Ministry of Health and Family Welfare
Government of India

NATIONAL FRAMEWORK FOR A GENDER-RESPONSIVE APPROACH TO TB IN INDIA

Central TB Division
Ministry of Health and Family Welfare,
Nirman Bhawan, New Delhi - 110011
www.tbcindia.gov.in

NATIONAL FRAMEWORK FOR A GENDER-RESPONSIVE APPROACH TO TB IN INDIA

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Government of India
Department of Health and Family Welfare
Ministry of Health and Family Welfare

Date: 24.10.2019

MESSAGE

As a signatory to the 2030 Agenda for Sustainable Development, India remains committed to achieving the Sustainable Development Goals (SDG) and aligned them and mirrored in our national development agenda – ending poverty, protecting our planet and ensuring peace and prosperity for all. At the Ministry of Health and Family Welfare, our focus is on achievement of SDG 3 goals, many of them ahead of the scheduled timeline of 2030, for ensuring good health and well-being of our people. We also recognize the need for a holistic approach and inter-ministerial collaboration to achieve the SDGs, given how they are intrinsically linked to one another. Achieving gender equity and equality is also an SDG-5 goal. Gender identities influence how people access health information and services and personal and public health outcomes.

Through the Revised National TB Control Programme, we are currently implementing the National Strategic Plan (NSP - 2017-2025), geared to achieving our goal of Ending TB by 2025. The NSP envisions a TB-free India with zero deaths, zero TB disease and no poverty due to TB. Achievement of these goals will only be possible if we adopt a comprehensive approach to ending TB – including a shift towards gender-sensitive and gender-specific interventions.

This understanding is echoed in the 2018 United National General Assembly Resolution on Tuberculosis, to which India is a signatory. The resolution "recognizes the various socio-cultural barriers to tuberculosis prevention, diagnosis and treatment services, especially for those who are vulnerable or in vulnerable situations and the need to develop integrated, people-centered, community-based and gender-responsive health services based on human rights". The resolution commits us to "developing community-based health services through approaches that protect and promote equity, ethics, gender equality and human rights in addressing tuberculosis".

In this context, I am pleased to present a framework for a gender-responsive approach to TB, as outlined in this document. I congratulate the RNTCP for the development of this framework and look forward to working together with state governments and all our partners to ensure an equitable, community-led and gender-specific response to TB in India.

Together, we can end TB. TB Harega Desh Jeetega !!

(Preeti Sudan)

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Ministry of Health & Family Welfare
Nirman Bhavan, New Delhi - 110011
October 24, 2019

MESSAGE

Tuberculosis remains a major challenge in India, with an estimated 26.90 lakh new cases every year. The Indian Government is committed to Ending TB by 2025, 5 years ahead of the SDG targets, and this is reflected in the ambitious National Strategic Plan (NSP 2017 – 25). Strategies and interventions designed under the NSP adopt patient-centered approaches and synergistic public private-patient partnership models that can help us in reaching the unreached, by extending patient support systems and social protection to affected communities.

One significant step is to adopt a gender-responsive approach to TB, as explained in this framework document. Though, TB affects more men than women, but this varies across age and socioeconomic groups. Social constraints and relationships can restrict women from freely accessing care in a timely manner and as such women remain a vulnerable group.

We also know that stigma and discrimination are a reality for people affected by TB and their families. People experience stigma in different ways at their homes, workplaces, healthcare settings and in their communities. The fear of stigma may also prevent people, women and transgender in particular, from seeking care and continuing or completing treatment.

By adopting this framework, we will ensure that every individual receives care, support and treatment that takes into account their gender-specific needs and complexities. We will accelerate our stigma-reduction efforts, keeping in mind those who are disproportionately affected by stigma within their families and communities. Finally, we will continue to work to strengthen our understanding of the ways in which people of different genders are impacted by TB.

We call on all stakeholders to join us in adopting a gender-responsive approach to Ending TB in India.

TB Harega Desh Jeetega !!

(Sanjeeva Kumar)

विकास शील
संयुक्त सचिव
VIKAS SHEEL
Joint Secretary

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24/10/2019

Message

Tuberculosis remains a public health challenge in India, impacting the lives of numerous families in India every year. In order to achieve our goal of Ending TB by 2025, the Ministry has been working to accelerate implementation of the Revised National Tuberculosis Programme (RNTCP) with focus of innovative approaches at the grassroots and community level. Our community engagement strategy recognizes the need to engage and involve communities affected by TB and support TB survivors and champions in their efforts. We are also working to ensure smooth and sustained coordination among different departments and ministries to ensure convergence of efforts.

In this context, I am pleased to note that RNTCP is adopting a gender-responsive approach to TB. Adopting such an approach will help ensure equitable access to TB care and services for all sections of the population. This framework builds on the findings of the TB and Gender Assessment published last year, according to which India was one of the first countries to utilize the Communities, Rights and Gender tools.

This is in keeping with our National Strategic Plan (NSP) that recognizes women as a section of priority population due to prevailing gender discrimination. More women die of TB in India than from all the causes of maternal mortality combined. Although more men are affected by TB, women experience the disease differently. In addition, the NSP recognizes the vulnerabilities of people living with HIV, those who use tobacco, are undernourished, use alcohol or drugs – and there are gender dimensions for all of these priority groups. Overall, gender is a significant factor that influences access to services, delays in diagnosis, access to social support and treatment adherence.

This framework for a gender-responsive approach to TB recognizes these disparities and outlines steps to mitigate gender barriers at all levels. I am confident that the implementation of this framework will contribute to our overall goals of increasing case detection, improving treatment outcomes and improving the quality of care.

TB Harega Desh Jeetega !!

(Vikas Sheel)

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Dated : - 24th October 2019

Message

It is well known that TB as a disease affects men more than women – this can be seen in case detection and notification data from across the country. However, TB impacts the lives of men, women and transgender of all ages, from infancy, adolescence, through the economically productive age group to old age. In addition, TB, pregnancy and fertility are linked, and impacts women in the reproductive age group.

As with any health issue, there are several gendered dimensions that interact with age, economic and social factors, that needs to be better understood. Gender affects susceptibility to TB, its diagnosis, access to treatment, adherence to treatment, the availability of supportive care and treatment outcomes. Addressing the gender aspect has the potential to help the RNTCP to accomplish its goals of equitable and better case detection and treatment of TB in India.

This framework draws on the findings of the first ever Gender and TB Assessment in India, published last year and reiterates our commitment to adopting a gender-responsive approach. The need for gender-responsive programming cuts across the pillars of the NSP – Detect, Treat, Prevent and Build. Gender issues are critical at every step and this framework document provides guidance for programme managers and implementers to put in place appropriate steps and mechanisms to institutionalize gender-sensitivity within the RNTCP.

I am grateful to all those who have provided valuable inputs to this document in a collaborative manner. We are committed to ensuring a paradigm shift in our response to TB – to become person-centred, community-led, rights-based and gender-responsive.

Dr K S Sachdeva
DDG (TB)

ACKNOWLEDGEMENTS

In keeping with India's commitment to ending TB, the Central TB Division is currently expediting all efforts to ensure a comprehensive, multi-sectoral, person-centred approach to TB. In this context, and with the objective of understanding the interaction of TB with gender and identifying actions that would lead to gender-responsive TB care services across the RNTCP, the Central TB Division constituted a National Technical Expert Committee on TB in Women, including gender issues, in October 2018.

We thank all the members of the Expert Committee for their participation in the various meetings and their inputs towards the framework. The members of the Expert Committee include Dr Ashok Kumar - Ex. Additional DGHS, Chairperson, NCG (Chairman); Dr. Anjali Tempe from Lok Nayak Jai Prakash Hospital (Chair); Dr. R.D. Pai representing FOGSI (Co-chair); Dr. Ramila Bisht - Professor, Centre of Social Medicine & Community Health, Jawaharlal Nehru University (Co-chair); DDG (TB) - CTD, MoHFW (ex-officio); Deputy Commissioner (MH) - MoHFW (ex-officio); Dr. J H Panwal - Joint Technical Advisor, Ministry of Women & Child Division; Dr. Jana Narayan – Centre for Social Studies, Kolkata; Dr J B Sharma, Department of Obstetrics and Gynecology, All India Institute of Medical Sciences; Dr. Beena Thomas, Department of Social and Behavioural Research, National Institute of Research in Tuberculosis, Chennai; Dr. Sundari Ravindran - Former Professor, Shri Chitirai Tirunal Institute of Medical Sciences & Technology, Trivandrum, Kerala;

Dr. Jaikishan Karahyla, MM institute of Medical Sciences, Ambala, Haryana; Dr. Rama V Baru - Professor, Centre of Social Medicine & Community Health, Jawaharlal Nehru University; Dr. Poonam Shivkumar – Mahatma Gandhi Institute of Medical Sciences, Wardha; Dr. Suman Vishwakarma - Deputy CS (TB) Bhiwani, Haryana; Dr. Lakshmi Murali – District TB Officer, Tiruvallur, Tamil Nadu; Dr. Upasna Aggarwal – National Institute of TB and Respiratory Diseases, New Delhi; Dr. Amita Pitre - Gender Consultant, REACH and currently Lead Specialist, Gender Justice, Oxfam India; Dr. Nalini Krishnan - Director, REACH and Dr Santosh Giri – Kolkata Rishta. We thank and acknowledge the valuable inputs of all others who contributed towards the document including Ms. Nandita Venkatesan, Ms. Rhea Lobo and Ms. Amrita Limbu from Bolo Didi; Mr. Sudeshwar Singh from TB Mukt Vahini; Ms. Gopa Kumar from Touched by TB; representatives from The Union, WHO, USAID, JEET, JHPIEGO, World Bank, National Tuberculosis Institute, Bengaluru and State TB Officers of Rajasthan and Mizoram.

The first meeting of the Committee was held on 28th January 2019 in New Delhi under the chairmanship of Dr. Anjali Tempe and it was decided to form a writing group that would be responsible for the development of the framework. The members of the writing group are Dr. Rama V Baru, Professor, Centre of Social Medicine and Community Health, JNU; Dr. Ramila Bisht - Professor, Centre of Social Medicine and Community Health, JNU; Dr. Beena Thomas, Department of Social and Behavioural Research, National Institute of Research in Tuberculosis, Chennai; Dr. Sundari Ravindran - Former Professor, Shri Chitirai Tirunal Institute of Medical Sciences & Technology, Trivandrum; Ms Anupama Srinivasan, Deputy Project Director, REACH; Dr. Amrita Pitre, Gender Consultant, REACH and currently Lead Specialist, Gender Justice, Oxfam India; Dr. Sanjay Kumar Mattoo Joint Director, Central TB Division and Dr. Deepak Balasubramanian, Consultant, Central TB Division. Dr. Amita Pitre, Ms. Anupama Srinivasan, Dr Raghini Ranganathan of REACH and Dr. Deepak Balasubramanian drafted, structured and revised the various sections to incorporate feedback from the group. The writing group met thrice to build on inputs and to finalise the framework under the chairmanship of Dr. Rama Baru, Dr. Ramila Bisht, Dr. K.S. Sachdeva and Dr. Sundari Ravindran

We thank the REACH team for facilitating and supporting the development of this framework. Our sincere gratitude to the United States Agency for International Development (USAID) for supporting the development of this document through their partner REACH. We hope the framework will help take us closer to the provision of gender-responsive TB care services in the Public and Private sectors.

EXECUTIVE SUMMARY

Tuberculosis (TB) affects an estimated 10 million people globally every year, of which around 3.2 million are women. India has the world's highest annual incidence of TB as well as the highest TB-related mortality. Although more men are affected by TB, women and transgender persons experience the disease differently. Gender differences and inequalities play a significant role in how people of all genders access and receive healthcare in the public and private sectors. There is adequate evidence to indicate that gender is a significant influencer of the epidemiology, risk factors, probability of diagnosis, access to healthcare, treatment adherence and overall impact of TB on communities. A gendered approach to TB care and prevention is a felt need in the Revised National Tuberculosis Control Programme (RNTCP) and this framework is a first step in that direction.

This framework reflects the interactions between TB and gender at various levels, and outlines the influences and impact of gender on the TB burden and response; defines actions which would help move towards a gender-responsive approach; and provides guidance to implement these actions. The framework is in keeping with the National Strategic Plan for TB for 2017-2025 and is intended to spark dialogue at all levels within the TB programme and among key stakeholders, thereby strengthening the collective understanding of TB and gender.

GENDER AS A DETERMINANT FOR TB

Gender differences in incidence of TB: A higher proportion of the 27.4 lakh diagnosed with TB in India are men and the ratio is approximately 2:1 (Global TB Report 2018) between men and women. Multiple studies on the incidence of TB across the country indicate that more men report microbiologically confirmed pulmonary TB and women are more likely to have clinically diagnosed pulmonary TB and extra-pulmonary forms of TB. Research shows that the prevalence of HIV-TB co-infection is higher among women and among transgender persons who live in overcrowded houses and consume alcohol. Pregnant women and women in the post-partum period face a higher risk of TB and TB is one of the leading non-obstetric causes of maternal mortality in low-income countries like India.

Gender differences in exposure, risks and vulnerability: Women are especially constrained by social norms which prevent prioritising of their nutrition, health and well-being. Undernutrition, their role as caretakers and the use of solid fuel for cooking puts women at risk for TB. While alcoholism and smoking among women is poorly accepted, these behaviours may be condoned or even encouraged as a result of the prevailing gender norms for men. Smoking and alcohol consumption are therefore specific gender-linked barriers to TB diagnosis and treatment for men. Men are at greater risk of developing TB due to their employment in mining, quarrying, metals and construction industries. Transgender persons often have low literacy, low education levels and are poor. A high proportion of transgender persons are known to smoke, consume alcohol and use drugs. All these factors make them vulnerable to TB.

Gender differences in health seeking and health system factors: While the fear of loss of income and the consequences of absence from work hinder care-seeking in women, men face difficulties due to perceived stigma, prioritisation of household chores, lack of money or financial dependence. Poor health literacy and fear of criminalisation hinders transgender persons from seeking care.

Besides gender differences influencing care-seeking, health system factors such as limited access, lower index of suspicion of TB for women and provision of inadequate information to care-seekers also significantly affect the access to services across all genders.

Gender differences in treatment outcomes: Traditionally, women tend to have better adherence and treatment outcomes as compared to men. The pressure to get back to work and lifestyle habits such as smoking or consumption of alcohol influence discontinuation of treatment in men. Migrant workers, mostly men, often face difficulties in adherence to treatment in

the face of extreme poverty and issues of daily survival. Stigma and discrimination are major impediments to treatment adherence, mainly among unmarried women, newly married women and the elderly.

NATIONAL FRAMEWORK FOR A GENDER-RESPONSIVE APPROACH TO TB

The overall framework is based on the principles of non-discrimination, informed choice, informed consent, confidentiality, respect for all, access for all, working in partnership, promoting rights of individuals and groups, fostering accountability and empowering communities. The framework deals with interventions under the heads of Detect, Treat, Prevent and Build as outlined in the National Strategic Plan. Each section outlines potential gender-responsive interventions under public and private sectors as well as by and with communities.

Detect: Actions proposed will include training of RNTCP staff in the public sector and private providers on gender differences along the diagnostic pathway between women, men and transgender persons. The programme will ensure that ACF teams are trained on gender-responsive questioning and that the fundamental principle of 'do no harm' is conveyed during training. The programme will also strengthen the involvement of TB Champions and survivor-led networks to improve care-seeking behaviour among all groups, especially women and transgender persons.

Treat: Key actions will include orienting health workers on adopting a respectful attitude, respecting the need for confidentiality, improving treatment literacy and providing gender-responsive counselling. Private sector providers will be trained on the need for gendered adherence support and TB Champions and survivor-led networks will be involved for the provision of gendered psychosocial support.

Prevent: Women and caregivers will be involved to strengthen contact screening and chemoprophylaxis; periodic screening of health workers for TB will be undertaken; involvement of communities in prevention drives will be strengthened.

Build: The emphasis will be on building the capacity of the programme and the private sector to provide gendered, comprehensive, patient-centric care. Promoting gender representativeness among survivor-led networks will be a priority.

The framework will guide the programme to mobilise, empower and engage women, men and transgender persons in the TB response at the health system and community levels. Once implemented, the framework envisages a gender-responsive programme which will catalyse and accelerate efforts to end TB in India.

ABBREVIATIONS

ACF	Active Case Finding
ACSM	Advocacy, Communication, and Social Mobilisation
AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Care
ANM	Auxiliary Nurse Midwife
ART	Anti-Retroviral Therapy
ASHA	Accredited Social Health Activist
AYUSH	Ayurvedic, Yoga and Naturopathy, Unani, Siddha and Homeopathy
BCG	Bacille Calmette Guerin
CHC	Community Health Centres
CTD	Central TB Division
DHS	District Health Society
DME	Department of Medical Education
DOTS	Directly Observed Treatment, Short-course
DR-TB	Drug Resistant TB
DS-TB	Drug Sensitive TB
EPTB	Extra-Pulmonary TB
FOGSI	Federation of Obstetric & Gynecological Societies of India
HWC	Health and Wellness Centres

ICDS	Integrated Child Development Services
IEC	Information Education and Communication
IMA	Indian Medical Association
IAP	Indian Academy of Pediatrics
LPG	Liquid Petroleum Gas
MDR-TB	Multi-Drug-Resistant Tuberculosis
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NFHS	National Family Health Survey
NPY	Nikshay Poshan Yojana
NRC	Nutritional Rehabilitation Centre
OPD	Out-patient Department
PLHIV	People Living with HIV/AIDS
PAF	Population Attributable Fraction
PHC	Primary Health Centre
PIP	Programme Implementation Plan
PMSMA	Pradhan Mantri Surakshit Matritva Abhiyan
PNC	Post Natal Care
PPM	Public Private Mix
REACH	Resource Group for Education and Advocacy for Community Health
RMNCH+A	Reproductive Maternal Newborn Child and Adolescent Health Programme
RNTCP	Revised National Tuberculosis Control Programme
STI	Sexually Transmitted Infections
STO	State Tuberculosis Officer
STS	Senior Treatment Supervisor
TB	Tuberculosis
VHND	Village Health and Nutrition Day
WCD	Women and Child Development
WHO	World Health Organization

SECTION

1

INTRODUCTION

Tuberculosis (TB) affects an estimated 10 million people globally every year, of which around 3.2 million are women. An estimated 1.6 million people die of TB every year, of whom 0.84 million are men and 0.5 million are women. An estimated further 3.6 million people with TB are not reported to health systems across the world. India has the highest annual incidence of TB in the world as well as the highest TB-related mortality. An estimated one million cases of TB go unreported in India every year. More than one million women and girls are diagnosed with TB in India every year.

Although more men are affected by TB, women experience the disease differently. Gender differences and inequalities play a significant role in how men and women access and receive healthcare in the public and private sectors. For instance, men are perceived to be more at risk of developing TB because of biological factors and predisposing lifestyle choices such as smoking and substance use. There is now adequate evidence to indicate that gender is a significant influencer of the epidemiology, risk factors, probability of diagnosis, access to healthcare, treatment adherence and overall impact of TB on communities. A gendered approach to TB care and prevention is a felt need in the Revised National Tuberculosis Control Programme (RNTCP) and this framework is a first step in that direction.

A. ABOUT THIS FRAMEWORK

This framework reflects the interactions between TB and gender at various levels, and aims to:

- Outline the influences and impact of gender on the TB burden and response, based on available literature and data;
- Define actions which would help move towards a gender-responsive approach;
- Provide guidance to implement these actions.

How to use this framework

This framework is intended for programme managers, healthcare providers at the district, state and national levels in the RNTCP as well as for civil society and community representatives, programme managers and healthcare providers involved in provision and evaluation of TB care services in the not-for-profit and private sectors. This framework can be used to:

- Understand the elements of a gender-responsive approach to TB;
- Train health providers and staff on providing gender-responsive care and support along the care cascade;
- Assess and improve the gender sensitivity of services and service providers.

This document is intended to spark dialogue at all levels within the TB programme and among key stakeholders, thereby strengthening the collective understanding of TB and gender.

Expected Outcomes: The expected actions and measurable outcomes are listed in detail in this framework. A key expected outcome is a change in the mindsets and behaviour of all stakeholders, including programme managers, healthcare providers, staff in the public and private sector who are providing services to people with TB, civil society and community leaders. Once implemented, the framework envisages a gender-responsive programme which will catalyse and accelerate efforts to end TB in India.

B. KEY DEFINITIONS

Sex refers to the biological and physiological characteristics of a person, including their internal and external reproductive organs, hormones and chromosomal composition.

Gender refers to a social construct that defines the roles, behaviours, activities, attributes and opportunities that any society considers appropriate for boys and girls, men and women. It also defines the relationships between people and reflects the distribution of power within those relationships. Gender intersects with other drivers of inequities, discrimination, marginalisation and social exclusion, which have complex effects on health and well-being (WHO, 2018).

Transgender persons means a person whose gender does not match with the gender assigned to that person at birth and includes trans-man or trans-woman (whether or not such person has undergone Sex Reassignment Surgery or hormone therapy or laser therapy or such other therapy), person with intersex variations,

genderqueer and persons having such socio-cultural identities as kinner, hijra, aravani and jogta (The Transgender Persons (Protection Of Rights) Bill, 2019). The term 'Transgender persons' includes transwomen (who transition from a given identity of boy or man to identify as a woman) and transmen (who transition from a given identity of girl or woman to identify as a man).

Sexuality and TB: Human sexuality is the way in which people experience and express themselves sexually. This involves biological, physical, emotional, social, sexual or spiritual feelings and behaviours *(Integrating Gender into HIV/AIDS Programmes in the Health Sector, 2009).* Though gender plays a role in determining the sexuality of a person, sexuality itself does not define a person's predisposition to TB (though sexuality is linked to vulnerability to HIV). However, the potential role of stigma in influencing access to TB services and quality of services received for those who are lesbian, gay or bisexual cannot be ignored.

C. GENDER AS A DETERMINANT OF HEALTH

Gender and resultant gender inequality are powerful and cross-cutting determinants of health, operating in conjunction with other forms of discrimination based on factors such as age, socioeconomic status, ethnicity or place of origin and sexual orientation. (World Health Organisation, 2011, n.d.). According to the WHO, gender has two important dimensions as a determinant of health:

1. *Gender inequality puts the health of millions of women, girls and transgender persons at risk globally. Addressing gender equality helps to counter the historic burden of inequality and deprivation of rights faced by women, girls and transgender persons in households, communities, workplaces and healthcare settings. Addressing gender equality in health enables the important work to improve the health of women and transgender persons.*
2. *Addressing gender norms, roles and relations enables better understanding of how socio-cultural identity construction (male and female), attribution of rights and unequal power relations can affect (among other things) risk and vulnerability, health seeking behaviour and – ultimately – health outcomes for women, men and transgender persons of different ages and social groups.*

Understanding and addressing gender-related causes and power dynamics that contribute to ill health and inequity is the first step to developing gender-responsive policies and programmes in the health sector. (Adapted from World Health Organisation, 2011, n.d.).

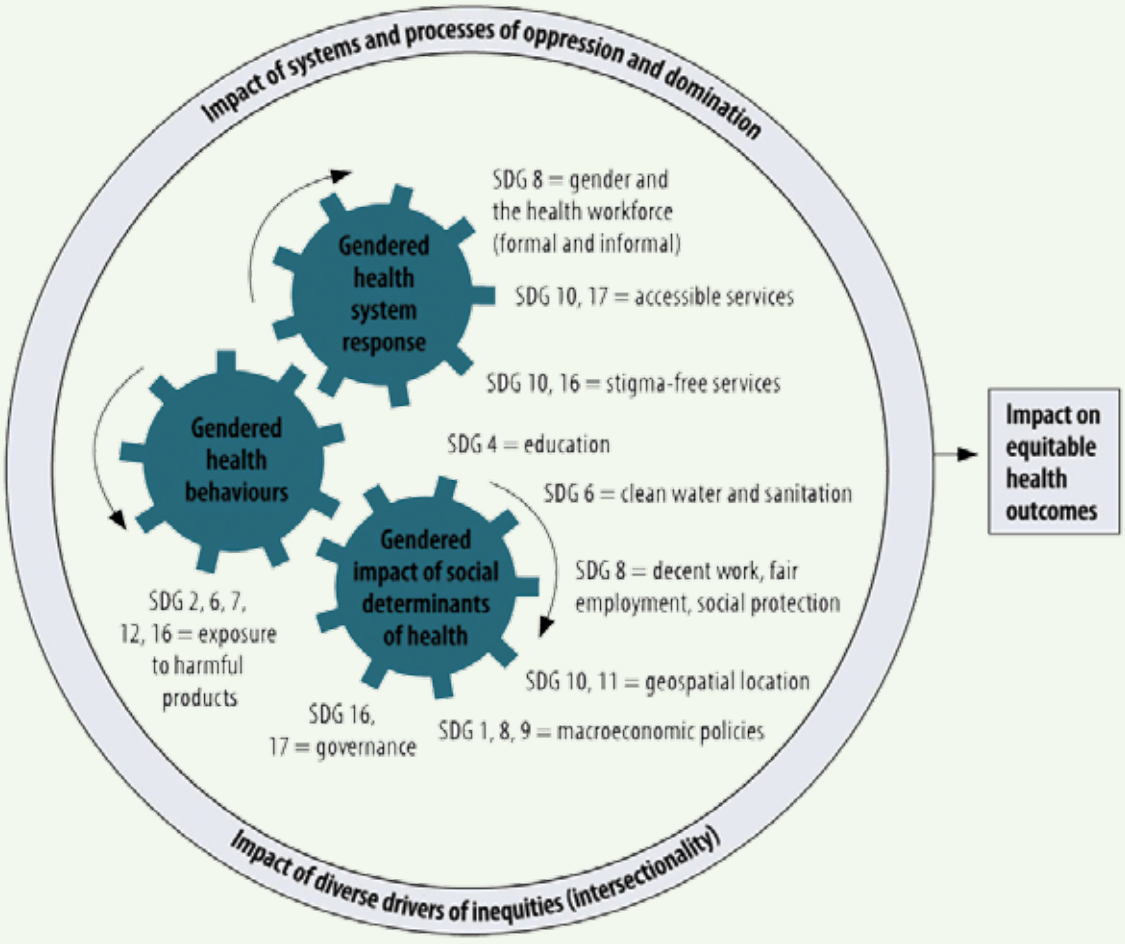
Figure 1 illustrates the impact of gender as embedded within other systems of oppression and domination such as class, caste, religion, ethnicity and sexuality, on the following aspects of health:

1. Social determinants
2. Health Behaviour
3. Response of the health system

Understanding and intervening in these gendered aspects will accelerate efforts towards achieving the Sustainable Development Goals, including elimination of TB.

FIGURE 1

GENDER AS A KEY DETERMINANT OF HEALTH



Source: 'WHO | Gender, health and the 2030 agenda for sustainable development', n.d.

D. WHO GENDER ANALYSIS FRAMEWORK

As per the WHO, a gender analysis in health identifies, assesses and informs actions to address inequality that stem from:

- Gender norms, roles and relations (e.g. women's role as primary caregivers for those who are ill may put them at risk for TB)
- Biological and socio-cultural factors interacting to enhance existing inequality (e.g. stigma attached to infertility which may be a result of genital TB)
- Unequal power relations between and among women, men and transgender persons in society (e.g. women's limited access to financial resources may prevent them from seeking healthcare early)
- Interaction of contextual factors such as ethnicity, education, sexual orientation or employment status with gender (e.g. delay in the diagnosis of TB among tribal women due to their limited access to health services)

The matrix given in Table 1 shows the different factors which influence health outcomes. Each of the gender related considerations has to be assessed vis-à-vis each of the health-related considerations.

TABLE 1

GENDER ANALYSIS MATRIX FOR HEALTH PROGRAMMES

Factors that influence health outcomes: *Health-related considerations*	**Factors that influence health outcomes: *Gender-related considerations***		
	Biological factors	**Socio-cultural factors**	**Access to and control over resources**
Risk factors and vulnerability			
Access and use of health services			
Health-Seeking behaviour			
Treatment options			
Experiences in healthcare settings			
Health and social outcomes and consequences			

Source: (WHO, Gender Mainstreaming for Health Managers: A Practical Approach, 2011)

A gender analysis contributes to understanding health differences and disparities among and between women, men and transgender persons in the following areas:

- Risk factors and vulnerability
- Patterns of disease, illness and mortality
- Health effects of policies, legislations and programmes
- Access to healthcare
- Decision-making processes

A gender analysis can increase effectiveness of the programme by:

- Identifying practical and strategic gender needs in health;
- Ensuring the right to health of different groups of women, men and transgender persons;
- Recognising and reducing the constraints women, girls and transgender persons face in protecting and promoting their health;
- Considering and addressing how male gender norms, roles and relations may harm the health of men and boys;
- Reviewing inappropriate, ineffective services, programmes or policies that ignore the realities of women's, men's and transgender persons' health needs and life conditions;
- Identifying and reducing gender bias in the health system;
- Developing and implementing gender-responsive policies, laws and services (primary, secondary and tertiary) and programmes; and
- Improving health information, documentation and use.

Using the above framework, this document undertakes a gender analysis of TB and illustrates the myriad ways in which gender and gender inequality affect TB. It also provides a comprehensive framework for developing a gender-responsive approach to TB.

This framework also takes cognisance of the laws in the Indian context that are applicable to women and transgender persons in particular, including but not limited to the Medical Termination of Pregnancy Act, 1971; The Sexual Harassment of Women at Workplace (Prevention, Prohibition and Redressal) Act, 2013; The Equal Remuneration Act, 1976; the Transgender Persons (Protection of Rights) Bill, 2019; and relevant provisions in the Indian Penal Code. A detailed discussion on socio-legal issues related to TB and gender is beyond the scope of this document. For more, please refer to the Legal Environment Assessment for TB in India (REACH, 2018).

E. MOVING TOWARDS A GENDER-RESPONSIVE TB PROGRAMME

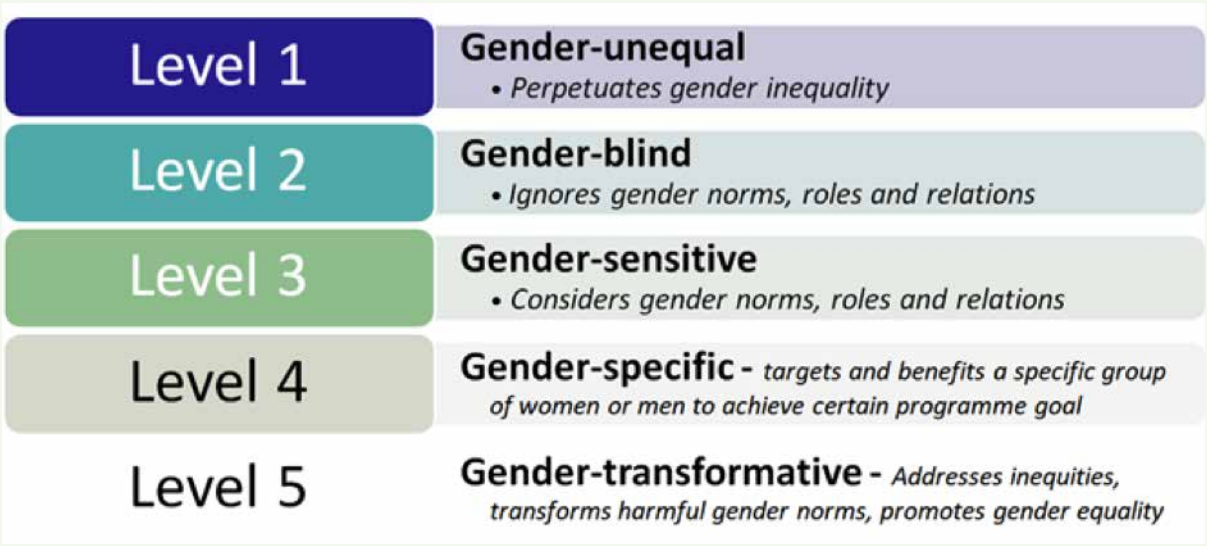
A gender-responsive health programme acknowledges different norms and roles for women, men and transgender persons; takes account of gender-specific needs; addresses the causes of gender-based health inequity; identifies ways to transform harmful gender norms, roles and relations; promotes gender

equality; and includes strategies to foster equal power relationships between women, men and transgender persons (WHO, Gender mainstreaming for health managers, 2011).

Figure 2 below outlines the different levels of recognition for 'Gender' in health programmes. Gender-unequal health programmes perpetuate gender inequality; gender-blind programmes ignore gender norms, roles and relations; and gender-sensitive programmes may consider norms, roles and relations but be doing little to respond to these considerations. Gender-specific and gender-transformative health programmes together add up to a gender-responsive approach in a health programme.

FIGURE 2

WHO GENDER-RESPONSIVE ASSESSMENT SCALE



Source: WHO, Gender mainstreaming for health managers, 2011.

The framework for a gender-responsive TB programme is outlined in this document. A gender-specific TB programme would take cognisance of gender differences and develop specific strategies to fulfil the healthcare needs of women, men and transgender persons. A gender-transformative TB programme would strive to go beyond this, to identify harmful gender norms which affect TB and play a proactive role in countering these norms and promoting gender equality. A gender-responsive approach to TB identifies and counters the influence of gender on the causes and consequences of TB, as experienced by women, men and transgender persons. A gender-responsive approach to TB is in keeping with the overall strategic framework adopted by the National Strategic Plan for TB for 2017-2025.

SECTION

II

SEX AND GENDER AS DETERMINANTS FOR TB IN INDIA

A. SEX AND GENDER WISE BIOLOGY AND EPIDEMIOLOGY OF TB

Incidence of TB among women, men and transgender persons

A higher proportion of the 27.4 lakh diagnosed with TB in India are men and the ratio is approximately 2:1 (Global TB Report 2018) between men and women. Even so, in absolute numbers, the number of women with TB globally as well as in India is significant. While a few studies suggest that the difference in prevalence between men and women can be attributed to epidemiological factors such as smoking, alcohol consumption and occupational risks, other studies point to an innate biological susceptibility in men owing to hormonal, genetic and immunological factors.

The incidence of TB in transgender persons is not known and needs to be measured. RNTCP records the gender of service-seekers under three categories – women, men and transgender. In the year 2018, a total of 1676 transgender persons were diagnosed with TB and notified to the RNTCP.

Studies also indicate that the reporting of fewer cases of TB among women may be due to various other reasons including poor access to healthcare services, poor diagnosis and poor reporting of cases among women (Uplekar et al., 2001). Studies have documented that the notification of TB among men and women, boys and girls is similar up to 20 years of age (Mukherjee et al., 2012). RNTCP data also shows nearly equal incidence of TB in both sexes in the age group of 15 to 24 years in most states

and higher incidence of TB in girls between 0 to 14 years. 15 to 24 years is also the age group which accounts for the highest number of cases among all age groups for both women and men. After this age, the incidence of TB among men steadily rises in comparison to women.

Multiple studies on the incidence of TB, across the country, indicate that more men report microbiologically confirmed pulmonary TB and women are more likely to have clinically diagnosed pulmonary TB and extra-pulmonary forms of TB (Balasubramanian et al., 2004; Dandona et al., 2004; Mukherjee et al., 2012; Weiss et al., 2006). There is also evidence to show that the presentation of pulmonary TB among women may be somewhat different from men, contributing to delays and making it difficult to diagnose TB in women. While men generally present with fever, hemoptysis and night sweats, women could present with common symptoms or non-specific findings such as fever, body ache, loss of appetite and fatigue (Long et al., 2002; Weiss et al., 2006).

In Asia, younger women are affected by EPTB and female genital TB (20 to 30 years) as compared to the high-income countries, thus putting younger women in the productive age group at higher risk for these forms of TB (Sharma et al., 2018). Research from India has also found menstrual dysfunction among adolescents and young women in more than 90% cases of both pulmonary and extra-pulmonary TB, which may be one of the earliest manifestations of TB in this age group. The dysfunction was in proportion to severity of the disease, including MDR-TB (Sharma, 2003).

Gender differences in TB among PLHIV: People living with HIV are especially vulnerable to TB. As per WHO data, the risk of TB for people living with HIV (PLHIV) is about 21 times greater than for those without HIV. TB is the most common opportunistic infection as well as the presenting illness in people living with HIV and the most common reason for HIV-related deaths. People living with HIV are also more at risk of drug resistant TB, especially if TB diagnosis is delayed (WHO, n.d.) (AVERT, 2019).

India has the third highest burden of TB-HIV co-infection in the world, with 86,000 new TB cases detected among PLHIV. TB caused the death of 11,000 HIV affected persons – this amounts to a fifth to quarter of all deaths among PLHIV (AVERT, 2019). Nearly 40% of TB infections in PLHIV globally and 58% in India remained undiagnosed in 2017 (WHO, n.d.)(AVERT, 2019). The RNTCP and National AIDS Control Programme (NACP) have made substantial progress in addressing HIV-TB co-infection, including active case finding for TB in HIV care facilities, providing HIV testing to a majority of people with TB, integrated HIV-TB care and prevention of TB among PLHIV. However, HIV remains a substantial risk for TB.

Research from India shows that the prevalence of HIV-TB co-infection is higher among women and the highest

among young persons, i.e. those aged between 21 and 40 years (Sawant 2011). TB-HIV co-infection is also high among transgender persons given that they are 49 times more likely to suffer from HIV as compared to others (AVERT, 2018). Those among transgender persons who live in overcrowded houses and consume alcohol face the highest prevalence of HIV-TB co-infection, illustrating the compounding effect of poverty and gender-linked risks (Hiregoudar V, 2016).

TB during pregnancy and post-partum period

Burden of TB in pregnant women: In 2011, it was estimated that globally more than 200,000 pregnant women suffered from TB, a majority of these in the WHO African and South East Asian regions. India ranked the highest in the estimated number of pregnant women with TB, with more than 44,000 women affected and 21% of the global burden. This is on account of the overall high burden of TB in the country, a large population as well as relatively high crude birth rates (Sugarman et al., 2014). Another estimate of burden of TB among pregnant women was similar, i.e. 20,000 to 40,000 cases (Jana et al., 2012).

Higher risk of TB in pregnancy and in the post-partum period: Physiological changes in pregnancy have an impact on the epidemiology of TB (Mathad and Gupta, 2012). Pregnant women and women in their post-partum period face a higher risk of TB. Women in the early post-partum period are twice as likely to develop TB as non-pregnant women (Gupta et al., 2016). Bates and others (Bates et al., 2015) also underline that immunological changes during pregnancy make new infections as well as activation of latent infection more common among this group. Gupta et al (2007) note that women who are living with HIV face an even greater risk of getting TB in the post-partum period (incidence of about 5 per 100 person-years) borne out by research on Indian women. Gupta et al (Gupta et al., 2016) also note that TB, generally diagnosed in the post-partum period, is also associated with increased mother-to-child transmission of HIV (30% vs 12%). This forms the basis of providing TB preventive therapy for pregnant women with HIV. However, scientists, researchers and practitioners note that despite substantial prevalence and mortality due to TB among women in the reproductive years, there is very little research or understanding about the epidemiology and presentation of TB in pregnancy and post-partum period (Jana et al., 2012; Mathad and Gupta, 2012).

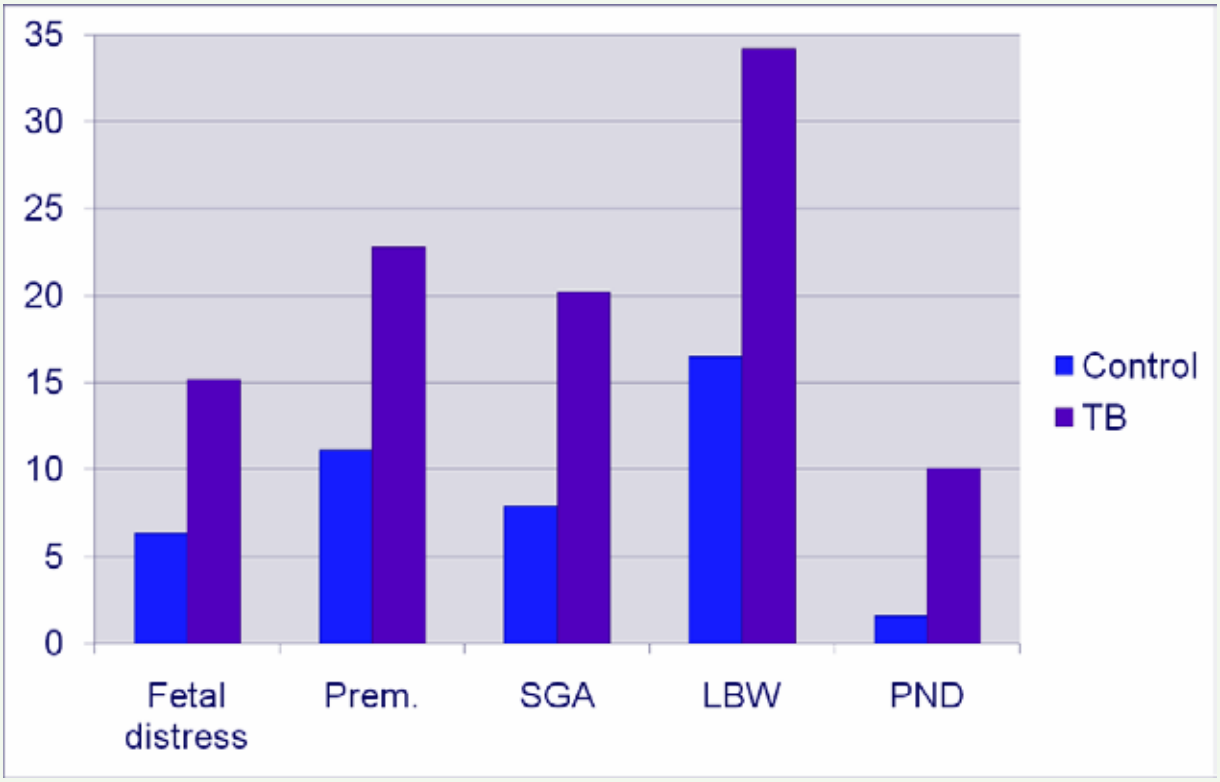
Increased health risk due to TB in pregnancy and post-partum period: TB is one of the leading non-obstetric causes of maternal mortality in low-income countries (Adhikari, 2009; Mathad and Gupta, 2012; Zumla et al., 2014). In India, Gupta and others (2007) found a high incidence of post-partum TB infection among women living with HIV. Co-infection with TB in women living with HIV substantially increased maternal deaths (more than 2 times) and infant deaths (about 3 and ½ times) in this group. While 12.5% of

HIV-TB co-infected women died (3 out of 24), only 1% of HIV infected women without TB (7 out of 691 women) had a maternal death (Gupta et al., 2007). Another study based on the causes of death found in post-mortem (autopsy) reviews of maternal deaths reported a more than 9% maternal mortality (26 among 227 deaths) on account of TB (Panchabhai et al., 2009). More studies are required in the Indian context.

The presence of TB disease during pregnancy, delivery, and postpartum is known to result in unfavourable outcomes for both pregnant women and their infants (4,7-16). These outcomes include a roughly two-fold increased risk of preterm birth, low birth weight, intrauterine growth restriction, and a six-fold increase in perinatal death (7). (Figure 3). With the exception of tuberculous lymphadenitis, extra-pulmonary TB – abdominal, vertebral, renal, and meningeal involvement – has adverse outcomes for pregnancy including increased antenatal hospitalisation and perinatal complications (9,10). Recent systematic analysis which included studies from India (7,9) and other countries (15-17) clearly showed that "active TB in pregnancy is associated with adverse maternal and foetal outcomes." (8). Compared with pregnant women without TB, pregnant women with active TB were associated with significantly increased risks of overall maternal morbidity [odds ratio (OR) 2.8], maternal anaemia (OR 3.9), caesarean section (OR 2.1), preterm birth (OR 1.7), low birth weight among neonates (OR 1.7), birth asphyxia (OR 4.6), and perinatal death (OR 4.2) (8). Recent Indian studies also re-affirmed these adverse effects of TB involving pulmonary and extra-pulmonary forms on maternal and perinatal morbidity and mortality (10,14). A recent post-mortem analysis of maternal deaths highlights that infections, including TB, are an important contributor to maternal deaths in India (18). Furthermore, it has been emphasised that TB results in nearly 10 million cumulative orphans because of parental deaths, which include maternal mortality due to TB (19). Therefore, active tuberculosis poses grave maternal and perinatal risks, for which early diagnosis, and appropriate and adequate anti-tuberculosis treatment of the mothers are mainstay for successful pregnancy outcome (4,20). Maternal care services could be used as a platform to improve case detection (19).

FIGURE 3

PERINATAL OUTCOME IN PREGNANCIES COMPLICATED BY PULMONARY TUBERCULOSIS



Source: Jana et al. 1994; Prem. – Prematurity; SGA – Small for Gestational age; LBW – Low Birth Weight; PND – Peri- Natal Death. Data in Y-axis are expressed in percentage, %

Adverse impact on foetus and infants: Jana and others (2012) as well as Mathad and Gupta (2012) note that both TB and HIV-TB co-infection in mothers add to the complications and also have an adverse impact on the foetus and infant. TB in pregnancy increases hospitalisation during pregnancy, increases incidence of pre-term births, miscarriage and other complications. Infants born to women with TB or HIV-TB coinfection face increased chances of foetal distress during delivery, generally weigh lower at birth, are small-for-date, may be born premature and experience increased mortality within the perinatal period as well as the first year. There is also the possibility of TB being passed on to the child both in the womb and through droplets in the immediate post-partum period. Again, diagnosis of TB in infants is very difficult, thereby increasing the chances of a missed diagnosis in the infant. Early and accurate diagnosis of TB among pregnant women can reduce many of these complications and improve outcomes for both the woman and her child.

The above discussion indicates that the full picture of the age, sex and gender-wise burden of disease, forms of the disease, presentations, progress from infection to disease and mortality, especially in girls, women and transgender persons are poorly understood and more research is required in this area.

B. GENDER DIFFERENCES IN EXPOSURE, RISKS AND VULNERABILITY TO TB

Gendered roles, responsibilities and expected behaviours can place women, men and transgender persons at an increased risk for TB.

Gendered risks and vulnerabilities for women

Traditional social norms: As per traditional patriarchal norms, women are expected to look after the home and family and be responsible for all household work, including cooking, cleaning, caring for children, the elderly and the sick. The perceived subordinate status of women reduces their access to resources, including money, nutritious food, mobility and decision-making powers over their own health. Gender norms also exposes them to greater stigma related to TB and gives them less control over their situation.

Women are especially constrained by social norms which prevent prioritising of their nutrition, health and well-being. For example, social norms dictate that woman eat last or eat the leftovers in the household. There is a lack of social acceptance to provide nutritious food to the daughter-in-law or daughter in a household. This increases their risk of undernutrition.

Women as care providers: As the principle care providers for the sick, women are vulnerable to exposure to TB either before or after the diagnosis of TB within the family. Women may be constrained from protecting themselves from the illness if they do not feel empowered enough to ask those with TB to practice cough hygiene or wear a mask or appropriately dispose sputum. All of this can increase a woman's risk of contracting TB infection. This coupled with the fear of being diagnosed with TB and poor attention within the family to women's health in general may result in delayed attention to the symptoms and a late diagnosis.

Undernutrition as a risk factor for TB: Undernutrition is the most common, widely prevalent risk factor for TB in India and it is responsible for the highest proportion of TB cases in India among women, men and transgender persons as compared to any other risk factor. The Population Attribution Fraction (PAF) of undernutrition as a causal risk factor for TB is more than 55% in India (Bhargava et al., 2014)(Cegielski et al., 2012). Overall women and children face higher levels of undernutrition as compared to men. The extent of undernutrition and the subsequent the risk of TB are higher for women as compared to men in the age groups of 20 to 39 years (Bhargava et al., 2014). For more information on this, please refer to the Guidance Document for Nutritional Care & Support for TB Patients in India.

Use of solid biofuels for cooking and risk of TB: There is growing evidence that use of solid mass or biofuels for cooking coupled with poverty, lack of ventilation, small homes or multipurpose rooms and spending prolonged time in the kitchen are associated with an increased risk of TB (Kurmi et al., 2014), (Lakshmi Singh and Jamal, 2012), (Jindal, 2014), (S.K Singh, Kashyap, & Puri, 2018). NFHS-4 points to a much higher prevalence of self-reported medically treated TB in households that use solid fuels for cooking (566 per 100,000 persons) as compared to households using non-polluting fuels (207 per 100,000 persons). Women spend long hours at home and in the kitchen, both increasing their exposure to smoke from the stove and resulting indoor air pollution.

Occupational risks due to TB: Some industries in South Asia employ a high proportion of women, for example upto 80% of workers in garment factories of Bangladesh (Zafar Ullah et al., 2012), more than 80% of beedi workers and upto 50% of workers in tea gardens of Assam are women (Talukdar, 2016), the latter two in India. These workers are also poor and undernourished, live in overcrowded conditions and often use solid fuels for cooking, besides lacking knowledge of causation, transmission and prevention of TB (Chelleng et al., 2014; Islam et al., 2015; John, n.d.; Joshi et al., 2014; Talukdar, 2016) thus compounding their risks for TB. Consequently, a high proportion of tea garden workers, garment workers and beedi workers (Farz et al., n.d.; Hassan et al., 2005; Joshi et al., 2014; The Economic Times, n.d.) are found suffering from TB as compared to the general population. Recommended steps for early diagnosis and treatment of TB at the workplace including prevention are making the workplace a point of contact for the TB program for awareness building, diagnosis and treatment of TB (DFID, 2011; Zafar Ullah et al., 2012).

Gendered risks and vulnerability for men

Men are expected to earn an income and run the household and this derives directly from their gender roles. Gender norms and expectations inflict pressure on men to appear strong, be masculine, hide feelings of vulnerability and be ready to take risks when required. This often translates into markers of masculinity such as smoking, drinking and taking risks regarding their health, in order to be accepted by the society at large. Therefore, while alcoholism and smoking among women is poorly accepted, these behaviours may be condoned or even encouraged as a result of the prevailing gender norms for men. This also makes men easy targets of promotional advertising for these products. Smoking and alcohol consumption are therefore specific gender-linked barriers to TB diagnosis and treatment for men.

Smoking, alcohol use and use of drugs pose additional risks for TB for women, men and transgender persons. According to NFHS-4, 45% of men and 7% of women aged 15-49 years reported use of any form of tobacco. Twenty-nine percent of men and one percent

of women aged 15-49 reported consumption of alcohol.

Smoking: Smoking is linked to increased incidence of TB as well as TB-related morbidity and increased risk of mortality (Balasubramanian et al., 2004; Gajalakshmi et al., 2003; Jain et al., 2014; Kolappan et al., 2006; Lavigne et al., 2006). Men who have ever smoked are three times as likely to report having had TB as compared to non-smokers — this indicates a higher progression of chronic sub-clinical infection to TB disease (Gajalakshmi and Peto, 2000). A case-control study done on the smoking habits of 43,000 men who died of medical causes showed that both cigarette and bidi smoking doubled the death rates for men who had ever smoked in the age group of 25 to 69 years. Among these deaths, nearly 25% were attributed to TB. A substantial risk of excess mortality among smokers in this analysis was attributed to TB (relative risk of death by TB was 4.5 and smoking attribution fraction was 61%). Overall TB mortality is four times higher among smokers as non-smokers (Gajalakshmi et al., 2003). For more information, please refer to the National Framework for Joint TB-Tobacco collaborative activities.

Alcohol consumption: Heavy alcohol consumption is associated with increased incidence of TB, increased interruption of treatment, higher treatment failure rates and increased mortality (Cox et al., 2007; Dhanaraj et al., 2015; Imtiaz et al., 2017; Jain et al., 2014; Kliiman and Altraja, 2009; Kolappan et al., 2006). Alcohol use is associated with higher risk of being diagnosed with microbiologically confirmed pulmonary TB in the context of poor, slum dwelling and undernourished men (Dhanaraj et al., 2015). A meta-analysis of studies looking into alcohol consumption and the risk of TB found not only a strong link between the two but also an increasing risk of TB with increase in alcohol consumption (Imtiaz et al., 2017). Male smokers who also consumed alcohol were 11 times more at risk of mortality than the general population on account of TB (Kolappan et al. 2006).

Occupational risks due to TB: About 8.3 million people in India, mostly men, are estimated to be at risk of silicosis. They are employed in mining, quarrying, metals and construction industries. Their socio-economic conditions may predispose them to TB, compounding the risk of TB secondary to silicosis. Besides, silicosis also makes diagnosis of TB, challenging owing to similar radiological features and decreased chances of microbiological confirmation secondary to silicosis fibrosis.

People who use drugs: A high proportion of people who use drugs were found to have TB in a study conducted in New Delhi and most of them were men (quoted in REACH, 2018). People who use drugs are often excluded from mainstream society and experience stigma and discrimination. They are also at a considerably higher risk for HIV, which increases their vulnerability to TB. Undernutrition is also a risk factor for this

group. Supportive measures are required to ensure that people who use drugs access care and treatment services without fear of discrimination.

Although most studies identify substance use, including alcohol consumption among women as lower than men, it is also acknowledged that this is changing, with an increasing number of women consuming alcohol and other substances globally as well as in India (Lal et al., 2015). Under-reporting of drug use in women due to social stigma is also documented, besides increased domestic violence, divorce, separation and increased experience of harassment by the police and others among women who use substances (Lal et al., 2015). Creating a conducive and non-judgmental environment will help women, men and transgender persons to acknowledge substance abuse and seek help.

Gendered risks and vulnerability for transgender persons

Transgender persons often have low literacy, low education levels and are poor. Many transgender persons have to live off begging and many are also forced to take up sex work. Poverty as well as hardships lead them to be undernourished. Undernutrition and poor health literacy places them at an increased risk of TB. Poor access to healthcare and a perceived lack of privacy in the health system also leads to delayed diagnosis of TB and transmission for a longer duration. Transgender persons and sex workers live in overcrowded communities housed in poorly ventilated places. This leads to higher and sustained exposure to the infection.

A high proportion of transgender persons are known to smoke, consume alcohol and use drugs. Up to 50% of transgender persons have been seen to have a high consumption of alcohol (Baba and Sogani, 2018). A NACO 2015 study showed high level (20%) of physical and sexual violence faced by transgender persons. Transgender persons often use alcohol, drugs and smoking as a coping mechanism for the severe hardships they face in their day-to-day lives (Baba and Sogani, 2018). Smoking and alcohol increase the risk for TB, as previously described. Transgender persons are also vulnerable to HIV, which in turn increases their vulnerability to TB. Not enough is known about their vulnerability to TB outside of the HIV context.

C. GENDER DIFFERENCES IN HEALTH SEEKING BEHAVIOUR AND ACCESS TO HEALTHCARE

TABLE 2

CONCEPTUAL MAPPING OF GENDERED DELAYS IN HEALTHCARE SEEKING

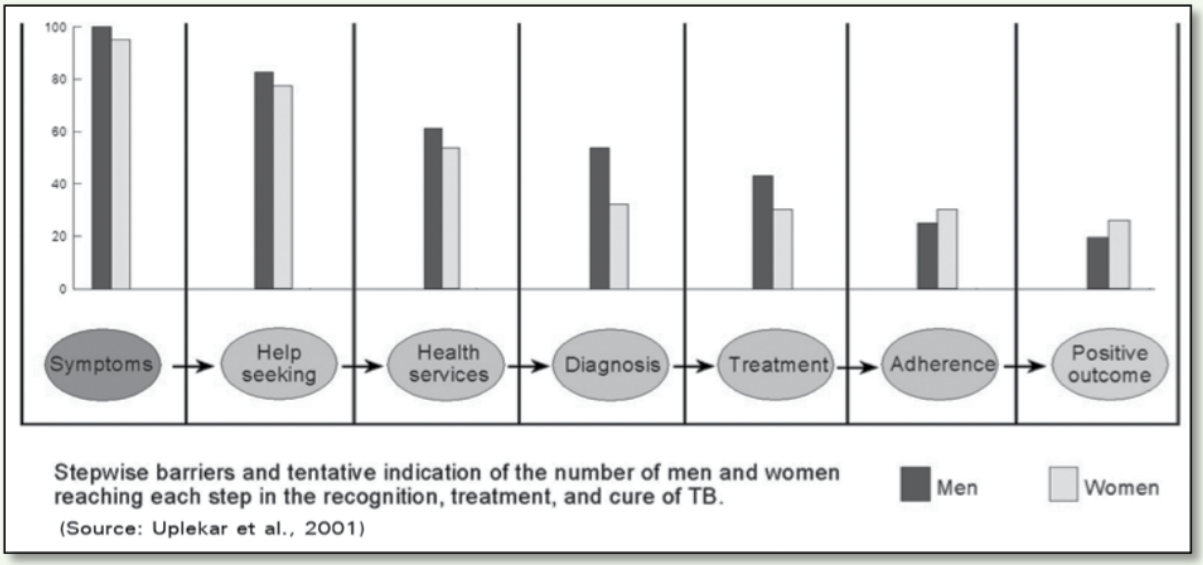
	Individual-level Delays	Health System Delays or Delays after Diagnosis
Men and Boys	◆ Lack of awareness about TB services ◆ Loss of income ◆ Inconvenience due to multiple visits to different health centers ◆ Difficulties in accessing healthcare e.g. for migrant workers and their families, miners working illegally or in place of formal workers ◆ Unsupportive environment such as no leave to attend TB clinics, difficulty in disclosing diagnosis due to stigma at the workplace, fear of losing their job and income ◆ Delayed care seeking by those using drugs and consuming alcohol	◆ Difficulties in accessing health care e.g. inconvenient clinic timings, lack of knowledge about TB services, multiple visits required, difficulties faced by migrant workers, miners working illegally or in place of formal workers ◆ Disrespectful or unwelcoming attitude of health staff ◆ High consultation charges for every visit in the private sector ◆ Uneven quality of care in private sector
Women and Girls	**Unmarried women:** ◆ Perceived need to hide symptoms or possible illness due to concerns about stigma and subsequent difficulties in getting married. Families may choose marriage over ensuring a confirmed diagnosis and treatment for TB	◆ Overall, absence of a gender perspective in TB ◆ Lower index of suspicion for TB, including among pregnant and post-partum women ◆ Lower incidence of microbiologically confirmed pulmonary TB and higher incidence of clinically diagnosed pulmonary TB and EPTB making diagnosis among women difficult

	Married women: ◆ Treatment may be interrupted after marriage due to stigma or relocation ◆ Priority given to household responsibilities ◆ Neglect and lack of seriousness about a woman's illness until she is seriously ill or cannot do any housework ◆ Lack of money/financial independence ◆ Lack of mobility ◆ Lack of decision-making powers to decide about their own health ◆ Need for permission to go to a doctor ◆ Need for an escort to leave the house ◆ Fear of rejection, being sent back to parental home or husband getting remarried ◆ Higher possibility of seeking care first with informal provider, pharmacist or private doctor	◆ Limited understanding of how to provide right quality sputum sample for testing ◆ Lack of privacy and confidentiality in health system. Privacy and confidentiality may be valued much more by women ◆ Lower diagnostic capabilities for pediatric TB. Girls are more at risk of TB than boys in this age group leading to further delay in diagnosis among girls
Transgender persons	◆ Poor health literacy ◆ Higher possibility of seeking care from informal, private providers and pharmacists ◆ History of criminalisation and associated violence which forces them to hide illness ◆ Lack of awareness about free TB services or navigation of the health system	◆ Lack of privacy and confidentiality ◆ Disrespectful and unwelcoming attitude of health staff ◆ High levels of stigma and reluctance to approach health services for TB because of presumed HIV infection ◆ Discrimination from the health system

Uplekar (2001) has provided a useful framework of the step-wise barriers to accessing healthcare faced by men and women and demonstrated the attrition in numbers at each stage (Figure 4). The study shows a steady attrition of cases for both men and women from the point symptoms are developed to a positive outcome of treatment. The details for each social group are discussed below.

FIGURE 4

FRAMEWORK OF THE STEP-WISE BARRIERS TO ACCESSING HEALTHCARE FACED BY MEN AND WOMEN



Source: Uplekar et al., 2001

Women, men and transgender persons, all face delays in diagnosis and care seeking for health. However, each is affected differently. Individual-level delays in health seeking by women is closely related to their gender roles, subordinate status in the family and society, gender-power relations, stigma associated with having TB and in the case of working women, inability to take time off and fear of losing their job. Individual-level delays in health seeking by men are related to financial concerns, inability to take time off from work, concerns with wage losses, fear of losing their job, inconvenient clinic timings and need for multiple clinic visits (Atre et al., 2004). Concerns for transgender persons include their social distance from the health system, poor access to health care and stigma. Stigma for them can be threefold — stigma of being socially discriminated as a transgender person, as a transgender person with TB and as a transgender person with HIV and TB or presumed to have HIV.

Factors affecting healthcare access at the individual level

Health Literacy: Women, including women living with HIV have been found to have lower health literacy for TB, its cause and modes of transmission (IIPS, 2015; Krishnan et al., 2014; Kulkarni et al., 2014; Weiss et al., 2008); (Yang et al., 2014). This is linked to lower education levels in women and less exposure to media such as television and newspapers. Both women and men have misconceptions related to the transmission of TB which accentuates the stigma related to TB. Increased health literacy in women, men and transgender persons will increase early recognition of symptoms and early access to the appropriate health facility.

Source of healthcare accessed: Nearly 50% of men and women report preferring to go to a private health facility when they seek healthcare. Common reasons given are close proximity to the home and perceived good quality of care (Sudha 2003). Women, more than men, are seen to access sources of healthcare other than the public health system — informal providers or pharmacists or private doctors — for symptoms of TB, before they are referred to a public facility (Weiss et al., 2006). Seeking help from a private provider is observed to delay the diagnosis of TB (McArthur et al., 2016). Men seek or are referred to public health services earlier than women are.

Weiss et al (2006) found that women actually sought help earlier than men - the average delay in seeking care among women is 48 days as compared to 57 days for men. But women took an additional 18 days to reach a Primary Health Centre (PHC), while men reached there in 11 days. This actually reduced men's overall delay in seeking formal healthcare services. In the final tally, women took 24 days to reach a PHC and get a sputum examination while men took 13 days, thus significantly accelerating the speed of diagnosis for men.

Rigid gender roles and relations: Household chores and looking after children are important priorities for married women. Rigid perceptions of these gender roles make these tasks more important than women's health. Families often neglect a woman's health unless it hinders her from performing her duties (Khan, 2012).

When they do seek healthcare, women negotiate a maze of obstacles including financial barriers, physical terrain related barriers and lack of decision-making powers thus reaching healthcare facilities substantially late for diagnosis (Yang et al., 2014).

Men may delay accessing healthcare due to the fear of loss of wages and workdays and are often under pressure to continue working to support the family. Men are also concerned with concealing their disease from their employers.

Stigma: Stigma associated with TB is seen for both women and men. 20% men and 15% women reported that they would not want anyone to know that a family member has TB (NFHS, 2015). Women as well as men

experience stigma and discrimination, but the domains in which they do so are different and the impact varies. Men have reported discrimination for TB in the context of high levels of alcohol consumption (Thapa et al., 2014). This could be because of reduced income and loss of status in the family.

Women face greater stigma with far-reaching implications on their lives. For women, the stigma is mostly associated with marriage and marriage-related problems, harassment and differential treatment within the household; whereas men experience a sense of shame because they cannot work, income levels drop and other women members of the household are required to work to augment the family income (Khan, 2012; Krishnan et al., 2014; McArthur et al., 2016).

Issues of privacy, anonymity and confidentiality are important for young girls and women, but also men and transgender persons. Young unmarried girls and their families fear that they will not be able to get married or the marriage may end because of a TB diagnosis. There are also instances of marriages being called off (Weiss et al., 2006). This leads to hiding of symptoms or illness, not seeking treatment or keeping the treatment secret and refusing home visits (Khan, 2012; McArthur et al., 2016).

Psychosocial support and supportive counselling can play an important role in removing misconceptions, providing accurate information, protection from infection and negotiating power relationships within the family. Emotional support can also help the woman value herself and facilitate her to find options for her problems. The story told by a counsellor who worked with a young woman's prospective parents-in-law and persuaded them to go ahead with the marriage despite the young woman having MDR-TB provides an example. With the counselor's support, the woman was able to take a dose of Bedaquiline even on the day of the wedding (REACH, 2019).

Factors affecting healthcare access at health system level

Health system factors that impact access to healthcare include lack of healthcare facilities for diagnosis and treatment, especially in rural and tribal areas; lack of communication by healthcare workers; lack of patient-friendly provision of health services leading to multiple visits and a lower index of suspicion for TB in women.

Rural areas, which include tribal areas, are characterised by high prevalence and low incidence rates. One of the reasons for this is limited access to healthcare resulting in delayed case detection. Access is also affected by difficult terrains, widely dispersed health facilities and limited transportation options. These access issues compound the financial and mobility related constraints faced by women, the poor and those workers who cannot spare time or take leave from work.

Inadequate information for people with TB: Lack of adequate information and

communication by the healthcare provider emerges as the most important reason for delays in diagnosis and initiation of TB treatment at the provider level, especially for men (Kulkarni et al., 2014). Those not informed about the possibility of having TB had the highest probability of not completing the diagnosis process. Those who completed the diagnosis but did not initiate treatment also cited health system barriers as the most common reason. Transgender persons too often find the health system unfriendly and avoid accessing care early.

Lower index of suspicion for TB in women: Delay in TB diagnosis may be linked to the epidemiological picture of the disease. There are different presentations for women and men, higher proportion of clinically diagnosed and extra-pulmonary TB in women and a general presumption that men suffer from TB more than women. These delays may affect an early and accurate diagnosis of TB in women. In the study by Weiss and others (2006), there was a steady attrition of women with symptoms of TB from the time they reached a public facility.

Delayed and missed diagnosis among pregnant women: Mathad and Gupta (2012) point out that there is inadequate evidence of the cost-efficacy of routine screening for TB among pregnant women. However, active screening is recommended for TB among HIV positive pregnant women given the high incidence as well as poor outcomes in this condition (Gupta et al., 2007). Sugarman et al estimate that more than 50% of TB in pregnancy could be diagnosed by making appropriate diagnostics available through maternal health programmes (Sugarman et al., 2014).

D. GENDER DIFFERENCES IN TREATMENT ADHERENCE AND COMPLETION

A number of studies show that women have a higher probability of successfully completing treatment, with better treatment outcomes, while men face challenges on this front, including in the case of MDR-TB. Men in general and men who consume alcohol, both have poor adherence to treatment (Das et al., 2014; Jain et al., 2014; Nair et al., 2017; Ramachandran et al., 2017; Veerakumar et al., 2016). The other principle attribute linked to not completing treatment is smoking (Jain et al., 2014; Veerakumar et al., 2016). In addition, anecdotal evidence indicates that this problem may be more widespread.

Studies on MDR-TB show that adherence to treatment and treatment outcomes are worse and mortality higher for people with MDR-TB who consume alcohol. Smoking and drinking are independently associated with poor treatment outcomes for people with MDR-TB (Jain et al., 2014).

Other reasons provided by affected persons for not completing treatment were (Jaggarajamma et al., 2007):

- Adverse drug reactions or toxicity to TB drugs
- Migration
- Feeling better, reduction in symptoms
- Taking treatment from other centers

People with TB, families and healthcare providers have strongly recommended alcohol intervention programmes to support alcohol users. In an alcohol intervention study, the strategy helped improve treatment outcomes in the intervention group (87% treatment completion) as compared to the control group (62%) (Thomas et al., 2017, 2011). Similarly, nutritional support programmes have shown a 50% reduction in risk of incomplete or unsuccessful treatment (Samuel et al., 2016).

Migrant workers: Migrant workers — the majority of whom are men — often find it difficult to adhere to treatment on account of poor mechanisms to support uninterrupted treatment in the face of their extreme poverty and issues of daily survival. These issues are often more important to them than continuity of TB care. Migrant workers often discontinue treatment without giving a forwarding address. This is probably because they do not have a forwarding address to give, do not have adequate identity proof or are reluctant to provide the address of the employer for fear of stigma and losing employment. The programme is working to strengthen the mechanism of care for migrant workers. Migration for work among women is increasing, especially as domestic workers, but there is a paucity of studies and data. The possibility of interrupted treatment would be similar for both men and women.

Interrupted treatment in married and pregnant women: Incomplete and irregular treatment is a common problem in pregnant women. To overcome this challenge, impediments at three levels need to be addressed — the health system, social and family level and personal levels. Married women may drop out of treatment for various reasons:

- TB has not been disclosed to the in-laws and the woman feels compelled to hide her TB diagnosis on account of stigma and fear of rejection.
- Pregnancy has not been ascertained before starting treatment, in which case the woman fears for the effect of drugs on foetus. Families may prioritise the health of the unborn child over that of the woman.
- Adequate information is not provided about interference of Rifampicin with oral contraceptives, and adequate counselling is not provided to the woman and her spouse for alternate means of contraception.
- Information on the safety of first line TB drugs in pregnancy is not adequately emphasised.
- Pregnancy is often encouraged in newly married women by their families once they begin to feel better and gain weight. Subsequently, treatment is discontinued either on account of morning sickness or fear of hurting the foetus. Here the pressure on pregnant women to prove their fertility after marriage and the stigma attached to infertility play a significant role.

Stigma faced by the elderly, widows and other vulnerable groups: Health of family members who are relatively powerless and subordinated in the family is often neglected. This includes the elderly — men and women — as also widowed, separated or divorced women. Studies show poor access to healthcare for elderly women and poor notification of TB cases in elderly women, though there is no evidence that the two are linked. Instances of harassment experienced by elderly women as well as isolation of elderly men and women with TB have been anecdotally documented.

E. GENDER DIFFERENCES IN SOCIAL AND ECONOMIC IMPACT OF TB

The socio-economic and psychosocial impact of TB ranges from high costs of diagnosis and treatment, expenditure on unnecessary tests and supplements, disruption in work and schooling, and stigma, harassment and rejection faced by those affected by TB. Though studies of catastrophic expenses on TB pertain to both men and women, most studies underline that the costs incurred by women were more than by men (Ananthakrishnan et al., 2012; Muniyandi et al., n.d.; Rajeswari et al., 1999). However, the reasons for this are not clear. Expenses incurred for extra-pulmonary TB, which is also found more among women, were greater than for pulmonary TB. Psychosocial impact, anxiety and stress of loss of income, depletion of savings, indebtedness, mortgaging ornaments and property, and loss of dignity for being dependent on others and inability to fulfil their gendered roles were seen in families, and among men and women as important consequences of TB.

The economic impact, effect on employment and the impact on their families causes the maximum psychosocial trauma for men. On the other hand, women, including elderly women, face the brunt of stigma, harassment and rejection much more than men. Women who become infertile due to genital TB face added stigma. There is no specific research on the socio-economic or psychosocial impact of TB on the lives of transgender persons but given their poor living conditions, poor health literacy, high costs of care in the private sector and the likelihood of their experiencing discrimination, the impact on their lives can be presumed to be severe.

Socio-economic impact

Direct and indirect costs of developing TB disease: Studies on the socio-economic costs of TB treatment and its consequences points to heavy costs — both monetary and non-monetary — contributing to impoverishment of families. Studies have noted nearly 19% or more of family income was spent on TB treatment which amounts to catastrophic expenses (Ananthakrishnan et al., 2012; Muniyandi et al., n.d.; Sajith et al., n.d.). Muniyandi and others have recorded that a high number of people with TB (71%) had to seek loans to aid in the direct and indirect costs of treatment. While they

recorded relatively low median costs, the range of direct and indirect costs on several fronts including doctors' consultations, investigations, travel and accommodation before and after treatment ranged from INR '0 to 1,200' to '0 to 13,000 'indicating substantial expenses for a section of those with TB. Sajith (2015) recorded a mean expense of INR 5474 on pulmonary TB, INR 10,574 on extra-pulmonary and INR 14,638 on TB with both pulmonary and extra-pulmonary involvement, especially in the context of hospitalisations. They have also noted that nearly 40% of those with TB or caregivers had to lose work days and up to 68% reported reduced earning abilities during the period of the illness.

Besides direct and indirect costs due to TB and catastrophic expenditure, boys and girls faced absenteeism from school. Some women were forced into employment when the main earning member of the family could not work or lost employment due to TB. There is a need for gender disaggregated data analysis in all socio-economic studies so that differences in impact on the lives of women, men and transgender persons become apparent.

Psychosocial impact on women

Studies note that considerable stigma found among people affected by TB was rooted in misconceptions related to the disease — of it being dangerously contagious, transmitted via sex and incurable. This stigma affected women more than men, feeding into the narrative of immoral women succumbing to the infection and caused substantial psychological trauma (Atre et al., 2011; Weiss et al., 2006). In the multi-country study by Weiss et al (2006), the stigma linked to misconceptions was found more in the South Asian countries of India and Bangladesh, and was the highest in India as compared to the other countries which were part of the study.

Stigma and psychosocial impact was also directly linked to women's gendered roles and responsibilities and subordinate status. Women faced rejection especially in joint families they were married into, but also at times from their parental families (Weiss et al., 2006). Rajeshwari and others (1999) document that approximately 15% of rural and 11% of urban women with TB faced discrimination and rejection by their families. A substantial proportion of harassment by the family as well as reduction of self-worth for the women themselves came from their inability to care for their children, and to perform routine household activities. Prior to their illness, 79% of women carried out household activities such as cooking, cleaning, washing and serving food. After diagnosis, this fell to 38%. Child care decreased from 69% to 34% (Rajeswari et al., 1999).

Ananthakrishnan and others note that 37.7% of study participants expressed fear of rejection by their family on account of TB, 30.7% of people with TB expressed fear of discrimination, 20% were unhappy because of dependency on others, 14% had

not revealed their disease status to their family, 5% suffered from excessive worry or mental anguish and 3% did not tell their spouse about their illness. Women faced these consequences more than men and the difference was statistically significant.

Some extreme forms of rejection reported by women include being sent away to the maternal home (Khan, 2012), facing domestic violence, being deserted by husbands (Singh, 2005), being instigated to commit suicide by the husband and in-laws and the fear of being killed (Weiss et al., 2006).

Nearly a third of the infertility in women is caused due to genital TB. Though TB in such conditions is treatable, very few women can regain fertility if the fallopian tubes or the endometrium is severely damaged. There is also increased possibility of ectopic pregnancy (pregnancy implanted in fallopian tube) and miscarriage when conception occurs (Grace et al., 2017). Childless women face additional stigma, are taunted for their childlessness and kept away from several socio-religious functions.

Psychosocial impact on men

Studies also point to men being impacted due to the diagnosis of TB, the impact being more in terms of their inability to work, inability to support the family and losing employment. Sometimes there is also rejection from the family.

A 40-year-old man working as an office assistant said, *"I told my employers that I had TB and wanted some leave. Immediately they told me that I should discontinue the job and come back only after the doctor gives me a certificate that I am cured."* (Ananthakrishnan et al., 2012)

While men also suffer psychosocial impact of TB, instances of rejection by families are fewer as compared to women. The economic impact, impact on employment and impact on their families causes the maximum psychosocial trauma for men. However, men do have the freedom and mobility to travel for work and live on their own. Such options are often closed to women.

F. GENDER AND HEALTHCARE SYSTEMS

Just as society is organised along lines of gender binaries resulting in gender inequalities, the health system is also a gendered institution. Some of the barriers linked to gender which affect the understanding of TB and provision of effective services are described below:

- This document acknowledges the need for a gender lens to understand various aspects of TB, including its epidemiology, risks and vulnerabilities to TB, what makes services easily accessible and factors linked to adherence to treatment and outcomes. However, so far, most staff in the public health system have not been trained to understand gender and apply it effectively in their work. This is a gap which will be bridged in the future.
- Most staff of the RNTCP, including the State TB Officers (STOs), District

TB Officers (DTOs), other Medical Officers and supervisory staff (STS, TB-HIV Coordinator, PPM Coordinator) are male. This reinforces the image of TB as a predominantly male disease. On the other hand, most community health workers, i.e. ASHAs (Accredited Social Health Activists), Sahiyas etc. are women. This can pose challenges, such as discomfort in counselling users of alcohol, drugs, cigarettes or other substances. A model of overwhelmingly male supervisory staff and overwhelmingly female field staff will not result in gender equitable services. Going forward, the programme will work towards gender parity in staffing at all levels so women, transgender persons and men all feel comfortable in accessing services.

- A person with TB requires counsellors to help them navigate the journey from diagnosis to cure successfully. Counsellors can also help to counter the stigma attached to TB but must be trained on and aware of gender-sensitive counselling needs.
- Other challenges brought out by the literature review are inadequate information and guidance at health facilities to negotiate the system, need for multiple visits before the diagnosis is confirmed, difficulties in getting an appropriate referral and poor attitudes of the staff. The RNTCP is proactively involving community members such as TB Champions and support groups to ensure that adequate feedback regarding such challenges reach the programme managers in real time. Making people with TB aware of their rights, providing adequate information at each stage of treatment, including regarding side-effects of medication and effective communication by the health system are enshrined in the NSP.

SECTION

III

NATIONAL FRAMEWORK FOR A GENDER-RESPONSIVE APPROACH TO TB

GOAL

To adopt and implement a gender-responsive approach to TB in India.

OBJECTIVES

- To aim for equitable, rights-based TB services for women, men and transgender persons by adopting a gender-specific programmatic approach at all levels
- To mobilise, empower and engage women, men and transgender persons in the TB response at the health system and community levels

OVERALL GUIDING PRINCIPLES

Non-Discrimination: Treat all people with TB fairly, regardless of age, sex, sexual orientation, gender identity, ethnicity, religion, class, occupation, disability and mode of transmission.

Informed Choice: Enable people with TB to make well-considered, voluntary decisions by providing a full range of information and options related to their healthcare.

Informed Consent: Provide sufficient information about medical procedures and tests to ensure that these are understood, and respect the individual's autonomy in making fully informed decisions.

Confidentiality: Ensure that all medical records and information are kept confidential. Only healthcare professionals with a direct role in the management of care seekers or people with TB should have access to such records, on a need-to-know basis.

Respect For All: Each programme stakeholder and beneficiary must be treated with respect and dignity.

Access For All: Make services accessible to as many people as possible with regard to availability, affordability and acceptability.

Working In Partnership: Build partnerships between government and civil society (including community- based organisations, women's groups, TB Champion and survivor-led networks), and among all social sectors, both public and private.

Linking Prevention, Treatment and Care: Build comprehensive programmes by linking TB prevention, treatment and care services, as well as other related health services needed by people with TB or TB symptoms.

Promoting The Rights Of Individuals and Groups: Promote, respect and enforce the human rights of people with TB, including the right to adequate health information

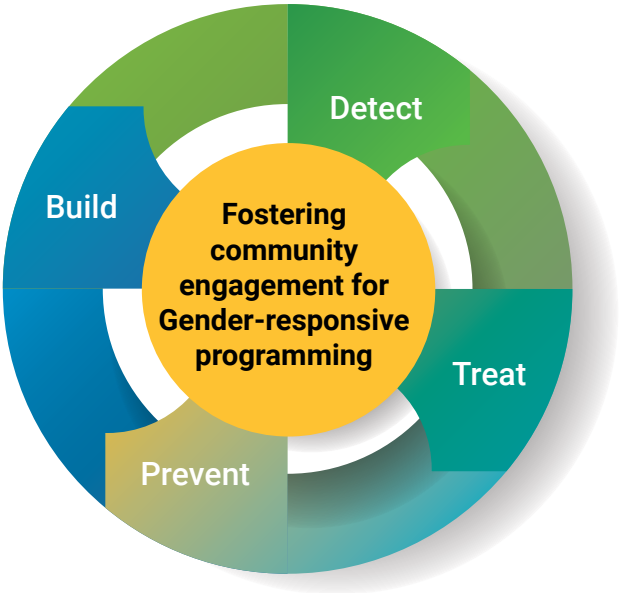
Fostering Accountability: Foster the accountability of all staff, including programme managers and decision makers, for the achievement of gender-related goals and objectives.

Empowering Communities: Contribute to the creation of an enabling environment for people with TB by empowering individuals and communities through outreach and community education about TB and related gender inequalities

Adapted from "WHO: Integrating Gender into HIV/ AIDS programmes in the health sector 2009"

BASIC STEPS FOR GENDER-RESPONSIVE PROGRAMMING:

- Assess provider knowledge on gender-responsive programming and existing gender-sensitive practices.
- Build capacity of providers on the gender perspective and providing comprehensive person-centric care.
- Conduct baseline assessment of facilities, infrastructure and linkages in the context of gender-responsive programming.
- Promote active involvement of people affected by TB of all genders in all aspects of the design, planning and delivery of programmes. The participation of people affected by TB and survivors must be supported through capacity-building and mentoring. Accordingly, all the activities outlined under the NSP heads - Detect, Treat, Prevent and Build - incorporates components of community engagement.



An effective and gender-responsive TB programme must incorporate elements of programmatic and institutional gender mainstreaming (WHO, Gender mainstreaming for health managers, 2011). The programmatic approach ensures gender mainstreaming in all matters concerned with running the programme including the causes and consequences of TB, risks and vulnerabilities, access to healthcare and treatment outcomes. The Institutional approach ensures that institutions which run the TB programme create an enabling environment for the programme by ensuring gender equality in agenda setting, policy development and governance, recruitment, staffing, budgetary allocations and administration. It ensures that organisational procedures and mechanisms do not reinforce or reproduce the gender inequalities found in society. The activities outlined in the subsequent sections incorporate both of these approaches.

This document outlines how the programme could make the health services in the public sector gender-responsive. In addition, it suggests actions for the programme to collaborate with private sector and community and engage them as key stakeholders to make all aspects of TB services gender-responsive.

NATIONAL FRAMEWORK FOR A GENDER - RESPONSIVE APPROACH TO TB IN INDIA

CORE VALUES

- Confidentiality
- Non-discrimination and non-stigmatising behaviour
- Respect for all
- Informed consent
- Accountability

DETECT

- Train providers (public and private) on gender-sensitive provision of care
- Integrate screening for TB into maternal health services
- Gender-sensitive Active case Finding
- Improve gender and age disaggregated notification for public and private sector.
- Strengthen referral and feedback mechanisms between program and community

TREAT

- Adopt comprehensive patient-centric care
- Ensure respectful behaviour and confidentially of identity
- Provide non-judgmental, safe space for all, especially women and transgender persons
- Enlist support of programme/private sector intervention for people with TB in the private sector
- Engage communities in community monitoring, peer psychosocial support and mitigation of stigma

PREVENT

- Institute air-borne infection control in health facilities, especially in MCH and ART clinics
- Prioritise screening for LTBI and management among transgender persons, women and children
- Enlist support for women for contact screening and chemoprophylaxis
- Screen care givers for TB and educate them on cough hygiene
- Support cough hygiene drives by TB champions and community groups

BUILD

- Strengthen linkages between program, private sector and communities
- Work towards gender-equitable planning and budgeting
- Assess and aim for gender parity in the workforce
- Ensure representation of women, men and transgender persons in all forums
- Promote participation of women's collectives in community response to TB

CORE VALUES

- Access for all
- Rights-based approach
- Empowered communities
- Work in partnership

The Framework aims at applying the gender lens to the existing and new strategies; programme functioning and implementation at all levels

I. DETECT

GENERAL PRINCIPLES

- Promoting free of cost services for all TB diagnostic methods, including free X-rays.
- Promoting accessibility to TB diagnosis and treatment services across all geographies, especially in tribal areas, rural areas and urban slums.
- Promoting improved understanding of the gender lens among public and private providers
- Promoting gender-sensitive Active Case Finding(ACF)
- Ensuring integration of TB screening into maternal and child health clinics
- Involving community in all case finding activities and improving accessibility to diagnostic testing by establishing community monitoring systems

KEY ACTIONS

A. Health Facility/Programme level:

1. Train RNTCP staff and peripheral health workers to apply the gender lens in diagnosing TB in women, men and transgender persons, including clinically diagnosed, EPTB and TB among pregnant and post-partum women. Some specific situations include:
   - When to presume TB, including EP TB and pulmonary TB in the absence of microbiological confirmation in the case of girls, women and transgender persons of all age groups, especially pregnant and post-partum women. For more information refer to the TB-Pregnancy Framework, the Technical and Operational Guidelines and the Index EPTB Guidelines
   - How to counsel and advice pregnant women with TB (Refer to Maternal Health Collaborative Framework for Management of Tuberculosis in Pregnant Women)
   - How to screen for and detect TB in pregnant women (Refer to Maternal Health Collaborative Framework for Management of Tuberculosis in Pregnant Women)
   - How to counsel and advice married women with Drug Sensitive TB (DS-TB) or Drug Resistant TB DR-TB, as well as their spouses or partners, on planning for pregnancy and use of contraceptives
   - How to advise transgender persons on hormonal therapy while they are on treatment for TB
   - Planning an alternative course of action where diagnostic tests including radiation pose a direct health threat to a pregnant woman and growing foetus
   - Providing guidance on how to bring up sputum for all genders including women, boys, girls and transgender persons

- Respecting the privacy and confidentiality of people of all genders including young girls, unmarried women and transgender persons while disclosing diagnostic test results or conducting house visits

2. Ensure screening of all pregnant and post-partum women for TB using the four symptoms complex through integration with maternal health services across all levels including:
   - Village Health and Nutrition Day (VHND) and in Anganwadis
   - Antenatal and Postnatal Care Clinics (ANC and PNC Clinics) in PHCs, Health and Wellness Centres (HWCs), Community Health Centres (CHCs), Rural Hospitals, District Hospitals, Urban Clinics and Hospitals
   - PMSMA – Pradhan Mantri Surakshit Matritva Abhiyan
3. Pay special attention to age and gender-disaggregated data to improve understanding of TB diagnosis trends among women, men, transgender persons and children of different age groups. For example, in the 0-6 age group, more girls than boys are diagnosed with TB
4. Promote gender-sensitive community-level ACF through the following potential actions:
   - Decide strategy for ACF in consultation with all stakeholders including patient representatives and TB Champions at District/Block level. Ideally, women, transgender persons and representatives of other vulnerable communities (e.g. tribal populations) should form at least 50% of those consulted. Separate meetings with these groups may provide valuable feedback
   - Ensure that the ACF teams are trained on gender-responsive questioning and the fundamental principle of 'do no harm' is conveyed during training
   - To promote representation and participation of all genders in the ACF team to the greatest extent possible
   - Ensure that people are given adequate information about the need for ACF, the process of ACF and provide verbal consent for home visits and further follow-up
   - Respect need for privacy and confidentiality while providing information on results of screening or referral for further testing for people of all genders, including unmarried women
   - Seek feedback from community on ACF to streamline processes in subsequent rounds of the activity
5. Orient RNTCP staff, peripheral health workers and other community health workers on essential messages and basic counselling to be provided to those presumed to have TB or diagnosed with TB

B. Private Sector:

1. Engage private providers through Indian Medical Association (IMA), Indian Academy of Pediatrics (IAP), the Federation of Obstetric & Gynaecological Societies of India (FOGSI), Public Private mix (PPM) unit of the RNTCP and various private sector interventions across the country to ensure that private practitioners are trained on and are aware of:
   - Overall, the gendered dimensions of TB diagnosis
   - When to presume TB, including EP-TB and pulmonary TB in the absence of microbiological confirmation in the case of girls, women and transgender persons of all age groups, especially pregnant and post-partum women. For more information refer to the TB-Pregnancy Framework, the Technical and Operational Guidelines, Training Module for Medical Officers and the Index EPTB Guidelines
   - When to refer to the public sector, based on an assessment of socio-economic factors
   - Identification of risk-groups / geographical areas with high prevalence, if any, and sharing this information with the RNTCP for planning of ACF drives
   - Utilising diagnostic tests available free of cost in the public sector to avoid catastrophic expenditure for people of all genders, including women, transgender persons, men from disadvantaged communities and the poor
   - Need to ensure complete data is reported with notification, including age and gender-disaggregated data

C. Community level:

1. Strengthen participation of TB Champions, survivor-led networks and people affected by TB in reaching out to the community to sensitise them about the symptoms of TB and facilities available for testing.
2. Strengthen the involvement of TB Champions in identifying and referring people with symptoms of TB to nearby health facilities.
3. Engage TB Champions in ACF drives to sensitise the community on the upcoming ACF activity to improve acceptance among all genders.
4. Establish and streamline mechanisms to ensure that those who refer (such as TB Champions) receive information on the diagnosis, to ensure follow-up for treatment initiation.
5. Strengthen feedback from the community regarding diagnostic facilities and their accessibility through community monitoring.
6. Foster collaboration on TB with other community structures such as the National Livelihood Mission, Mahila Aarogya Samiti, and Integrated Child Development Services centres etc.

B. TREAT

GENERAL PRINCIPLES

- Improving quality of services available to a person with TB
- Improving continued access to services by reducing the number of visits required and the waiting time
- Adopting and promoting comprehensive person-centric care, in all steps of interacting with the person with TB guided by her/his/their preferences for people with TB of all genders, including women and transgender persons
- Ensuring consent for home visits and visits to communities prior to carrying out the visit
- Ensuring respectful behaviour towards people with TB, confidentiality of their diagnosis and personal health information, and anonymity of identities during and beyond the treatment period
- Empowering communities and people with TB to understand their rights and responsibilities

KEY ACTIONS

A. Health Facility / Programme level:

1. Implement a comprehensive person-centric care and support system:
   - Ensure that all RNTCP, state and district TB programme staff, counsellors, treatment supervisors, peripheral health workers, treatment supporters and all others key stakeholders in policy and decision making have undergone gender-training to address the different needs of people with TB and their families
   - Make available counselling support to people with all forms of TB, through counsellors or peer counsellors from the community. Emphasise on the crucial role that counselling can play in successful treatment outcomes to all these groups
   - Empower people with TB by informing them about their rights and responsibilities
   - Adopt a respectful and supportive attitude towards those affected by TB, irrespective of the status of treatment
   - Respect the need for confidentiality of personal health information and anonymity of identities for all people with TB of all genders, including women and transgender persons, particularly with neighbours and sometimes also with family members
   - Strengthen treatment literacy by providing all necessary information on TB to those affected, including any gender-specific messages

- Provide nutritional counselling to the person with TB as well as family, particularly for children, women and transgender persons with TB. Enlist family members to support women's nutritional needs, especially in the case of elderly, widowed, divorced or separated women
- Actively support those with addictions to smoking, tobacco consumption, alcohol and drug use through linkage with deaddiction services
- Ensure timely availability of social support schemes to those eligible in order to ensure successful treatment outcomes and mitigate socio-economic impact
- Plan with parents of children about taking leave from school, providing a medical certificate and supporting the students to reintegrate in the education system. This is important especially in the case of children with DR-TB who may require longer leave of absence from school/college. This may result in drop-outs from the education system, especially for girls

2. Provide support to manage side effects:
   - Ensure that people with TB, especially DR-TB, have a full understanding of all possible side-effects and when to seek medical support
   - Manage minor side-effects with psychosocial support and counselling and ensure that major side-effects are brought to the attention of the medical practitioner.
   - Provide a private and non-judgemental safe space for all people with TB of all genders, especially women and transgender persons to enable them to speak freely. It is important to not be dismissive of any suffering due to side-effects. The table below is an example of how a conversation on side-effects can be conducted in a gender-sensitive manner:

Person with TB	Gender-sensitive adherence support	Gender-blind adherence support
Good morning sister, I have come to collect medications	Good morning, Lakshmi. It's been a month since you began taking medications for TB. How are you doing?	Have you been taking your medication all the time?
Well, I've been taking my medication as I'm supposed to … I just am very nauseous, tired all the time and then I want to sleep. I can't cook and clean like before. I'm so tired I find it difficult to do everyday activities	It sounds like it's been difficult for you. Do you think your tiredness could be a side-effect of the medication?	It's very important that you don't miss doses. You know that you have to take your that medication at the same time every day!
Yes, I think it is. The doctor told me that I might feel like this. He also said that I might get nausea because of the tablets	Has knowing this made it any easier for you to cope - knowing that what you're experiencing is common?	I'm sure it will go away soon. Just keep taking your medication
(Laughing) Yes! But, Sister, some days I'm tempted not to take my medication. I don't like the way it's making me feel	Perhaps you have days when you wonder if it's worth it. Maybe the side-effects make you feel worse than the TB was making you feel before you started treatment?	You know that it's really important to keep persisting. Everyone feels that way
Yes. (Starts crying) I know it's really important for me to take the drugs every day, and I'm scared that I will miss doses and then the drugs won't work anymore and I'll get sick and die. There'll be nothing left for me	I can see that you realise how important it is to adhere to your medication, but it seems like you're putting a lot of pressure on yourself, too. Would you like to spend some time looking at how you can manage these side-effects more easily?	You have to pull yourself together, otherwise you'll make yourself sicker than you are now. Do you want that?

Yes, please. I really need to see if there are things that will help me to get through this	Tell me more about your nausea. When do you feel it most?	
Usually in the morning when I reach the market to sell my goods. I have the tablets on an empty stomach. I get late because I have to make breakfast for my husband and get my children ready for school, then I have to hurry to the market. I barely have time to eat breakfast myself (Gender role)	One reason for your nausea could be that you don't get time to eat breakfast. One suggestion is that you carry some bread or biscuits with you and have them as you go to the market or after getting there. Do you think you could enlist your husband's help in getting your children ready for school and get some time to eat something yourself? (Addressing gender role)	Your nausea is because you are not eating. You have only yourself to blame. Eat breakfast and your nausea will go away

Adapted from "WHO: Integrating Gender into HIV/ AIDS programmes in the health sector 2009"

3. Take actions specific for priority and vulnerable populations:

Women and Girls

- Enlist active family support, especially of the husband and parents-in-law, to ensure nutrition, rest and uninterrupted treatment in case of women, including married women, widowed, divorced or separated women and elderly women
- Offer counselling for the people with TB and their family to dispel unfounded stigma about the disease which often disproportionately affects women and unmarried young girls
- Provide, where relevant, information on interference of TB drugs with other medication, especially oral contraceptive pills and advise on other methods of contraception
- Reiterate the safety of first line anti-TB drugs in pregnancy. Emphasise the importance of completing TB treatment to ensure better outcomes for the mother and child. Involve families in this conversation as much as possible
- Emphasise the importance of completing TB treatment even if the woman becomes pregnant during the course of the treatment
- Screen all those being initiated on DR-TB treatment for pregnancy and advise to avoid pregnancy during treatment. If

a pregnant woman has been diagnosed with DR-TB, provide the option of medical termination of pregnancy if the period of gestation is less than 20 weeks. (Refer to RNTCP and Maternal Health Collaborative Framework for Management of Tuberculosis in Pregnant Women)

Persons using Alcohol, Tobacco or Drugs

Men, transgender persons or women may be in the habit of using tobacco or drugs, consuming alcohol and may also smoke. Therefore:

- Ask all TB-affected persons about these habits in a respectful and sensitive manner, maintaining a non-judgemental attitude
- Provide information about poor outcomes and offer counselling for uninterrupted treatment
- Enlist family support for de-addiction and link people with TB to de-addiction services

For more information, refer to the National Framework for Joint TB-Tobacco Collaborative Activities.

Transgender persons

Transgender persons with TB also may use drugs or alcohol, or may smoke. They may not disclose their habits because of the judgemental attitudes they could face from providers

- Maintain a non-judgemental attitude towards those seeking diagnosis and care and establish respectful, empathetic and consistent communication to build their confidence
- Ensure screening for HIV and TB, if not already done and link to appropriate centres to screen for STIs if required
- Provide information about poor outcomes with addictive substances as mentioned above

4. Provide, to the greatest extent possible, integrated health services for all:
   - Those with TB may need to access services from various health departments. E.g. Pregnant women need to access ANC and PNC services along with TB treatment; people living with HIV may need to access care for HIV and TB; pregnant women with HIV may need all three services. Planning and providing TB services in an integrated manner is important to ensure that multiple visits to different clinics is avoided as far as possible. This can be done through efficient coordination and alignment of services of different departments
   - Seek feedback from people with TB, TB Champions and peripheral health workers through regular group meetings. This enables identification of any gaps in service delivery. Ensure the equal participation of women, transgender persons and representatives of vulnerable communities through mixed and separate groups, taking care that participation of vulnerable groups is not tokenistic

- Collaborate with Integrated Child Development Services (ICDS) and Nutrition Rehabilitation Centres (NRCs) to provide specialised diet and nutrition counselling to extremely undernourished women and children with TB, on an out-patient basis

B. Private Sector:

1. Organise and facilitate workshops for the private sector in coordination with professional bodies to ensure orientation of the private sector to the need for gender-responsive treatment provision
2. Emphasise on the need for gendered treatment adherence support. Private practitioners can provide treatment adherence support either by referral to the programme or by enlisting the support of private sector interventions or peer-support groups operational in the vicinity
3. Encourage private providers to avoid catastrophic costs to people with TB during treatment by referral to the public sector or enlisting the support of private sector interventions for medicines and follow-up investigations
4. Educate and encourage private providers to:
   - Enlist family support and counselling at diagnosis and during follow-up visits for people of all genders, especially women
   - Ensure linkages to de-addiction centres for substance abuse and smoking cessation by identifying service providers in the vicinity in the public or the private sector
   - Arrange for provision of nutritional counselling in the clinic or enlist support of the RNTCP for relevant IEC materials
   - Support people with TB by facilitating leave from workplace / school / university as well as reintegration into the workplace/educational institution
   - Adopt a non-judgmental attitude towards transgender persons in the habit of using alcohol or other addictive substances, if and when they seek care in the private sector

C. Community level:

1. Encourage and support the training of TB survivors in providing psychosocial support to people with TB who are on treatment
2. Involve TB Champions in regular patient-provider meetings, ensuring participation of women TB Champions
3. Enlist the support of TB forums, TB Champions and survivor-led networks for community monitoring and feedback on the quality of treatment services
4. Involve TB Champions in providing people with TB with information on available social support schemes, including but not limited to Nikshay Poshan Yojana

C. PREVENT

GENERAL PRINCIPLES

- Devising and implementing mechanisms to screen healthcare workers for TB
- Implementing preventive actions including contact screening and chemoprophylaxis by enlisting the support of women and men in the family
- Involving community influencers of all genders to improve cough hygiene in the community

KEY ACTIONS

A. Health Facility/Programme level:

1. Ensure effective household contact tracing and provision of chemoprophylaxis:
   - Motivate and counsel those affected by TB and their family members to ensure screening of household contacts, especially children and women
   - Ensure that family members who go to school, college or work, or are travelling are not missed out in contact tracing
   - Identify the following as having special vulnerability for TB and screen them
     - Women in the family who are care-givers of people with TB
     - Women who use solid fuels for cooking
     - Pregnant and post-partum women in contact with people with TB
     - People of all genders including men who smoke, use drugs or tobacco, drink alcohol
     - Adolescent boys and girls in the family
     - Transgender persons and their contacts who live in crowded communities and have poor access to healthcare
2. Implement effective airborne infection control:
   - Ensure the implementation of existing airborne infection policies/revise according to assessment findings, with a focus on pediatric, maternal and ART clinics and while planning for privacy
   - Effectively implement the policy of periodic screening of staff nurses and other healthcare workers for TB (Refer to Healthcare Workers Surveillance for TB in India – A Handbook)
   - Ensure adherence to infection control guidelines in sputum collection and transport

(Refer to Health and Safety Guidelines for Staff/ Workers involved in Sputum Transportation)

For more information on this, refer to Guidelines on Airborne Infection Control in Healthcare and Other Settings

3. Prioritise Latent TB Infection (LTBI) screening of people of all genders,

including women, children and other vulnerable populations and ensure LTBI screening and management, including counselling, for all beneficiaries identified under the programme

B. Private Sector:

1. Ensure that private providers are educated and encouraged to:
   - Educate staff nurses and healthcare workers about airborne infection control in the context of prevention of TB
   - Arrange for periodic screening of healthcare workers for TB, with a focus on extra-pulmonary TB, given majority of the health workforce in terms of nurses/nursing assistants are women
   - Provide counselling and follow up for all contacts, with a focus on educating women and men in the family to take the lead in completion of contact screening
   - Educate parents on chemoprophylaxis and initiate chemoprophylaxis as per guidelines after ruling out active TB infection

C. Community level:

1. Ensure that the education materials provided to people affected by TB represents all genders and outlines the importance of contact screening/ chemoprophylaxis and measures for prevention
2. Ensure that all people with TB and caregivers of all genders, including men are counselled on the need to practice cough hygiene and take the lead in sharing the message among their communities
3. Seek feedback from people with TB and TB Champions about common socio-cultural problems faced by people with TB of all genders, especially girls and women, both as people affected by TB and care providers, in maintaining cough hygiene. Work together to provide acceptable solutions
4. Support and encourage cough hygiene drives/campaigns by TB Champions/ community health workers or through educational institutions

D. BUILD

GENERAL PRINCIPLES

- Building the capacity of RNTCP staff and healthcare workers for the provision of gender-sensitive care
- Strengthening linkages between the programme, private sector and the community to synergise efforts towards the provision of gender-sensitive care and receive regular feedback
- Strengthening the community response to TB by building the capacity of TB survivors and establishing networks/forums
- Aiming for gender parity in the RNTCP workforce

KEY ACTIONS

A. Health Facility / Programme level:

- Build the capacity of the healthcare system to provide gender-responsive, person-centered care as outlined in the above sections
- Aim for gender parity in the work-force to achieve nearly equitable participation of all genders in the long-term
- Adopt a gender-sensitive approach in the selection of treatment supporters in the community
- Orient treatment supporters on essential messages and basic counselling to be provided to those with TB in order to clear misconceptions and improve treatment adherence
- Use gender budgeting as a strategy to analyse the planning, provisioning and implementation of health programmes in general and RNTCP in particular. Take steps towards more equitable planning and budgeting for TB programmes at the National and State levels
- Display information on local support services available for women, men and transgender persons who experience gender-based violence

B. Private Sector:

- Strengthen linkages with the programme/ private sector interventions for the provision of gender-responsive, person-centric care
- Strengthen linkages to peer support groups for treatment adherence support
- Incorporate training on gender-sensitive provision of care into regular capacity-building /Continuous Medical Education programmes for private providers

C. Community level:

- Identify TB Champions including women, men and transgender persons, who are survivors of TB and keen to support others in the community to access TB services

- Facilitate or support the formation of support groups for people with TB involving women, men and transgender persons, wherever possible. There may be separate groups for women and transgender persons to enable them to voice their opinions effectively
- Ensure that all State and District TB forums have the participation of male and female TB Champions and transgender persons, wherever possible
- Promote the active participation of women's collectives in the community response to TB
- Encourage the community to speak up about gender-based violence as a result of TB and identify resources to support those affected

SECTION

IV

I. SUPERVISION, MONITORING AND EVALUATION WITH A GENDER LENS

Conventionally, monitoring and evaluation is focussed on interpreting and instituting corrective mechanisms to address gaps in case finding and treatment outcomes. Monitoring and evaluation in implementation of the gender framework should, in addition, also focus on recording, interpreting and applying gender disaggregated data to devise mechanisms that ensure gender-responsive interventions. Evaluation of gender-responsive programming should be incorporated into the existing evaluation framework used by the programme at all levels and should not be undertaken as a standalone activity.

A. USE OF GENDER/AGE DISAGGREGATED DATA

- Ensure that all data published in national and state reports are disaggregated by sex, gender and age, to the greatest extent possible, to enable a better understanding of the epidemiological profile of TB in India
- Use gender and age-disaggregated data for active programme monitoring, trend analysis and decision-making at national, state and district levels. Age and gender-disaggregated data can reveal the following:
  - The epidemiological profile of TB in a state and district, including age and gender distribution
  - Comparison with national figures and local trends can reveal if there are any difficulties in access to services for some sub-populations. For example, limited diagnosis of TB among the following groups

indicates poor access to TB services:

a. Girls and women below the age of 35 years

b. Transgender persons (in districts with communities of transgender persons)

c. Pregnant and post-partum women

- Map geographical distribution of people with TB to help trace underserved areas.
- Analyse ACF data by gender on a regular basis for increased understanding of local trends.
- Overall, the study of differences in age and gender disaggregated data can call attention to disparities or unusual trends in certain geographic areas. Further qualitative investigation would be required to identify the causative factors and tailor measures to address these differences.

B. FEEDBACK FROM SERVICE USERS

- Ensure that State and District TB forums seek feedback from peer support groups and TB Champions on various aspects of programme performance, which should be used for suitable modifications in programme implementation.
- Seek regular feedback to understand the acceptance of TB services and the problems people face in accessing services.

C. GENDER-RESPONSIVE MONITORING AND EVALUATION

- All components of monitoring and evaluation will consider gender as an important criterion at all levels.
- Ensure proportionate participation of all genders as part of the monitoring and evaluation teams to the greatest extent possible
- Evaluate gender training of staff and mainstreaming of gender in all programme components.
- Some indicators for the monitoring of a gender-responsive TB programme include:
  - Age (0-4, 5-14, 15-24, 25-34, 35-44, 45-54, 55-64, >65) and gender-(women, men and transgender persons) disaggregated data among total TB cases notified
  - Age and gender-disaggregated data among TB cases initiated on treatment among those notified
  - Age and gender-disaggregated data for TB cases notified in the previous year and successfully treated, (<15 years, 15 - 24 years, 25-34 years & >34 years need to be specifically included)
  - Age and gender-disaggregated data on number of deaths during treatment
  - Age and gender-disaggregated data on number of people with TB

Lost-to-follow-up before and after initiation of treatment

- Age and gender-disaggregated data on proportion of household members undergoing contact screening for TB and no. of household members started on chemoprophylaxis according to prevailing guidelines
- Proportion of male, female and transgender persons among people with DR-TB
- Proportion of pregnant and post-partum women diagnosed with TB
- Proportion of pregnant and post-partum women initiated on treatment among those diagnosed
- Proportion of male, female and transgender persons diagnosed with microbiologically confirmed, clinically diagnosed and EPTB
- Proportion of male, female and transgender persons initiated on treatment from among those diagnosed with microbiologically confirmed, clinically diagnosed and EPTB
- Proportion of RNTCP programme staff who have undergone gender sensitisation training
- Proportion of male, female, transgender persons among RNTCP staff at various levels
- Proportion of children by sex who received BCG vaccination

II. GENDER-SENSITIVITY TRAINING FOR HEALTH STAFF

Gender-sensitivity training is a first, critical step in building a gender-responsive programme. All RNTCP staff, at the national, state and district levels, will be trained to understand gender conceptually as well as how gender and TB interact. The main objective of the trainings will be to bring about a change in the knowledge, attitudes and practices of all staff, so as to ensure that the implementation of the programme moves to being gender-responsive.

- Create gender focal persons at the national and state levels to handhold and oversee strategies for a gender-responsive TB programme
- Create a national and state level pool of gender trainers within the RNTCP by organising a 'Training of Trainers' at the national and state levels
- Provide gender sensitisation training to all RNTCP staff at the national, state and district levels on an incremental basis, especially medical officers, service providers, healthcare workers, counsellors, treatment supporters, and managers and also ACSM staff and those responsible for monitoring the programme. The training must be participatory with hands-on demonstration of gender-responsive care
- Involve civil society organisations working with a gender focus, including those working with transgender persons as resource persons in trainings
- Include the following components in a standardised gender sensitisation training. The training will emphasise

actions that can be taken to make the TB programme gender-responsive at all levels. The training will focus on action points for Medical Officers, Programme staff, peripheral health workers and ACF teams and will be demonstrated through interactive activities and role-plays. Participants will be encouraged to recognise and address any inherent biases they may have

a. Concept of patriarchy, gender, gendered division of labor, power in gender relationships and access to education, finances, property, mobility etc.
b. Gender as a fluid everyday concept, gender diversity and diversity of sexual orientations
c. Gender as a determinant of health
d. Age and gender specific epidemiology of TB in India
e. Role played by gender in vulnerabilities and risk factors to TB, access to healthcare, adherence to treatment and outcomes including the interactions between biological and socio-cultural factors
f. Gender barriers in access to healthcare in general and particularly for TB
g. Gender power relationships within the health system
h. Gender responsive strategies for TB and steps towards a gender equitable TB programme
i. Providing linkages to organisations working on gender issues and to services to address gender-based violence

- Integrate components and strategies for a gender responsive TB programme in all existing, regularly scheduled modules and trainings conducted in the TB programme
- Adapt the gender sensitisation training module as required for different audiences and for shorter and longer trainings
- Review existing training modules, including all training materials and tools with a gender lens and make appropriate changes to make them gender-responsive
- Strengthen the capacity of all state and district TB programme staff, including counsellors, treatment supporters and community health workers to provide women, men and transgender persons with TB prevention, screening, treatment, and treatment literacy in a gender-sensitive manner as a routine part of their work

III. ADVOCACY, COMMUNICATION AND SOCIAL MOBILISATION ACTIVITIES

Gender dimensions are important in the planning and implementation of ACSM. Gender-responsive ACSM activities can convey to the beneficiaries that the programme is sensitive to the gender norms and needs. The following are suggested interventions to make ACSM more gender-responsive

- Use a gender lens in planning, defining, implementing and reviewing the advocacy, communications and social mobilisation strategy
- Create role models among women TB Champions and encourage survivor networks to reach out to women and transgender persons among survivors in particular.
- Adapt and widely publicise a gender-responsive charter for people with TB.
- Provide platforms for recognition and appreciation of TB Champions of all genders, particularly women and transgender persons for exemplary work in advocating for the groups / communities they represent
- Involve TB Champions to carry out continued advocacy for TB-free Panchayats to Panchayati Raj Institutions at various levels, Self-Help Groups and other community structures, to highlight TB in general and its gendered dimensions.
- Ensure regular meetings with affected community groups, survivor-led networks and others to discuss access to and quality of gender-responsive services, and get feedback.
- Strengthen capacity of civil society organisations and community-based

groups to provide gender-responsive services and conduct gender-sensitive awareness campaigns.

- Include gendered aspects of TB in advocacy to other stakeholders including but not limited to elected representatives at various levels, industry leaders and the media. State-level IEC officers can strengthen the news media's understanding of TB and gender issues.
- Ensure equal representation of women, girls, men and transgender persons in all mass media, mid media, social media and traditional media about TB.
- Adopt communication strategies aimed at:
  - Communicating to care seekers of all genders about the availability of gender-responsive services for diagnosis and treatment of TB.
  - Increasing awareness about TB with specific messaging that takes into account gender identities and vulnerabilities among women, transgender persons and tribal communities. For this, communication campaigns will need to be adapted and taken to tribal areas, urban slums and other areas with vulnerable populations.
  - Increasing awareness about TB for pregnant and post-partum women among medical professionals, including public and private practitioners, ANMs, ASHAs, urban health workers and the community.
  - Improving messaging about clinically diagnosed TB and EP TB to ensure people with TB know which forms of TB are infectious and which forms are not.
  - Communicating to people with TB of all genders on the importance of contact screening urging them to take responsibility for screening all members of a household where required.
  - Addressing stigma and discrimination faced by women, men and transgender persons with TB.
  - Ensuring that people with TB are aware of their rights and responsibilities.
  - Focusing on campaigns for men as caregivers for women and children affected by TB.
  - Increasing awareness of social support schemes meant for people with TB.
  - Focusing on people with TB who are using drugs, tobacco or alcohol and encouraging them to seek support.

- Developing state, context, site-specific and stakeholder specific materials.
- Developing audio-visual communication materials as well as using innovative new media options including mobile technology, to communicate everyday gender issues
- Ensure that all job aids for health staff include messages about providing respectful, gender-responsive care and support.

IV. ROLES AND RESPONSIBILITIES OF VARIOUS STAKEHOLDERS

Building a gender-responsive response to TB in India is a joint process that requires the understanding and sustained efforts of everyone within the programme and other stakeholders outside the programme. The following table lists the roles and responsibilities of key institutions and players who are part of the TB response:

INSTITUTION	RESPONSIBILITIES
Central TB Division	◆ Formulating guidelines ◆ Making policy decisions that would be required to implement the gender framework ◆ Planning and provision for training on the gender framework and its implementation ◆ Promoting and approving activities pertaining to gender-responsive programming/training in the state PIPs ◆ Ensuring collection, analysis and publication of gender-disaggregated data in all reports and documents ◆ Budgeting for gender-surveillance and activities related to the implementation of the gender framework ◆ Guiding and promoting inter-departmental coordination (Refer to National Framework for inter-ministerial collaboration)

	◆ Monitoring and evaluation of indicators pertaining to gender-responsive programming ◆ Prioritising and implementing research pertaining to gender differences along the natural history of the disease and the care cascade
State TB Cell	◆ Adopting a gender lens in all programme implementation as outlined in the framework ◆ Providing guidance to districts on integrating the gender framework and requisite budgeting ◆ Compilation of district budgets on integration of the gender framework and inclusion of the same in the state PIP ◆ Ensuring compilation, and publication of gender disaggregated data in all reports and documents ◆ Engaging the private sector in the implementation of the gender framework through dialogue with relevant medical bodies such as IMA, IAP, FOGSI etc. ◆ Establishing TB forums with representation from all genders ◆ Liaising with relevant departments such as DHS and DME for coordination to implement the gender framework ◆ Ensuring gender-responsive recruitment at all levels ◆ Ensuring that all behavioural change strategies and IEC materials that are developed are gender-sensitive ◆ Consolidated and disseminating good gender practices on a regular basis
District TB Cell	◆ Implementing the gender framework in day-to-day activities ◆ Engaging and training private sector on the gender framework ◆ Forming and sustaining TB forums at the district level that are representative of all genders and key affected populations ◆ Ensuring that all peripheral health workers are trained in the gender dimensions of TB

	◆ Establishing and fostering linkages between the private sector, TB survivors and people with TB for sustained and comprehensive TB response ◆ Reporting gender-disaggregated data and any gender-relevant observations to the State TB Cell and Central TB Division (CTD) ◆ Engaging TB Champions and survivors in all relevant activities, including case detection, prevention, provision of treatment ◆ Conceptualising, implementing and sharing good gender practices at all levels of implementation
Medical officers - MOTC and Medical officers of Peripheral Health Institutions	◆ Understanding gender differences in vulnerabilities, health seeking, treatment adherence, outcomes and socio-economic determinants ◆ Handholding of peripheral health workers in understanding and implementing the gender framework ◆ Ensuring and nurturing a friendly and respectful ethos devoid of stigma in the health facility for people of all genders and vulnerable population groups ◆ Regular review of facility-level gender-disaggregated data ◆ Monitoring and providing feedback to district on implementation of the gender framework
Peripheral healthcare workers	◆ Understanding gender differences in vulnerabilities, health seeking, treatment adherence and outcomes ◆ Treating with respect and dignity people of all genders and vulnerable groups ◆ Ensuring generation of gender-disaggregated data ◆ Seeking and enlisting the support of people with TB and social influencers to address harmful gender norms in the community and families ◆ Providing access to person-centric quality TB care services, including detection, prevention and treatment

Civil society organisations and community groups	◆ Assisting the National, State, District TB cells and peripheral institutions with the implementation of the gender framework ◆ Integrating the gender perspective into service provision, research and all aspects of support to the TB programme wherever relevant ◆ Supporting the District/State TB cell in capacity building of medical officers/health workers and affected communities on gender dimensions ◆ Integrating TB in implementation of Reproductive, Maternal, Newborn and Child health Programme or women's health programmes and projects
TB Champions and survivor networks	◆ Incorporate the gender perspective in provision of support to people with TB in the public and the private sector ◆ Apply the gender lens to community-based monitoring of TB care services ◆ Provide constructive feedback to District and State TB Cells on the provision of care at all levels ◆ Ensure the participation of women and transgender persons in survivor-led networks and other community groups

V. RESEARCH AND KNOWLEDGE BUILDING WITH A GENDER LENS

Women in general and specifically adolescent girls, elderly women, pregnant, post-partum women and transgender persons as well as other vulnerable populations have been inadequately represented in research on TB. In addition, there has been inadequate gender and social group analysis of data generated through studies on TB. Drawing on the 'Research in Gender and TB' document (World Health Organization, 2004)', the following key areas of gender-responsive research on TB are proposed:

A. SEX AND GENDER EQUITY IN RESEARCH

- Ensure equal or proportionate participation of women, men, girls and boys in research
- Ensure proportionate representation of pregnant and post-partum women, adolescent girls and boys and elderly women in research study samples, where relevant
- Adopt a policy of presumed inclusion of pregnant and post-partum women in clinical trials and operations research unless there are reasons to exclude them. Such reasons should be documented
- Ensure participation of transgender persons, sex-workers, men who have sex with men, drug users, consumers of alcohol and tobacco and persons who smoke, people living with HIV and other priority populations
- Ensure participation of tribal women, men and transgender persons
- Place an equal emphasis on tribal, rural and urban areas in TB research

- Disaggregate all research data by age, gender, class, caste, ethnicity, religion, occupation and other relevant socio-demographic indicators for analysis to the greatest extent possible
- Advocate with the Indian Council of Medical Research (ICMR) and the Indian Council of Social Science Research (ICSSR) to provide guidelines for this purpose

B. BIOLOGY AND EPIDEMIOLOGY OF TB

- Bridge gaps in understanding the biology and epidemiology of TB, including TB presentations and natural course in women, men and transgender persons as also their interaction with gender and socio-cultural factors
- Research priorities include studies to better understand:
  - The epidemiology, biology and immunology of TB among women, girls and boys, pregnant and post-partum women, women living with HIV, transgender persons and transgender persons living with HIV
  - Clinically diagnosed TB and EPTB in women, men and transgender persons
  - The progression of TB infection to TB disease in women, men and transgender persons and in pregnant and post-partum women; including gendered aspects of women's, men's and transgender persons' lives which contribute to social stress and support
  - The proportion of maternal deaths and morbidities on account of TB and interaction with gender and socio-cultural realities of women's lives
  - Social, psychological, economic and perinatal implications of TB among pregnant women
  - Psychosocial and medical issues related to female genital TB, especially for those who present with infertility
  - Gender-based vulnerabilities with reference to particular risk factors & social dynamics of TB co-infection with HIV, diabetes etc.

C. DIAGNOSIS, TREATMENT AND TREATMENT ADHERENCE

- Undertake research to study provider-level delays in diagnosis and its impact on treatment outcomes of people with TB of all genders, including for women and transgender persons
- Study the utility and efficacy of bronchodilators in helping women with symptoms to bring up good quality sputum and its effect on early diagnosis and treatment of women affected by TB
- Study improvement in patient-provider interactions on early diagnosis and treatment
- Study specific impediments to treatment adherence in women, men

and transgender persons and study factors helping women in better treatment adherence

- Comparative study of innovations in community and facility-based treatment support and impact on treatment adherence
- Study and understand gender-specific reasons for TB-related stigma, provider and patient level delays and treatment outcomes

D. HEALTH SEEKING BEHAVIOUR

- Design and implement an operations, interventions and qualitative research agenda that focuses on gaps in the understanding of gender dimensions of care seeking and access to TB services
- Undertake gender and age-group wise analysis of healthcare seeking behaviour among people with symptoms of TB, especially in girls, women, pregnant and post-partum women and transgender persons, with a specific emphasis on pathways to health services, access to diagnosis and care, delays in diagnosis and treatment initiation and barriers to care
- Analyse gender-specific determinants of poor treatment, reasons for drop outs, discontinuation of treatment and factors associated with relapse and poor outcomes especially among migrants, transgender persons, those using addictive substances and smokers
- Assess reasons to opt for public sector or private sector or AYUSH providers or informal care among women, men and transgender persons
- Analyse and understand gender-specific outcomes and develop appropriate policies to counter their effects

E. QUALITY OF CARE

- Design and implement studies on quality of care and perceptions of quality of care in the public and private sectors, especially experiences of women, men, transgender persons, men who have sex with men, sex workers, people who use drugs, migrants, smokers and tobacco users, those addicted to alcohol, tribal populations etc.
- Undertake an analysis of the perceptions and behaviour of providers and administrators regarding the importance of understanding gender dynamics
- Assess the perceived and actual value and utility of gender training in improving the quality of care and the consequent change in health seeking behaviour

F. UNDERNUTRITION AND TB

- Undertake research studies on the relationship between undernutrition in women, adolescent girls, pregnant and post-partum women and TB
- Undertake research studies on the relationship between anaemia in women including adolescent girls, pregnant and post-partum women and TB

- Undertake research studies to understand the comparative impact of supplementary nutrition in various forms (e.g. food supplies, conditional cash transfers, provision of supplementary meals) on TB treatment and outcomes

G. OTHER AREAS FOR QUALITATIVE/ IMPLEMENTATION RESEARCH

- Social psychological and economic implications of TB in pregnant women
- Assess utility of universal screening and strategies for early diagnosis and treatment among women in antenatal clinics
- Evaluate utilisation of TB services among hard to reach areas
- Study change in clinic attendance on account of innovations undertaken such as
  - enhancing social and communication skills for healthcare personnel
  - community advocacy addressing identified gender-specific needs of people with TB
  - flexible clinic timings and other similar interventions
- Determine factors leading to favourable outcomes for women on TB treatment
- Undertake research to understand particular socio-culture and gender-specific misperceptions of risks and social exclusion and stigma, which can be used to devise ACSM strategies
- Study gender-specific feedback on service-delivery in public and private health institutions
- Assess employer and employee perceptions of value of TB diagnostics and treatment services in the workplace and employer responses in terms of the potential economic benefits of less absenteeism, greater productivity and reduced travel expenses
- Design studies for a better understanding of TB and social suffering

VI. STATE-SPECIFIC INNOVATIONS WITH A GENDER LENS

States are encouraged to come up with innovative methods to address the gender differences in vulnerabilities, risks, health seeking, treatment adherence, outcomes or other points along the care cascade. This could focus on improving treatment adherence by providing support services for men who consume alcohol, provision of nutritional support to improve outcomes, addressing stigma among women through ACSM activities, improving community engagement in ACF by involving women and transgender persons, etc. States are encouraged to identify gender-based issues specific to the local context and tailor innovations to address those issues with the help of the TB Champions and the TB forums at the district and the state.

VII. INTER-MINISTERIAL COLLABORATION AND MULTI-STAKEHOLDER ENGAGEMENT

As a socio-economic disease with consequences beyond health, TB requires a multisectoral response. This involves building and strengthening collaboration with ministries and departments beyond health at national and state levels to achieve a gender-responsive approach to TB. A detailed National Multisectoral Action Framework is available. To achieve a gender-responsive approach, the following can be considered:

- Collaborating with the Ministry of **Women and Child Development (WCD)** at the Centre and WCD departments at the state level to provide supplementary nutrition and take-home rations to people with TB. They are well placed to provide special attention to nutrition of children, pregnant and post-partum women with TB. WCD can also help strengthen linkages to local support services for people with TB who experience gender-based violence.
- Collaborating with the Ministry of **Panchayati Raj** to
  - Engage women's collectives and female elected representatives at the community level as leaders in the response to TB
  - Strategise for stigma reduction and creation of TB-free Panchayats by involving local elected representatives
  - Improve awareness of TB in the community
- Collaborating with the Ministry of Social Justice and Empowerment and departments under the ministry

- To review available social support schemes for women, men and transgender persons and expanding them to include those affected by TB where possible. Some examples are:

- Provision of disability benefits
- Provision of travel benefits
- Pensions
  - For schemes to offset wage loss during the treatment period for women, men and transgender persons affected by TB
- Collaborating with the **Public Distribution Ministry/System** to augment the nutrition supplies for families with one or more people with TB (Ministry of Consumer Affairs and Food, Public Distribution).
- Collaborating with the Ministry of **Education** for
  - Special concessions such as a long-term leave for students — girls, boys as well as transgender persons with TB
  - Ensuring minimal disruption in the education of students with TB
  - Special measures to integrate students who are non-infectious and those who have completed treatment into the education system
  - Special measures to maintain the anonymity and confidentiality of students with TB
  - Incentivising the completion of schooling for students with TB
- Collaborating with other ministries/ departments including but not limited to:
  - The Ministry of **Tribal Affairs** to include intervention strategies for TB elimination in the Tribal Sub-Plan
  - The Ministry of **AYUSH** for sensitisation of AYUSH providers on gender-responsive approach
  - The Ministry of **Law and Justice** to undertake an analysis of legal and policy scenarios around gender and TB
  - The Ministry of **Communications and Information Technology** and Ministry of **Information and Broadcasting** to
- Help in implementing the ACSM strategy
- Raise awareness on services and benefits available through the RNTCP for care and prevention of TB
  - Ministry of **Petroleum & Natural Gas** to undertake studies on use of solid fuels and TB incidence and promote the use of LPG in all homes, especially in tribal and rural areas
  - Ministry of **Road Transport & Highways** and Ministry of **Railways** to provide travel concessions for people with TB

- Ministry of **Housing & Urban Poverty Alleviation** for prioritisation of people with TB in the provision of well-ventilated housing
- Ministry of **Labour and Employment** to develop labour policies to support those affected by TB in getting special medical leave, re-joining the workforce after a gap, reimbursement of medical expenses etc.
- Ministry of **Skill Development and Entrepreneurship** to provide vocational training and entry into the workforce post recovery from TB
- Ministry of **Coal, Ministry of Micro, Small and Medium Enterprises** and Ministry of **Heavy Industries and Public Enterprises** to sensitise employers in implementing the Employer Led Model for care and prevention of TB in workplaces

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ANNEXURE : CHECKLIST TO ASSESS IMPLEMENTATION OF THE GENDER FRAMEWORK AT VARIOUS LEVELS

S. No	Question	Yes (Score = 1)	In progress (Score = 0.5)	No (Score = 0)
POLICY AND STRATEGIC DOCUMENTS, GUIDELINES (NSP, TOG)				
1.	Are gender issues clearly articulated in the policy and strategic development and review process, via the following major components? - Vision/mission statement - Strategic objectives - Target audience - Guiding principles - Activities - Budget/Finance - Monitoring and Evaluation (M&E)			

S. No	Question	Yes (Score = 1)	In progress (Score = 0.5)	No (Score = 0)
2.	Does the policy and/or strategic framework take cognisance of the various vulnerabilities of women, men and transgender persons of different age groups and socio-economic backgrounds?			
3.	Does the policy and/or strategic framework clearly stipulate specific measures for targeting special groups, and disadvantaged and vulnerable women, men and transgender persons?			
4.	Do all the policy documents and technical or operational guidelines issued by the program incorporate a gender perspective?			
SERVICE DELIVERY				
5.	Has the programme developed and implemented a patients Charter with a gender perspective?			
6.	Does the TB programme provide gender-sensitive couple/family counselling for people with TB/symptoms of TB to ensure diagnosis and treatment adherence?			
7.	Does the programme provide gender sensitive counselling to address stigma and discrimination in the household / community / workplace?			
8.	Does the TB programme provide nutritional support to all people with TB to promote TB adherence to treatment by ensuring that provision of standardised treatment includes nutrition support to all genders?			

S. No	Question	Yes (Score = 1)	In progress (Score = 0.5)	No (Score = 0)
9.	In order to ensure access to services by women, men and transgender persons (especially those that cannot afford indirect costs, such as transport), has the program decentralised diagnosis health services for TB diagnosis and treatment?			
10.	Are diagnosis and treatment services free?			
11.	Does the programme provide for mobile clinic services to communities to increase access to services for women, men and transgender persons?			
12.	Is the programme ensuring collaborative TB/HIV initiatives that address the specific needs of women, men and transgender persons, both in the public and private sector?			
13.	Does the programme integrate MCH and TB care services in all health facilities?			
14.	Does the programme sensitise private providers on gender-sensitive provision of TB care services?			
STRENGTHENING THE GENDER-RESPONSIVENESS OF THE HEALTH SYSTEM				
15.	Has the programme developed a module for gender sensitisation of its officers, programme managers and health staff?			
16.	Has the programme undertaken gender sensitisation training for all its officers, programme managers and health staff?			
17.	Has the gender module been incorporated into the induction training curricula for all staff?			

S. No	Question	Yes (Score = 1)	In progress (Score = 0.5)	No (Score = 0)
18.	Has the programme made provisions to ensure the gender module is included in the refresher training held annually?			
19.	Has the programme devised mechanisms to ensure gender parity in recruitment at all levels?			
	ACSM			
20.	Does the programme engage people with TB, caregivers in designing IEC materials with a view to ensuring that IEC materials on TB reflect the views and realities of people with TB and caregivers?			
21.	Does the programme promote the use of gender- and culturally-sensitive IEC materials to deconstruct negative stereotypes about women, men and transgender persons? For e.g.: Women will not be able to marry because they acquired TB, men should be terminated from their jobs if they develop TB			
22.	Does the programme ensure parity in visual representation that counter stereotypes of gender roles? E.g.: A husband taking care of a woman with TB, A transgender health worker proving counselling to a person with TB, A woman doctor attending to a person with TB			
23.	Does the programme promote equal involvement of male, female and transgender person role models in TB awareness campaigns?			

S. No	Question	Yes (Score = 1)	In progress (Score = 0.5)	No (Score = 0)
24.	Does the programme encourage equal participation of women, men and transgender persons (including community leaders and traditional healers) in all community-based mobilisation campaigns to increase knowledge and understanding on disease prevention measures?			
25.	Does the programme encourage open discussions in communities on stigma and discrimination due to TB?			
26.	Do IEC materials and sessions target different groups of people, including mothers, fathers, pregnant women, adolescent girls and boys, and school children, with a major focus on prevention and early treatment-seeking?			
27.	Does the programme ensure equal representation of all genders in the TB forums constituted at all levels?			
MONITORING AND EVALUATION				
28.	Has the programme established Gender Focal Points and coordinating committees from existing staff with clear terms of reference to oversee activities related to Gender sensitive-programming and service delivery?			
29.	Has the programme integrated specific responsibilities related to Gender-responsive programming in staff job descriptions and staff result areas that have to be appraised periodically?			

S. No	Question	Yes (Score = 1)	In progress (Score = 0.5)	No (Score = 0)
30.	Do the M&E frameworks have gender-specific indicators to reflect the differential impact of TB on women, men and transgender persons?			
31.	Has the programme developed or reviewed M&E systems to routinely capture gender- and sex-disaggregated information?			
32.	Does the programme collect, analyse and utilise gender-and age-disaggregated information for: - Diagnosis - Health-seeking - Access to health services - Treatment adherence - HIV and TB co-infections - TB-related mortality rates - Positive outcomes			
33.	Has the programme built the capacity of relevant staff in gender- sensitive M&E?			
34.	Do quarterly/annual reports have sex-disaggregated data? (i) Quarterly (ii) Annually			
35.	Has the programme built the capacity of M&E and surveillance experts in gender-sensitive M&E? E.g.: WHO consultants, expert evaluation groups, CIE teams etc.			

S. No	Question	Yes (Score = 1)	In progress (Score = 0.5)	No (Score = 0)
	RESEARCH			
36.	In order to inform policy development, does the programme conduct periodic gender-sensitive research on: - Knowledge and awareness - Treatment-seeking behaviours - Sociocultural factors/barriers and the effects of treatment on women, men and transgender persons?			
37.	Does the programme ensure that all biomedical researches and surveys take into account the sociocultural issues of women, men and transgender persons?			
38.	Does the programme ensure that all genders are included in drug and vaccine trials to determine gendered differences in response to drugs and vaccines?			
39.	Does the programme ensure that all research commissioned by the program generates and publishes sex - disaggregated data?			
	INTER-SECTORAL COORDINATION MECHANISMS			
40.	Are there functional coordination mechanisms with relevant stakeholders in the following sectors to achieve a gender responsive program - Ministry of Women and Child Development - Ministry of Social Justice and Empowerment - Public Distribution Department - Any other			

S. No	Question	Yes (Score = 1)	In progress (Score = 0.5)	No (Score = 0)
41.	Has the programme formed strategic partnerships with relevant stakeholders who can influence policy change with regards to gender responsive programming E.g.: National Commission on Women National Human Rights Commission of India			
BUDGETING				
42.	Does the programme conduct sensitisation on gender-responsive budgets for anyone involved in preparation of sub-district, district, state or national budgets?			
43.	Does the programme provide adequate financial resources to support gender-sensitive surveillance and M&E systems?			
HEALTH FACILITY LEVEL IMPLEMENTATION				
44.	Have all the health staff undergone training in gender-responsive programming?			
45.	Is the medical officer trained on gender-responsive M & E and gender-responsive budgeting for TB?			
46.	Are facilities available for diagnosis of TB?			
47.	Are the diagnostic tests for TB provided free of cost?			
48.	Does the programme provide gender-sensitive counselling which involves the spouse and the family wherever relevant?			
49.	Do the timings of functioning of the health facility take into account the convenience of the women, men and transgender persons the facility caters to in the context of geographic, climatic and occupational conditions?			

S. No	Question	Yes (Score = 1)	In progress (Score = 0.5)	No (Score = 0)
50.	Does the facility provide linkages for HIV counselling and testing?			
51.	Does the facility display IEC materials that deconstruct/challenge negative gender norms in the community it caters to?			
52.	Does the facility engage with the community to popularise services available for TB and influence gender norms affecting diagnosis and outcomes in TB?			
53.	Does the facility integrate TB screening in the maternal and children OPDs?			
54.	Do ACSM activities conducted by the facility ensure equal participation of women, men and transgender persons?			
55.	Does the facility have a gender focal point to monitor aspects of gender responsive programming?			
56.	Does the health facility employ measures for prevention of transmission in the OPDs to the fellow attendees and the health workers?			
57.	Were the health workers — women, men and transgender persons screened for TB in the last year?			

Note: Questions 44 onwards can be separated into a separate check-list and used at the facility level.

Adapted from: Checklists for Measuring Implementation of the Gender Mainstreaming Guidelines in HIV and AIDS, Tuberculosis and Malaria Programmes, Southern African Development Community (SADC) Secretariat.

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