁴ and any person who commits such offence shall be punished.¹⁰⁵ Beside this, there is also punishment for buying or selling of human or forcing someone into prostitution but there is no prohibition for individual engaged in prostitution with free will but there is prohibition on forcing someone into prostitution or work for the same in organized way and strict punishment is also imposed for the same.¹⁰⁶

c) Sexual and Gender Minorities (LGBTIQ +)

Sexual and Gender Minorities has secured their rights in the Constitution of Nepal. Nepal's constitution has provision of not discriminating citizens on grounds of sex or on similar other grounds but prevent

⁹⁵ Section 3,4 and 5 of Nepal Citizenship Act.

⁹⁶ Issues raised during discussion: Citizenship of father or his family required while making birth certificate or citizenship from mother's name, birth certificate or citizenship cannot be initiated from mother's address, discriminatory and stigmatization from father's identity.

⁹⁷ Sabina Damai vs Government of Nepal

⁹⁸ Nakkali Maharjan vs Government of Nepal

⁹⁹ Domestic Violence (Offence and Punishment) Act, 2066 (2009)

¹⁰⁰ Domestic Violence (Offence and Punishment) Act, 2066 (2009) Section 2

¹⁰¹ Domestic Violence (Offence and Punishment) Act, 2066 (2009) Section 4. Filing of complaint: (1) A person who has knowledge of an act of domestic violence has been committed, or is being committed, or likely to be committed, may lodge a written or oral complaint setting out the details thereof, with the Police Office, National Women Commission or Local body.(2) In case a complaint is received pursuant to Sub-section (1), in a written form, it shall be registered immediately and if it is received in an oral form it shall be registered upon setting out details in a written form and putting the signature of the complainant.(3) In a case the complaint is filed before the National Women Commission, necessary action shall be taken in accordance with Prevailing National Women Commission law.

¹⁰² Section .. of Domestic Violence (Offence and Punishment) Act, 2066 (2009).

¹⁰³ Constitution of Nepal Article 17 (1) section f

¹⁰⁴ Section 4 (d) of Human Trafficking and Transportation (Control) Act, 2064

¹⁰⁵ Section 15 of Human Trafficking and Transportation (Control) Act, 2064

¹⁰⁶ Section 18 of Human Trafficking and Transportation (Control) Act, 2064: Seizure of Property: (1) Any movable or immovable property acquired as a result of an offence under this Act shall be seized. (2) If it is proved that anyone uses or provides to use any house, land or vehicle for any offence under this Act, that house, land or vehicle shall be seized.

the making of special provisions by law for the protection, empowerment or development of gender and sexual minorities.¹⁰⁷ Beside this, under the Right to Social Justice, there is provisions of right to participate in the State bodies on the basis of inclusive principle for this communities.¹⁰⁸ Supreme Court of Nepal has also different judgments for the protection of rights of Gender and Sexual minorities or homosexuality.¹⁰⁹ Specially, issues raised by the Committee formed for Same Sex Marriage according to Supreme Court's Judgment has not implemented yet.¹¹⁰ However, based on Supreme Court's decision¹¹¹ there is provision of mentioning "Others" along with Male and Female in Sex section of Birth Certificate, Citizenship Certificate and Passport¹¹²

d) Drugs User:

In Nepal, there are some provisions for drug users in the laws and policies related to drugs which are linked HIV and Hepatitis treatment, however there is still need to link the drugs users to tuberculosis diagnosis and treatment services. Narcotics Drug Control National Policy 2063 BS (2007 AD) has many positive provisions for drug users. In this policy, there are provision to reduce incidence of drug abuse, increase access of drugs users to quality, reliable and affordable medical and rehabilitation services, control and reduce risk of infection of HIV, Hepatitis, Sexually Transmitted disease in the family or society by drug users and its objective is to control and reduce risk through co-ordination and collaboration with extensive promotion of participation.¹¹³ According to this policy, programs are carried out in the areas of supply control, demand reduction, drug abuse prevention, treatment and rehabilitation, risk reduction, research and development, collaboration, partnership and resource mobilization. Government of Nepal has implemented separate operational guidelines for rehabilitation centers and for oral substitution therapy on drug use.¹¹⁴ However none of these policies mention about the diagnosis and treatment of drug users with tuberculosis.

e) Migrant Population

Fifteenth five year plan has strategy to reduce risk in the public health through migration by development of Migration Health Management Information System, health check-up of immigrants before departure at destination and upon arrival and policy and institutional provisions for easy access to Health Services and usage.¹¹⁵ Nepal and India's open boarder witness migration of thousands of people every day. These migrants face various kinds of health problems including tuberculosis. Due to stigma, (more due to self-stigma), they are afraid of accessing TB diagnosis and treatment services. Also due to the lack of proper documentation and frequent migration, these people can't access the TB

¹⁰⁷ Provision of Article 18 of Part 3 of Constitution: The State shall not discriminate citizens on grounds of origin, religion, race, caste, tribe, sex, economic condition, language, region, ideology or on similar other grounds. Provided that nothing shall be deemed to prevent the making of special provisions by law for the protection, empowerment or development of the citizens including the socially or culturally backward women, Dalit, indigenous people, indigenous nationalities, Madhesi, Tharu, Muslim, oppressed class, Pichhadaclass, minorities, the marginalized, farmers, labours, youths, children, senior citizens, gender and sexual minorities, persons with disabilities, persons in pregnancy, incapacitated or helpless, backward region and indigent Khas Arya. Explanation: For the purposes of this Part and Part 4, "indigent" means a person who earns income less than that specified by the Federal law.

¹⁰⁸ Constitution of Nepal, Article 18 sub clause: (1): Right to Social Justice: Right to social justice:(1) The socially backward women, Dalit, indigenous people, indigenous nationalities, Madhesi, Tharu, minorities, persons with disabilities, marginalized communities, Muslims, backward classes, gender and sexual minorities, youths, farmers, labourers, oppressed or citizens of backward regions and indigent Khas Aryashall have the right to participate in the State bodies on the basis of inclusive principle.

¹⁰⁹ Sunil Babu Pant Vs Government of Nepal, Writ No. 7958/061, Final Decision: 2064/10/04, NKP 2065 Volume 4

¹¹⁰ Committee formed by Supreme Court of Nepal in case of Sunil Babu Pant Vs Government of Nepal has submitted the study report to Office of Prime Minister and Councils of Ministers in 2071 but there has been No implementation yet.

¹¹¹ Citizenship: NKP 2070, Vol. 8, Decision No. 9048, Supreme Court, Nepal, NKP 2074, volume 9, Decision No. 9758, Supreme Court of Nepal, Amendment in the Passport, Dilu Biduja Vs Government of Nepal, NKP 2070, Volume 8, Decision No. 9048, Supreme Court of Nepal

¹¹² Nepal Citizenship Regulation, Annex 2 related to sub rule 1 of rule 7 of Passport Regulation.

¹¹³ Drugs Control National Policy 2063, Ministry of Home Affairs 2063.

¹¹⁴ Operational guidelines for oral substitution therapy on drug use, 2070

¹¹⁵ Fifteenth Plan (2076/77-2080/81), 7.3/ Health and Nutrition, Pg. 192

diagnosis and treatment services on time.¹¹⁶ This is also hampering on Nepal government's annual and periodic, targets as well as goals including SDG.

f) Health professionals

The Public Health Service Act states that health institutions and health practitioners need to follow professional code of conduct set by related councils.¹¹⁷ However, it does not have special provisions for health professionals working in the Tuberculosis sector but general laws regarding medical practitioners include issues related to Tuberculosis. Specially, provision related to privacy in the treatment and code of conduct can be considered. Code of Conduct of Nepal Medical Practitioner also mentions that every medical practitioners needs to respect confidentiality of details of their patients.¹¹⁸ This code of conduct also mentions that health condition of patients cannot be used for any other purpose than for scientific research and purpose mentioned with adequate care and without disclosing personal details of the patients maintaining privacy.¹¹⁹ Code of Conduct of Nepal Medical Council also has provision of maintaining confidentiality and not disclosing confidentiality unless it is exception in the confidentiality law of the country.¹²⁰ Even if it is mentioned in the laws, information can be provided only after informing concerned patients formally otherwise such act shall be considered as misuse of professional conduct and there is also provision of punishment for such misconduct.¹²¹

Rules of Nepal Medical Council also has provision to keep details of patients confidential other than that needs to be mentioned as per the decision of the court.¹²² Nepal Health Practitioners Rules also mentions that information related to individual life or health of person coming for medical checkup should not be shared with others than those according to law.¹²³

Nepal Nursing Council Rules also has provision to maintain confidentiality regarding personal details and disease of persons by Nurse or ANM. According to which, it has provision according to which Nurse or ANM should not disclose any details of the patients to other than those concerned as per the law.¹²⁴ Similarly, it has also ensured right to confidentiality according to which information related to health condition of the patients can only be disclosed to authorized persons only.¹²⁵

Proposed Tuberculosis Control Bill 2073 BS (2018 AD) has provision that make medical personnel obliged not to discriminate TB patients and provide health related services without discrimination, otherwise they may face fine from NRs. 1,000/- to 5,000/-.¹²⁶

g) Prison Inmate

There are provisions of providing basic health care to the prison inmates in the prison as per Prison Regulation 2020.¹²⁷ According to this provision, prison administration needs to make arrangement of proper food for prisoners or detainees, arrangement of sports and proper management of cleaning but there is no separate laws or specific mention in the existing laws about the provision of medical supplies or treatment services related to tuberculosis for prison inmates. Infectious disease Act has provided

¹¹⁶ KII with Dr. Bhavana Shrestha, Head of NATA, Kalimati dated December 28, 2022 AD.

¹¹⁷ The Public Health Service Act, Section 13: Health Institution and Practitioners need to follow professional code of conduct set by related councils.

¹¹⁸ Nepal Medical Council, Code of Conduct and Professional Conduct, No. 4 (h), 2017, Kathmandu

¹¹⁹ Nepal Medical Council, Code of Conduct and Professional Conduct, No. 4 (f), 2017, Kathmandu

¹²⁰ Nepal Medical Council, Code of Conduct and Professional Conduct, No. 4 (h), 2017, Kathmandu

¹²¹ Nepal Medical Council, Code of Conduct and Professional Conduct, No.9, 2017, Kathmandu

¹²² Nepal Medical Council Rules, 2024, 22 (i)

¹²³ Nepal Medical Practitioner Council, 2056, Rules 13(1) (b)

¹²⁴ Nepal Nursing Council Rules, 2053, Rules 22

¹²⁵ Nepal Nursing Council Rules, 2053, Rules 22 (a)

¹²⁶ Proposed Tuberculosis Control Bill 2073 BS, Section 22 (4).

¹²⁷ Prison Regulation, 2020, Rule 38

rights to Government to issue any order that can be implemented in any area or group to prevent infection of infectious diseases.¹²⁸ Prison Management Act has provision of keeping sick prisoners or detainees separate from others as far as possible.¹²⁹ Prison Act also has provision of treatment from Government doctor in regard to physical or mental sickness.¹³⁰ According to this, in case of serious sickness, sick should be admitted to the hospital on recommendation of doctors for the treatment.¹³¹ If any detainee or prisoners need to be hospitalized because of serious disease, then period of hospital stay will be deducted from one's imprisonment period.¹³² However, there is no provision or laws or guideline that dealt with the detainee or prisoners on the basis of tuberculosis infection or other health condition.

There are no provisions on privacy of health and personal information of detainee in the Prison Act and Regulation and other bylaws related to prison. Prison Act has control over meeting and letters and has provided right to chief of prison in relation to control of other materials including letters beside the things censored by prison.¹³³ There are no laws in relation to the privacy of health condition and personal details of persons in the prison because of which their information can be disclosed.

6.3.8 Areas of Concerns

a) Social Security

The Constitution of Nepal, guarantees the right to social security¹³⁴ to the indigent citizens, incapacitated and helpless citizens, helpless single women, citizens with disabilities, children, citizens who cannot take care themselves and citizens belonging to the tribes on the verge of extinction, in accordance with law. The Social Security Act 2075 has provided provision of social security amounted to cash, allowance or support system for indigent people, people with disability, widows, single women and people/community those are economically disadvantaged and unable to care him/herself¹³⁵ and also provision to manage the budget from the government fund¹³⁶ for this. If indigent people being suffering from various diseases that s/he cannot take care of himself, in such case they need to submit Doctor's recommendation of the same.

Similarly, the Act has also provided for child nutrition allowance but it has only provided social security allowance to the extremely poor/endangered and children below the age of five which should be specified by the Government of Nepal¹³⁷. The Government of Nepal has been providing monthly Allowance for senior citizens and widows with conditions through annual policies and programs. However, there is no provision in the law for special social security for those infected and affected by HIV or tuberculosis in such programs.

National Policy on drug-resistant tuberculosis management 2076 BS (2019 AD) has provided different types of support arrangements¹³⁸ for patients who are involved under drug-resistant tuberculosis management which includes consultation, psychosocial counselling, social and financial support in monthly livelihoods and accommodation heading. Under this, there is a provision of NPR 1000/- per month for each hostel-based patient that include accommodation and food and NPR 3000/- per month for clinic-based patient to support the nutrition needs. However, due to complicated and cumbersome procedural arrangements in this system, not all the infected individuals have been able to get this

¹²⁸ Infectious Disease (Control) Act, 2020, section 2(1)

¹²⁹ Prison Management Act, 2019, 6 (1) (e)

¹³⁰ Prison Management Act, 2019, Section 11

¹³¹ Prison Management Act, 2019, Section 11

¹³² Prison Management Act, 2019, Section 11

¹³³ Prison Regulation, 2020, Rule 26

¹³⁴ Constitution of Nepal, Article 43.

¹³⁵ Social Security Act 2075 BS (2018 AD) Section 2.

¹³⁶ Social Security Act 2075 BS (2018 AD) Section 20.

¹³⁷ Social Security Act 2075 BS (2018 AD) Section 9.

¹³⁸ National Guideline on Drugs Resistant Tuberculosis Management 2076 BS (2019 AD) P 60.

support. Proposed Tuberculosis Control Bill 2073 BS (2018 AD) has provision that allow to provide financial and material support for TB patient at the time of treatment.¹³⁹

b) Employment

Generally, employees those seeking to join public services including civil service are required to submit a certificate of non-contagious disease¹⁴⁰ before being appointed. For new appointments in the Nepal Army¹⁴¹, Police Service¹⁴² and Armed Police Force¹⁴³, health check-ups are carried out inside the institution or by a designated medical board or doctor and recruit only if they are healthy. The law does not specifically require to submit health certificate for employment in the private sector. However during new appointments in the private sector, some have to undergo their own type of health examination which may sometime not allow for appointment if s/he is tuberculosis patient. There is no legal prohibition or requirement for employees working in both public and private establishments to be tested for tuberculosis for appointment, promotion, training or other facilities. However, if the physician specified by the institution recommends that s/he can perform the prescribed job ToR, s/he is given discretionary right to make the appointment¹⁴⁴.

Nepal's labor law¹⁴⁵ provides for 12 days of paid sick leave per year for private sector's workers as well as 12 days of full paid sick leave per year for government employees¹⁴⁶. The Civil Service Regulations¹⁴⁷, Nepal Health Service Regulations¹⁴⁸, Police Regulations¹⁴⁹, Army Service Regulations¹⁵⁰, Armed Police Force Regulations¹⁵¹ have made provision for one-year additional leave in case of serious illness.

Similarly, the Civil Service Act and the Nepal Health Service Act have provided provisions¹⁵² to count up to seven more years for retirement purpose if the medical board constituted by the Government of Nepal certifies that s/he is unable to work due to physical or mental illness.

Proposed Tuberculosis Control Bill 2073 BS (2018 AD) has provision that requires employers not to discriminate and protect employment of their TB infected employee¹⁵³. It further mandates such employer to allow special leave for their TB infected employee as follow¹⁵⁴:

- a) Special Sick leave with full remuneration for first two months of treatment;
- b) Special Sick leave with half remuneration for second four months of treatment;
- c) Special Sick leave without remuneration for remaining months of treatment;

¹³⁹ Proposed Tuberculosis Control Bill 2073 BS (2018 AD), Section 18.

¹⁴⁰ Civil Service Regulation 2050 BS (1993 AD) Rule 19.

¹⁴¹ Army Service Regulation, 2069 BS (2012 AD) Rule 1,10, 32.

¹⁴² Police Regulation 2071 BS (2014 AD) Rule 12, 40, Schedule 3.

¹⁴³ Armed Police Force Regulation 2060 BS (2012) Rule 8 & 9.

¹⁴⁴ Civil Service Regulation 2050 BS (1993) Schedule 3, for instance.

¹⁴⁵ Labour Act 2074 BS (2017) Section 44, Previous Law only provides 15 days half paid sick leave.

¹⁴⁶ Civil Service Regulation 2050 BS (1993 AD) Rule 58 (1) & (2), Army Service Regulation, 2069 BS (2012 AD) Rule 6, Police Regulation 2071 BS (2014 AD) Rule 55 (1) , Armed Police Force Regulation 2060 BS (2013) Rule 8.

¹⁴⁷ Civil Service Regulation 2050 BS (1993 AD) Rule 59(9).

¹⁴⁸ Nepal Health Service Regulations 2049 BS (1992 AD) Rule 50 (9).

¹⁴⁹ Police Regulation 2071 BS (2014 AD) Rule 54 (4)

¹⁵⁰ Army Service Regulation, 2069 BS (2012 AD) Rule 57, 85.

¹⁵¹ Armed Police Force Regulation 2060 BS (2013 AD) Rule 104 (7).

¹⁵² Civil Service Act 2049 BS (1992 AD) Section 34 (A), Nepal Health Service Act 2053 BS (2000 AD) Section 44 (A)

¹⁵³ Proposed Tuberculosis Control Bill 2073 BS (2018 AD), Section 19 (1).

¹⁵⁴ Proposed Tuberculosis Control Bill 2073 BS (2018 AD), Section 19 (3).

c) Health insurance

The Constitution of Nepal guarantees the right of every citizen to basic health and also ensures access to health services¹⁵⁵. The Constitution of Nepal (2015 AD)¹⁵⁶ also provided for the right to basic health and to implement this, the 15th Periodic Plan aims to reach out 60 percent of the population with equitable health insurance scheme by the end of the plan to provide quality basic health care at the local level free of cost and specialized health services¹⁵⁷. In particularly this periodic plan also aimed to implement social health insurance as a trial. As a result, the National Health Insurance Policy¹⁵⁸ has also been implemented. This policy includes the necessary preparations for social health insurance under the Social Health Security Program as well as the necessary legal provisions. The state is allocating funds through its annual budget for the implementation of this scheme¹⁵⁹. Many of tuberculosis patient also getting benefit from these facilities.

d) Possible Criminalization

The Country's Criminal Code has provision that if anyone commits any act that is likely to spread or cause any kind of infectious disease that may threat to life of others, such act shall be booked under criminal offence and shall be punished.¹⁶⁰ However no provision is clearly stated for tuberculosis and it is general one as like there is specific provision for HIV and hepatitis. Further individual shall have to abide by rule, directive or order relating to communicable diseases that is issued by the Government of Nepal, State Government or Local Level or the competent authority under law¹⁶¹ and if anyone fail to abide by such orders he/she shall be punished with up to six months or a fine up to five thousand rupees or both the sentences.

e) Access to Justice

Access to justice for tuberculosis infected and affected people is below the level of satisfaction. Especially due to the fear or influence of stigma and discrimination, these community usually stay away from contact with the law. On the other hand, although the state has been gradually increasing some special arrangements to drive them in the process of access to justice. Due to this, the situation of tuberculosis infected and affected people and access to justice has not been remarkable.

Priority on Case Hearing: Nepal's law has made provision of priority and preference to certain cases in order to facilitate and expedite the judicial process. According to this, during the hearing of the case in the court, there is a provision to give priority/preference to the case of a person above 75 years of age, old age or with physical disability. This provision has been made by the District Court¹⁶², High Court and Supreme Court as well as the Country Civil Procedure Code¹⁶³.

Free Legal Aid Service: Nepal's constitution guarantees the indigent people's right to get free legal aid in accordance with the law¹⁶⁴. The Legal Aid Act sets the standard for a person to receive free legal

¹⁵⁵ Constitution of Nepal 2015, Article 35.

¹⁵⁶ Interim Constitution of Nepal 2007 AD, Article

¹⁵⁷ Fifteenth Periodic Plan (2019/020- 2023/024), Government of Nepal, National Planning Commission, P.No. 160.

¹⁵⁸ National Health Insurance Policy 2069 BS (2012 AD).

¹⁵⁹ <http://www.mof.gov.np/uploads/document/file>. Budget speech Para 240, P.38.

¹⁶⁰ Country Criminal Code 2074 BS (2017 AD) Section 104 further provides that If committed such act intentionally or deliberately, shall be punished with imprisonment up to 10 years and fine up to NRs one hundred thousand rupees; If committed such act in recklessness, shall be punished with imprisonment up to 5 years and fine up to NRs fifty thousand rupees; If committed such act in negligence, shall be punished with imprisonment up to 3 years and fine up to NRs thirty thousand rupees.

¹⁶¹ Country Criminal Code 2074 BS (2017 AD) Section 106.

¹⁶² District Court Regulation, 2075 BS (2018 AD) Rule 31; High Court Regulation 2073 BS (2016 AD) Supreme Court Regulation 2074 BS (2017 AD) Rule 76; Country Civil Code 2074 BS (2017 AD) Rule 170.

¹⁶³ Constitution of Nepal Article 28; Right to Privacy: The privacy of any person, his or her residence, property, document, data, correspondence and matters relating to his or her reputation are inviolable.

¹⁶⁴ Constitution of Nepal, Article 20

services from the state. Accordingly, there is a provision to provide free legal aid only to those earning less than NRs 40,000 per annum¹⁶⁵. Each courts has provision of paid lawyers to provide free legal aid to indigent service seekers, if requested, in order to ensure the representation of legal practitioners in the courts.¹⁶⁶

In addition, the Nepal Bar Association operates Legal Aid Centers for indigent women and children in its majority of bar units for proper representation on issues of women and children¹⁶⁷. Although there are various arrangements for free legal aid, there is no provision for additional training on public health law as well as human rights of these communities among the legal practitioners which directly impacted on legal aid services.

Voluntary Legal Aid (Pro Bono)

Legal practitioners of Nepal have been practicing free legal aid voluntarily in their own since long ago, however law related to voluntary legal aid or Pro- Bono related laws are recently introduced. The rules of various court including Supreme Court introduced rules¹⁶⁸ that the court may make necessary arrangements to provide voluntary legal assistance (pro bono service) to the indigent, person with disability, minor, financially deprived or jail inmates. For this, the court has made an arrangement to prepare a list of legal practitioners providing voluntary legal aid and to appoint a legal practitioner if s/he accepts the request of the court to represent any party in the case.

6.4 Recommendations from legal review

From Moscow 2018, UNHLM on TB and recent WHO-SEARO countries commitment, Nepal has been repeatedly expressing its commitment in the international forum on tuberculosis as well as with HIV. We have various fundamental instruments to protect rights of TB infected and affected communities. In Nepal, there are 16 more laws enacted and implemented for the implementation of various fundamental rights. Among this, Public Health Service Act 2075 BS (2018 AD) covers various issues including stigma and discrimination, violation of rights, access to health care. However deeply rooted stigma and discrimination against TB infected and affected people can't be eliminated overnight. There is demand of legal provision to create more legal enabling environment to let community/individual get more access to justice along with survivor centric approach. Therefore, there is also demand of tuberculosis specific laws that will cover every aspect of tuberculosis and there is a proposed bill on the same which has various positive and affirmative provisions. Further there are some unclear provisions in law specifically on Country Criminal Code which may prosecute tuberculosis patient for transmission of TB by intention or recklessness or negligence. These provisions may create issues in future however deciding Court have to have proof or evidence of 'intentional transmission' or 'recklessness' or 'negligence' before passing its judgement against any suspected individual. There are various favorable and supportive legal provisions on access to justice for tuberculosis survivor in place namely confidentiality, priority in case hearing, free legal aid etc. However, there are not any cases registered and prosecuted till date. It leads that there is still prevalent stigma and discrimination related to TB and the self-stigmatization is high. There haven't been any kind of study to measure the stigma and discrimination related to TB, so we don't know the actual burden. Furthermore, tuberculosis patient are getting some sort of social security, however it is nominal and not enough. Under social security, state itself arranges provision of nutrition expenditure

¹⁶⁵ Legal Aid related Act 2054 BS (1997 AD) Section 3 (1) and Legal Aid related Regulation 2055 BS (1998 AD) Rule 6(1).

¹⁶⁶ District Court Regulation, 2075 BS (2018 AD) Rule 101; High Court Regulation 2073 BS (2016 AD) Rule 157 Supreme Court Regulation 2074 BS (2017 AD) Rule 143.

¹⁶⁷ Source Nepal Bar Association.

¹⁶⁸ District Court Regulation, 2075 BS (2018 AD) Rule 104; High Court Regulation 2073 BS (2016 AD) Rule 157 (C) Supreme Court Regulation 2074 BS (2017 AD) Rule 146.

of Rs. 3,000 / - or Rs. 1000/- and hostel for of drug resistant TB patients. However Social Security Act has failed to cover these provisions. This means above mentioned facilities are still not covered by the legislative framework. Proposed TB control Bill has tried to cover this aspect. In this scenario, here are some legal specific recommendations for the betterment of TB patient, survivor and key vulnerable populations:

- **Fulfillment of international commitments:** As a signatory, Nepal is very affirmative to adopt and abide by international declaration or commitments. Nepal has also internalized this in its constitution and other legal documents which is highly commendable. However, Nepal always lags behind to achieve such commitment or target set by international or national mechanism. Tuberculosis is not an exception to this trend. Therefore, it is recommended that Nepal should stick on such international commitments and act accordingly.
- **Realization of Fundamental as well as legal rights:** Nepal already enacted various 17 laws related to fundamental rights that are enshrined in the constitution. More specifically tuberculosis related aspects are covered by the Public Health Service Act 2075 BS (2018 AD). Further other laws are Confidentiality related Act, Legal aid related law which has supportive measures. However due to many reasons, including stigma and discrimination, patient or affected individual and communities are still not exercising rights those are enshrined by the laws. Especially self-stigmatization of TB patient needs to be addressed for self-initiation in early diagnosis and treatment of TB. Therefore, government and non-government agencies now should bring programs and strategies on how community/individual can realize such fundamental legal rights.
- **Address on need of separate/specific law or Inclusion in Public Health Service Act:** There is proposed Tuberculosis Control Bill 2073 BS (2016 AD) which tried to bring umbrella laws for TB related issues. This has various provisions including non-discrimination during treatment and at public sphere, equality, access on treatment, support mechanism and facilities, affirmative actions like financial and material supports, employment security and special sick leave for TB patient, legal action and penal provisions for law infringers. However Public Health Service Act 2075 BS (2018 AD) has also such provision for all kind of health related issues and this Act is enacted under fundamental rights. It has various provisions that proposed by the proposed TB Bill. Therefore authority must decide whether there is need to enact TB specific law or revision/incorporation of TB related issues in the Public Health Service Act can address the issues of TB patient/survivor or KAV.

As Public Health Service Act has broader aspect of rights and protection measures, therefore following issues of proposed TB Bill should be incorporated in the Public Health Service Act:-

- a) Financial and material support related provision (which is also made available under existing National Policy on drug-resistant tuberculosis management 2076 BS (2019 AD).
- b) Employment security during tuberculosis infection and treatment phase.
- c) Special sick leave for TB patient those are in treatment as well as flexible working hours.

Further Social Security Act 2075 BS (2018 AD) should be revised and incorporate above mentioned special measures to ensure rights of TB patient.

- **Awareness on complaint mechanism on Health Care Setup/health workers:** There are few issues of discriminatory behavior of medical personnel or health worker at the time of treatment and they are not aware of complaint related provision in the existing professional ethics. Therefore, TB patient/survivor or affected population should get awareness on such

provisions as well as health worker's rights to take precautionary or protective measures during treatment of patient.

- **Mandatory reporting by private health service providers:** Public Health Service Act 2075 BS (2018 AD) has provision for reporting of any kind of infectious disease and it does not have further detail provisions even in the Public Health Service Regulation 2077 BS (2020 AD) which is major setback. Therefore, this regulation should be amended and should incorporate provision of reporting or mandatory reporting of any kind of infectious disease including tuberculosis by the each and every health facility. (as Public Health Act has wider definition of Health Setups). Further for the time till Public Health Regulation is not amended, National Tuberculosis Center may include reporting related provision in the National Tuberculosis Management Guidelines 2019 and Public Private Mix Guideline to End Tuberculosis 2019 AD (PPM Guideline) in line with Public Health Act's provision, as stated above.
- **Legal Awareness/Sensitization:** TB patient/survivor or KVPs should get legal awareness regarding their rights related to access to justice, existing legal procedure for filing case/complaint before any judicial or quasi-judicial agencies. They should get informed about free legal support by legal practitioner those are made available of state or court system. Further they should get informed about court procedure in detail before making any court case.
- **Link with One Stop Crisis Management Center (OCMC):** Government of Nepal has operating One Stop Crisis Management Center in all 77 districts aiming to provide various service for survivor of violence no matter sexual and gender identity of survivor. It has provision of medical, psychosocial, legal, security, shelter, reintegration etc. service from one roof. Many of TB patient or survivor are also been victim of violence, however there is no linking program or even awareness activities for them to bring in One Stop Crisis Management Center. Therefore TB patient or survivor or KAV should be linked with this program.
- **Budgetary Allocation:** Government of Nepal is raising Health Risk Tax on tobacco, cigarette and pan masala by Fiscal Act as well as budget speech since long ago which shall be allocated in difference budgetary program. However, tuberculosis, which is also one of the consequences of above-mentioned tobacco smoking is not getting any kind of budget from this budget heading. Therefore, concerned agencies should coordinate with Inland Revenue Department who has authority of regulate and administer Health Risk Tax to allocate certain percentage of such tax revenue for tuberculosis prevention and control program.
- **Health Insurance Coverage:** Government led health insurance is now almost covered 77 districts and it has special measures for certain type of disease like HIV. HIV infected individual and their family members can get free health insurance. However, TB patient are not included for such special measures. As tuberculosis is curable disease and can be cured within period of one or two year; government should include such free health insurance scheme to tuberculosis patient and his/her family member to facilitate them to enroll and continue treatment. Tuberculosis diagnosis and treatment is provided free of cost in Nepal but Tuberculosis patient could benefit in treating other health related complications by enrolling in such scheme.

7. Community System Strengthening Action Plan for TB

Nepal is committed to an equitable, rights-based TB response to identify and overcome human rights barriers to accessing quality TB services and to find the missing people with TB. A rights based and gender sensitive TB response is not only an ethical imperative but also a pillar of public health. As guided by the Global Plan to End TB 2023-2030 - as a means of realising the commitments made, Nepal has developed a Community System Strengthening Action plan for TB based on this assessment.

Community system strengthening action plan for TB

Costed Community System Strengthening Action Plan for TB

| | List of activities | Cost considerations | Total Estimated Budget for three years (in NRs.) | Responsibility | Indicators | Link to Global Fund CRG Intervention Areas |
|---|---|---|--|----------------|--|--|
| Theme 1: Availability, accessibility, acceptability, and quality of TB services. | | | | | | |
| Objective 1: Strengthen availability, accessibility, acceptability, and quality of TB services | | | | | | |
| Activity 1.1 | Identify a CRG focal point at NTP | No cost activity | | NTP | National CRG focal person at NTC identified | Ensuring people-centered and rights-based TB services at health facilities |
| Activity 1.2 | Form a CRG working group at national level and conduct quarterly meetings | Meeting cost for quarterly meeting of CRG working group | 600,000 | NTP and CBOs | No. of meetings of CRG working group | Ensuring people-centered and rights-based TB services at health facilities |
| Activity 1.3 | Provide orientation to the NTP staffs and service providers on CRG | Expenses for orientation to the staffs and service providers | 150,000 | CBOs | No. of individuals oriented | Ensuring people-centered and rights-based TB services at health facilities |
| Activity 1.4 | Develop and integrate training curricula and materials on how to provide rights-based, gender-sensitive and people-centred services into pre- and in-service training of all health-care providers | Consultant Contract; Curriculum development Training events: Facilitators Fees; venues; training; refreshments | 3,282,000 | NTP and CBOs | No. of health care providers trained on rights-based, gender-sensitive and people-centred services | Ensuring people-centered and rights-based TB services at health facilities |
| Activity 1.5 | Mobilise peer educators (TB survivors) to support people who are receiving TB care to complete treatment | Consultant to develop training curriculum and training cost for TB survivors | 5,195,000 | NTP and CBOs | No. of individuals trained | Ensuring people-centered and rights-based TB services at health facilities |
| Activity 1.6 | Conduct community-led supportive supervision | Supportive supervision cost | 3,000,000 | CBOs | No. of supportive supervision visits | Ensuring people-centered and rights-based TB services at health facilities |
| Activity 1.7 | Conduct Mid-term review and final review on the implementation of CRG action plan | Consultancy for mid term and final review | 1,200,000 | NTP and CBOs | | Ensuring people-centered and rights-based TB services at health facilities |
| Activity 1.8 | Use the One Impact approach to implement CLM in the monitoring of TB response and rights-based, gender-sensitive and people-centred services included patients' adherence to treatment in health-care facilities and at community level | Recruit a consultant (25days) - Task team meetings(Fees, per-diems, transport, venues, refreshments) | 3,750,000 | NTP and CBOs | WHO approved diagnostics tools are available in the country | Ensuring people-centered and rights-based TB services at health facilities |
| Theme 2: Freedoms to information (privacy, confidentiality, access to information) | | | | | | |
| Objective 2: Improve freedoms to information especially for people with low literacy | | | | | | |
| Activity 2.1 | Organize trainings of journalists and media professionals on TB, Stigma reduction and health related Community, Rights, and Gender issues | National consultant (1 X 15 days); Training events: Facilitators Fees; venues; training; refreshments | 2,035,000 | NTP and CBOs | Number of media professionals trained (by type of media and by sex) | Eliminating TB-related stigma and discrimination |
| Activity 2.2 | Organize a workshop to develop communication materials to reduce stigma of TB (translated in local and | Workshop events (3 days session): 2 Facilitators Fees; venues; training; | 3,930,000 | NTP and CBOs | Communication materials are available | Eliminating TB-related stigma and discrimination |

| | List of activities | Cost considerations | Total Estimated Budget for three years (in NRs.) | Responsibility | Indicators | Link to Global Fund CRG Intervention Areas |
|---|---|---|--|----------------|---|--|
| | official languages) in health facilities and in the community | refreshments; training materials, meals; travel | | | | |
| Activity 2.3 | Organize mass media and social media campaigns on TB, removing human right and gender barriers to TB services (SMS, radio, TV, social media, theatre, advertising spots etc.) | Contract with mass media for the duration of the activity; Recruitment of 3-5 community managers: Contracts; fees. Smart phones for community managers | 28,590,000 | NTP and CBOs | No. of mass media campaigns conducted | Eliminating TB-related stigma and discrimination |
| Activity 2.4 | Strengthen mass awareness, both in the community and schools, so that everyone knows about TB and how it is transmitted (which will help reduce stigma among TB patients) | Fees for CHW, Peer educators, etc. - Transport for CHWs | 16,200,000 | NTP and CBOs | | Eliminating TB-related stigma and discrimination |
| Theme 3: Stigma and Discrimination | | | | | | |
| Objective 3: Eliminate TB-related stigma and discrimination in communities, health care settings and workplaces. | | | | | | |
| Activity 3.1 | Roll out the TB Stigma Assessment, using the STP TB Stigma Assessment tool- "Implementation Handbook and Data Collection Instruments" | Consultant (2X30 days): fees, travels, per-diems, Technical working group meetings, venues, refreshments, | 22,890,000 | NTP and CBOs | TB Stigma Index report is available | Eliminating TB-related stigma and discrimination |
| Activity 3.2 | Organize workshop to validate and share the findings of the studies with collaboration of NTP | Facilitation: fees, travels, per-diems, Technical working group meetings, venues, refreshments, | 639,000 | NTP and CBOs | TB Stigma Index report is disseminated | Eliminating TB-related stigma and discrimination |
| Activity 3.3 | Conduct policy makers TB CRG dialogues to advocate for increased collaboration between TB and HIV national response using existing governing structures | Technical working group meeting. Facilitator fees - Key stakeholder dialogue workshop (NTP, TB and HIV CSO representatives); venues, travels; refreshments, | 1,424,000 | NTP and CBOs | No. of Consultations with Policy makers | Eliminating TB-related stigma and discrimination |
| Activity 3.4 | Mobilize parliamentarians, medical professional associations, TB survivors, and celebrities for stigma reduction. | Facilitators: fees, Technical working group Meeting, venues, travel. | 360,000 | NTP and CBOs | No. of People reached | Eliminating TB-related stigma and discrimination |
| Activity 3.5 | Mobilize social media platforms | | 3,000,000 | CBOs | | Eliminating TB-related stigma and discrimination |
| Theme 4: Gender | | | | | | |
| Objective 4: Reduce TB-related human rights and gender barriers, harmful gender norms against TB Key and vulnerable populations (KVP) included women and people affected by TB in accessing TB services in communities, health care settings and workplaces. | | | | | | |
| Activity 4.1 | Sensitize and engage community, religious and opinion leaders on gender and TB | Facilitator Fees, Task team meeting: Travel,venue, refreshment | 339,000 | NTP and CBOs | No. of community meetings held | Reducing TB-related gender discrimination, harmful gender norms and violence |

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| | List of activities | Cost considerations | Total Estimated Budget for three years (in NRs.) | Responsibility | Indicators | Link to Global Fund CRG Intervention Areas |
|---|---|---|--|----------------|---|--|
| Activity 4.2 | Create/ Strengthen CSO/CBO network for meaningful engagement and community-led advocacy and leadership of women in all their diversity against TB related stigma | Consultant (1X30 days) fees, travels, per-diems, Core group meetings, venues, | 4,476,000 | NTP and CBOs | No. of CBOs working | Reducing TB-related gender discrimination, harmful gender norms and violence |
| Activity 4.3 | Engage communities and community-led organizations and TB affected people, in advocacy community-led outreach campaigns to address harmful gender norms and stereotypes and other gender and human rights-related barriers including stigma reduction and human rights literacy | Facilitator Fees; Task team meeting: Travel, venue, refreshment Advocacy material development | 2,339,000 | NTP and CBOs | Communities and community-led organization raised awareness on harmful gender norms | Reducing TB-related gender discrimination, harmful gender norms and violence |
| Activity 4.4 | Develop and disseminate communication materials on patient rights and other human rights. | Key messaging production workshop (3 X days); facilitator (transport, venues, refreshments), printer contract for communication materials, | 1,371,000 | NTP and CBOs | Number and type of communication materials on Know Your Rights and legal literacy | Legal literacy (“Know-Your Rights”) |
| Activity 4.5 | Support the inclusion of TB in national human rights commission operational guidelines and human rights observers’ networks | Task team meeting, travel, venue, refreshments), reports prints; | 2,355,000 | NTP and CBOs | National human rights commission and Human Rights bodies operational guidelines included TB | Monitoring and reforming policies, regulations and laws |
| Activity 4.6 | Develop a gender equity policy: draft, task team review, revise, finalise, print | Technical working group meeting (travel, venue, refreshments); Desktop publishing, printing, | 1,272,000 | NTP and CBOs | A gender equity policy is developed | Monitoring and reforming policies, regulations and laws |
| Theme 5: Key and Vulnerable Populations | | | | | | |
| Objective 5: Mobilize and empower Key and vulnerable populations to engage and influence the TB response | | | | | | |
| Activity 5.1 | Conduct mapping of TB related CSOs/CBO and use the results to develop a community engagement strategy including TB survivors’ engagement | Consultant (1X15 days): fees, travels, per-diems, Technical working group meetings, venues, refreshments, | 2,070,000 | NTP and CBOs | Community engagement strategy on CRG is available | Community mobilization and advocacy, including support to TB survivor-led groups |
| Activity 5.2 | Organize Know-Your Rights” and legal literacy trainings, for key and vulnerable populations | Curriculum development (1x 15 days). Training events(2days session): 2 Facilitators Fees; venues; training; refreshments; training materials, meals; travel | 1,786,500 | NTP and CBOs | Number of TB migrants trained on Know-Your Rights” and legal literacy | Monitoring and reforming policies, regulations and laws |
| Activity 5.3 | Strengthen TB Champions interventions in hard- to-reach areas | Sensitization materials (design) printingPeer educators/CHWs/TB survivors Travels incentives | 495,000 | NTP and CBOs | Number of TB champions involved in TB response | Community mobilization and advocacy, including support to TB survivor-led groups |

| | List of activities | Cost considerations | Total Estimated Budget for three years (in NRs.) | Responsibility | Indicators | Link to Global Fund CRG Intervention Areas |
|--|--|--|--|----------------|---|--|
| Activity 5.4 | Recruit and train TB survivors to become Peer Counselors and involve in the implementation of Snowball Approaches for supporting TB case detection amongst hard to reach populations | Peer educators/CHWs/TB survivors travels, incentives | 4,050,000 | NTP and CBOs | | Community mobilization and advocacy, including support to TB survivor-led groups |
| Theme 6: Participation of TB survivors and TB key and vulnerable populations in TB responses | | | | | | |
| Objective 6: Increase a greater involvement and participation of key and vulnerable populations to TB prevention, case finding, care, and treatment | | | | | | |
| Activity 6.1 | Create, coordinate, and support a network of TB champions that includes Patient Clubs and representatives of TB key populations a National TB CBO and TB survivors Network or platform with regular meeting for meaningful engagement in TB response | Core group meetings, venues, refreshments | 585,000 | NTP and CBOs | Number of CBO of TB survivors created Number of members of each TB survivors CBO | Community mobilization and advocacy, including support to TB survivor-led groups |
| Activity 6.2 | Create a linkage between communities and formal health systems in emergency settings, and support community health workers to provide rights-based and gender-responsive TB services to key and vulnerable populations | Facilitators fees, Technical working group meeting, venues, travel. | 504,000 | NTP and CBOs | Number of people reached | Community mobilization and advocacy, including support to TB survivor-led groups |
| Activity 6.3 | Reinforce the capacities of the national Network of TB CBO and TB survivors to engage in governance structures and decision making | Core group meetings, venues, refreshments, facilitator fees, communication materials | 474,000 | NTP and CBOs | Number of governance and operational document elaborated | Community mobilization and advocacy, including support to TB survivor-led groups |
| Activity 6.4 | Create a community CRG work group which can be a subgroup of the national Network of TB CBO and TB survivors with a monthly based meeting for oversight of the CRG Action plan and related issues | CHWs/peer educators transport, sensitization materials | 540,000 | NTP and CBOs | | Community mobilization and advocacy, including support to TB survivor-led groups |
| Activity 6.5 | Roll out training/capacity-building of TB survivors community health workers, | Recruitments of CHWs/peer educators transport, sensitization materials | 4,500,000 | NTP and CBOs | | Community mobilization and advocacy, including support to TB survivor-led groups |
| Activity 6.6 | Develop TB survivor and TB affected community Communication materials based on TB responses and access to services | Transport, meetings, venues, refreshments | 480,000 | NTP and CBOs | | Community mobilization and advocacy, including support to TB survivor-led groups |

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| | List of activities | Cost considerations | Total Estimated Budget for three years (in NRs.) | Responsibility | Indicators | Link to Global Fund CRG Intervention Areas |
|---|---|--|--|----------------|--|--|
| Activity 6.7 | Raise awareness on TB, human rights, and legal literacy in the communities through the TB Champions, Peer supporters, and community outreach workers. | Trainers/facilitators fees, venues, training materials, meals, participants' travel | 274,500 | NTP and CBOs | | Community mobilization and advocacy, including support to TB survivor-led groups |
| Activity 6.8 | Engage TB survivors as TB champions to demystify TB and serve as treatment counselors at the facility and community levels to improve case finding among vulnerable and hard-to-reach populations | Facilitator Fees, Task team meeting, Travel, venue, refreshment Advocacy material development | 336,000 | NTP and CBOs | | Community mobilization and advocacy, including support to TB survivor-led groups |
| Activity 6.9 | Review and implement advocacy communication and social mobilization (ACSM) strategy to include gender, stigma, discrimination, and human rights issues related to TB | Core group meetings, venues, refreshments, | 750,000 | NTP and CBOs | | Community mobilization and advocacy, including support to TB survivor-led groups |
| Activity 6.10 | Conduct community-based capacity building sessions on the Community, Rights and Gender for KVP. | Trainers/facilitators fees, venues, training materials, meals, participants' travel | 756,000 | NTP and CBOs | | Community mobilization and advocacy, including support to TB survivor-led groups |
| Theme 7: Legal remedies, laws and policies | | | | | | |
| Objective 7: Strengthening the legal remedies and policies that facilitate an enabling environment for key and vulnerable people to access TB services | | | | | | |
| Activity 7.1 | Strengthen linkage of One Impact community-led monitoring (CLM) to legal counselling and support | Representation allowances Technical working group meeting: travels, venues, refreshments. | 270,000 | NTP and CBOs | Number of actions taken by legal counselling and support in response to community reporting. | Increasing access to justice |
| Activity 7.2 | Develop a partnership with national associations of lawyers including young lawyers, women lawyers and support legal networks and related costs. | Technical working group meeting: travels, venues, refreshments. | 210,000 | NTP and CBOs | TB is integrated in the community paralegals' work | |
| Activity 7.3 | Develop Communication materials on the human rights of people affected by TB | MoU; Representation allowances - Technical working group meeting: travels, venues, refreshments. | 300,000 | NTP and CBOs | | Increasing access to justice |
| Activity 7.4 | Organize trainings of prison personal (both in prisons for women and men) on public health, access to TB services, human rights and gender related to TB and HIV/TB responses | Training events: Facilitators Fees; venues; training; refreshments | 342,000 | NTP and CBOs | Number of prison personal trained on TB CRG | Ensuring people-centered and rights-based law enforcement practices |
| Activity 7.5 | Conduct/Update an Assessment of the legal and policy environment (LEA) | Consultant contract (fees, travel, per-diems, transport) task team meetings | 1,455,000 | NTP and CBOs | | Monitoring and reforming policies, regulations and laws |

| | List of activities | Cost considerations | Total Estimated Budget for three years (in NRs.) | Responsibility | Indicators | Link to Global Fund CRG Intervention Areas |
|--------------|---|--|---|-----------------------|---|---|
| | for TB, TB/HIV and make recommendations | (travel, venues, refreshments, printings) | | | | |
| Activity 7.6 | Engagement of parliamentarians in laws and policies reforms, particularly decriminalization and in the role of protective legal framework in the TB response. | task team meetings(travel, venues, refreshments, | 240,000 | NTP and CBOs | Number of legislators met, and Number of advocacy visits conducted to legislators | Monitoring and reforming policies, regulations and laws |
| Activity 7.7 | Review and integrate CRG approaches in key NTP policies and guidelines | Consultant Cost | 600,000 | NTP | NTP policies and guidelines integrate CRG | Monitoring and reforming policies, regulations and laws |
| Activity 7.8 | Conduct final review and final dissemination on the implementation of CRG action plan | Consultant Cost and Dissemination workshop | 1,050,000 | NTP | | |
| | Total Budget (in NRS) | | 130,465,000 | | | |

Annex A: General Information Sheet Guide

We are currently working with Save the Children and Trishuli Plus and doing an assessment related to Community Rights, Gender and Key population in TB program. Through this assessment we are trying to understand why so many people who have TB do not get diagnosed or treated to cure. We are looking at the ways in which gender and the legal environment affect vulnerability to TB and access to care. We are also looking at how some key populations are particularly at risk of TB and what accessing care is like for these populations. This is to help inform better policy and health care provision.

We are including lots of different people in this assessment - from people making policy, people advocating for better treatment, to people who have been affected by TB.

We are gathering information in lots of different ways, including:

- Talking to people about their experiences of seeking, receiving, and providing care; Conducting semi-structured individual interviews.
- Conducting focus group discussions.
- Running facilitated activities.

We may ask you if you are willing to participate in this assessment. This does not mean that we think that you necessarily have TB. It just means that we think you may have a valuable opinion or expertise on the subject.

It is entirely your choice whether to participate or not, and you may choose to participate in one aspect, but not another. If you do choose to participate in any aspect, you will be asked for consent. This gives us permission to use the information you provide. You may change your mind later and stop participating even if you agreed earlier. If you choose not to participate; it won't affect you in any way.

Annex B: Information sheet for the FGD and KII Participant**Annex B.1. Focus Groups Information Sheet: TB-affected Individuals**

Focus groups are small group discussions where specific questions relating to the research are asked by the focus group leader and discussed by the groups. We are asking you to participate in a focus group discussion because I think you might know something about what makes people vulnerable to TB, and what getting treatment is like for people including accessibility, availability, acceptability, quality of services, stigma & discrimination etc

To participate in a focus group discussion, it is important that you understand the contents of the “General Information Sheet” for this assessment, as everything said there is relevant to the focus groups as well. It is also important that you know that the focus group will be held in a private space, and everyone in the group will be asked to regard everything that is said in the group as confidential. This means that what is said in the group is not discussed outside of the group and after the event. Every participant will be asked to sign a document that agrees to this. Please note, however, that while I can guarantee that I will not identify any individual personally in my own work, I cannot promise that other people will not do so. Please be aware of this.

The focus group leader will record the discussion. Care will be taken to protect these recordings and we will ensure that these remain confidential.

The discussion will take between 45 minutes to an hour and a half.

Annex B.2: Key Informant Interview Information Sheet

I am asking you to participate in a one-to-one semi-structured interview for this assessment because we are interested in your personal perspective, knowledge, and experience on what makes people vulnerable to TB infection and what it is like getting care.

To be interviewed for this assessment, it is important that you understand the contents of the attached “General Information Sheet”, as everything said there is relevant to interviews as well.

The interview is “semi-structured” because in addition to talking about the themes of the interview, we may also discuss additional related topics that arise. If you do not want to answer a particular question, you do not have to.

This interview will be conducted in a private space, and you can decide whether you are comfortable with a voice recording or would rather that the interviewer only writes interview notes. The interview is expected to take between 30 minutes to an hour and a half, and your available time will be taken into consideration.

Annex C: Consent form for participation in FGD and KII

Annex C.1: Focus Groups Consent Form: All Focus Group Participants

I agree to participate in this assessment entitled ‘Assessment of impact of gender, key population affiliation and the National legal environment on tuberculosis vulnerability, diagnosis, and treatment in Nepal’. I am familiar with the contents of the General Information Sheet, the Focus Group Information Sheet, and this Focus Group Consent Form.

I have had the opportunity to ask questions about these documents, and I understand their contents. I agree to my responses being used for research on the condition that my privacy is respected.

In addition:

- I understand that what is said in this focus group is confidential and I agree that I will maintain the privacy of other members in this group. That means that what is said in the focus group discussion is not discussed with other people later.
- I understand that I will not be in any way identifiable in the assessment
- I understand that I am not obliged to take part in this project
- I understand that I have the right to withdraw from this project at any stage
- I agree to let the focus group leader make a voice recording of the focus group discussion based on the understanding that this will be kept confidential.

Participant:

Signature: _____ Name: _____ Date: _____

Researcher:

Signature: _____ Name: _____ Date: _____

Annex C.2: KII Interviewees Consent Form: All Interviewees

I agree to participate in this assessment entitled ‘Assessment of impact of gender, key population affiliation and the National legal environment on tuberculosis vulnerability, diagnosis, and treatment in Nepal’. I am familiar with the contents of the General Information Sheet, the Interview Information Sheet, and this Interview Consent Form.

I have had the opportunity to ask questions about these documents, and I understand their contents. I agree to my interview responses being used for research on the condition that my privacy is respected.

In addition:

- I understand that I will not be in any way identifiable in the assessment
- I understand that I am not obliged to take part in this project
- I understand that I have the right to withdraw from this project at any stage
- I agree to let the interviewer take written notes/make a voice of the interview.

Participant:

Signature: _____ Name: _____ Date: _____

Researcher:

Signature: _____ Name: _____ Date: _____

Annex D: Guidelines for the FGD

General questions:

1. What is your understanding on Tuberculosis?
2. What are the social and economic barriers that you have been facing/faced as a male/female while seeking health services related to TB such diagnosis, medication, and treatment?
3. Has economic hardship (such as arranging cost to visit health facility) created any impact on your decision of service seeking or treatment?
4. What are the information barriers to access and adhere to TB diagnosis and treatment that that you have been facing/faced as a male/female?
5. What are the barriers in health facilities that you face as a male/female that prevents you from timely service seeking or delivery? (Such as lack of gender friendly health facility)
6. What are your experiences and its impact on TB care that you faced or have been facing as a male/female from family, community or health center? (Such as discriminated against, mistreated, isolated or hate)
7. Do you as a male/female fear expulsion from family/community if your TB status is known?
8. What type of support do you expect from family, community, and health system level to facilitate easy access to TB prevention and care?

Stigma and Discrimination

1. Have you ever lose friends/ not invited in social functions like marriage ceremony or any other celebration after getting diagnosed with TB? Or know someone who experienced this?
2. Have you had experienced job loss or loss of income generating activities after being diagnosed with TB?
3. Was it/ is it easy to disclose your TB status to the people in community? If yes why and if no, why not? (For e.g.: fear of gossiping, scolding, shaming and social shunning)
4. Seeking medical care until get worse (for male as sign of masculinity and the diagnosis of TB)
5. If you are working men/women, what do you do at the days when you feel pain in the body. Do you skip work or continue with the necessity to earn money?

Women's psychological, economic, and social dependency to male counterpart to initiate TB treatment:

1. For women- what was the reaction of your spouse/husband (if you are married) when he knew you had TB?
2. If female seek together with male, why? (Explore for emotional, social, and psychological dependency to male counterpart to initiate TB treatment)
3. Does the responsibility of managing household chores affect your hospital visits or treatment in any way? (For instance: struggle to manage time to visit health center)

Community Engagement

1. Have you ever got opportunity to participate in policy and program activities related to TB like (discussion meeting or program planning meeting). If yes, was it meaningful/were your voices heard?
2. Do you wish to be part of such activities in near future? If yes/No, why? (Like budget planning)

Healthcare Settings

1. Do you choose any specific time to go health Centre (so that people don't notice you are going to hospital and taking medications against TB)
2. For women- do you ever feel during treatment that service provider was/is women?

Other Information

- Problem getting married despite cured
- Desire to keep others from knowing
- Others have avoided or refused to visit
- Fear of divorce or abuse from husband if TB status is known

Annex E: Guidelines for KII

1. What is most used TB diagnostic Tool? Are we using rapid molecular tests?
2. Have there been any medicine stock outs in the last year - if so of what drugs (TPT; DS; Pediatric; DR). If yes, how for how long it was and how was it managed for patients?
3. What type of social support / counselling / nutrition/ is provided to TB survivors
4. Is there any peer support provided to the TB survivor?
5. What is the opening hours, opening times of health facilities, and time preferred by TB affected?
6. What is the language spoken by health care provider (languages of local people), and is distance to facility barrier to health service utilization in this area?
7. What are the activities/initiations from the government level to ensure privacy, confidentiality, and the step to reduce stigma and discrimination?
8. How women access services, how trans access services (do they prefer confidentiality or feel hesitation to visit health centers)
9. How frequent are the contact tracing with family?
10. What is the situation of MDR-TB (greater among male or female, if greater among one group, probable reason why greater among one group?)
11. What is the status of TB under reporting case between male and female?
12. What is the status of TB case identification s between male and female?
13. What is the status of adherence to TB treatment?

Additional questions for KII with Government/ focal person

1. Ask about drugs and diagnostics - are the best available for all e.g., rapid molecular diagnostics?
2. Financing - financing for communities and civil society as part of this.
3. Freedom from discrimination - opportunities for participation.