Community Rights and Gender rapid assessment

Among Vulnerable Communities in Karnataka

Community consultations under the initiative

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ABBREVIATIONS AND ACRONYMS

ACF -Active Case Finding

AIDS – Acquired Immunodeficiency Syndrome

ANC-Antenatal Care

ART – Antiretroviral Therapy

ASHA- Accredited Social Health Activist

CRG- Communities, Rights Gender

CB-NAAT- Cartridge Based Nucleic Acid Amplification Test

DBT Direct Benefit Transfer

DTO -District Tuberculosis Officer

ILO – International Labour Organization

Jogappas-Transgenders

LEA – Legal Environment Assessment

LGBTI –Lesbian, gay, bisexual, transgender, and intersex

MDR-TB – Multidrug-resistant Tuberculosis

NEP- New Extra Pulmonary

NTEP-National Tuberculosis Elimination Programme

PHC - Primary Health Center

PLHIV – People Living with HIV

PNC-Postnatal Care

PWUD – People Who Use Drugs

STO State TB Officer

TB – Tuberculosis

UN – United Nations

UNAIDS – Joint United Nations Programme on HIV/AIDS

UNDP – United Nations Development Programme

UNFPA – United Nations Population Fund

UNICEF – United Nations Children's Fund

UNODC – United Nations Office on Drugs and Crime

WHO – World Health Organization

Executive Summary

KHPT's Jilla Samudaya Vedike (JSV) project, funded by the STOP TB Partnership, aims to address specific challenges including stigma and gender barriers faced by the urban vulnerable, PLHIV and mining communities in Bellary, Bagalkot and Belgaum districts of Karnataka state.

Methodology

KHPT conducted a rapid CRG assessment in the project geographies among the focused vulnerable communities, which was designed to elicit information on the barriers and inequalities in the community. The CRG assessment was conducted through FGDs with people with TB from different communities, including the urban vulnerable, mining communities, and PLHIVs, as well as in-depth interviews with service providers.

Key Findings

- Gaps found in awareness and information about TB across all the communities and gender - misinformation, myths, and misconceptions lead for fear about TB.
- Stigma in the workplace is the big barrier for TB responses in mining community
- TG community affected by stigma hence access to services is very low among them especially in the government sector, and the death rate is high but no data on TG s in Nikshay
- Gaps in the quality and quantity of the service delivery
- Stigma bothers much the co infected, the prime reason for not accessing the services
- Gap in knowing the rights among all the populations
- Gaps in person centric approach at the services hence less access of other schemes benefits by people with TB
- Gender interfering with TB in case of awareness, service access and also Gaps in gender segregated data (TG s, ANC/ PNC etc)

Recommendations

Information Dissemination

- Scientific and specific information pattern of TB spread, treatment duration should be disseminated among the people, so that untoward myths and misconceptions can be dispelled and stigmas of various forms can be prevented.
- A sharpened and enhanced psychosocial support approach, along with regular support group meetings for HIV-TB coinfected, are recommended.
- There is a need for separate data on men, women, non-binary groups, TGs, and those with HIV and TB-HIV co-infections.

Gender

- There is a need to strengthen IEC activities and Active Case Finding, along with the utilization of medical mobile units with diagnostic facilities in rural villages. It is essential to reach vulnerable populations, especially women and children, where public transport is scarce.

- Exclusive days and timings may be fixed at the health facility for the service of TGs and non-binary groups. One day in a month (2nd Wednesday of every month as the community will be comparitively free) can be fixed for TB tests for TGs; this would need to be communicated to the TGs' Community Based Organization (CBO) by the NTEP.

Stigma

- There is a need for dissemination of information on epidemiological facts like TB burden, human rights and legal provisions to dispel the existing stigma associated with TB.

- Capacity building and refresher trainings on a patient-centred approach, patients' rights and legal provisions are suggested for NTEP staff.

- Considering the rampant existence of stigma faced by employees with TB at the work place, NTEP may encourage an employee-led model with employer/company engagement.

- There is an immediate need for special psychosocial support focused on dispelling self-stigma and initiating TB awareness through CBOs. Special efforts may be taken to identify and record TGs in Nikshay to ensure tailor made services or the gender specific approach.

Services

- CBNAAT machines can be installed at medical colleges and mobile medical units equipped with CBNAAT machines can be deployed to hard-to-reach mining areas.
- NTEP can regularly organize Care and Support Group meetings for the facilitation and linking of DBT / bank accounts etc.

Rights

- Involve District Legal Service Authority / Taluk Legal Service Authority as resource persons for legal literacy in TB champions training and during Care and Support Group meetings of people with TB.

- DLSA may also form a TB patients' rights violation redressal mechanism with trained legal professionals at the district/taluk level, so that speedy redressal of grievances can be ensured.

Data

- There is a need to collect information on movement of migrants and monitor their health status through a multi-stakeholders approach involving representatives of employers as well as employees.

- An epidemiological study among the mining population can throw light on specific TB-related health issues among the mining community.

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Introduction and Background

In India's National Strategic Plan (NSP) for TB Elimination (2017-25), priority populations are defined on the basis of the disadvantages they suffer, such as increased exposure to TB due to the place where they live and/or work, their limited access to TB services or their increased risk of TB disease because of biological or behavioural factors which compromise immunity to TB.

Although women have more chances of TB exposure, the cultural and behavioural factors, gender frames and norms, as well as social and economic barriers, prevent these communities from prioritizing their health. Stigma exacerbates the medical and social hardships of TB, and is responsible for delays in diagnosis and treatment initiation, treatment interruptions, and poor outcomes. Stigma is, therefore, a barrier to TB elimination.

Human rights

The Universal Declaration of Human Rights (1948) emphasizes the fundamental dignity and equality of all human beings. Based on this concept, the notion of Patient Rights has been developed across the globe in the last few decades. India is among the most diverse nations of the world and has the most representative democracy. It has a robust Constitution that protects the plural, secular nature of the country and guarantees to all its citizens, their equality before law under Article 14.

Right to Health is a part and parcel of Right to Life and therefore right to health is a fundamental right guaranteed to every citizen of India under Article 21 of the Constitution of India. Members of disadvantaged communities are often unable to defend their rights and to access remedies in cases of rights violations. In the case of Paschim Banga Khet Mazoor Samity v. State of West Bengal (1996) 4 SCC 37, the scope of Article 21 was further widened, as the court held that it is the responsibility of the Government to provide adequate medical aid to every person and to strive for the welfare of the public at large.

The Ministry of Health and Family Welfare (MoHFW) had shared the Charter of Patients' Rights recommended by the National Human Rights Commission (NHRC) in 2019 with the Government of all States and Union Territories (UTs). Further, it is also for the respective State/UT Government to display the Patients' Rights Charter in public and private healthcare facilities as well as on their health department websites, allocate budget for promotion of the Patients' Rights Charter, and set up a grievance redressal mechanism for patients as recommended by the NHRC advisory.

Some of the relevant Patients' Rights related to TB prevention, diagnosis and treatment are:

1. Right to Information

Every patient has a right to adequate relevant information about the nature, cause of illness, provisional / confirmed diagnosis, proposed investigations and management, and possible complications. This is to be explained at their level of understanding in a language known to them.

2. Right to confidentiality, human dignity and privacy

   All patients have the right to privacy, and doctors have a duty to hold information about their health condition and treatment plan in strict confidentiality, unless it is essential. Female patients have the right to the presence of another female person during physical examination by a male practitioner.

3. Right to non-discrimination

   Every patient has the right to receive treatment without any discrimination based on his or her illnesses or conditions, including HIV status or other health condition, religion, caste, ethnicity, gender, age, sexual orientation, linguistic or geographical /social origins.

4. Right to be heard and seek redressal

   Every patient and their caregivers have the right to give feedback, make comments, or lodge complaints about the healthcare. Patients and caregivers have the right to seek redressal in case of infringement of any of the above-mentioned rights.

Legal Rights

In India, there are various legal provisions related to patient rights which are scattered across different legal documents, e.g. The Constitution of India, Article 21, Indian Medical Council (Professional Conduct, Etiquette and Ethics) Regulations 2002; The Consumer Protection Act 1986; Drugs and Cosmetic Act 1940, Clinical Establishment Act 2010 and rules and standards framed therein; there are also various judgments given by Hon'ble Supreme Court of India and decisions of the National Consumer Disputes Redressal Commission.

Other than this, there are various women and transgender-specific laws like Transgender Persons (Protection of Rights) Act, 2019.

Scope of CRG assessment under KHPT Stop TB Partnership - Jilla Samudaya Vedike (JSV) project

The Jilla Samudaya Vedike (JSV) project, funded by the STOP TB Partnership and implemented by KHPT, aimed to address specific challenges including stigma and gender barriers faced by the urban vulnerable, PLHIV and mining communities in Bellary, Bagalkot and Belgaum districts of Karnataka state.

PLHIVs are 21 times more likely to develop TB than persons without the virus. TB-HIV co-infection results in higher mortality rates. (NSP) Nearly 25 percent of all deaths among PLHIV are estimated to be due to TB, according to the 2019 India TB report. PLHIV community is covered by the project in Bellary and Belgaum districts. The mining community in Bellary district is covered under STP- JSV project. The earlier research shows that the TB prevalence among the construction workers, quarry workers and stone crushing workers is higher than the general population; such occupations are vulnerable to TB due to a greater level of exposure to silica dust. It was reported that silicosis is a common occupational disorder seen all over India, especially among the mining workers, an important cause of respiratory morbidity. The JSV project covers urban vulnerable populations in Bagalkot and Belgaum districts. Slums are informal settlements with inadequate housing and poor living conditions. Usually, migrants working in industry and construction workers form this urban vulnerable population. There are delays in access to treatment and care due to work-income related trade-offs. Due to rights violations in accessing the facilities for services- either intentionally by the employers or/and lack of awareness among the workers and employers.

The Global Plan to End TB 2016–2020, acknowledges that TB programming will not be successful unless global and national programmes utilize approaches grounded in human rights and gender equity. The major approach of the intervention is to train the community leaders and civil society organisation on aspects of community rights and gender. The JSV project aims to achieve the following:

1. Strengthen the TB response with rights-based, people-centred approaches, through community-led monitoring forums, among PLHIVs, population related to mining industries, and urban poor.
2. Sensitize and engage the elected representatives of local self-governments (PRI) in TB awareness, stigma reduction and better linkages of service, schemes and supports.
3. Participate and engage in various TB advocacy and accountability initiatives at national, regional and global levels.

Vulnerable population coverage in the project geography:

The JSV project covers around 700,000 urban vulnerable, PLHIV, and population related to mining industries, as well as around 19,000 PLHIV currently on ART. A district and gender-wise breakup is given in the table below:

Table 1a: coverage of vulnerable population in the project

District	Community type	Male	Female	Total	PLHIV Alive on ART
Bagalkot	Urban vulnerable	116487	111773	228260	
Belgaum	Urban vulnerable	150228	144603	294831	
Belgaum	PLHIV				14207
Bellary	Mining community	156562	17034	173596	
Bellary	PLHIV				4755
Total		**423277**	**273410**	**696687**	**18962**

The community, rights, gender and stigma assessments were proposed to understand the barriers related to gender and stigma among the urban vulnerable, PLHIV and mining community.

Methodology

Scope and outcomes

The rapid CRG assessment in the project geographies among the focused vulnerable communities aimed to elicit information on the barriers and inequalities in the community.

Objective of the CRG assessment in STP – JSV project:

1. To understand barriers to TB awareness, access to care, and treatment outcomes for key populations addressed by the CRG intervention with a special focus on gender and rights
2. To understand the perceived and enacted stigma among the vulnerable communities and among the staff of health facilities
3. To undertake a rapid review of the available literature on community rights and gender pertaining to TB

Details of CRG assessment:

Community, Rights, Gender and Stigma assessment tools: The Stop TB Partnership has worked with partners to create three tools to bridge the data gap and ensure that human rights and gender issues are addressed, especially among vulnerable populations. These are designed for implementers and national programs, and provide a current and improved perspective to support the review of national policies and practices.

The three tools that form part of the CRG initiative as proposed by the STOP TB Partnership are:

1. Data for Action Framework for Key Populations, which focuses on measuring the burden of TB among key, vulnerable and priority populations in the country
2. Gender Assessment tool for national TB response, which applies a gender lens to TB in the country and assesses ways in which gender affects and interacts with TB
3. Legal Environment Assessment Tool that looks to understand and examine the legal environment for TB through a rights-based framework

KHPT undertook the CRG assessment with the gender and the legal environment assessment tools. Qualitative information was collected through these assessments among each of the vulnerable communities on the following

:

A. Information on disease and services among the vulnerable communities
B. Barriers to access to services
C. Availability of services and health care
D. Stigma and behaviour towards TB
E. Data Gaps- data use in terms of importance of gender segregated data
F. Service delivery - IEC, intersection coordination, counselling services, sputum transportation, utilization of other health facilities like mission hospitals etc
G. Health effects of policies, legislations and programs (e.g. OPD care for TB is not covered under Health Insurance).

Sample, type of studies and data collection mode

The CRG assessment was conducted through FGDs with people with TB from different communities, as well as FGDs and in-depth interviews with the service providers. Sixty-two men, 60 women, 35 TGs and 24 service providers (17 men and seven women) were part of the data collection for the assessment.

Data collection and types of participants

SNO	Type of Community	Vulnerable Population	Male	Female	TGs	Total
1	Urban Vulnerable	People with TB	11	10	0	21
2	PLHIV	People with TB	10	10	0	20
3	Mining	People with TB	10	10	0	20
4	TGs	People with TB	0	0	27	27
5	Caretaker	People with TB+PLHIV	10	23	0	33
6	Service providers	NTEP staff	17	7	0	24
7	Community Structure Leaders	Urban vulnerable/ poor	6	25	0	31
	Total		64	85	27	176

The outcome of this exercise will be the report including the following:

1. Understanding and awareness about the disease
2. Gender and TB and how gender is interfering with TB among these vulnerable population
3. Stigma and attitude towards health seeking, practices prevalent in the communities. Stigma in the facility.
4. Service delivery – gender/stigma sensitiveness
5. IEC – gender sensitiveness
6. Communities understanding of health and other human rights and access to different government schemes
7. Discussion and recommendations

Ethical Considerations

An Information sheet describing the purpose, process and implication of the study was read out for all participants of FGDs and IDIs. Pre structured Informed consent describing the advantages, confidentiality and risk involved was provided to each participant and their signature was obtained, which was counter signed by the research team representatives. The consent process verbally also briefly described the study, requested voluntary participation, and assured confidentiality of participants.

Study Limitations

Several of the participants of FGDs were sometimes indifferent to some questions and never bothered to answer as they felt uncomfortable in a known group of people. To keep the rapport intact, the facilitators carried forward to the next question, which may have affected the mood of participants. There is a risk of response bias, particularly with regard to sensitive topics such as self-stigma and discrimination from the family members, as most of the participants were from a lower educational and economic background. A few of the non-binary group were not very open to discussions.

Findings and Discussions

Urban Vulnerable

Information on disease and services among the urban vulnerable: The participants had superficial knowledge from the media, wall posters and word-of-mouth from friends and relatives. However, this information was mostly incorrect and incomplete and often embedded with misinformation, myths, and misconceptions, which triggers unnecessary fear and anxiety. These psychosocial perceptions, coupled with unscientific views towards life and health related issues, aggravate stigma and discrimination in the communities, families and workplaces. One of the female participants revealed that *"I was mistaking TB as an extreme cold and cough situation until one of the woman in the neighborhood died due to TB and the health worker started to visit our area and mobilized us for testing."*

Barriers to access to services: Through the FGDs, we learned that although IEC and – sometimes - ACF activities are conducted in urban vulnerable areas, the awareness level among women and girls is still low as they are less mobile and less educated. Many of the women affected by TB working as domestic help or involved in other small-time jobs are dealing with self-stigma and they do not disclose their TB diagnosis to their employers because they fear that they may lose their job.

> The discussions at the FGD echoed that the general community believes that something terminal and incurable is in the basic health condition of the people with TB and it will persist throughout the life time.

Availability of services and healthcare to urban vulnerable: Some of the participants of FGD have interacted with healthcare workers from the government hospital and received the message that TB is a curable disease but one has to follow protocol and nutrition advised by the health care staff. Once the diagnosis is confirmed, the dominant feeling was fear, self-stigma and 'what will happen to my family?', and 'Why has this happened only to me?'

People with TB

Being in a state of anxiety and fear, most of people with TB were not able to share their feelings or thoughts with the staff of the testing centre. However, immediate family members, particularly the spouses, and frontline workers were found to be the easily accessible and confidential sources to share feelings, emotions and apprehensions.

Stigma and behaviour towards TB: Most of the participants shared that they had disclosed their TB status to their spouses or parents; they are believed to be sincere well-wishers and won't leave them at any cost. Since the treatment was a stressful and anxious period, the TB status was shared gradually only to them. There exists an anticipated stigma about how some of their friends and neighbors would react and if they would spread the rumors when disclosed.

Although most of the community members were aware about being TB a communicable disease, they were not aware when to take the treatment and how fatal the disease is. The hospital staff and field staff are interacting with general public and people vulnerable to TB; nevertheless, the knowledge level and significance of testing is not a scientific one. The health system, in recent years, is taking more initiatives to identify the vulnerable, diagnose and treat TB. They also feel that support through DBT is meagre and fulfilling the long procedures for it is long. The DBT also comes very late, mostly after the completion of treatment.

Caregivers

Information on Disease and Services among urban vulnerable: Only a small portion of the general population has adequate awareness about TB. The caregivers told said that the TB patient faces a lot of psychosocial issues once they come to know of their diagnosis, stemming from fear, and the feeling of victimization due to social stigma. Most of them want to skip the medicines as they face a number of painful side effects, and caregivers, especially family members need to support them and give them hope.

Stigma and behaviour towards TB: There is a lot of stigma from the community, which is reflected in the family also. The people without the knowledge and information about the TB , the laymen in the society stigmatize more. Almost none of them wanted to disclose their TB status to the neighbors, friends or at the workplaces, as there was a greater chance of discrimination and losing their jobs.

Barriers to access to services: The TB patientsm especially the poor, are affected in many ways, especially financially, due to the loss of income/job, cost of transportation or maintaining a nutritious diet. Healthcare workers support the family, as well as the patient, psychosocially. Some of the patients have enough money but they do not know about easily available nutritional foods.

The patients or their family members get information about treatment, management of side effects and benefits like DBT, insurance or other schemes during the discussions at support group meetings. However, support group meetings are not regular in some facilities.

Community structure leaders

Information on disease and services among the urban vulnerable: The awareness about TB among the general public is low. When there is a health problem, the people from their community usually visit unqualified private medical practitioners because the visits to the government facilities are perceived to be time-consuming, in a crowded and unfriendly environment. The women and girls are less aware about TB, however, once they are diagnosed, it is easy to convince them and ensure adherence to the TB treatment.

Barriers to access to services: The people with TB face a lot of problems like side effectives of medicines, financial problems etc although the field staffs from the project are cooperative. Lack of money for nutritional diet, transportation and loss of income faced when visiting the health facility are the major hindrances.

The society has got lot of deformed pictures about prejudices about TB like it is an incurable disease and the community stigma is rampant. Due to perceived stigma, TB patients are isolated at community functions and workplaces. If the employers or coworkers come to know about their TB status, they will get often get fired. They are aware about Nikshay-DBT benefits and some of them have got the benefits of health schemes, however, insurance is only applicable to patients who gets admitted in the hospital.

Service delivery – gender/stigma sensitiveness: Although the availability of health services is better in urban areas, the urban vulnerable have limited access to it. The most common issue are the long queues and waiting period to consult the doctors. The hospital timing and working time of the people do not match, which often means that visiting a hospital amounts to the loss of one day's wages. Non-binary people, due to self-stigma and image consciousness, do not want to wait in queue. The staff at the health facility are not much oriented on gender sensitivity.

Mining community

Information on disease and services among the mining community: The knowledge level of TB among mining community is comparatively low as they are from rural areas and less exposed to general health awareness through media or health systems. Many of the mining community members consider TB as a more chronic cough and cold, which cannot be cured and is thus fatal.

Gender and TB and how gender is interfering with TB among mining community women: It has been observed that men in the community have more awareness as they have mobility, access to information and greater interactions with community structures and government agencies. Among women, the minority community are found to have no knowledge or they just heard about TB. The polluted environment, as well as alcohol and tobacco abuse among men makes them more vulnerable to

TB. Once they are counseled by the ASHA workers and identified, they are then given TB-related information. Women's exposure is limited to the mining environment; they also have little access to information, nutrition and are exposed to unhealthy working conditions inside the house, which makes them more vulnerable, hidden and hard to reach.

Migrants

Barriers to access to services: A substantial proportion of the mining communities are migrants, mostly from Uttar Pradesh and Bihar. They are brought from their native villages by the labour contractors in groups and for a specific period of time. Their data is not made accessible to the local health systems by labour contractors or the management of the company. Whenever there is an IEC activity or ACF initiative, they do not cooperate with NTEP staff. The company claims to have they have their own systems for screening, diagnosis and treatment.

> There is no mechanism to find out migrants number, seasonal migration patterns or any systems screening them for TB on arrival

Women in Mining community

Understanding and awareness about the disease: Many of the women from the mining community have heard about TB from neighbors and relatives unless they came to know from the process of treatment by themselves or others from the TB facility and one to one interaction from NTEP staff. In the rural community, awareness level is low and there are lot of misconceptions, like TB is not curable and death is certain. People view TB with stigma and spread rumours. Now, the situation is changing slowly due to the activities of ASHAs and other health workers from the NGOs.

Gender and TB and how gender is interfering with TB among migrant women: A participant woman said that her sons and brothers supported her during her diagnosis and treatment. Most of the women adhere to the treatment regimen and do not delay treatment as they feared that it will get in to more complications. Although few explained their difficulties faced during the treatment

> One of the participants shared that she felt sad and anxious after diagnosing TB. The brothers kept her out of their family and stayed alone in a nearby house for two months. This made her more sad, depressed and guilty

Health services are available at the district headquarters, taluka hospitals and PHCs, however, some patients are finding it difficult to access services due to distance, cost of travel, and loss of daily wages.

Stigma and attitude towards health seeking, practices prevalent in the communities: Some of the women had not even shared their TB status with the family members fearing stigma and discrimination.

One woman was told by the family and villagers to stay at the hospital when they came to know about her TB status and to not come to the village until her TB is fully cured.

Stigma in the facility: Women with HIV tend to self-stigmatize when they get TB and many times lose hope in life. The ASHA workers are of help, as they counsel the TB-affected persons and family.

Side effects like body pain, knee pain, headache, fever, giddiness, vomiting which sometimes compels them to stop medicines. However, these symptoms subside in one to two months. According to discussions, none of the women, to their knowledge, have discontinued the medicines permanently. However, they have faced loss of livelihood and had problems maintaining a nutritious diet.

Gender and TB and how gender is interfering with TB among women in mining community: The women said that they have not felt any discrimination based on gender at the health facility. However, lack of money for transportation to the health facility, long queues, long waiting time and absenteeism of key staff there often do not result in a good experience. The patient and their family members fear disclosing their TB status as they fear community stigma and discrimination from friends, neighbors and relatives.

Barriers to accessing services: According to women, getting time out from their household chores, getting permission from their in- laws and the lack of money to travel to a health facility are major hindrances to accessing and adhering to TB treatment for women. This also delays the diagnosis of TB among women. Some of the women said that they feel insulted by family and at their workplaces due to their TB status.

Most of the women we spoke to were not able to follow a nutritious diet as they could not afford it. Due to cultural and gender norms, women give the least preference to their own nutrition in the family, and since they are not always the primary breadwinners in the family, they are not in a position to demand nutritious food as defined in the gender norms in the family. While the government and some NGOs offer nutritional support, some women are unable to avail of these benefits since they are unable to follow the procedures to register for them.

> One woman with TB has lost her job at Anganwadi after the staff came to know about her TB status

Service delivery – gender/stigma sensitiveness: The women from the mining community said that they had not experienced any kind of gender discrimination from the health facility and they felt that whatever es they are getting from the facilities are a favour from the government, not their right. They are scared about discrimination and the ensuing firing from the job at the workplaces and being thrown out of their in-laws' house if they are found TB positive. Generally, support group meetings are regularly taking place only health facilities where BTB project is conducting the care and support group meetings

Few of them have received DBT benefits. Some of them have got Ayushman Bharat card but have not got any benefit out of it.

PLHIV

Information on disease and services among the PLHIV community: PLHIVs are aware that they are more prone to HIV-TB coinfection, as they are engaged with the ART centre. Most of them undergo screening/tests at regular intervals. These situations lead to self-stigma and the PLHIV isolating themselves from the society and even from the family. This affects the adherence level of the co-infected. They complained that they experienced more severe side effects of TB medicine. *Among HIV-TB coinfected psycho-social issues are very high since they are already having a lifelong disease which made them loss of hope towards* There were cases of PLHIV stopping ART for a period of time due to the prolonged side effects of TB medicines.

HIV-TB coinfected women

PLHIV women face acute issues due to lack of sufficient finances and community stigma. Women staying in rural villages find it difficult to pay for transportation costs of travel to the facility and additional nutritional supplement, and also experienced stigma. The participants felt that Their health also observed to be feeble; many times they feel TB medicines deteriorates their health to an extent that affects their daily routines. They cannot work and earn nothing. The spouse and family sometimes disown them, as they feel like an extra burden to the family.

PLHIV TGs and non-binary groups

Information on disease and services among PLHIV TGs and non-binary groups: Among TGs and non-binary groups, the awareness levels on TB is low and self-stigma is high. They feel that they are already stigmatized by general society, and will be devalued more by their fellow community members and society, if they come to know about their TB status. This anticipated stigma is also a factor delaying the diagnosis and treatment process.

> "Non-binary groups are likely to hide their TB status from the public/society and that is why mostly in Nikshay portals they are identified as binary groups."

TG Charu (54) from Bellary, died a year ago, was on second line ART. after TB treatment, the side effects like ulcers in the mouth, there was bleeding from the mouth ulcers due to bleeding mouth he was kept away from others in the hospital. then the TG died. Earlier when the TG was once treated with the TB treatment, she had continued to have the symptoms even after the treatment completion

Stigma and Behaviour towards TB among the TG : The Jogappas (TGs), a group which worship the goddess, particularly avoid going to the government facility as they fear stigma from the public as a result of them being engaged in sex work. The Jogappas (TGs) who have money usually visit private doctors and undergo treatment in private hospitals. Many of them have not revealed their TB diagnosis even to their family members as they fear stigma from them will increase.

Barriers to access to services: The financial conditions of most of these groups are poor and that are mostly daily wage earners/ laborers. So, their loss of income challenges the adherence level as well as the nutrition availability. Many of them were not able to access DBT benefits as their social entitlement documents related to ID proofs are not available. Some of them, living in rural areas, are not interested in the benefits as they think DBT is too low and they do not want FLWs visiting their houses in the village as they fear that others will get to know about their TB status.

Gender and TB among TGs: The condition of coinfected TGs are very badas they lose their income because they cannot not move around due to their sickness. The only emotional support they receive from their community members as their family members disown and isolate them due to secondary stigma. One of the TGs from Bellary narrated she knew a PLHIV-TG who used to earn her livelihood through blessings and collecting contributions. She fell sick and was disowned by the family once they found that she was infected with TB. She was living with her siblings and whatever she earned was given to the family. Once her health started to deteriorate and her everyday trip to the markets for blessings stopped, the family disowned her. Later, the family assumed that she would not be able to recover from the current health condition, they told her to leave the house, saying that others would also contract the infection. She had no other option than to take shelter and support from her fellow TGs.

Dakshyan- (46) died 3 years ago. He did not disclose to his family that he is a TG and he did sex work. He used to do sex work in the evening. He was Co infected, got TB while he was started with second line ART, continued to have symptoms even after the TB treatment but did not go for the TB test for the second time, and died.

Stigma among TB-HIV coinfected TGs: The TG s die of co infection (HIV and TB) and there is mostly pulmonary TB among the TG . This was observed during the data collection after hearing to the case stories. Due to the high stigma and the fear of getting thrown out of the family, village or the group, they delay getting tested for TB. They also lack awareness about TB, so they often do not get tested. The stigma is so high among the TGs, that they do not even disclose having had TB in the past, and never say it in group meetings.

> TG Rashmi (32), known as Jindal Rani, she controlled the TG community of Bellary district. She was a Guru and she was a leader of community. She was very popular among the TG community in Bellary. But she never went for HIV TB test, while her health deteriorated, she was detected with co infection and she died. The delayed detection of TB and HIV caused her death, but she always neglected for going for the test, as a Guru she was un comfortable to get herself tested. Being more powerful made her more scare of stigma and discrimination made her avoid test and confirming the sickness.

Barriers to access to services by the TG: The stigma, fear of discrimination, lack of nutrition, the living conditions, and difficulty in accessing health services due to low self-confidence, make the community more vulnerable to TB. The layers of stigma of being TG, HIV infected and TB makes them avoid the government facilities and prefer the private doctors many times. Even after detecting the TB they discontinue the treatment due to the stigma so that they can avoid visiting the hospital. The TGs those who are in to blessing and collecting money, may lose their social respect and image because of their clients will doubt 'godly' powers and end up losing their livelihood.

Analysis of Cross Cutting Issues

1. Barriers to accessing services

Information on disease and services among the vulnerable communities: Due to the lack of information, many of the vulnerable groups mistake TB for common cold and cough and start to self-medicate. Only after the appearance of severe symptoms do they consult local unqualified/alternative systems / quacks. Unqualified doctors start treatment based on symptoms and take time to refer persons for TB testing. By the time, they persons reach the government facility, there is a delay and sometimes infection is acute.

Urban Women

The awareness about TB among urban women is comparatively low when compared other vulnerable groups, because their mobility is restricted outside their dwellings. They are mostly migrants from rural

areas of the state and still follow the culture and practices mixed with superstitions and unscientific conclusions health related issues. They are also face stigma and discrimination at their workplaces.

Mining Community

The mining community is comprised of mostly migrants from villages of other states like Bhihar, Uattar Pradesh, Haryana, Jharkhand, Andra Pradesh, Telangana, Maharastra etc and do not have any kind of awareness about TB in. Their access to information or health services in mining areas are limited and testing is practically non-existent. Usually, once they get sick, they go back to their hometowns and there is no system to find out how many TB patients are coming to the area for work.

PLHIV

Although PLHIVs have basic information about TB from the ART centres they visit regularly, many of them do not want to get screened and their adherence level is low. Gender-based household responsibilities for women and loss of daily income and discomforts/side effects felt at the beginning of the treatment are some of the hinderances for TB test and treatment. Psychosocial support efforts are taken by the healthcare providers in ART in this situation to some extent.

> "I was getting cold and cough for long time, I thought it is common as I spend my time in firewood kitchen without chimney and my village is in a dusty mining area. Further I got chest pain and extreme fatigue, then I have to request permission from me in laws for relieving from my daily household chores to visit a PHC"

Existing stigma and discrimination People who are less aware of TB in the community stigmatize TB patients. Most of the participants in the urban, mining or TG community are fearful and anxious, sometimes reluctant to enroll in government facilities as they fear that healthcare providers, especially the ASHAs will visit their houses and the neighbours will come to know and stigmatize them. Many of them deny permission to ASHAs to visit their houses because of this fear.

Persons vulnerable to TB and affected people visit health facilities after overcoming considerable challenges including long distance, hardships in commuting, leaving household responsibilities, loss of income, transportation expenses etc. The services at the health facility may sometimes are delayed, not provided or persons may be asked to come another day due to absence of key staff. It has also been observed that a minor section of the staff at the health facility interact with prejudice, stigma and even talk rudely or resort to shouting at the patients. Due to these experiences, the community prefers to go to the private practitioners.

Side Effects of TB medicines

Side effects in the initial months of the treatment, such as vomiting, muscle cramps, knee/body pain, and overall discomfort led to some persons discontinuing the medicines and reluctance to take medicines for a period of time.

> "Some of the staff at the testing centre do not allow us to touch the furniture or any other equipment and tell us to hold sputum container in our hands and do not put it anywhere"

Lack of cooperation from mining companies and factories

The urban vulnerable mostly work in factories, and the mining companies mostly employ people from rural villages as well as migrant populations from other states. There is no networking or data sharing on the number of workers or their health status, so the existing health systems are not able to plan or make available the health facility. There is a conducive environment for TB transmission and there are no periodic health checkups happening in this sector. It was learnt that once a worker is identified with TB or another disease, he/she is fired quietly by the employers.

2. Availability of services and healthcare

Initially, people visit private neighbourhood doctors because they are often friendly, easily accessible and there is no waiting time. A few of the affected families also look for unscientific treatment methods based on word of mouth/rumours. Once the symptoms become worse, they approach the government hospital or private hospitals. These observations are also almost same with different groups.

Health services are available at the district headquarters, taluka hospitals and PHCs, however some patients are finding it difficult to approach due to distance, financial issues to travel, loss of daily wages. *Long queues and waiting hours, not so friendly attitude absenteeism of key staff at the government health facility are the problems faced by the community.* There is also a gap in the patients who are diagnosed and undergoing treatment in private medical hospitals needs to be integrated with NTEP system for counseling and effective prevention.

3. Stigma and Behaviour towards TB

Stigma is rampant among the urban vulnerable, mining, PLHIVs particularly among TGs and co-infected non-binary groups within the communities. They consider it as incurable and sometimes a fatal disease. The people are more afraid of associated stigma and discrimination than the disease itself.

> In one case, the TB affected woman was instructed to stay in the district hospital and return only to house after completing the treatment

Stigma and discrimination are very subtle and not visible in the communities. Even in the families, the members try to avoid them as far as possible and taunt the TB affected person in some instances. In

extreme cases, some of them are put in a separate room and separate utensils are given to them to prevent the spread of infection, particularly to another person in the house. In one case, the housewife was made to stay in another house nearby until her treatment was over.

Families and persons with TB want to hide theit TB status, as they fear formidable social and secondary stigma and discrimination from extended family members, friends, neighbours and the community. Some of the participants said that some community people are stigmatized such a extent, that even getting in to a marriage with affected families can result in discrimination in the community. One participant at Sandur said that the daughters who have got married and are staying with their in-laws are not told about their father's TB status as they fear their in-laws may send their daughters back.

> The young girls at Sandur are send to their relative's house in other village as they fear in their village people come to know about TB infection, she could not get a proper match for marriage." Was said by women during the FGD

PLHIVs are already discriminated against due to their HIV status, and TB makes them more vulnerable to stigma. Some of the community members judge, isolate and reject them, believing that they are carrying a highly communicable disease.

The participants of FGD were ashamed and did not want to disclose their TB diagnosis. However, during the course of treatment and after attending support group meetings, slowly their self-stigma faded away. Some of the participants of FGD for people with TB avoided marriage functions and social gatherings, which they found as a way of not spreading the disease or social stigma felt. And also due to the fear of discrimination they practiced social isolation they said.

Mine workers

Mining workers never disclose their TB status at the workplace to colleagues and supervisors as they are sure that they will be fired from the job. They are more vulnerable to TB due to (silica) dust in atmosphere, and their vulnerability is aggravated with the use of alcohol and tobacco products; often there will be no money left to buy nutritious food. However, there is no data available separately for the mine workers with the government department

The mining companies ignore the workers' vulnerability to TB or are not wanting to to share the number of people employed with them or conduct TB testing camps in their working places. They claim that they have got their own health facilities and systems to treat TB or any other disease, however there are cases of firing from due to workers' TB status.

Gaps in gender-segregated data

Gender-segregated data, especially on miners, is not available; however, data on non-binary group and PLHIVs in the districts are available. There is a need to derive data to find out the prevalence of TB among adolescence and youth, ANC or PNC from further studies on TB prevalence . To win the fight against TB in the mining areas, the data about the number of people employed in the mining companies, both native and migrants, is indispensable.

Service Delivery- gender/stigma sensitivity

In some health facilities, support group meetings are held monthly, with around 20 people participating and discussing psychosocial issues and health care workers update knowledge and asks to share in any issues faced by them. This gives them a lot of strength. It was revealed during the discussions that males, females, care givers or health care providers that the non-binary groups are facing many issues related to their gender. However, the non-binary group especially the TGs said that they face uncomfortable and stigmatized by general public at the facility. Those TGs who are Jogappa and having the status of giving blessings feels anxious that how the public perceive them and that may tarnish their image of spiritual aura. Women, due to their household responsibilities and restricted mobility, are not able to wait in the queues at facilities for a long time to access services. Some of the young women especially unmarried do not want to mingle with others as their identity of being on TB treatment can tarnish their image in the marriage market. A separate day and timing can make the TGs, women and men more comfortable to access services. Gender specific approach is suggested.

Health effects of policies, legislations and programs

In Bagalkot, the participants affected by TB said that misdiagnosis and incorrect treatment by unqualified doctors can lead to avoidable long-term complications and delayed treatment. These Private doctors must made accountable for wrong diagnosis and treatment under Clinical Establishments Act, 2010.

A mining worker at Bellary was fired from the job once the management came to know that he was diagnosed with TB. This is against the designed policy framework by Ministry of Health and Ministry of Labour which proposes to safeguard employees. Which includes **The Occupational Safety, Health and Working Conditions Code, 2020,** The Factories Act, 1948., The Contract Labour (Regulation and Abolition) Act, 1970, The Mines Act, 1952, The Dock Workers (Safety, Health and Welfare) Act, 1986.

Action can be taken against the company management as per the provisions of existing labour laws in India.

Instances of Human and Legal Rights Violations

At Bellary, transgender PLHIV was thrown out of the house by the family members because she was infected with TB; this is a clear violation of the human rights under the succession and inheritance laws of the land. The inheritance is a convention of passing or rather transferring properties, titles, debts, rights, and obligations to the legal heir of a person upon his/her death. It can be done by either a will or through laws of succession. The regulation of inheritance differs among religions, societies, and communities. The laws include The Indian Succession Act 1925, The Hindu succession Act 1956 / 2005 and others

Although many of the TB patients have enrolled themselves for government-sponsored insurance schemes, they could not avail the benefits, because TB cases do not need admission to hospitals. Appropriate legislation is needed for providing insurance coverage for eligible people with TB .

The people with TB at Sandur FGD revealed that they do not feel very comfortable in the unfriendly environment of certain TB facilities in Sandur. Government hospitals and clinics need to be put under medical negligence and consumer protection acts in order increasing their efficiency and accountability.

Reasons for human and legal rights violation

It is observed that NTEP activities in the area are limited to the medical aspects of TB and not yet focusing on rights-based empowerment. Because of this lack sensitization and rampant violation of rights, people with TB and community are accepted it as a part of life. Any attempt towards defending rights can attract unnecessary conflict in existing systems of society as well as government. Even if there is a grievance, communities are not at all aware about redressal forums. However, it is noted that awareness about rights is comparatively more among PLHIVs and TGs as they are attached with TI NGOs and health facilities, and low among mining populations.

However, the TB patients or public do not have awareness about these human and legal rights. There is no grievance or redressal mechanism existing at the various levels. There is a need to undertake awareness drives among public and training to the staff. Of NTEP and government health facilities.

Gap Analysis on Awareness Level among Vulnerable Communities narrative

Vulnerable Communities	Gap	No Gap	Analysis
Urban Vulnerable			
Women	√		Since women's mobility is restricted and governed by various patriarchal norms, their access to information

			on TB service is poor. Still, they follow myths and misconceptions based on unscientific beliefs.
Transgender	√		TGs fear stigma and discrimination from public. have the social pressure to maintain their "special social/spiritual status". So, they do not want to expose themselves to information or services provided/accessed in the public.
Men		√	Men are more mobile and can independently take decisions, they can access information from various public sources like IEC activities, health workers, health facilities.
PLHIV			
Women		√	Since PLHIV women are attached to ART centres, self-help groups and other facilities like NGOs, they have access to information.
Transgender		√	Since PLHIV TGs are attached to ART centres, self-help groups and other facilities like NGOs, they have access to information
Men		√	Since PLHIV Men are attached to ART, self-help groups and other facilities like NGOs, they have access to information.
Mining			
Women	√		Women from the mining community mostly stay in remote villages where access to health facilities/information is still difficult. They have to put on hold the household chores and take money and permission from elders/ working husbands to travel.
Transgender	√		TGs in the mining community are mostly illiterate and they stay in the remote villages. These barriers are aggravated by the social pressure to maintain their 'representation godman/woman'. As they are treated by the community
Men	√		Long hours working in mines, less free time and no access information at the workplace makes men miners less aware about TB and services available.

Conclusions and Recommendations

TB related information prevalent in the area is mostly incorrect and incomplete and are often embedded with misinformation, myths, and misconceptions which triggers unnecessary fear and anxiety in the individual and society. **Scientific and specific information like how does the TB spread? What and where is treatment available? TB is curable, etc should be disseminated among the people, so that untoward myths and misconceptions dispelled and stigmas of various forms can be prevented.**

The vulnerable population faces lot of physical, psychological and social issues during the diagnosis and treatment period**. Counseling for psychosocial support needs to be strengthened and made available to TB patients.**

Mining Population

Among the mining population, the overall TB burden seems to be high compared to the population size, rural/ urban areas etc based on the number of TB cases notified. However, this is not reflected in NIKSHAY data portal and it is likely that NTEP is missing out a substantial number of TB cases. **There is a need to address this issue through multi stakeholders' approach including representatives of employers as well as employees, different departments and community etc.**

In Sandur's mining population, young people aged 1 to 18 years are affected by TB comparatively more than in other regions. There is also a high incidence of women in PNC affected by TB in the mining regions. **An epidemiological study can throw light on this phenomenon and appropriate strategies may be evolved with a multi departmental approach to testing and treatment follow up.**

HIV co-infected

PLHIVs observed to be vulnerable to psychological breakdown and mental health issues due to the complexities of co-infection and side effects of TB medications. **A sharpened and enhanced psychosocial support approach along with regular support group meetings are recommended.**

2nd line ART and delayed TB detection is proved to be fatal, more so among the TG s as per the case stories heard from the CBO, but this data is not available as they are registered as men or women**. There is a need for separate data for men, women, non-binary groups with HIV and TB-HIV coinfected persons in Nikshay.**

Rights

The rights-based and patient-centric approach is sidelined by practice in the NTEP system as the staff as well as the patients are not aware about the patient rights and the laws pertaining to it. Right-based perspectives, advocating law as an enabling and empowering tool for tackling social structural issues, marginalization and inequity are needed, especially in relation to TB elimination efforts. **Rights-based and patient-centric approaches must be incorporated in the IEC activities, trainings and undertake advocacy efforts with judiciary and local government authorities by the CBOs and civil society and people with TB. The treatment initiation counselling must include various benefits available to the TB patient.**

Involve District Legal Service Authority / Taluk Legal service authority as resource persons for legal literacy in TB champions training and during Care and Support group meetings of people with TB.

Presently, there is no patients' rights violation grievances or redressal mechanism. **DLSA/Taluk Legal Service Committee may encourage lawyers to take pro-active role in giving legal advice, aid and litigation services to people affected by TB. DLSA may also form a TB patients' rights violation redressal mechanism with trained legal professionals at the district/taluk level, so that speedy redressal of grievances can be ensured.**

Gender

When compared to males, women are less aware about the symptoms of the disease and TB prevention, treatment and care as per the CRG assessment . **There is a need to strengthen the IEC activities and ACF, along with provision of medical mobile units with diagnostic facilities visit in rural villages where public transport is scarce.**

Non-binary groups and TGs , especially the Jogappas (TGs) face a lot of self-stigma while waiting for the services at the health facilities among the common public. This stigma is also aggravated by their feeling that their 'spiritual powers' can be challenged/doubted by the public, if they fall ill. **Exclusive days and timings may be notified at the TB facility for the service of Jogappas (TGs) and non-binary groups. One fixed day in a month (2nd Wednesday of every month which is convienient for the TG community) can be for TB tests for TG s and that needs to be communicated to the TGs CBO by NTEP.**

The abuse of tobacco, dependency on drugs and alcohol as well as stigma among men is common in the region where the CRG assessment was done which makes them more vulnerable, delays diagnosis and hinders them from adherence. **There is a need to address these issues and dispel myths and**

misconceptions related to TB through awareness drives, counselling etc. If treatment for de addiction is needed for drugs/alcohol dependency the networking with local government authorities and NGOs working the field to be done .

Stigma

High level of stigma is faced by the people with TB from their families, neighbors, communities, relatives, co-workers and employers. **There is a need for dissemination of information and advocacy on epidemiological facts, human rights and legal provisions.**

It is learnt that stigma and discrimination is still exists in the attitude and behaviours of NTEP staff especially towards HIV coinfected. **Capacity building and refresher trainings on patients centred approach, patients' rights and legal provisions are suggested for NTEP staff**.

Stigma and discrimination is very high in the workplace.
Considering the rampant existence of stigma faced by employees with TB at the work places, NTEP may encourage employee led model with employer/company engagement effectively

Among the TGs including coinfected, the stigma is so high that they not only disclose their TB status to Peer educators and ORWs but also, they hide it even after the treatment completion. **There is an immediate need for special psychosocial support focusing on dispelling self-stigma and initiating TB awareness through CBOs**

Superficially it looks like there are high TB related deaths among TG s through the case stories but it is not recorded with the data because the TGs are not notified as TGs in NIKSHAY**. So, efforts may be taken to identify and record them separately to ensure tailormade services.**

Services

There are cases of loss of potential patients from referral networks such as community structures. **CBNAAT machines can be installed at medical colleges and mobile medical units equipped with CBNAAT for mining areas which are hard to reach are suggested to be a effective solution for addressing this challenge.**

DBT benefits are not availed by many TB patients because they are not able to register on the Nikshay portal in time due to inconsistent social entitlements. **NTEP can regularly organize Care and Support Group meetings for new persons initiated on treatment for the facilitation and linking of DBT / bank accounts etc**

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Annexures

FGD: persons with TB from vulnerable population

We need to complete the bio-sketch for all the participants as given in the last page

Please read the Subject information sheet and also collect the informed written consent from each of the participant before starting the discussion.

Thank you for participating in this interview and we would like to learn from you about the health care service delivery for vulnerable population

Background

1. Please introduce yourself. Please mention briefly about how many days you have been taking treatment/or competed treatment and how are you feeling today.

General information

2. What were your reactions when you learned of having TB? (Probe: please share your first thoughts) OR Once you were diagnosed with TB, what was your reaction? (Probe: fear/anxiety, disbelief, angry, not sure what to do, depressed) Was the information clear to you? Did you share your feeling with the person who told that you had TB and what did he/she tell you?
3. What were the decisions made when you started having the symptoms of TB? (Probe: who helped with these decisions, what are the reasons for delay if any? What could have you done differently?) (collect narrative about the process from the point of diagnosis to present)
4. Did you share the diagnosis with anyone immediately? if no, what thoughts prevented you from doing so? Who was the person you shared the result with about your diagnosis at first and why?
5. Were you aware of TB before you were diagnosed with TB? Do you feel you could have prevented and if so how? (Probe: those who said they were aware, where or from whom did they learn about TB; was the information clear to you or you were not sure? What different sources of information you can remember of and which do you prefer most?)
6. How is the awareness and feeling about TB in your community/groups? Did you perceive any change over the awareness and access to services related to TB in the community over the recent years? What might have led to these changes? Can you specify a few important points you learned about the disease (Probe: signs/symptoms, causes, prevention, nutrition, treatment duration, medication, side effects, any other)
7. Did you have any problem thus far during the treatment due to medicines or to go to the health facility or even to undergo tests? (Probe: side effects, lack of money, nutritional food, anything else) Did you stop medicine? Further, did you begin the treatment and what might have led to resumption of treatment?
8. Usually is there any difference in access to health care and treatment amongst male, female, or a non-binary person in your community? Please elaborate and also the reasons for these differences.

Gender related risks of TB and health including stigma

9. Can you explain your first interaction with the health care worker at the government facility, during diagnostic stage and also TB treatment initiation stage? How has your experience been with different health care providers - TB-HV or counsellor or doctor? (Probe: staff is friendly or not…why do they think so… Are you able to meet doctor whenever needed?) Do you think being a man or a woman or a non-binary person the experience would differ (Probe: going to health facility for tests, sputum tests or any other tests, cost, interaction with staff)
10. How did your family members react to this news? Who else did you share the information with (Probe: among relatives, friends, workplace, community group members) and why did you feel you needed to share this with them? Were you hesitant/ashamed to share this information? Did your relationship change with any of them (Probe: did they avoid you or were they supportive, if so how)? Do you think being a man or a woman or a non-binary person the experience would differ?
11. What according to you are some of the hindrances in accessing treatment? What could be done to avoid these? (Probe: what will you or family or community or the health care provider need to do) What is your opinion on access to treatment, especially by male or female or non-binary persons from your community? (Probe: delay in going for test/initiation of treatment for fear of social banishment, loss of work, health of family, cost, distance to treatment facility, alcohol/tobacco use, any other)
12. What according to you are some of the hindrances in adhering to treatment? What could be done to avoid these? What is your opinion on treatment adherence, especially by male or female or non-binary persons from your community? How can you or your family or community or the health care provider help to improve these? (Probe: stigma- family/community, work related, affordability of nutritious food, financial support, psycho-social support)
13. Did you feel ashamed/stigmatized about your illness? Can you explain what makes you feel like that? Are these gender-specific…keeping in mind your community? (Probe: Not able to socialize, neglect from family, neglect from community and friends, fear of spreading the disease, may have other diseases such as HIV/AIDS, the burden of caring, ashamed of careless behaviors such as smoking, drinking, visiting sex workers etc.,) At any point in the treatment period did you feel to discontinue the treatment because of this feeling? If so how did you overcome the feeling?
14. In continuation, can you explain seeing or knowing any other patient uncomfortable or insulted or hurt by anyone/ anything (including family, neighbours, colleagues, health care provider) while visiting health facilities for seeking care for TB, accessing diagnostics for TB, and treatment for TB? Did you feel that counsellors or nurses and doctors were unwilling to take care of other patients or were trying to avoid them? Can you tell us specifically about such situation/s? At any point in the treatment period did they feel to discontinue the treatment because of this feeling?
15. During your treatment were/are you having any problem in maintaining a nutritional diet? Any reasons if you are having any problem?

Rights

16. How have been your experience in taking treatment from the health facility? Did you experience or observe any discrimination meted out to yourself or any other person? Do you feel that the experience would have been different for males, females or non-binary persons? If so, why do you feel so?
17. Have you attended support group meetings? What is your opinion about these meetings? Any difficulty you have experienced which you see are gender specific in attending the meetings?

18. Did anyone explain or inform you about the rights of a person while taking treatment, like, what medications and treatment you are supposed to get or DBT scheme or any counselling services you or your family members can consult with? Do you know anyone who has taken TB treatment from private facility and whether they had any different experience than what you have had?
19. Have you heard of any other schemes which could be applicable to you while you were on TB treatment, like, any insurance schemes, other applicable schemes? Did you avail the services? How have they helped you or people from your community?

Bio sketch information sheet_Persons with TB

District: Date:

Taluka: Interviewer:

Group (Mining/PLHIV/UV): Gender (Male/Female/Other):

Name	Age (in completed years only)	NIKSHAY ID	Education (completed standard/ "0" if no education)	Month/Year of treatment initiation MM/YYYY	Status of treatment Ongoing…….1 Discontinued…2 Completed……3

FGD: Community leaders from vulnerable population

We need to complete the bio-sketch for all the participants as given in the last page

Please read the Subject information sheet and also collect the informed written consent from each of the participant before starting the discussion.

Thank you for participating in this interview and we would like to learn from you about the health care service delivery for vulnerable population.

Background

20. Please introduce yourself. Please mention briefly about how many days you have been taking treatment/or competed treatment and how are you feeling today.

General information

1. What kind of health issues are common in your community? Why do you think that people in the community fall sick of these diseases? How are these different for males/females/non-binary people? (Probe: also specifics about TB)
2. Where do people seek treatment- is this different in case of TB? Why do they go there- is it different for TB? How are these different for males/females/non-binary people- how is it in case of TB? (Probe: Private/Govt/home remedies/ alternate medicine systems, traditional and spiritual healers)
3. What is the general awareness about TB in the community? what are the sources of awareness? Does the community have any preference for any specific medium based on accessibility, clarity of information, authenticity of the information?

Gender related risks of TB and health including stigma

4. What barriers do people in your community/area face in seeking treatment- any different for TB? Is this specific to your community? does being (male or female) non-binary affects differently? (Probe: affordability- cost if any, nutritious food, accessibility, availability, user friendliness of the health facility, beliefs and practices) How do you think these barriers can be overcome? (Probe: role of community leaders, elected representatives, any other)
5. Do you think TB is associated with stigma in your community? How is it expressed? (it may be in the family, community, work place) could you provide examples for it? How does it affect treatment seeking for TB- especially keeping in mind the gender of the person?
6. How do you think getting affected by TB changes relationships and life at the individual level, family level, community level? (Probe: gender differentials in experiences of losing job, disrupted family life, hiding status from friends) How will be or was your relation with someone you knew got TB- your opinion about how persons having TB should be treated?

Rights

7. Are you aware of the support systems for persons with TB require to help them through the treatment process? Who do you think in your community is or can be the person who can help persons with TB? What support a person with TB belonging to your community might need for completion of treatment, especially with regards to gender differentials? (Probe: about any health worker who visits the houses, counselling, legal cells for rights violations)
8. Are you aware of the social schemes like DBT or any health insurance which can be availed by persons taking treatment of TB?

Bio sketch information sheet_community members

District: Date:

Taluka: Interviewer:

Group (Mining/PV/UV):

Name	Age (in completed years only)	Gender	Education (Completed standard/ "0" if no education)	Type of Member Caretaker of person with TB……1 Person cured of TB……2 CS member…….3 Community member….4

FGD: Health care providers- NTEP staff (STS/STLS/TB-HV) and ASHA

We need to complete the bio-sketch for all the participants as given in the last page

Please read the Subject information sheet and also collect the informed written consent from each of the participant before starting the discussion.

Thank you for participating in this interview and we would like to learn from you about the health care service delivery for vulnerable population

TB awareness and health seeking

1. In your experience how is the awareness of TB among the specific groups susceptible to TB (mining/PLHIVs/urban vulnerable)? (Probe: gender differentials) What are the most common challenges faced by the specific groups susceptible to TB in accessing TB related services? (Probe: gender differences in awareness, interpersonal communication barriers, accessibility, affordability, mental preparedness, stigma and discrimination)
2. How can the health care providers at different levels (FLWs/Counsellors/ STS, STLS, TBHV) help them overcome the challenges? Please mention of any efforts that have been made to address these challenges. Do you think there are gaps that can be filled at the health systems level…if so what are the gaps (Probe: training of staff, infrastructure, supplies- medicines, testing kits, anything else)
3. How is the acceptance of the NTEP services? If there is lack of acceptance for services, what may be the reasons (Probe: for any differences by gender and specific groups susceptible to TB)? Do you see any scope for improvements or changes that could help better services?
4. Can you explain about acceptance of IPT prophylaxis for contacts and family members? What do you think are the reasons for lost to follow up and challenges in tracking TB patient during the TB

treatment? Did you experience any problem for women undergoing tests, especially sputum tests? (Probe: for any differences by gender and specific groups susceptible to TB)

5. Can you explain about the case finding activities within the catchment area? What are strategies employed with respect to specific groups susceptible to TB (Probe: active and passive case finding, gender differences)? What is your role? (FLWs/Counsellor/STS, STLS, TBHV) Do you feel there is a possibility of increasing the TB case notifications amongst the specific groups susceptible to TB, especially any gender specific strategies?
6. How do patient- provider meetings help you and/or TB patients? Do they happen in your facility and if so how frequently? Can you share your experiences?
7. How do the frontline health workers link patients to the facility and are there any challenges they face in doing so? If so, what are they and how can it be resolved? (Probe: separately for specific groups susceptible to TB and for gender)
8. Do you know what is the male-female proportion of presumptives during the recent screening? Is it as expected? What about the male-female proportion in case notifications? Are they as per expected? If not, what might be the reasons? Can you say approximately the number of migrant/PLHIV/urban poor persons who are currently under treatment?

Gender related risks of stigma

9. Do you think TB is associated with stigma? How is it expressed in mining/PLHIV/urban poor communities? (it may be in the family, community, work place) could you provide examples for it? How does it affect treatment seeking for TB- especially keeping in mind the gender of the person? How do health care providers deal with stigma attached to TB? How is it addressed by health system at community level and facility level?
10. How do the health care providers deal with TB patients? Do you feel any concerns for personal safety, stress, anxiety or distress in dealing with the patient and their issues? Do you make home visits? If so what are the challenges there? (Probe: any difference for the vulnerable communities and more so in terms of gender?)
11. Do you think women, girls and TGs need gender responsive approach in NTEP facilities? What differences can be made for the women and girls can access the services comfortably?

Rights

12. Are you aware of the support systems for persons with TB require to help them through the treatment process? what changes need to be brought about in improving identification to cure of persons with TB, especially with regards to any gender differentials? (Probe: about any health worker who visits the houses, counselling, legal cells for rights violations)

13. How the rights based approach can be helpful in END TB by 2025? Who all can play a role in it? (how the human rights protection and stigma mitigation, right to live empower the people with TB and complete their treatment?

Bio sketch information sheet NTEP staff and ASHA

District: Date:

Taluka: Interviewer:

TU:

Name	Age (in completed years only)	Gender	Education (Completed standard/ "0" if no education)	Type of cadre STS……..1 STLS……2 TB-HV…….3 ASHA……..4 Pharmacist …….5

IDI: STO/DTO

Please read the Subject information sheet and also collect the informed written consent from each of the participant before starting the discussion.

Thank you for participating in this interview and we would like to learn from you about the health care service delivery for vulnerable population

TB awareness and implementation

14. What is the level of awareness about TB amongst different groups like mining/PLHIVs/urban poor? How has this affected case-finding and what more do you think can be done to improve awareness and case finding…do you see any need of population groups (Probe: mining/PLHIV/urban poor) or gender specific strategies?
15. What are the challenges in its implementation for a provider…any gender differentials? How to ensure this is practiced across facilities? If not, what support do you think is needed to support providers to offer patient centred care…gender differentials? (Probe: can health and wellness centre with a mid-level health provider can play any role)
16. According to you who or which agencies can support the activities of NTEP to prevent and control TB to achieve the objective of Stop TB by 2025? (Probe: Involvement of Private sector, pharmacists/labs in the notification, community level organisations, RDPR)

Gender related risks of TB and health including stigma

17. To what extent do you think TB is affected by stigma? How is it expressed in mining/PLHIV/urban poor communities? (Probe: in family, community, work place) How does

it affect treatment seeking for TB- especially keeping in mind the gender of the person? How is it addressed by health system at community level and facility level?

18. How do the health care providers deal with TB patients? Do you feel any concerns for health worker or the person being treated, especially in terms of gender of the person? Did you feel there are any gender skewness in counselling staff? If so what are the challenges there? (Probe: any difference for the vulnerable communities and more so in terms of gender?)

19. Do you think women, girls and TGs need gender responsive approach in NTEP facilities? What differences can be made for the women and girls can access the services.

Rights

20. The National Strategic Plan talks about the need for adopting a Patient centred approach. What according to you is the most important aspect of patient centred care? How do you think the plan touches upon gender or rights specific issues? Who all can play a role in it? Would you like to suggest any aspect which the guideline should include? (Probe: how the human rights protection and stigma mitigation, right to live empower the people with TB and complete their treatment?)

21. Can you please tell about the support systems for persons with TB to help them through the treatment process? do you think there is a need to adapt more approaches- may be community led, to increase identification and improve cure rate among persons with TB, especially with regards to any gender differentials? (Probe: about health worker who visits the houses, distance of the facilities available, counselling, legal cells for rights violations, the government schemes meant for people with TB and other government policies can help people to complete treatment? (schemes like DBT, free treatment, health insurance etc)

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