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TB STIGMA ASSESSMENT REPORT

ONEIMPACT
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Executive Summary

Tuberculosis (TB) continues to pose a significant public health challenge in Pakistan, which ranks among the top five highest-burden countries globally. With an annual incidence of approximately 686,000 new cases, TB deeply affects communities nationwide. This burden is exacerbated by pervasive stigma, rooted in associations with poverty, misconceptions about transmission, and perceived moral failings. Stigma creates barriers to timely diagnosis, treatment, and social support, impacting individuals with TB (PWTB), their families, and healthcare providers.

The TB Stigma Assessment in Pakistan, conducted using the Stop TB Partnership's Stigma Assessment Tool, examined stigma across various dimensions, including self-stigma, family stigma, community stigma, and healthcare-related stigma. The findings reveal that stigma that inhibits TB service access is most severe in community settings (60%) and healthcare environments (53%). PWTB and their families reported experiencing the most stigma during the early stages of the TB journey, particularly while recognizing symptoms and seeking care in health and community settings. These stages are critical, as stigma during this period often delays care-seeking and service access.

Among PWTB, self-stigma is prevalent, with nearly half experiencing feelings of shame, guilt, and social isolation. This self-stigma is compounded by specific stigmatizing attitudes, such as fear of disclosing their status, concerns about being judged, and internalized guilt. Families face secondary stigma, characterized by secrecy, fear of judgment, and anxiety about infection, all of which led to social isolation and strain within households. Community stigma against PWTB is marked by misconceptions about contagiousness and associations with socially undesirable behaviors, leading to social distancing and discrimination. Within healthcare settings, stigmatizing attitudes among healthcare workers (HCWs) are prominent, with 79% of surveyed HCWs supporting the isolation of PWTB.

Statistically significant differences in stigma experiences were observed across key vulnerable populations (KVPs) at the 0.05 level. Rural poor populations reported the highest levels of community stigma (65%), reflecting socioeconomic disadvantages and limited access to health education. Transgender individuals faced particularly high stigma levels in community (39%) and workplace settings (67%), highlighting severe social exclusion. Women reported significantly higher stigma in community (55%) and family settings compared to men. People living with HIV (40%), miners (52%), and people who use drugs (58%) experienced stigma compounded by intersecting vulnerabilities related to their health and social identities. These findings emphasize the need for tailored, data-driven interventions to address stigma in these disproportionately affected groups.

The absence of formal protections against TB-related discrimination in Pakistan further exacerbates these challenges. Workplace stigma and misconceptions within the community further deter individuals from accessing care, completing treatment, or reintegrating into society post-treatment.

Addressing these challenges requires multi-level interventions, particularly for stigma in the early stages of TB Journey (recognising symptoms, seeking care) in health and community settings. Recommendations include public awareness campaigns to address most prevalent stigmatizing attitudes by dispelling myths and misconceptions about TB, targeted education and training for healthcare providers, and legal reforms to protect individuals against discrimination. Family-centered programs, workplace policies, and community engagement initiatives can help create supportive environments, reducing stigma at all levels. Strengthening person confidentiality and ensuring respectful, inclusive care are also essential to mitigating the impact of stigma.

The findings underscore the urgency of addressing TB stigma as a societal challenge, not merely a healthcare issue. Collaborative efforts among government agencies, healthcare providers, civil society, and affected communities are vital to creating an inclusive and stigma-free environment for TB care. By implementing these strategies, Pakistan can improve access to services, enhance treatment outcomes, and align its efforts with global goals to end TB by 2030.

Introduction

Tuberculosis (TB) remains a pressing public health challenge in Pakistan, contributing significantly to illness and mortality across communities. With an estimated 686,000 new cases annually, Pakistan ranks fifth among the world's highest-burden TB countries, despite notable progress in diagnosis and treatment. In 2023, the TB incidence in Pakistan stood at 277 cases per 100,000 people, with an annual death toll of approximately 47,000. However, TB control efforts face critical barriers, including stigma, which remains one of the most significant challenges to accessing care and achieving successful outcomes.

Stigma related to TB impacts not only individuals diagnosed with the disease but also their families and communities. In Pakistan, TB is often associated with poverty, unhygienic living conditions, and perceived moral failings. These misconceptions lead to social isolation, discrimination, and emotional distress, discouraging individuals from seeking timely medical help or adhering to treatment. This not only worsens individual health outcomes but also increases TB transmission within communities. Families of people with TB (PWTB) experience secondary stigma, exacerbating emotional stress and social isolation, while healthcare workers, influenced by stigmatizing beliefs, may unintentionally perpetuate discrimination in healthcare settings, compromising the quality of care.

The root causes of TB stigma are deeply entrenched in societal and institutional norms, cultural beliefs, and community attitudes. Stigma manifests in multiple forms, including internalized self-stigma, anticipated stigma (fear of judgment), and enacted stigma (discrimination), each of which creates barriers to care. Internalized stigma results in feelings of shame and fear, causing individuals to hide symptoms, delay seeking care, or withdraw from social interactions. At the community level, negative attitudes reinforce these challenges, limiting access to healthcare services and increasing the risk of untreated TB cases.

Stigma within healthcare settings is particularly concerning, as it undermines the trust and quality of care that individuals with TB receive. Healthcare workers, if inadequately sensitized, may contribute to stigma through judgmental attitudes or discriminatory practices, further discouraging persons from accessing care or completing treatment. In addition, structural stigma, reflected in the lack of protective laws and policies, perpetuates inequalities in accessing TB services.

Despite significant efforts by government agencies, NGOs, and international organizations, TB-related stigma in Pakistan remains underexplored and inadequately addressed. Limited public awareness campaigns and persistent cultural misconceptions further entrench stigma, underscoring the need for comprehensive educational initiatives that promote accurate knowledge about TB, its causes, and its treatment.

This report utilizes the Stop TB Partnership's Stigma Assessment Tool to examine the multifaceted dimensions of TB stigma across family, community, healthcare, and workplace settings in Pakistan. By employing a mixed-methods approach, it seeks to identify where stigma is most prevalent and provide evidence-based recommendations for reducing its impact. These findings align with the global recognition that stigma is not only a personal or medical issue but a systemic and societal one, requiring multi-sectoral collaboration for meaningful change.

The assessment highlights the critical need for targeted interventions to address stigma and promote person-centered, rights-based approaches to TB care. Public education campaigns, healthcare worker training, and the establishment of protective policies are essential to creating an environment that encourages care-seeking, treatment adherence, and recovery. Addressing TB stigma is a collective responsibility, involving governments, healthcare providers, civil society, and communities.By advancing the conversation on stigma reduction and its integration into Pakistan's TB response strategies, this report aims to improve access to care, support adherence to treatment, and ultimately save lives. It emphasizes that tackling TB-related stigma is central to achieving national and global TB elimination goals, ensuring that no one is left behind in the fight against TB.

Assessment Goals and Objectives

The overarching objective of the TB Stigma Assessment was to evaluate the extent to which TB stigma hinders access to and provision of TB services and to develop actionable recommendations to address these barriers. The assessment aimed to ensure that quality TB services were available, accessible, and acceptable to all, with special emphasis on key, vulnerable, and underserved populations in both government and private healthcare settings. The assessment was aligned with the guidance provided in the Stop TB Partnership's framework, ensuring a thorough examination of stigma across multiple dimensions and levels.

Specific Objectives:

1. **Understanding the Levels and Dimensions of Anticipated, Self, Enacted, and Observed Stigma Among People Diagnosed with TB:**

    - Objective 1a: Explore how and to what extent self-stigma manifests among individuals diagnosed with TB.
    - Objective 1b: Identify the settings (e.g., home, workplace, healthcare facilities) and stages of care (e.g., diagnosis, treatment) where stigma is experienced and observed by people diagnosed with TB.

2. **Understanding the Levels and Dimensions of Secondary Stigma Among Family Members and Primary Carers of People Diagnosed with TB:**

    - Objective 2a: Investigate how and to what extent secondary stigma manifests among family members or primary carers of individuals with TB.
    - Objective 2b: Identify the settings and stages of care where secondary stigma is experienced or observed by family members or primary carers.

3. **Understanding Community-Level Perceived and Observed Stigma Against People Diagnosed with TB:**

    - Objective 3a: Examine how and to what extent stigma against people diagnosed with TB manifests within communities.
    - Objective 3b: Identify the community settings and stages of care where TB stigma is observed by community members.

4. **Understanding the Levels and Dimensions of Perceived Stigma Against People Diagnosed with TB in Healthcare Settings and Stigma Experienced by Healthcare Workers:**

    - Objective 4a: Assess how and to what extent perceived stigma against people with TB manifests in healthcare facilities.
    - Objective 4b: Explore the settings where healthcare workers involved in TB care experience stigma.
    - Objective 4c: Identify the settings where stigma against healthcare workers is observed by other healthcare professionals.

5. **Exploring the Role of Structural Stigma (Laws, Policies, and Media Coverage) in Influencing TB Stigma:**

    - Objective 5a: Assess how existing laws, policies, their enforcement, and corresponding media coverage may contribute to or mitigate stigma against people diagnosed with TB.
    - Objective 5b: Identify structural barriers or protections that affect the delivery of stigma-free TB services.

6. **Supporting the Development of Recommendations and Action Plans to Address TB Stigma:**

    - Objective 6a: Develop actionable recommendations and action plan to reduce stigma and decrease vulnerability to TB infection.
    - Objective 6b: Increase access to TB services for individuals and communities affected by stigma.
    - Objective 6c: Improve treatment outcomes by addressing the impact of stigma on health-seeking behavior and adherence to treatment.

Assessment Design

The TB Stigma Assessment in Pakistan was designed to evaluate the various dimensions and manifestations of stigma associated with tuberculosis (TB). A mixed-methods approach was employed, integrating both qualitative and quantitative research. The study focused on understanding how stigma affected access to TB services and the provision of care. The comprehensive assessment included the participation of individuals diagnosed with TB, their families, healthcare workers, community members, and key stakeholders.

Study Design Overview

The assessment employed a cross-sectional study design, incorporating semi-structured questionnaires, focus group discussions (FGDs), and a desk review of secondary data to capture a well-rounded understanding of TB-related stigma from diverse respondent groups. Data collection spanned two months, with the entire assessment process completed in approximately six months. This approach provided valuable insights into the multifaceted nature of TB stigma across different perspectives.

Study Participants

The study involved diverse groups of participants, including individuals currently or previously diagnosed with TB, family members, healthcare providers, and community members. The inclusion criteria focus on people aged 18 or older who are directly involved in TB care or treatment.

- **Inclusion Criteria**: Individuals with a history of TB (current or previous), their family members, TB healthcare providers, and community members residing with TB-affected individuals.
- **Exclusion Criteria**: Individuals without a TB history, non-family members, healthcare providers not involved in TB care, and community members not directly connected to TB affected by TB.

This study analyzed the perspectives and experiences of five groups:

1. **People with TB**

   This group comprised adults who either currently have or previously had TB. The sample was designed to be representative of TB-affected individuals across diverse demographic characteristics, including rural and urban residence, age, and gender.

2. **Family Members and Close Contacts of People with TB**

   This group included family members, caregivers, and other close contacts who provide support during the TB screening and treatment process. Participants included both men and women, as well as parents or children of individuals diagnosed with TB.

3. **Community Representatives**

   This category covered community leaders and those working near TB clinics or in close interaction with people affected by TB. Surveys were conducted within communities in the study's designated regions.

4. **Healthcare Workers**

   Participants included doctors and nurses from TB Basic Management Units (TBMUs), where they were involved in TB testing, prevention, and treatment services for affected individuals.

5. **Stakeholders**

This population included representatives from the Common Management Unit, Provincial TB Control Programs, media, donors, implementing partners, NGOs, medical facility representatives, and community members who had experienced TB.

Study Duration

The study took place over a period of **6 months** starting from June 2024 – Dec 2024.

Key Research Components

1. **Semi-Structured Questionnaires**:

   Questionnaires were tailored for four key respondent groups: individuals diagnosed with TB, their family members, healthcare professionals, and community members. These questionnaires assessed various forms of stigma—including anticipated, self, enacted, and observed stigma—across different stages of the TB care journey. The tools were adapted from validated TB stigma scales and the **Stop TB Partnership's Stigma Measurement Guidance.**

2. **Focus Group Discussions (FGDs)**:

   FGDs involved a range of stakeholders, such as representatives from national and provincial TB programs, the legal sector, media, and policymakers. These discussions examined how **current laws, policies, and media narratives influence TB stigma.** The qualitative insights gathered from these FGDs enriched and contextualized the quantitative findings from the questionnaires.

3. **Desk Review**:

   A comprehensive **review of existing literature and secondary data** provided essential background for understanding TB stigma in Pakistan. This analysis highlighted knowledge gaps and guided the formation of targeted recommendations.

Multi-Stakeholder Group

A series of initial meetings were conducted with the Common Management Unit, followed by virtual consultations with provincial stakeholders, CBO, People affected by TB who formed part of the multi-stakeholder group. These sessions aimed to ensure comprehensive stakeholder engagement by discussing and aligning on the assessment objectives, approach, and methodology. The meetings also served to orient stakeholders to the process and secure their endorsement, fostering a shared understanding and commitment to the assessment.

After data analysis, a validation workshop was held with stakeholders to finalize the findings and agree on recommendations. This event brought together representatives from national and provincial TB programs, policymakers, donors, and implementing organizations. The workshop aimed to validate the findings and recommendations of the Stigma Assessment, foster collaborative review of the assessment results among stakeholders, and develop actionable recommendations for a Stigma Reduction Action Plan.

Target Audience for TB Stigma Assessment in Pakistan

The TB Stigma Assessment was a community-driven initiative, with strategic guidance provided by the **Common Management Unit / National TB Programme (NTP)**. This multi-stakeholder approach ensured wide engagement and the uptake of recommendations. Key groups involved include:

1. **Common Management Unit / National TB Programme (NTP)**:

   Provided strategic and technical guidance throughout the assessment, ensuring alignment with national health policies.

2. **TB-Affected Community**:

Community members were actively involved in collecting data, and validating results. Their involvement ensured that the process remained focused on the needs of those most affected.

3. **Lead Community-Based Organization (CBO)**:

   Dopasi Foundation was responsible for coordinating the assessment, including recruitment of the TB Stigma Expert and data collectors, organizing training sessions, and facilitating discussions.

4. **TB Stigma Core Group**:

   This group provided **technical guidance** and **oversight**, ensuring the assessment adheres to best practices and yields actionable results. The core group consisted of representatives from Common Management Unit, Provincial TB Control Programs, technical and development partners, CBOs and People affected by TB. The core group had 20 members ensuring a mix of gender and composition.

5. **TB Stigma Expert (Technical Lead)**:

   The Stigma Expert led the technical aspects of the assessment, training data collectors, analyzing results, and producing the final report with recommendations and an Action Plan.

6. **Statistician**:
   The statistician was responsible for calculating population sampling and ensuring that the sample size is representative of the TB-affected population.

Sampling Methodology

The sample size was calculated based on the **TB burden in Pakistan**. The sampling ensured representation from all four provinces (Sindh, Punjab, Khyber Pakhtunkhwa, and Balochistan), two regions (Azad Jammu & Kashmir, Gilgit-Baltistan), and Islamabad Capital Territory (ICT). **Multi-stage sampling** was used, starting with population-based stratification, followed by the random selection of **Primary Sampling Units (PSUs)** in rural and urban areas. **Systematic random sampling** was applied to select participants from health facilities, ensuring randomness and representativeness.

For other key groups—family members, community representatives, and healthcare workers—uniform sampling was applied, with 25 participants from each group.

Questionnaire	AJK/GB	Balochistan	ICT	KPK	Punjab	Sindh	Total
PWTB	400	400	400	400	400	400	**2,400**
Family Members	25	25	25	25	25	25	**150**
Community	25	25	25	25	25	25	**150**
Health Care Workers	25	25	25	25	25	25	**150**
Total	475	475	475	475	475	475	**2,850**

Table – 1: *Planned number of questionnaires for each category and province*

Data Collection and Analysis Methodology

The TB Stigma Assessment in Pakistan employed both qualitative and quantitative approaches to thoroughly assess the extent and nature of TB-related stigma. This section outlines the procedures, training, and data management techniques to ensure accurate data collection and analysis.

Training of Data Collectors

Before the commencement of data collection, all field staff, including interviewers and research assistants, received a comprehensive training to enhance their understanding and ensure consistent data collection:

1. **Technical Training on TB Stigma**: Led by a TB Stigma Expert, this training covered key concepts, including different forms of stigma (anticipated, self-stigma, enacted, and observed stigma). The objective was to ensure data collectors are well-versed in the subject matter.
2. **Operational Training**: This segment focused on survey methodology, ethical considerations, questionnaire administration, and interview techniques. Data collectors learned to maintain respondent confidentiality, ensure high data quality, and minimize bias during interviews. Confidentiality statement was part of the engagement agreements that were signed with data collectors.

Data Collection Process

1. **Data Collection Instruments**:

   Semi-structured questionnaires were administered to all respondent groups, ensuring consistency in data collection. The instruments were adapted from validated STP TB stigma measurement tools, which incorporates the **Van Rie TB Stigma Scale for PWTB and community**[1] **Arcencio TB Stigma Scale for family members,**[2] **and Corrigan 9 Stigma Domains (AQ-9) for healthcare workers.**[3] The **OneImpact application hosted by Dopasi Foundation** was used to collect data from respondents.

2. **Training of Data Collectors**:

   12 Data collectors were recruited from various parts of all provinces who underwent training led by the TB Stigma Expert to ensure consistency and minimize bias during data collection. In addition, there were 5 female volunteers who supported in collecting information specially from female and transgender respondents.

[1] Van Rie A, Sengupta S, Pungrassami P, Balthip Q, Choonuan S, Kasetjaroen Y, Strauss RP, Chongsuvivatwong V. Measuring stigma associated with tuberculosis and HIV/AIDS in southern Thailand: exploratory and confirmatory factor analyses of two new scales. Trop Med Int Health. 2008 Jan;13(1):21—30. doi: 10.1111/j.1365—3156.2007.01971.x. PMID: 18290998.

[2] Arcencio RA, de Almeida Crispim J, Touso MM, Popolin MP, Rodrigues LB, de Freitas IM, Yamamura M, Santos Neto M. Preliminary validation of an instrument to assess social support and tuberculosis stigma in patients' families. Public Health Action. 2014 Sep 21;4(3):195-200.

[3] *KNCV Stigma Measurement Guidance, Chapter 5, Table 3 (2018) https://www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf, Psychiatry Research 2014;215:466–70, Community Mental Health Journal 2004;40(4):297–307, Journal of Family Psychology 2006;20(2):239–46.*

Note: pictures have been taken and attached with consent of respondents and data collectors.

3. **FGD Guides**:

   Discussion guides were developed, for facilitators, to explore the **legal and policy environment** surrounding TB care and stigma in Pakistan. These FGDs yielded rich qualitative data that supplements the quantitative findings.

Data Analysis

1. **Quantitative Analysis**:

   The collected data was entered into the **TB Stigma Assessment Workbook** and analyzed using statistical software to measure the prevalence and dimensions of stigma. **Radar charts** and **bar graphs** have been used to visualize the data across different settings.

   Key Variables:

   - **Self-Stigma:** Levels of internalized stigma among PWTB.
   - **Secondary Stigma:** Stigma experienced by families of PWTB.
   - **Healthcare Worker Stigma:** Attitudes and behaviors of HCWs toward PWTB.
   - **Community Stigma:** Social attitudes and misconceptions about TB.

   Quantitative data analysis mainly used descriptive statistics, such as calculating frequencies, percentages, mean values, and standard errors for aggregated stigma measures. For quantifiable outcome variables, like total self-stigma scores, multiple linear regression was employed to identify differences between groups by examining the influence of multiple factors simultaneously.

   For categorical binary outcome variables, such as the presence or absence of stigma experiences, multiple linear probability models were used. This approach enabled the calculation of adjusted percentage differences (prevalence) for specific stigma experiences within a population, along with 95% confidence intervals and p-values. The confidence interval indicates that, if repeated across multiple analyses, 95% of results would lie within this range. Confidence intervals that do not include the null value, along with p-values below 0.05, indicate statistically significant differences between groups.

2. **Qualitative Analysis**:

Thematic coding was applied to the data from FGDs and open-ended questionnaire responses. The qualitative data will be triangulated with quantitative findings to provide a comprehensive understanding of the barriers posed by TB stigma.

3. **Data Analysis Software**:

   Quantitative data was analyzed using SPSS, while qualitative data was analyzed using NVivo. The analysis focused on identifying patterns of stigma across different populations and key variables such as gender, age, and socio-economic status.

4. **Data Storage**:

   All data has been securely stored on encrypted servers, with access restricted to authorized personnel only. Data will be kept for five years and then destroyed in line with data protection regulations.

Ethics and Validation

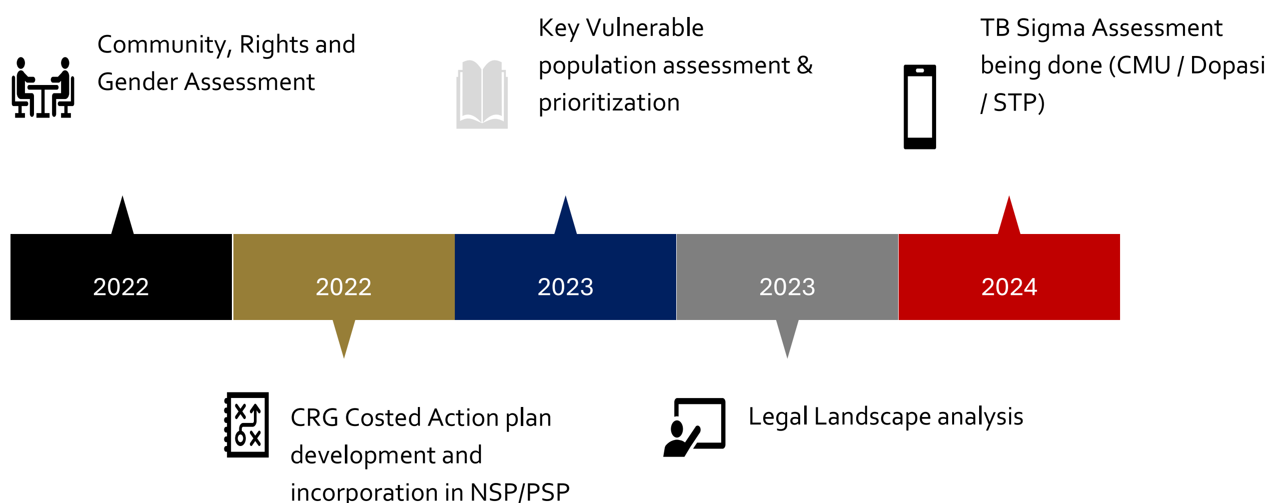
1. **Ethics Review**:

   Ethical approval was given by the Ethical Committee of Health Services Academy.

   - **Informed Consent**: Informed consent was obtained from all participants. For those unable to read or write, verbal consent will be recorded.
   - **Confidentiality**: All personal identifiers were removed from the data, and responses were treated with strict confidentiality.

2. **Validation Workshop**:

   After data analysis, a validation workshop was held with stakeholders, including representatives from the **CMU/NTP, PTPs,** community and other relevant stakeholders, to finalize the findings and agree on recommendations.



Results

Participant Profiles

Overall, 2,982 participants were interviewed from all provinces.

Questionnaire	AJK	Balochistan	GB/ICT	KPK	Punjab	Sindh	Total
PWTB	388	429	284	440	440	411	**2,392**
Family Members	43	23	17	32	107	27	**249**
Community	37	26	11	33	90	25	**222**
Health Care Workers	38	26	11	29	30	25	**159**
Total	506	504	323	534	667	488	**3,022**

Table – 2: *Province based disaggregation of questionnaires filled*

To ensure representativeness, the data was analyzed using weighted sampling. This approach adjusted the analysis to account for variations in the PWTB population across provinces and territories, providing more accurate and meaningful insights. Weighted sampling was applied by assigning a weight to each respondent based on the proportion of PWTB in their respective provinces relative to the total population surveyed. This adjustment ensures that provinces with larger PWTB populations have a proportionate influence on the overall findings, while smaller populations remain appropriately represented.

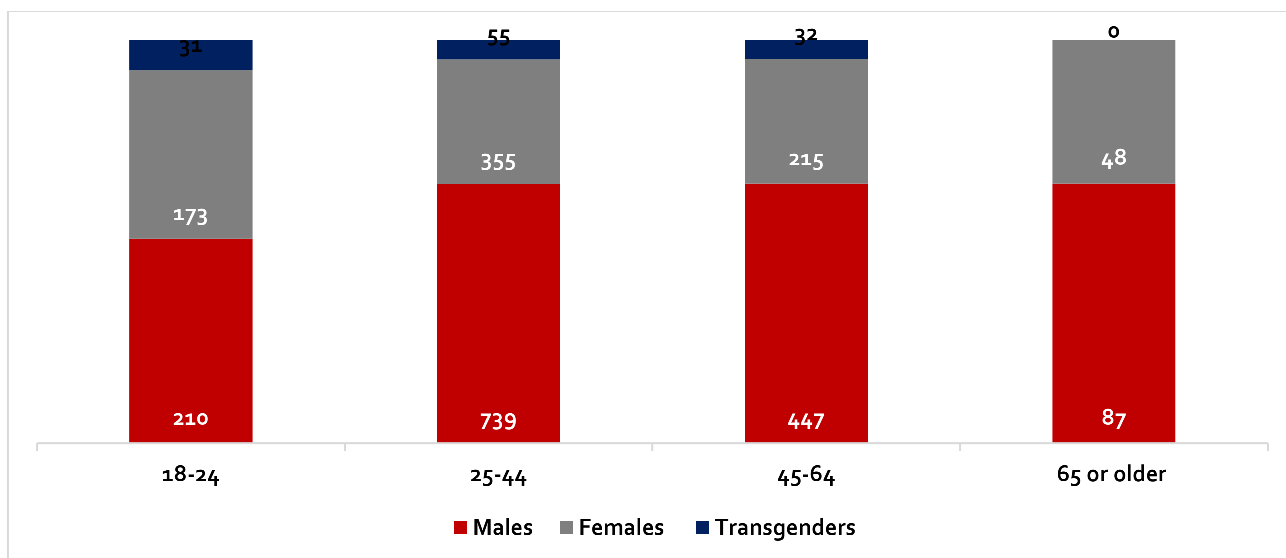
Questionnaire	AJK/GB	Balochistan	ICT	KPK	Punjab	Sindh	Total
PWTB	58	145	23	395	1234	537	**2,392**
Family Members	6	15	2	41	129	56	**249**
Community	5	13	2	37	115	50	**222**
Health Care Workers	4	10	2	26	81	36	**159**
Total	73	183	29	499	1559	679	**3,022**

Table –2a: Province based weighted Population

The weighted sampling methodology improves the reliability and validity of the analysis by ensuring the findings are reflective of the national population distribution. This adjustment is particularly important in studies like this, where certain provinces or territories have disproportionately smaller or larger populations. By applying weights, the data mitigates the risk of over- or under-representing any particular province, resulting in a more balanced and equitable interpretation of stigma across regions.

People with TB or who had TB

Most individuals with TB (65%) were men, with the largest age groups being 25-44 years (48%) and 45-64 years (29%). A notable gender difference emerged among people aged 45-64, where only 30% were women (see Graph 1). Additionally, there were nine transgender participants in the study.



Graph 1: *Distribution of PWTB by gender and age, participants (n=2392)*

Approximately 8% of respondents did not identify with any specific key population (see Graph 2). The majority, 48.3% (1137 individuals), identified as rural poor, making this the largest group in the sample. Urban slum residents accounted for 7.2% (169 individuals), while miners represented 5% (118 individuals). A smaller portion of the sample, 2.7% (63 individuals), identified as people living with HIV. Healthcare workers comprised 4.2% (98 individuals), and refugees made up 2.5% (58 individuals) of the sample. Indigenous persons represented 8.7% (204 individuals), and former prisoners accounted for 11.6% (272 individuals). People who use drugs constituted 1.5% (36 individuals), while persons with disabilities were the smallest group, at 0.8% (18 individuals).

Self-Identify as Key population	n	%
Person living with HIV	68	3.0%
Miner	125	5.5%
HCW	123	5.4%
Refugee	56	2.5%
Urban Slums	197	8.7%
Rural Poor	1042	45.9%
Person who use drugs	37	1.6%
Person with disability	43	1.9%
Indigenous Person	140	6.2%
Former Prisoner	321	14.1%
Transgender Individuals	118	5.2%
Total	2270	100%

Table – 3: *Self-identification by PWTB with key populations, participants and % (n=2270)*

Most respondents (54%) were undergoing TB treatment at the time of the interview. Nearly a quarter (23.5%) had completed their treatment more than a year prior, while 19% had finished treatment within the past year. Additionally, 81 participants (3.4%) had been diagnosed on the day of the interview; they had not yet started TB treatment but expressed a clear intent to begin.

Around 8% of participants could not identify the disease site. Among those who could (n=2174, 92%), almost 81.6% (n=1920) had pulmonary disease. Of the total respondents, 59 (2.5%) had MDR-TB and 11 (0.5%) had Pre-XDR/XDR-TB.

Province	Number	%age
AJK/ GB	388	16.2%
Baluchistan	429	17.9%
ICT	284	11.9%
KPK	440	18.4%
Punjab	440	18.4.0%
Sindh	411	17.2%
Total	**2392**	**100%**

Table – 4: *Province wise disaggregation of PWTB respondents*

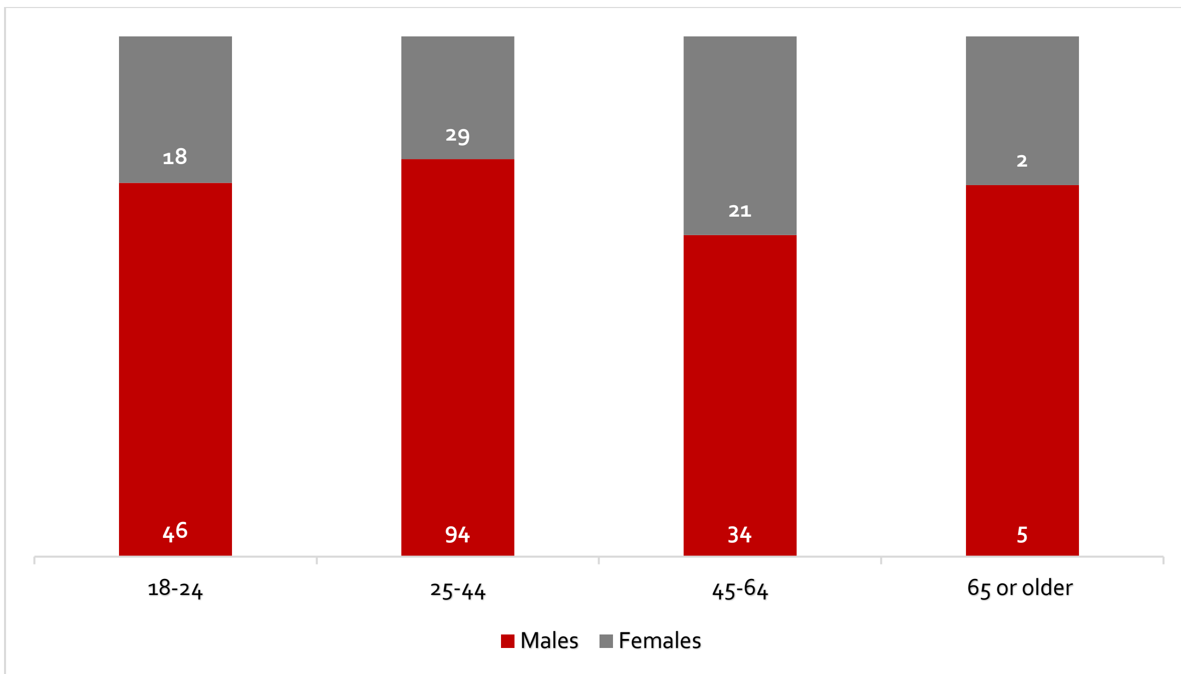
The table (shows the distribution of study participants by province and region, illustrating the representation of each area in the sample of 2352 respondents.

- **Khyber Pakhtunkhwa (KP), and Punjab** had the highest representation, with 440 participants each, accounting for 18.4% of the total sample.
- **Balochistan** followed closely with 429 participants, making up 17.9%.
- **Sindh** contributed 411 participants, or 17.2% of the sample.
- %.
- **Azad Jammu & Kashmir/Gilgit-Baltistan (AJK/GB)** had 388 participants, comprising 16.2% of the sample.
- **Islamabad Capital Territory (ICT)** had the smallest share with 284 participants, or 11.9%.

This distribution shows a relatively balanced representation across most provinces and regions, ensuring that the study captures a wide range of geographic perspectives.

Family Members

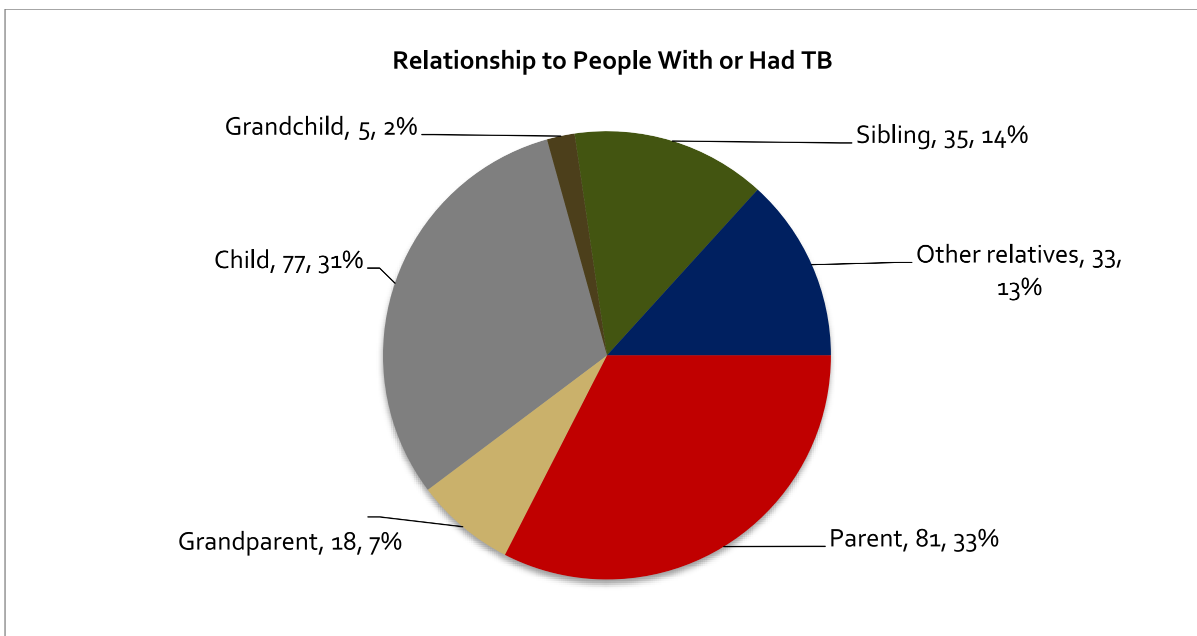
The sample of family members of PWTB was represented mostly by men (179 out of 249 respondents, 72%), aged between 25 and 44 (123 out of 249, 63%) as seen in Graph-2.



***Graph 2:** Distribution of PWTB family members by age and gender, respondents (n=249)*

There were no transgender individuals among family members of PWTB.

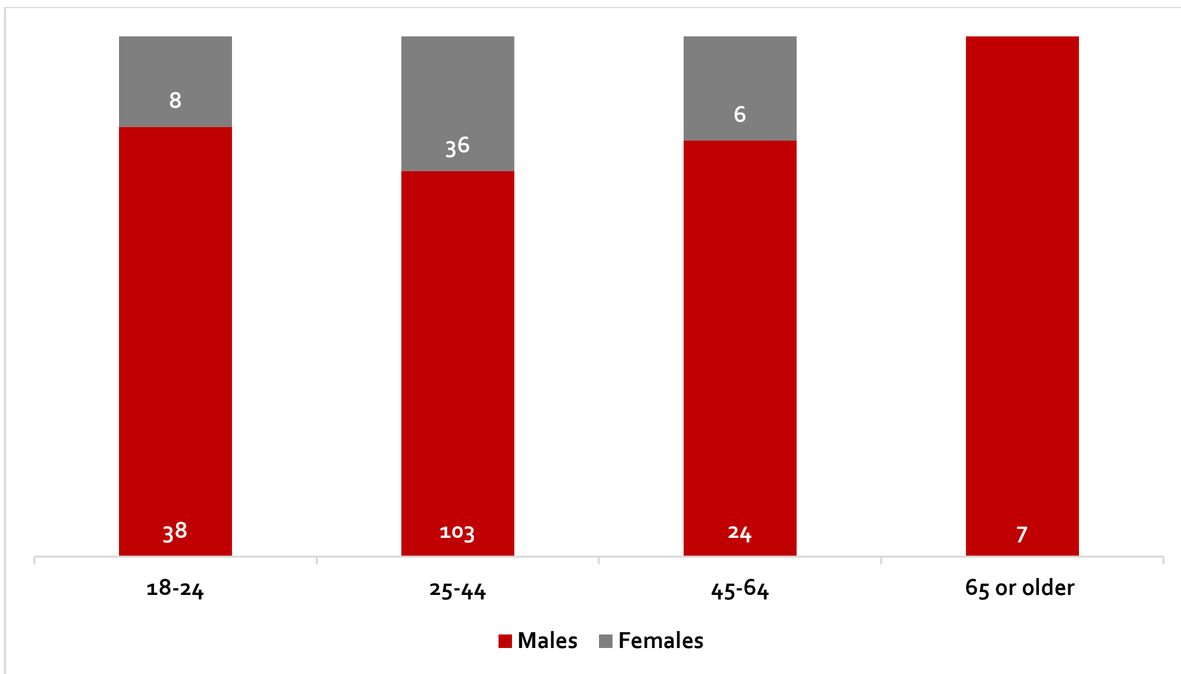
The first line family members, e.g., parents, siblings and children constitute 77.5% out of the total number of respondents (Graph 3). Overall, Parents constituted 33%, Children 31%, Siblings 14%, Grandparents 7%, Grandchildren 2% while 5% other relatives responded.



***Graph 3:** Distribution of PWTB family members by relationship (n=249)*

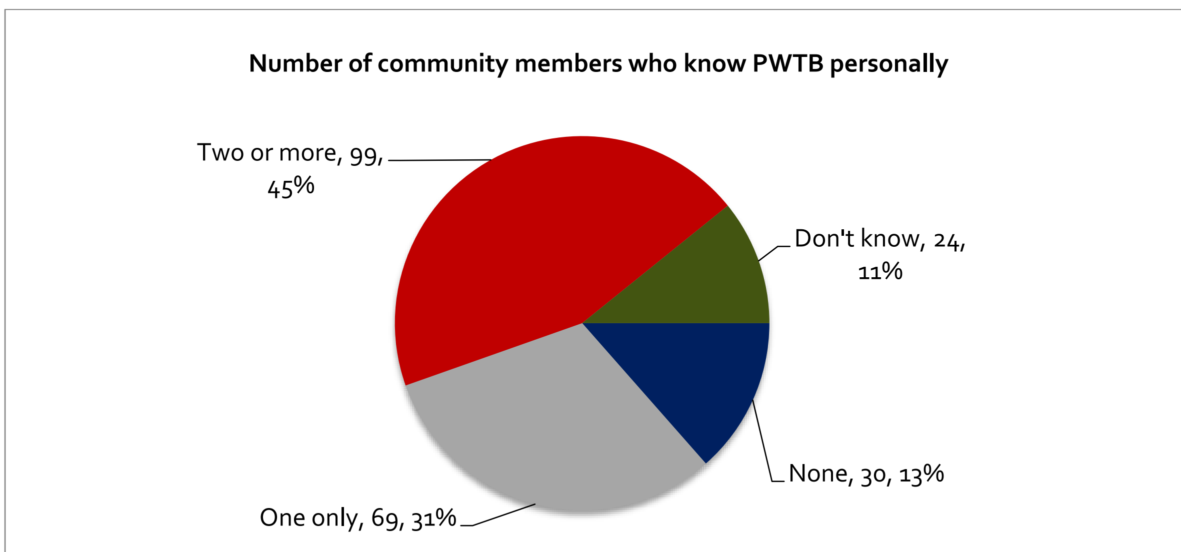
Community Representatives

The group of community representatives is mostly represented by men (172 out of 222 respondents, 77.5%) (Graph 4). The majority is aged between 25 and 44 (103 out of 222, 46%).



Graph 4: *Distribution of community representatives by age and gender, respondents (n=222)*

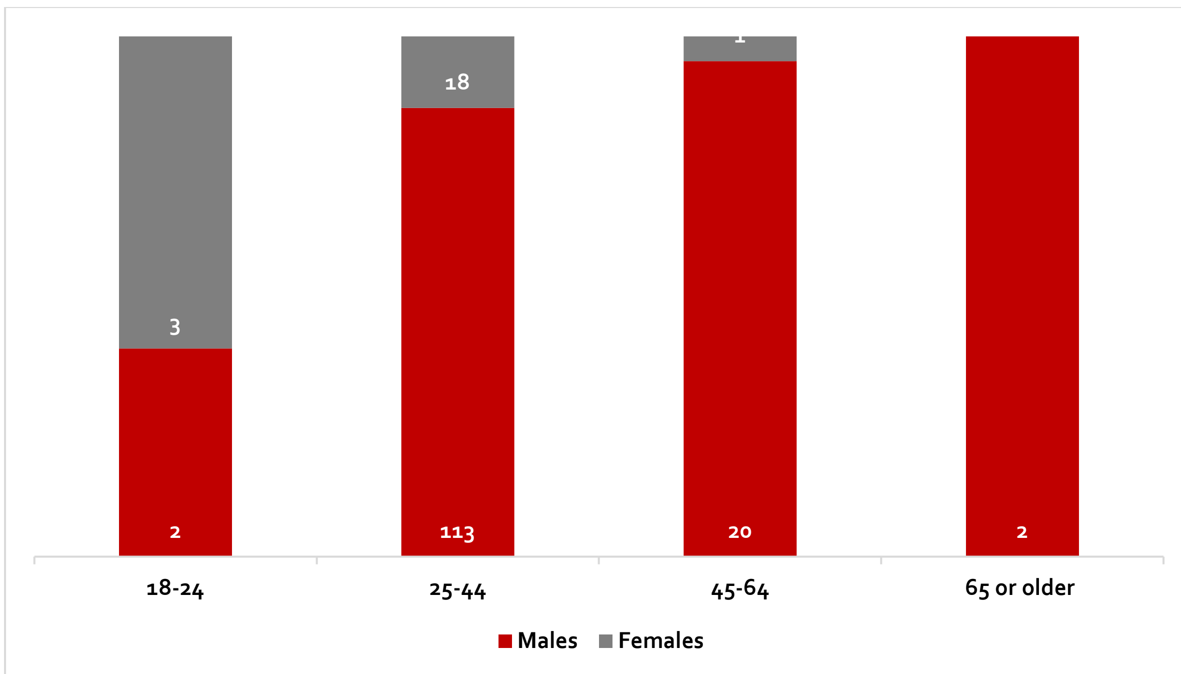
Nearly 45% of community representatives reported having a personal connection with two or more individuals affected by TB, while 11% indicated that they had no direct connection to anyone with TB within their community.



Graph 5: *Number of community members who know PWTB personally (n=222)*

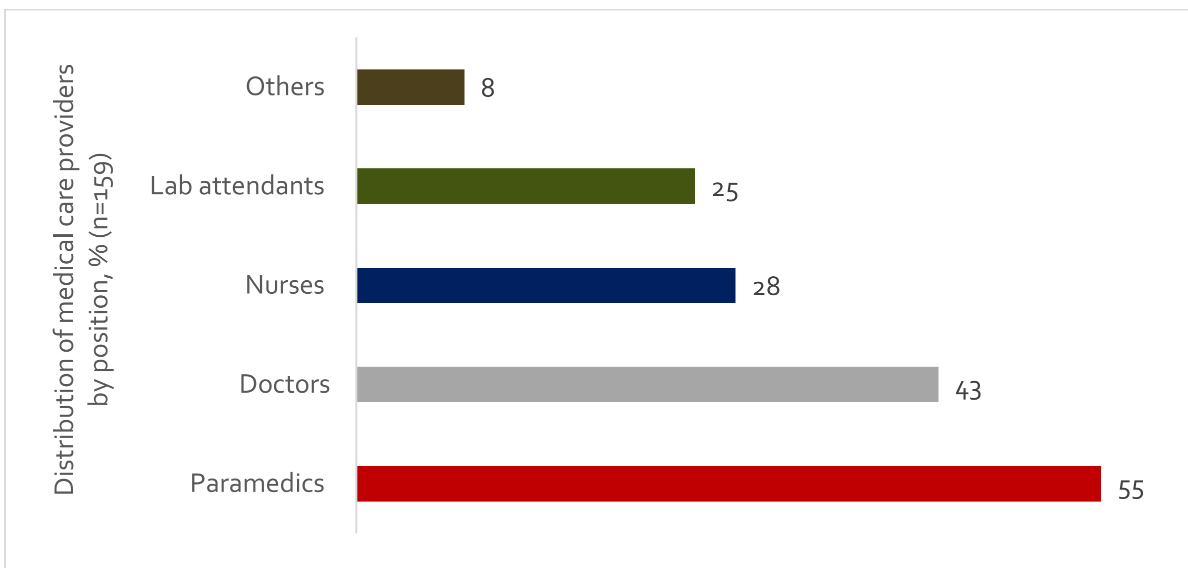
Healthcare Workers

Over 85% of the surveyed healthcare workers were men (Graph 6). Majority of these respondents (82%) were aged between 25 and 44.

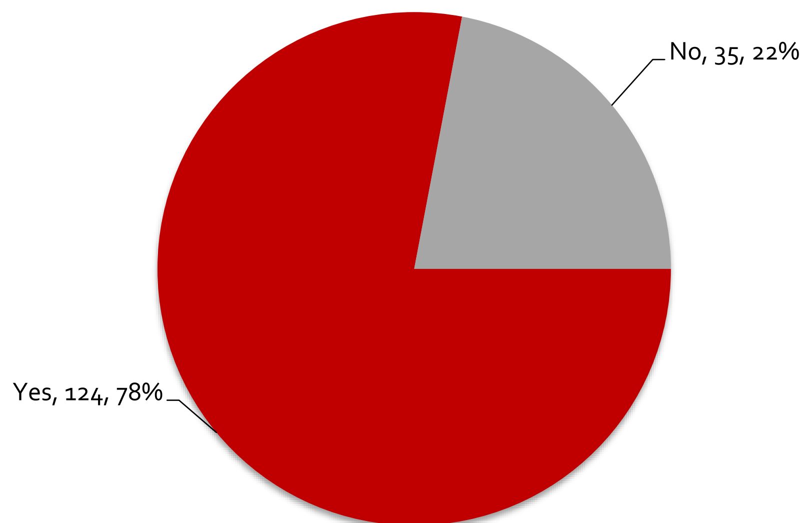


Graph 6: *Number of community members who know PWTB personally (n=159)*

Approximately one-third (35%) of the healthcare workers interviewed were paramedics, followed by 27% who were doctors, 17% nurses, and 16% ward attendants. The remaining 5% fell into other categories of healthcare workers.



Graph 7: *Number of community members who know PWTB personally (n=159)*



Graph 8: *Number of community members who know PWTB personally (n=159)*

Most of these healthcare workers (78%) had experience of providing services to people with TB, including tertiary care settings, District headquarter, tehsil headquarter and Rural health centre TBMUs.

The health care workers are convinced that the anticipated stigma associated with tuberculosis is widespread within the medical community. An overwhelming majority (75%) have confirmed the fact that there are medical providers who would support quarantining PWTB during the more intense stages of treatment (Graph 8). Eighty-eight percent of the respondents have expressed support for mandatory TB treatment. Almost three quarters (73%) say that some health care providers try to avoid PWTB.

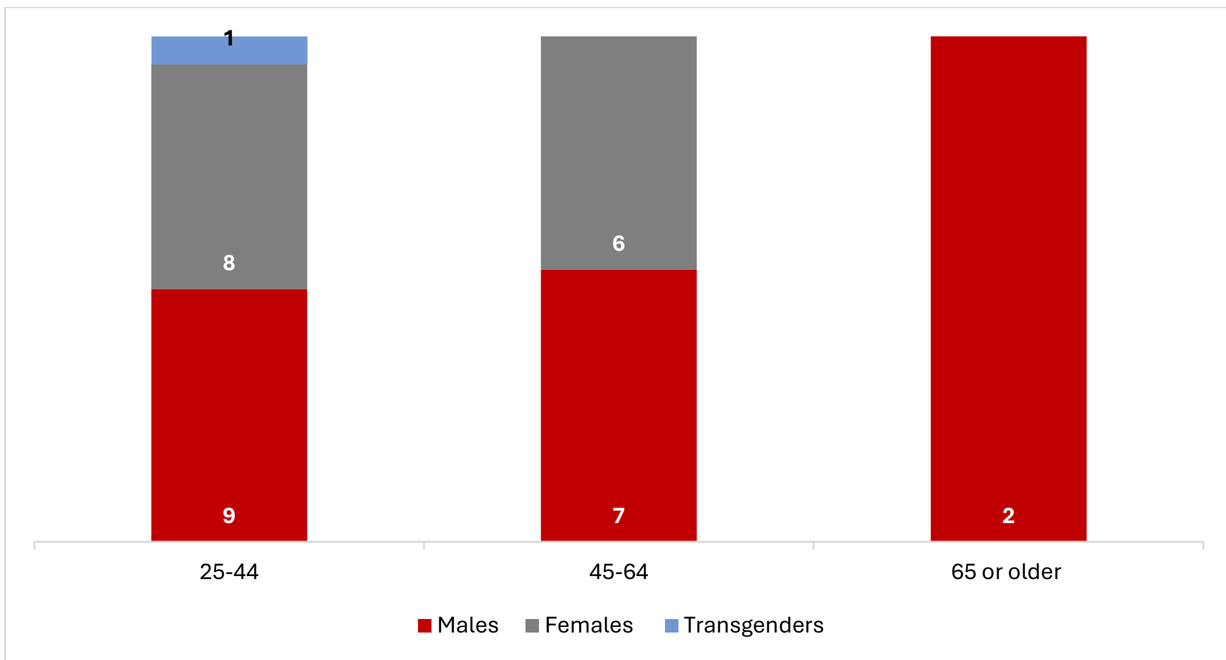
Focus Group Discussion on TB Stigma Assessment

The focus group for the TB Stigma Assessment included a diverse mix of 33 participants, featuring experts in law, journalism, media, policymakers, TB stigma specialists, and representatives from the community of individuals who have experienced TB. Male participants made up a slight majority (18 individuals or 54.5%), while females accounted for 42.4% (14 individuals). The group also included one transgender participant who had previously undergone TB treatment.

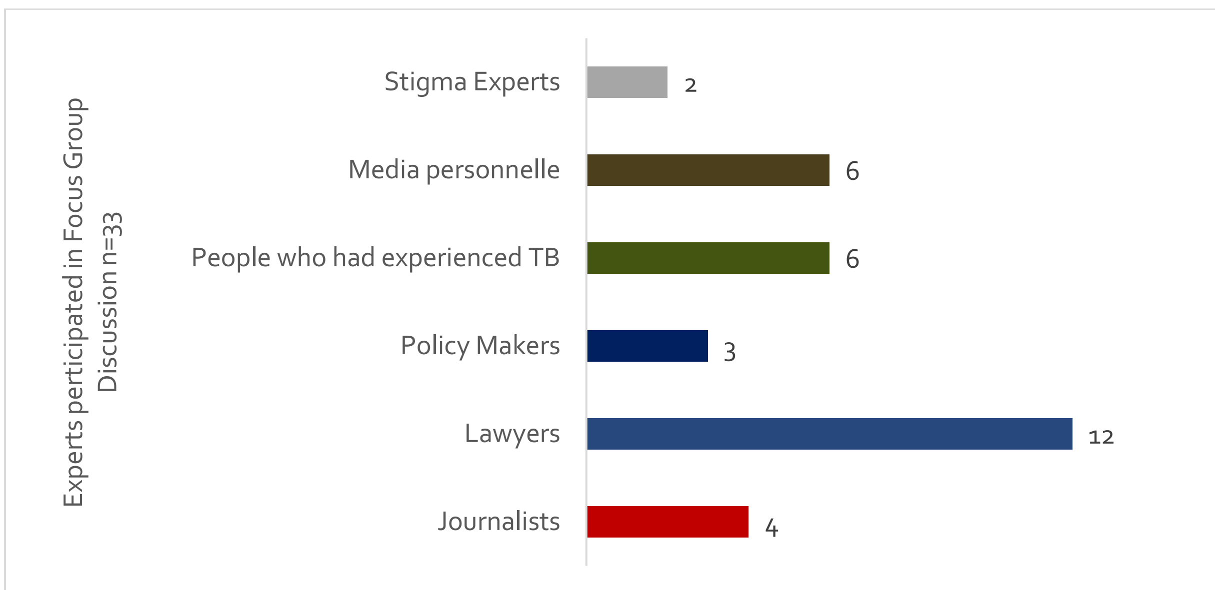
Age-wise, participants were distributed across three groups Graph 9):

- **25-44 years**: This group consisted of 17 participants, with a near balance between males (9) and females (8), and included the transgender participant.
- **45-64 years**: Comprised of 13 individuals, with males (7) slightly outnumbering females (6).
- **65 years or older**: Represented by two male participants.

This composition ensured a range of perspectives on TB stigma, considering both gender diversity and age distribution.



Graph 9: *Number of Experts Participated in Focus Group Discussion (n=33)*



Graph 10: *Experts Participated in Focus Group Discussion (n=33)*

The focus group discussion on TB stigma assessment included a diverse array of 33 experts and stakeholders, representing different professional backgrounds and perspectives on TB stigma.

- **Lawyers** formed the largest group, with 12 participants, reflecting the importance of legal perspectives in addressing stigma-related issues and supporting the rights of people affected by TB.
- **Media Personnel** and **People with Lived TB Experience** were equally represented, with 6 participants each. Media professionals contribute to shaping public perceptions, while individuals with lived TB experience provide first-hand insights into stigma challenges.
- **Journalists** accounted for 4 participants, offering additional perspectives on how TB is portrayed in news and public discourse.
- **Policy Makers** were represented by 3 participants, highlighting the role of governance and policy in stigma reduction efforts.

- **Stigma Experts** comprised the smallest group, with 2 individuals, providing specialized knowledge on stigma dynamics and effective interventions.

Pictures from Focus Group Discussion chaired by the Manager NTP / Dep. National Coordinator CMU Pakistan

Multi Stake Holder Validation Workshop on Stigma Assessment

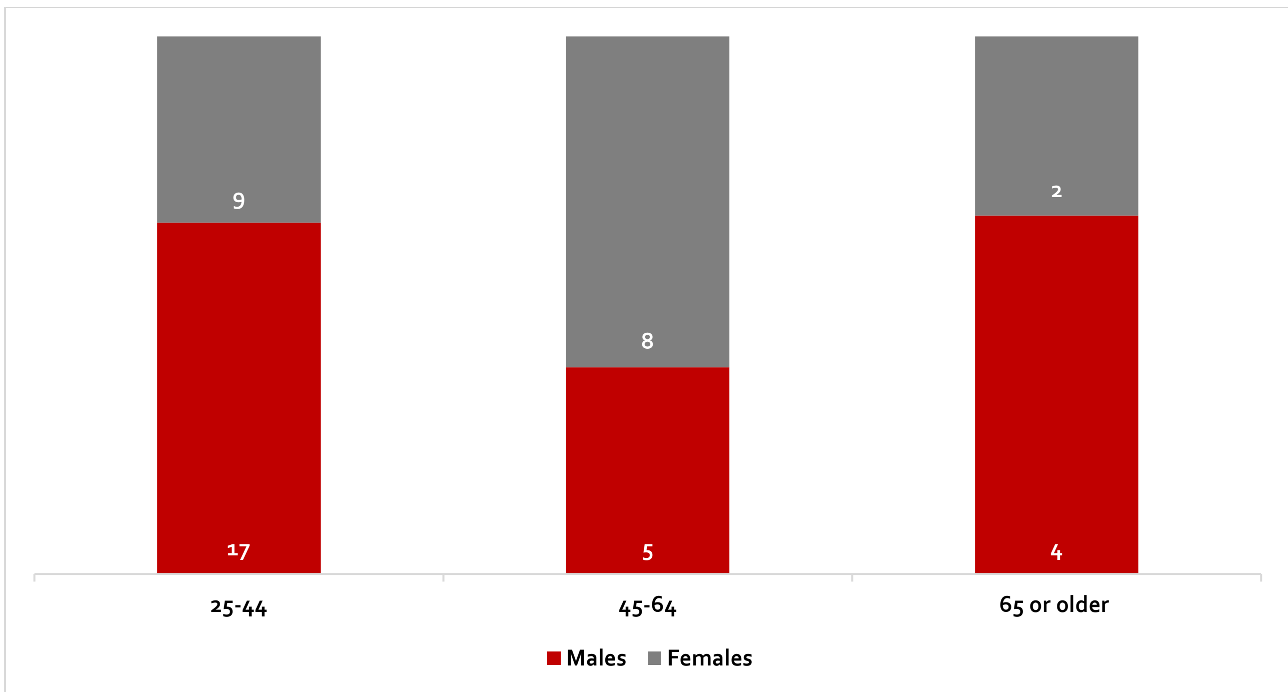
This focus group discussion gathered 45 experts, including national, international, and regional TB program managers; representatives from the Ministry of Health, the Common Management Unit for AIDS, TB & Malaria / National TB Program; as well as representatives from Provincial / Regional TB programs KP, Balochistan, GB and AJK, Communicable disease control Sindh, donors, NGOs, and individuals who have experienced TB. Of the 45 participants, 26 were male and 9 were female, with approximately 12 participants joining the discussion virtually, including Provincial TB Control Program Punjab.

Age distribution among participants was as follows:

- **25-44 years**: The largest group, comprising 26 individuals (58%), included 17 males and 9 females.
- **45-64 years**: This group had 13 participants, with 8 females and 5 males.
- **65 years or older**: Represented by 6 participants, including 4 males and 2 females.

This diverse assembly provided a comprehensive range of perspectives, with a majority of participants in the 25-44 age group, allowing for a balanced discussion of TB program challenges and strategies across various demographics and expertise levels.

Pictures from Multi-stakeholder validation workshop chaired by Special Secretary Health and joined by Managers and technical teams from all PTPs, among others.

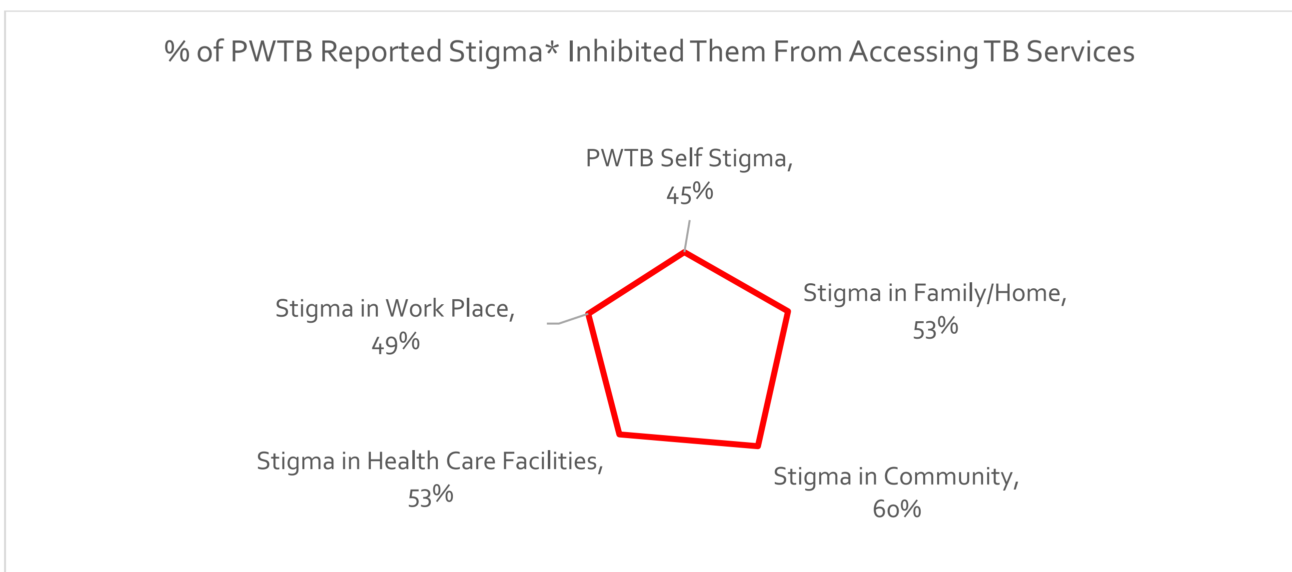


Graph 11: *Experts Participated in Multi Stake Holder Validation Workshop on Stigma Assessment (n=33)*

Stigma Radar and Stigmatizing Attitudes Intensity (n=2,352)

xxx

The TB Stigma Radar is a comprehensive, standardized tool that assesses various dimensions of TB-related stigma affecting people with TB (PWTB) and their families in Pakistan. This tool evaluates internalized (self) stigma, the impact of stigma on access to TB services, stigma experienced within family and community settings, as well as stigma perpetuated by healthcare workers. Additionally, it examines stigmatizing attitudes and the legislative and policy environments to identify structural barriers that may reinforce stigma and discrimination against PWTB. The radar chart visually represents the extent of each type of stigma, where a larger web indicates a more severe issue. These indicators should be tracked over time (i.e., assessment should be repeated in 2-3 years using the same methodology including sampling approach and sample sizes, etc) to measure impact of the implementation of anti-stigma interventions in the action plan developed as part of this assessment.



Graph-12: *illustrates to what extent the different types of stigma encountered by people with TB (PWTB) across various settings inhibited them accessing TB services.*

1. Healthcare Facilities: Over half of the respondents (53%) encountered stigma in health care settings that inhibited them from accessing TB services. This high percentage indicates that many persons experience negative treatment or judgment from healthcare providers or feel uncomfortable due to a lack of privacy and sensitivity in these settings.

- **Implications**: Stigma within healthcare facilities can severely impact persons' willingness to seek timely treatment or follow-up care, thereby hindering their recovery. Implementing training programs to sensitize healthcare staff on stigma-free care, ensuring person confidentiality, and establishing feedback systems for persons can contribute to a more supportive healthcare environment.

2. Community Stigma: Community stigma is the most prominent, with 60% of respondents feeling stigmatized within their neighborhood or social circles. This type of stigma stems from misconceptions about TB's contagiousness and perceived association with socially undesirable behaviors.

- **Implications**: Community-based stigma can lead to social isolation and discourage individuals from openly discussing their diagnosis or seeking help. Public health awareness campaigns that educate communities about TB's nature, transmission, and treatability can be crucial in dispelling myths and reducing stigma within communities.

3. Workplace Stigma: Almost half (49%) of the respondents reported experiencing stigma in their workplace. Colleagues or employers may distance themselves due to fear of infection, or persons may face discrimination affecting their job security and social interactions at work.

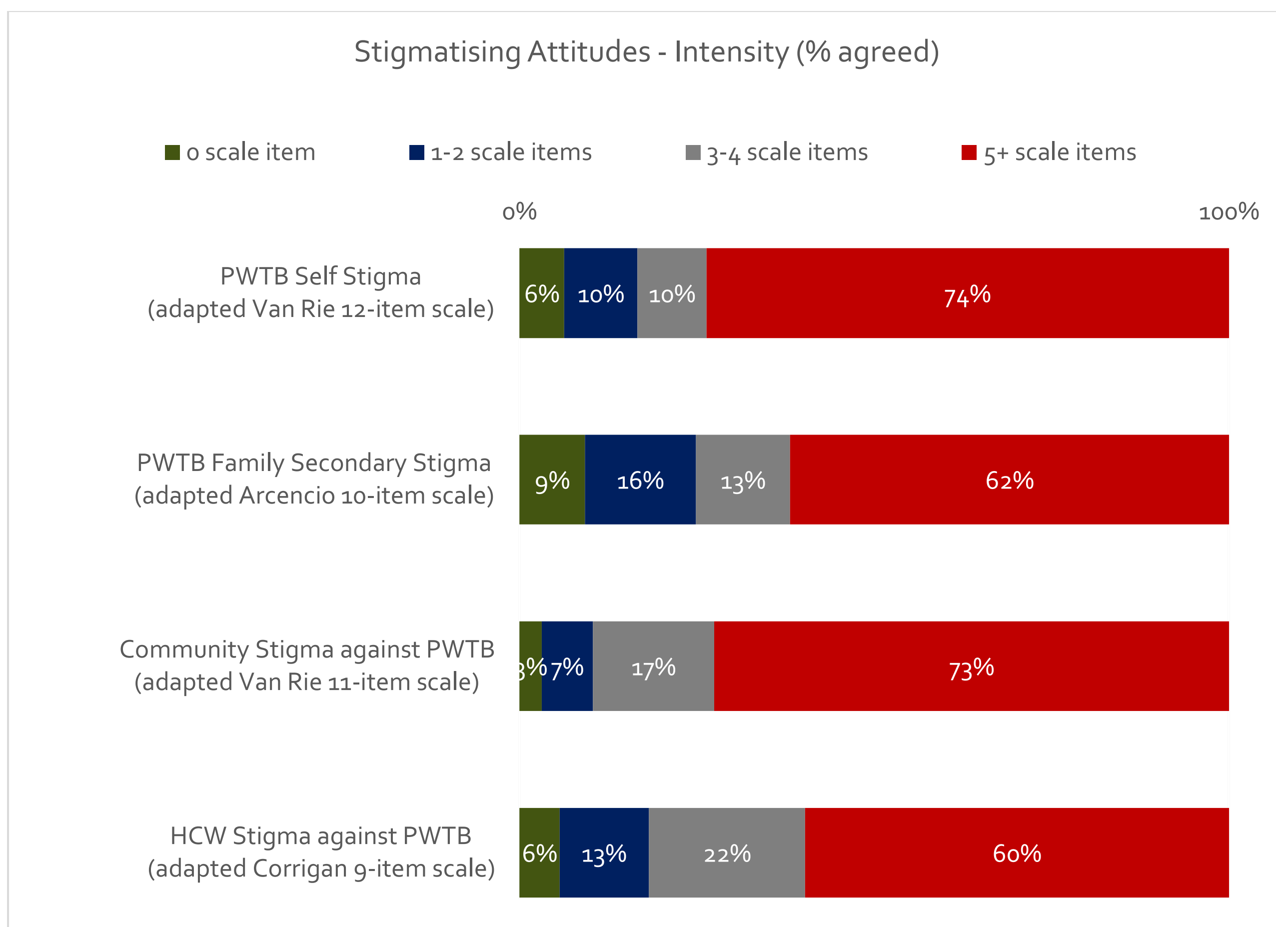
- **Implications**: Workplace stigma can have serious economic and psychological effects on PWTB, potentially leading to job loss or limited career opportunities. Implementing anti-discrimination policies, providing TB education in the workplace, and establishing protections for employees with TB can help create a more inclusive work environment.

4. Family/Home Stigma: More than half of the respondents (53%) reported stigma from their family or household members. Family stigma may arise from concerns about infection, shame, or the perceived burden of caring for a family member with TB.

- **Implications**: Family stigma can increase persons' feelings of isolation and guilt, impacting their mental health and recovery. Family-centered education programs and counseling can help create a more understanding and supportive home environment, empowering families to provide essential support during the treatment journey.

5. Self-Stigma: Around 45% of PWTB experienced self-stigma, where they internalized negative societal attitudes towards TB, leading to feelings of shame, guilt, and unworthiness. This self-stigma can deter persons from accessing healthcare services due to fear of judgment or discrimination.

- **Implications**: Self-stigma can significantly hinder recovery, as persons may avoid seeking necessary care or delay treatment. To combat self-stigma, support programs that provide counseling, peer support, and education about TB can help persons understand that TB is treatable and that they are not to blame for their illness.



Graph 13: *illustrates the intensity of stigmatizing attitudes*

- Self-stigma – 74% reported 5 items of more in the 12-item self-stigma scale
- Family secondary stigma - 62% reported 5 items of more in the 10-item family secondary stigma scale
- Community stigma against PWTB - 73% reported 5 items of more in the 11-item community stigma scale
- Health care workers stigma against PWTB - 60% reported 5 items of more in the 9-item HCW stigma scale

The data reveals intense and pervasive stigma affecting individuals with TB (PWTB) across multiple settings, including self-stigma, family, community, and healthcare workers. Self-stigma is alarmingly high, with 74% of respondents reporting significant internalized stigma, as measured by the 12-item self-stigma scale. Within families, 62% of respondents reported secondary stigma, highlighting the significant burden of stigma within domestic settings. Community stigma against PWTB is equally severe, with 73% of respondents experiencing stigmatizing attitudes on the 11-item community stigma scale. Among healthcare workers (HCWs), 60% of respondents reported stigmatizing attitudes toward PWTB, indicating a critical barrier to accessing respectful and supportive healthcare.

This widespread stigma reflects deeply ingrained misconceptions and biases about TB, further marginalizing PWTB and complicating their treatment and recovery journey. Below, we detail specific stigmatising attitudes identified within each domain and propose tailored interventions to combat these challenges.

Implications for anti-stigma interventions:

1. **Community Education Campaigns**: Targeting community stigma through widespread public awareness campaigns is essential. These campaigns should focus on dispelling myths about TB transmission and emphasizing the curability of the disease, aiming to foster empathy and reduce exclusionary attitudes.
2. **Healthcare Provider Training**: Sensitizing healthcare workers to the stigma faced by PWTB can significantly improve their experience in healthcare settings. Training programs should emphasize person confidentiality, the psychological impact of stigma, and the importance of non-judgmental care.

3. **Workplace Anti-Stigma Policies**: Implementing inclusive workplace policies to protect PWTB and educating employers and employees about TB transmission and treatment can create a more supportive environment, ensuring PWTB can maintain employment without fear of discrimination. **Family Support Programs**: Addressing family secondary stigma through educational initiatives can help families understand TB transmission and reduce fear and misinformation. Counseling and family-oriented support groups can foster a nurturing environment for PWTB, which is critical for adherence and recovery.

4. **Self-Stigma Reduction Initiatives**: Programs aimed at reducing self-stigma are vital for empowering PWTB. These could include counseling, peer support groups, and access to educational materials that address internalized stigma, promote self-efficacy, and encourage timely healthcare access.

Addressing TB-related stigma demands a multifaceted strategy that simultaneously targets individuals, families, communities, and healthcare systems. By combining public education, professional training, and policy implementation, these interventions can create a supportive and stigma-free environment, enabling PWTB to access the care, support, and acceptance they need for successful treatment and recovery.

Self-Stigma in people with TB

The self-stigma experienced by people with TB (PWTB) was evaluated using 12 statements addressing their attitudes toward TB disclosure, feelings of guilt, social isolation, and other related factors. Nearly all respondents provided clear responses, with less than 1% abstaining or unable to answer (Diagnram-12).

Key findings indicate that a substantial proportion of participants experience self-stigma. More than half of respondents identified with feelings of guilt about burdening their families, reported pain from negative reactions upon disclosure, feared disclosing their TB status, and limited social interactions to prevent the spread of TB (Table-5 Annexed.

Below are detailed insights based on specific statements:

1. **Disclosure-Related Fears**

   - **54%** of respondents reported feeling hurt by how others react to their TB status (Statement A1).
   - **43%** indicated a fear of sharing their TB status outside the family (Statement A5).
   - **48%** expressed apprehension about going to TB clinics where they might be seen by someone they know (Statement A6).
   - These fears illustrate the reluctance to disclose their condition in public spaces or to people outside close circles, reflecting a deep concern for privacy and fear of social judgment.

2. **Impact on Relationships and Social Isolation**

   1. **47%** reported losing friends after disclosing their TB status (Statement A2), and **59%** stated they intentionally kept a distance from others to avoid spreading TB germs (Statement A4).
   2. A considerable **21%** felt alone due to TB (Statement A3), which underscores the social isolation experienced by many PWTB, often driven by stigma.

3. **TB and HIV-Related Stigma**

   3. **27%** agreed with statements linking TB with HIV stigma, fearing that others may assume they also have HIV if their TB status is disclosed (Statement A7).
   4. Among respondents with HIV, **54%** expressed concerns that others might link their TB status with HIV, indicating a compounded stigma. This association with HIV stigma significantly heightens the fear and isolation experienced by people with TB.

4. **Feelings of Guilt**

   5. **42%** of respondents reported feeling guilty because their family has to care for them due to their TB condition (Statement A8).

6. **34%** felt guilt associated with their illness, attributing it to behaviors like smoking or drinking (Statement A10). These guilt-related responses show that many PWTB internalize blame, which may intensify their self-stigma and impact their mental health.

5. Family and Social Fear

7. **39%** felt afraid to disclose their TB status to their family (Statement A12), and **30%** carefully chose whom to tell about their TB condition (Statement A9) to control the spread of information. These responses indicate the fear of judgment within both family and broader social circles, contributing to further isolation.

6. Worries About TB and HIV/AIDS

8. **22%** of respondents worried about being associated with HIV/AIDS due to their TB diagnosis (Statement A11), reflecting the overlap of stigma between these diseases.

General Self-Stigma Score Trends

Research on TB-related self-stigma across different settings consistently reports moderate to high levels of self-stigma among people with TB. A study by Van Rie et al. (2008) in South Africa found that PWTB frequently reported shame, fear, and self-isolation, resulting in moderate to high self-stigma scores.[4] Similarly, Heijnders and Van Der Meij (2006) noted that self-stigma is a prevalent issue among PWTB globally, often linked to the social stigma surrounding the disease and internalized beliefs of blame and guilt.[5]

In terms of demographic variations, multiple studies highlight that women and older individuals tend to exhibit higher levels of self-stigma. This trend is often attributed to societal expectations and perceived vulnerability.[6] These experiences were often exacerbated by gendered cultural norms, which place a higher burden on women to uphold familial and social reputation. Studies also documented that older PWTB reported greater levels of self-stigma, primarily due to concerns about being a burden to their families and the perception that illness reflects personal weakness or moral failure.[7]

These findings emphasize that self-stigma among PWTB is influenced not only by the nature of the disease but also by sociocultural factors, gender roles, and individual fears around transmission. Addressing these trends requires targeted interventions, particularly in community education, to reduce misconceptions about TB transmission and support those who experience higher levels of stigma, such as women, the elderly, and those with pulmonary TB.

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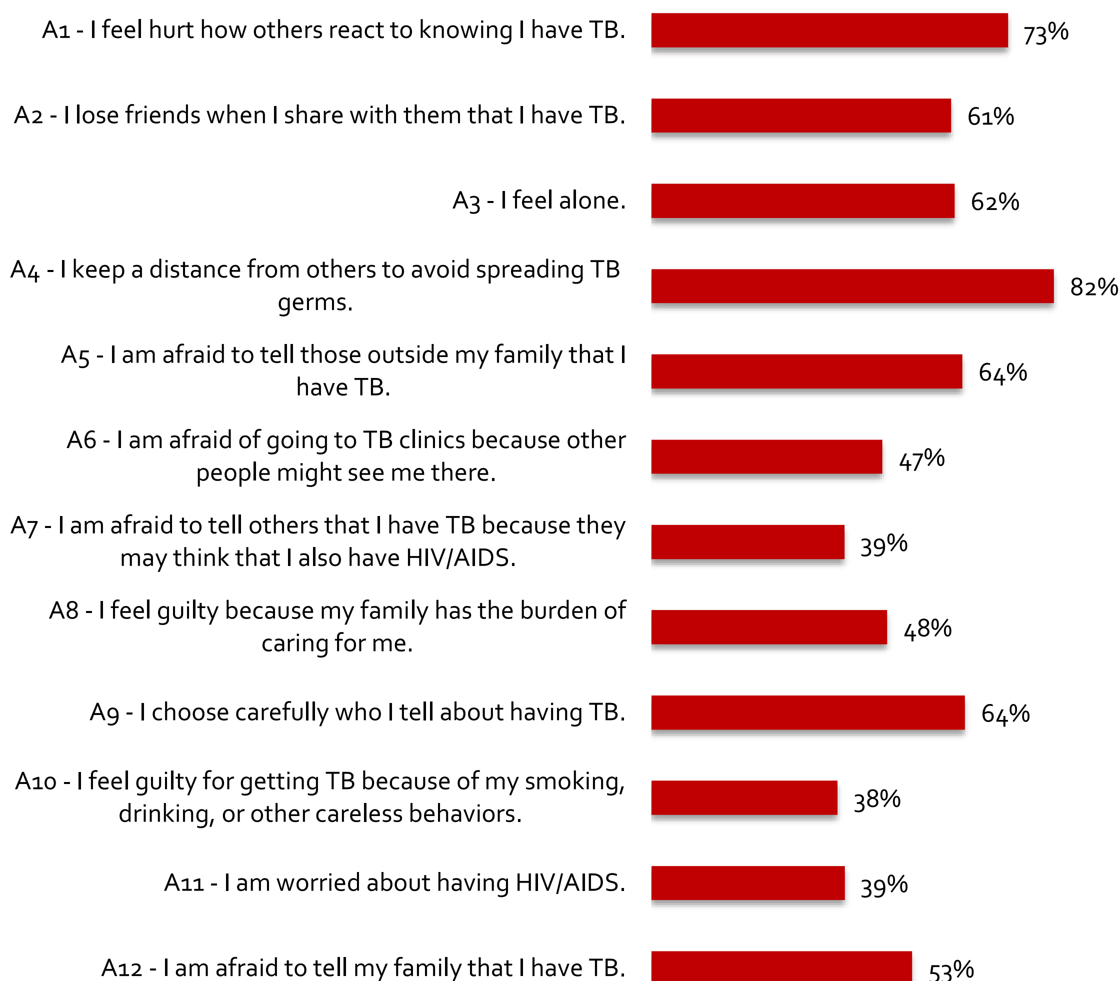
[4] Van Rie A, Sengupta S, Pungrassami P, Balthip Q, Choonuan S, Kasetjaroen Y, Strauss RP, Chongsuvivatwong V. Measuring stigma associated with tuberculosis and HIV/AIDS in southern Thailand: exploratory and confirmatory factor analyses of two new scales. Tropical medicine & international health. 2008 Jan;13(1):21-30.

[5] Heijnders M, Van Der Meij S. The fight against stigma: an overview of stigma-reduction strategies and interventions. Psychology, health & medicine. 2006 Aug 1;11(3):353-63.

[6] Somma D, Thomas BE, Karim F, Kemp J, Arias N, Auer C, Gosoniu GD, Abouihia A, Weiss MG. Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia [Special section on gender and TB]. The International Journal of Tuberculosis and Lung Disease. 2008 Jul 1;12(7):856-66.

[7] Cheng, Q., Mak, W. W., Lau, C. H., & Gu, J. (2019). A cross-sectional study of self-stigma, stigma stress and depression in people with tuberculosis: the role of age and gender. *International Journal of Tuberculosis and Lung Disease*, 23(4), 426-432.



Graph 14: *Dimensions of self-stigma in PWTB: level of support for each statement which refers to living with TB, % (n=2352)*

Provincial Distribution

- **5+ Scores by Province:** The distribution shows higher self-stigma scores across several provinces, particularly in **ICT** and **Khyber Pakhtunkhwa (KPK)**, where 26**%** and 19% respectively (P value < 0.05 for both) of respondents in each region reported above-average self-stigma scores. In contrast, provinces like **AJK, and Sindh** showed lower proportions of above-average scores (7-10%).

PWTB Experiencing Self Stigma that inhibited them from accessing TB services	N=2392	Number experienced Stigma (5+ Score)	%age experienced stigma
Province			
AJK/ GB	58	4	7%
Bal	146	23	16%

ICT	23	6	26%
KPK	394	74	19%
Punjab	1234	224	18%
Sindh	537	52	10%
Gender			
Male	1483	188	13%
Female	791	120	15%
Transgender	118	76	64%
Age			
18-24	413	85	21%
25-44	1150	178	15%
45-64	694	106	15%
65 or older	135	14	10%
Localization of TB			
Pulmonary	2163	340	16%
Extra Pulmonary	123	23	19%
Extensively Drug-Resistant TB	11	5	45%
Multi Drug Resistant TB	43	6	14%
Others	52	8	15%
Self-Identify as			
Person living with HIV	68	8	12%
Miner	125	11	9%
HCW	123	29	24%
Refugee	56	15	27%

Urban Slums	197	23	12%
Rural Poor	1042	174	17%
Person who uses drugs	37	7	19%
Person with disability	43	27	63%
Indigenous Person	140	20	14%
Former Prisoner	321	44	14%
Transgender Individuals	118	76	64%

***Table – 6:** Self Stigma experienced by that inhibited them from accessing TB services (N=2,392). The data with statistically significant p-values (<0.05) has been highlighted in grey.*

Age Distribution

- **Age-Based Self-Stigma Trends:** The data reveals that the **18-24** age group constitutes nearly half (21%) of above-average self-stigma scores (P value < 0.05), followed by **25-44** and **45-64** (15% ach), and **65 or older** (10%).
- This trend is consistent with findings by Cheng et al. (2019), where younger to middle-aged adults showed higher self-stigma due to societal responsibilities, employment pressures, and greater social interaction. Older adults, though vulnerable, may have lower self-stigma due to reduced social exposure and perhaps greater acceptance of their health status.

Type of TB

- **Pulmonary TB and Higher Stigma:** Those with pulmonary TB represent **81%** of above-average self-stigma scores, significantly higher than those with extra-pulmonary TB (**12%**). Individuals with drug-resistant TB, including **MDR-TB** (2%) and **XDR-TB** (1%), represent smaller proportions but are still notable.

Differences Among Key Populations

Stigma levels among **Key Vulnerable Populations (KVPs)** were found to be alarmingly high, with over half of respondents scoring 5 or higher on the stigma scale. This underscores the pervasive nature of the challenge. The highest stigma levels were reported among **Transgender Individuals** (**64%, P < 0.05**), reflecting compounded vulnerabilities and systemic neglect. This was followed by **Persons with Disabilities** (**63%, P < 0.05**), who face significant barriers in both healthcare access and societal inclusion.

Healthcare Workers (**54%, P < 0.05**) experienced substantial stigma, often tied to their professional association with infectious diseases. **Refugees** (**27%**) reported stigma linked to displacement and social exclusion, while **People Who Use Drugs** (**19%**) faced stigmatization driven by societal prejudices and criminalization. **Rural Poor** (**17%**) experienced stigma shaped by economic marginalization and limited access to health education, and **Prisoners** (**14%**) were impacted by biases tied to their incarceration history.

Stigma was also noted among **People Living with HIV** (**12%**), reflecting persistent societal misconceptions and discrimination. Additionally, **Residents of Urban Slums** (**12%**) and **Miners** (**9%**) reported significant stigma linked to social exclusion, occupational hazards, and restricted healthcare access.

These findings highlight the layered and multifaceted nature of stigma, with each group facing unique challenges influenced by societal norms, economic disparities, and systemic inequities. Addressing these disparities requires **population-specific interventions** that target the root causes of stigma. Key strategies should focus on **awareness campaigns**, **community engagement initiatives**, and **policy-level advocacy** to promote inclusivity and equitable access to healthcare and social support services.

Moreover, **education and training programs** for healthcare providers and policymakers are essential to reducing biases and fostering environments where vulnerable populations feel empowered to seek care without fear of discrimination. By adopting a **comprehensive approach** to stigma reduction, these efforts can drive equitable healthcare outcomes and significantly enhance the quality of life for marginalized communities.

In response to open-ended questions, participants frequently shared experiences of emotional distress following their TB diagnosis. Many expressed feelings of shame, guilt, and a reluctance to disclose their condition to others.

One participant, a 28-year-old man from Quetta, explained, "I know how people view this disease, so I don't talk about it with anyone, even my family. My uncle had TB and once I saw that he was forced to sit outside in the waiting are and only his attendants were allowed to meet the physician. This is wrong".

A 27-year-old woman from Hyderabad said "When planning to get married, I won't disclose my status. I'm sure people's attitudes toward me would change if they found out."

These accounts reveal the deep-seated stigma and emotional burden associated with TB, affecting individuals' self-worth, relationships, and mental health.

Stigma experienced by PWTB along the TB Journey

Stigma Experienced by PWTB in Healthcare Settings

PWTB in Azad Jammu & Kashmir/Gilgit-Baltistan (AJK/GB) reported the highest stigma in healthcare settings, with 86% (P value < 0.05) experiencing stigma, followed closely by Khyber Pakhtunkhwa (KPK) at 77% (P value < 0.05). In contrast, Sindh had the lowest percentage of healthcare-related stigma at 9%. This disparity suggests regional variations in healthcare experiences and perceptions of stigma.

Transgender group reported highest stigma (98%, P value < 0.05), females reported experience of stigma in healthcare settings (51%) compared to males (44%). Stigma affects significantly to females and transgenders.

Younger PWTB (18-24 years) had the highest rates of healthcare-related stigma (64%, P value < 0.05), suggesting that younger individuals might be more sensitive to the stigma or receive more judgment in healthcare settings. Those aged 45-64 reported the lowest healthcare-related stigma (44%, P value < 0.05).

Stigma was most prevalent among individuals with Extensively Drug-Resistant TB (64%), people with pulmonary TB, the more contagious form, reported a 49% stigma rate in healthcare settings.

Among vulnerable groups, Transgenders (98%), people with disabilities (81%) and those who use drugs (65%) reported higher levels of stigma in healthcare settings. Former prisoners (44%) and rural poor (51%) also indicated notable stigma levels. These findings reflect the compounded stigma which certain populations face due to both their TB diagnosis and social identity.

PWTB Experiencing Stigma in a health care setting that inhibited them from accessing TB services	N=2392	Number experienced Stigma	%age experienced stigma

Province			
AJK/ GB	58	50	86%
Bal	146	74	51%
ICT	23	9	39%
KPK	394	303	77%
Punjab	1234	695	56%
Sindh	537	46	9%
Gender			
Male	1483	655	44%
Female	791	403	51%
Transgender	118	116	98%
Age			
18-24	413	263	64%
25-44	1150	529	46%
45-64	694	306	44%
65 or older	135	78	58%
Localization of TB			
Pulmonary	2163	1061	49%
Extra Pulmonary	123	66	54%
Extensively Drug-Resistant TB	11	7	64%
Multi Drug Resistant TB	43	16	37%
Others	52	25	48%
Self-Identify as			
Person living with HIV	68	36	53%

Miner	125	50	40%
HCW	123	63	51%
Refugee	56	30	54%
Urban Slums	197	90	46%
Rural Poor	1042	532	51%
Person who uses drugs	37	24	65%
Person with disability	43	35	81%
Indigenous Person	140	68	49%
Former Prisoner	321	141	44%
Transgender Individuals	118	116	98%

Table – 7: *Stigma experienced by PWTB in a healthcare setting that inhibited them from accessing TB services (N=2,392). The data with statistically significant p-values (<0.05) has been highlighted in grey.*

Stigma Experienced by PWTB in Community Settings

Community stigma was most severe in AJK/GB (95%) and KPK (90%); both with P value < 0.05, suggesting that TB stigma is highly pronounced in certain regions, possibly due to cultural beliefs or a lack of awareness. Sindh reported the lowest level of community stigma at 10% (P value < 0.05), indicating regional differences in public perceptions of TB.

Transgender individuals experienced the highest community stigma (86%, P value < 0.05), highlighting their vulnerability to public judgment. Females (52%, P value < 0.05) also reported higher community stigma than males (42%, P value < 0.05).

Community stigma was particularly high among the 18-24 (63%) and 25-44 or older age groups (46%), suggesting that both younger mid aged individuals may be more impacted by societal perceptions of TB.

People with extensively drug-resistant TB (64%) experienced higher levels of community stigma compared to those with pulmonary TB (47%), which may reflect a general lack of understanding about TB types and transmission.

Transgender individuals (86%) and rural poor (52%) faced higher levels of community stigma. This reflects the compounded effect of poverty and addiction on the public's perception of PWTB. Persons with disabilities (84%) also reported a high level of stigma in community, underscoring the social challenges faced by vulnerable populations.

PWTB Experiencing Stigma in their community that inhibited them accessing TB services	N=2392	Number experienced Stigma	%age experienced stigma
Province			
AJK/ GB	58	55	95%
Bal	146	66	45%
ICT	23	19	83%

KPK	394	354	90%
Punjab	1234	585	47%
Sindh	537	56	10%
Gender			
Male	1483	624	42%
Female	791	410	52%
Transgender	118	102	86%
Age			
18-24	413	262	63%
25-44	1150	524	46%
45-64	694	292	42%
65 or older	135	58	43%
Localization of TB			
Pulmonary	2163	1023	47%
Extra Pulmonary	123	63	51%
Extensively Drug-Resistant TB	11	7	64%
Multi Drug Resistant TB	43	21	49%
Others	52	23	44%
Self-Identify as			
Person living with HIV	68	30	44%
Miner	125	56	45%
HCW	123	66	54%
Refugee	56	17	30%
Urban Slums	197	84	43%
Rural Poor	1042	537	52%

Person who uses drugs	37	14	38%
Person with disability	43	36	84%
Indigenous Person	140	71	51%
Former Prisoner	321	139	43%
Transgender Individuals	118	102	86%

Table – 8: *Stigma experienced by PWTB in their community that inhibited them from accessing TB services (N=2,392). The data with statistically significant p-values (<0.05) has been highlighted in grey.*

Stigma Experienced by PWTB at Home

Home-based stigma was reported most frequently in AJK/GB (90%, P value < 0.05) and KPK (86%, P value < 0.05), suggesting that family stigma is more intense in these regions. Sindh, on the other hand, reported a very low level of stigma at home (7%, P value < 0.05).

Female PWTB experienced higher levels of family-related stigma (47%, P value < 0.05) compared to males (36%). Transgender individuals again reported highest level of stigma within their homes (94%, P value < 0.05), indicating that family stigma impacts them more severely.

Younger individuals (18-24) faced higher home-based stigma (55%, P value < 0.05), perhaps due to family concerns about future prospects or marriageability, while those aged 45-64 reported the lowest stigma (38%, P value < 0.05).

People with Extensively drug-resistant TB faced more family stigma (55%) than people with pulmonary TB (42%). This could be due to misconceptions about the severity of TB or transmission risks within the family.

Transgender individuals (94%) and person with disability (84%) reported high levels of stigma at home. Healthcare workers (52%, P value < 0.05) and the rural poor also experienced significant family stigma (47%), reflecting the added stigma associated with exposure to affected people and socioeconomic status.

PWTB Experiencing Stigma at home that inhibited them accessing TB services	N=2352	Number experienced Stigma	%age experienced stigma
Province			
AJK/ GB	58	52	90%
Bal	146	63	43%
ICT	23	11	48%
KPK	394	338	86%
Punjab	1234	515	42%
Sindh	537	39	7%
Gender			

Male	1483	534	36%
Female	791	373	47%
Transgender	118	111	94%
Age			
18-24	413	226	55%
25-44	1150	475	41%
45-64	694	263	38%
65 or older	135	55	41%
Localization of TB			
Pulmonary	2163	914	42%
Extra Pulmonary	123	60	49%
Extensively Drug-Resistant TB	11	6	55%
Multi Drug Resistant TB	43	17	40%
Others	52	21	40%
Self-Identify as			
Person living with HIV	68	27	40%
Miner	125	45	36%
HCW	123	64	52%
Refugee	56	15	27%
Urban Slums	197	61	31%
Rural Poor	1042	494	47%
Person who uses drugs	37	16	43%
Person with disability	43	36	84%
Indigenous Person	140	53	38%
Former Prisoner	321	120	37%
None	118	111	94%

Table – 9: *Stigma experienced by PWTB at home that inhibited them from accessing TB services (N=2,392). The data with statistically significant p-values (<0.05) has been highlighted in grey.*

Stigma Experienced by PWTB in the Workplace

Workplace stigma was highest (with significant p values) in AJK/GB (93%) and KPK (75%), showing that regional stigma extends beyond family and community settings into professional spaces. Sindh again reported the lowest stigma in the workplace (8%).

Workplace stigma affected transgender individuals most (63%), highlighting their vulnerability to discrimination in employment settings. Female respondents (34%) also reported higher workplace stigma than male respondents (29%).

PWTB having age 18-24 (45%) and PWTB having age 25-44 (32%) faced greater workplace stigma, which might stem from concerns about their health affecting job performance or workplace interactions.

People with Extensively Drug-Resistant TB faced the highest workplace stigma (64%), reflecting a lack of understanding about TB transmission risks across different types. People with pulmonary TB reported lower workplace stigma (41%).

Persons with disabilities (77%) and people who use drugs (49%) reported significant stigma in the workplace. Transgender individuals (63%) also faced stigma, which suggests that social identities play a strong role in workplace discrimination.

PWTB Experiencing Stigma at work that inhibited them accessing TB services	N=2352	Number experienced Stigma	%age experienced stigma
Province			
AJK/ GB	58	54	93%
Bal	146	60	41%
ICT	23	13	57%
KPK	394	296	75%
Punjab	1234	314	25%
Sindh	537	43	8%
Gender			
Male	1483	433	29%
Female	791	272	34%
Transgender	118	74	63%
Age			

18-24	413	186	45%
25-44	1150	373	32%
45-64	694	180	26%
65 or older	135	41	30%
Localization of TB			
Pulmonary	2163	689	32%
Extra Pulmonary	123	51	41%
Extensively Drug-Resistant TB	11	7	64%
Multi Drug Resistant TB	43	10	23%
Others	52	22	42%
Self-Identify as			
Person living with HIV	68	18	26%
Miner	125	42	34%
HCW	123	50	41%
Refugee	56	12	21%
Urban Slums	197	57	29%
Rural Poor	1042	344	33%
Person who uses drugs	37	18	49%
Person with disability	43	33	77%
Indigenous Person	140	37	26%
Former Prisoner	321	94	29%
Transgender Individuals	118	74	63%

Table – 10: *Stigma experienced by PWTB in work setting that inhibited them from accessing TB services (N=2,392). The data with statistically significant p-values (<0.05) has been highlighted in grey.*

Overall Insights and Recommendations

Across all settings, certain groups, such as individuals in AJK/GB and KPK, females, younger (<25) and vulnerable populations like Persons living with HIV, Rural poor, people who use drugs, healthcare workers, transgenders, prisoners

etc., consistently experienced higher stigma levels. This demonstrates the compounded stigma faced by PWTB with additional social vulnerabilities.

Stigma Experienced by PWTB across the TB Cascade

1. **Recognizing Symptoms**
   Stigma significantly impacted the recognition of symptoms, with 14% of respondents identifying hospitals as a setting where stigma delayed this stage. Community settings accounted for 7%, while family settings were slightly lower at 6%. Workplace settings contributed 5%, reflecting a lower but still notable influence of stigma. The stigma during this stage often leads to delays in acknowledging symptoms out of fear of judgment, which can worsen health outcomes and increase transmission risks.
2. **Seeking Care**
   Stigma-related delays were most prominent in hospitals (19%), followed by community settings (14%), family environments (7%), and workplaces (8%). High levels of stigma in healthcare settings and communities discourage individuals from seeking care promptly, underscoring the need for targeted educational campaigns to address misconceptions and stigma at this critical stage.
3. **Getting an Accurate Diagnosis**
   Stigma during the diagnosis stage was relatively less pronounced compared to earlier stages, but it still posed significant barriers. Family settings accounted for 14% of stigma-related delays, making them the largest contributor at this stage. Hospitals were identified as a source of stigma by 6% of respondents, while community settings contributed 4%. These findings underscore the critical need for family-focused awareness campaigns to address misconceptions and fears within households. Promoting supportive family environments can encourage timely diagnostic testing and reduce delays caused by stigma, ultimately improving health outcomes for individuals with TB.
4. **Beginning Treatment**
   Stigma during treatment initiation was reported by 17% in workplace settings, 9% in community settings, and 8% in family environments, with 1% citing hospitals. Workplace stigma, particularly, creates barriers to starting treatment, driven by fears of disclosure and discrimination. Addressing workplace stigma through inclusive policies could enhance treatment initiation rates.
5. **Getting Treatment Adherence Support**
   Stigma-related barriers to treatment adherence were reported as 4% in family settings, 3% in workplaces, 2% in community environments, while hospitals were at 1%. These findings show that stigma within families and workplaces disrupts adherence to treatment regimens, emphasizing the need for targeted interventions in these settings.
6. **Completing Treatment**
   Delays in completing treatment due to stigma were relatively low but still present, with 3% in family settings and 3% in workplaces. These disruptions can undermine treatment success and recovery, highlighting the importance of sustained support for persons throughout the treatment journey.
7. **Getting Post-Treatment Follow-up Services**
   Post-treatment follow-up services showed the least impact of stigma, with 1% delays reported in family settings and 2% in workplaces. While the impact of stigma at this stage is minimal, ensuring stigma-free access to follow-up care is essential to preventing relapses and maintaining long-term health outcomes.

TB Cascade	Hospitals	%age	Community	%age	Family	%age	Work	%age
Recognizing Symptoms	334	14%	174	7%	148	6%	120	5%
Seeking Care	446	19%	328	14%	176	7%	202	8%
Getting an Accurate Diagnosis	154	6%	92	4%	328	14%	76	3%

Beginning Treatment	33	1%	363	15%	191	8%	398	17%
Getting Treatment Adherence Support	15	1%	54	2%	91	4%	77	3%
Completing Treatment	5	0%	12	1%	65	3%	65	3%
Getting Post-Treatment Follow-up Services	6	0%	16	1%	25	1%	21	21%

Table – 11: *Components of the patient pathway and stigma: proportion of PWTB who responded «yes» to Question: «Have you ever experienced stigma in the following settings which was responsible for delays in …?» (n=2,392)*

This table reveals that stigma affects each stage of the TB care pathway, with community, family, and workplace settings showing substantial impacts on persons' experiences and decisions. Hospitals, while central to the healthcare process, also see stigma-related delays, particularly in the early stages of symptom recognition and seeking care.

The pattern of high stigma in the community setting during the first two stages of the TB journey (symptom recognition and seeking care) is consistent across certain regional, gender, and Key Vulnerable Population groups. Below are the details:

1. **Regional Patterns**:
   - In Azad Jammu & Kashmir/Gilgit-Baltistan (AJK/GB), community stigma during symptom recognition and care-seeking is notably high at 36%, followed by Khyber Pakhtunkhwa (26%) and Balochistan (18%), likely due to strong cultural taboos and limited awareness about TB. In Punjab, the stigma is relatively lower at 15%, possibly reflecting moderate awareness and better access to healthcare services. The lowest levels of stigma during these initial stages of the TB care cascade were observed in Sindh and Islamabad Capital Territory (ICT), highlighting significant regional disparities in awareness, cultural attitudes, and acceptance of TB.
2. **Gender-Specific Patterns**:
   - **Females**: Women experience higher community stigma as compared to males, likely due to societal pressures and gender norms, which also affect their ability to seek care.
   - **Transgender Individuals**: Community stigma is highest among transgender individuals, highlighting severe social exclusion and compounded vulnerabilities.
3. **Key Vulnerable Populations (KVPs)**:

Key Vulnerable Populations (KVPs) face varying levels of stigma throughout their **TB journey**, which includes the stages of **Recognizing Symptoms, Seeking Care, Getting Diagnosed, Beginning Treatment, Treatment Adherence, Completing Treatment,** and **Post-Treatment Follow-Up**. The highest levels of stigma were reported during the first two stages—**Recognizing Symptoms** and **Seeking Care**—where societal and cultural factors significantly delay early intervention. These stages are heavily influenced by a combination of social, economic, and occupational factors.

During the **Recognizing Symptoms** stage, the **rural poor** face exceptionally high levels of community stigma (**65%**), driven by socioeconomic disadvantages and limited access to accurate health education. This stigma often delays the acknowledgment of symptoms and subsequent care-seeking. Similarly, at the **Seeking Care** stage, **urban slum residents** report significant stigma (**51%**) due to misconceptions about TB transmission in densely populated living conditions, further discouraging healthcare access. **Former prisoners** also experience moderate stigma (**48%**), exacerbated by societal biases related to their incarceration history. **Miners** face stigma (**52%**) linked to occupational hazards and widespread misconceptions about their vulnerability to TB.

At later stages of the TB journey, stigma persists but tends to be less pronounced. However, it continues to pose challenges, particularly during the **Treatment Adherence** stage, where stigma and the inability to maintain steady employment during treatment create barriers to consistent adherence.

Throughout the TB journey, transgender individuals face significant stigma at various stages, with the most pronounced challenges occurring during **Recognizing Symptoms** and **Seeking Care**. At the symptom recognition stage, stigma in **family settings** was highest (**32%**), followed by **community settings (20%)**, **hospitals (22%)**, and the **workplace (14%)**. During the care-seeking stage, the **workplace** emerged as a major source of stigma (**37%**), followed by **family settings (18%)**, **community settings (20%)**, and **hospitals (9%)**.

At the diagnosis stage, stigma was relatively lower, with **16%** reported in the **workplace**, **2%** in both **family settings** and **hospitals**, and none in community settings. Similarly, during treatment initiation, stigma remained minimal, with **9% in hospitals and family settings**, **4% in community settings**, and **3% in the workplace**. Notably, no stigma was reported during the stages of **treatment adherence**, **treatment completion**, or **post-treatment follow-up**, except for **13% in family settings** during post-treatment follow-up.

These findings highlight the critical need for **stage-specific interventions** to address stigma at each phase of the TB journey. Tailored strategies, such as **community education programs**, **workplace stigma-reduction policies**, and **enhanced support systems**, are essential to mitigating stigma's impact. Early interventions, particularly during the **Recognizing Symptoms** and **Seeking Care** stages, are vital for promoting timely healthcare-seeking behavior, ensuring treatment adherence, and ultimately improving health outcomes for KVPs.

Summary:

- **Prevalent Stigmatizing Attitudes**:
  - Fear of Judgment and Social Exposure: PWTB and families avoid disclosing TB diagnosis (71% concealment in families) due to fear of stigma, leading to delays in care-seeking and isolation.
  - Misconceptions About TB Transmission: Stigma driven by fears of contagion affects interactions at home, work, and community settings, particularly for extra-pulmonary TB.
  - Workplace Discrimination: Stigma in workplace settings is significant (11% during treatment initiation), creating barriers to treatment adherence and support.
- **Most Impactful Setting-TB Journey Combinations**:
  - Healthcare Setting and Symptom Recognition: High stigma in hospitals (20%) impacts persons' willingness to seek medical advice.
  - Community Setting and Symptom Recognition: Stigma in communities (17%) delays early care-seeking and beginning care.
  - Community Setting and Seeking Care: Community stigma (16%) deters individuals from accessing healthcare services promptly.
  - Family Setting and Treatment Adherence: Family stigma (10%) hinders consistent support for treatment adherence, reducing recovery rates.
  - Workplace Setting and Treatment Initiation: Workplace stigma (10%) discourages persons from starting or continuing treatment due to discrimination.

  Note: Percentage represents responses to the question: *"Have you experienced stigma in these settings: hospitals, community, home, workplace, that inhibited you from ……………* "

  - **Transgender Individuals** faced the highest stigma at multiple stages of the TB journey. For instance:

    - **Recognizing Symptoms (32% in family settings)**: Stigma related to fear of judgment within family settings, which inhibited timely symptom acknowledgment.

    - **Seeking Care (37% in the workplace)**: Stigma in workplaces discouraged access to healthcare services. Derived from responses to: *"Have you experienced workplace stigma that inhibited you from seeking TB care?"*

    - **Diagnosis (16% in the workplace)**: Workplace discrimination hindered PWTB from seeking diagnostic services.

- **Regional Disparities in Community Settings**:
  - **AJK/GB (95%) and KPK (90%)**: Stigma in community settings, including misconceptions about TB transmission, inhibited access to healthcare services during the **Recognizing Symptoms** and **Seeking Care** stages.
- **Younger PWTB (18-24 years)**:
  - **Recognizing Symptoms (55% in family settings)**: Stigma driven by concerns over marriageability and social judgment delayed symptom acknowledgment.
  - **Seeking Care (63% in community settings)**: Fear of public stigma discouraged care-seeking behavior.
- **People with Disabilities** experienced substantial stigma:
  - **Seeking Care (81% in healthcare settings)**: Stigma from healthcare workers affected access to diagnostic and treatment services.
- **People with Extensively Drug-Resistant TB (XDR-TB)**:
  - **Diagnosis (64% in healthcare settings)**: Stigma from healthcare providers inhibited access to diagnostic testing.
  - **Family Settings (55%)**: Fear of transmitting TB led to stigma within families, delaying care.

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Secondary Stigma in Families of PWTB

The Graph-14 highlights the prevalence of secondary stigma among family members of people with TB (PWTB), focusing on attitudes related to secrecy, fear of disclosure, and concerns about infection. Secondary stigma here is primarily marked by the fear of TB transmission and the desire to conceal a family member's TB status to avoid social judgment.

1. **Secrecy and Concealment**

A significant proportion of family members (64%) reported being asked to keep the TB diagnosis a secret (A1), reflecting a strong inclination toward maintaining privacy to avoid societal judgment. Nearly three-quarters (71%) indicated that the PWTB actively hide their diagnosis from the community (A4), while 59% of family members also avoid disclosing it (A3). This suggests that PWTB and their families perceive a high risk of social stigma, motivating them to keep the diagnosis private. Over half of family members (64%) avoid discussing TB in the presence of other relatives or neighbors (A5). This reflects a reluctance to bring up the disease within social circles, likely due to fear of gossip or negative perceptions.

2. **Use of Euphemisms and Alternate Terms**

Over half of the respondents (54% with family, 55% with friends) use euphemisms or alternative words when discussing TB (A7, A8). This behaviour demonstrates the stigma's impact on language, where family members may feel compelled to disguise the nature of the illness to minimize the risk of judgment or discrimination.

3. **Fear of Status Disclosure and Social Exposure**

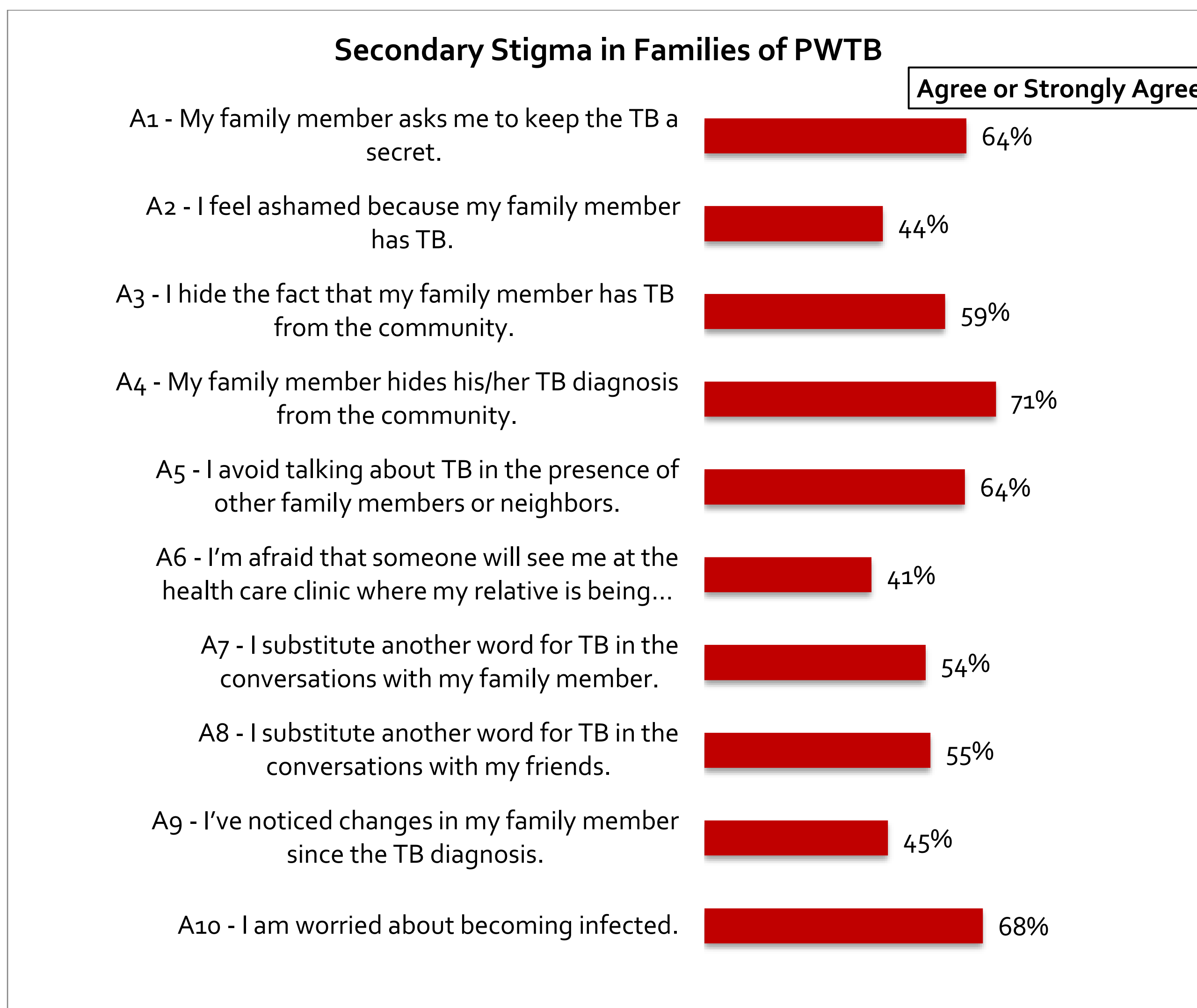
A notable 41% of family members expressed concern about being seen at a healthcare clinic where their relative is receiving treatment (A6). This concern about public visibility reflects the fear of association with TB, as being seen in such a setting may lead to assumptions about the family or social gossip.

4. **Emotional Responses of Guilt and Shame**

Approximately 44% of family members felt ashamed that their loved one has TB (A2). This level of shame indicates that TB is not only viewed as a personal health issue but also as a potential social blemish, affecting the entire family's reputation. Around 45% of respondents noticed changes in family dynamics after the TB diagnosis (A9). This suggests that the diagnosis impacts family interactions and may introduce strain or tension within the household.

5. **Fear of Infection**

The fear of infection is highly prevalent, with 68% of family members concerned about contracting TB themselves (A10). This fear is likely driven by misconceptions about TB transmission, leading to additional strain and social distancing within families.



Graph - 15: *Dimensions of secondary stigma in families of PWTB: level of support for each statement which refers to living with TB, % (n=249)*

The data indicates that secondary stigma among families of PWTB is strongly influenced by a desire for secrecy, a fear of social judgment, and concerns about infection. The high levels of concealment and euphemism usage reflect the stigma's pervasive impact, compelling family members to avoid openly discussing TB. The significant fear of infection further exacerbates social distancing within families, potentially isolating PWTB and reducing their support network.

	AJK/ GB	Bal	ICT	KPK	Punjab	Sindh	Total
Gender							
Male	32 (74.4)	11 (47.8)	9 (52.9)	22 (68.8)	87 (81.3)	18 (66.7)	**179 (71.9%)**

Female	11 (25.6)	12 (52.2)	8 (47.1)	10 (31.2)	20 (18.7)	9 (33.3)	**70 (28.1%)**
Age							
18 - 24	4 (9.3)	8 (34.8)	1 (5.9)	6 (18.8)	37 (34.6)	8 (29.6)	**64 (25.7%)**
25 - 45	25 (58.1)	10 (43.5)	11 (64.7)	7 (21.9)	53 (49.5)	17 (63)	**123 (63%)**
45 - 64	13 (30.2)	4 (17.4)	5 (29.4)	15 (46.9)	16 (15)	2 (7.4)	**55 (22.1%)**
65 or older	1 (2.3)	1 (4.3)	0 (0)	4 (12.5)	1 (0.9)	0 (0)	**7 (2.8%)**
Relation with PWTB							
Child	3 (7)	2 (8.7)	2 (11.8)	4 (12.5)	60 *56.1)	6 (22.2)	**77 (30.9%)**
Grandchild	1 (2.3)	2 (8.7)	0 (0)	1 (3.1)	1 (0.9)	0 (0)	**5 (2%)**
Grand parent	2 (4.7)	5 (21.7)	0 (0)	4 (12.5)	7 (6.5)	0 (0)	**18 (7.2%)**
Other Relative	14 (32.6)	5 (1.7)	2 (11.8)	4 (12.5)	8 (7.5)	0 (0)	**33 (13.3%)**
Parent	10 (23.3)	3 (13)	5 (29.4)	15 (46.9)	28 (26.2)	20 (74.1)	**81 (32.5%)**
Sibling	13 (30.2)	6 (26.1)	8 (47.1)	4 (12.5)	3 (2.8)	1 (3.7)	**35 (14.1%)**

Table – 12: *The general level of secondary stigma in families of PWTB, per social and demographic populations, (n=249). The data with statistically significant p-values (<0.05) has been highlighted in grey.*

1. Gender Distribution of Secondary Stigma

Male family members represent a significant portion of those experiencing secondary stigma, accounting for 71.9% (179 out of 249) of all cases. This suggests that men in families of PWTB are more likely to experience or perceive stigma due to their association with PWTB.

Women account for 28.1% of the secondary stigma cases, indicating that, while stigma affects both genders, men report a higher level of stigma within families dealing with TB. This could be due to men's traditional role as providers, making them more sensitive to societal judgment when family members are unwell.

2. Age Distribution of Secondary Stigma

The 18-24 years age group represents 25.7% (64 out of 249) of the stigma cases. Younger family members may feel more acutely the societal judgment around TB, possibly due to the impact on their social interactions and concerns about their family's reputation. The 25-45 years age group has the highest representation of stigma experiences, with 63% (123 out of 249) of cases. Adults in this age range are often active in their communities and workplaces, where social perception and judgment may be more impactful. This age group might also face pressure to keep the family's image intact, leading to heightened awareness of stigma.

Family members in the 45-64 years age group represent 22.1% of stigma cases. While stigma remains significant, the impact is somewhat less than younger age groups, possibly due to reduced social interactions or a more accepting attitude toward illness with age. Secondary stigma is least prevalent in the elderly, with only 2.8% (7 out of 249) experiencing stigma. Elderly family members may have a different perception of stigma or might not feel the need to conceal the condition as much due to lesser social interaction or an acceptance that comes with age.

3. Relation to PWTB and Secondary Stigma

The most affected group is the children of PWTB, representing 30.9% (77 out of 249) of secondary stigma cases. Children might feel a strong sense of stigma due to concerns about their family's reputation and fear of judgment from peers, leading them to hide or feel ashamed of their parent's TB status.

Parents account for 32.5% (81 out of 249) of secondary stigma cases, making them the second most affected group. Parents may experience stigma as they worry about societal perceptions and the impact on family honor or reputation, particularly if they feel responsible for their child's illness.

Siblings represent 14.1% (35 out of 249) of stigma cases, reflecting a moderate level of secondary stigma. Siblings might experience stigma in social circles or feel the need to protect family reputation, but they are less affected than children and parents.

Extended family members, such as cousins, uncles, and aunts, make up 13.3% (33 out of 249) of cases. This group's lower level of stigma might stem from their more distant relationship with the PWTB, reducing their personal responsibility or social impact. Grandchildren and grandparents represent the lowest levels of secondary stigma, with 2% (5 out of 249) and 7.2% (18 out of 249), respectively. These groups might not feel the same societal pressures, as grandchildren are often young and less affected by social judgment, while grandparents may be less concerned with social perception due to their age.

Regional Variation in Secondary Stigma

AJK and KP regions have reported the highest levels of secondary stigma, particularly among male family members. In AJK/GB, 74.4% of male family members and 25.6% of females experience stigma, while in KP, the levels are 68.8% for males and 31.2% for females. This reflects regional differences where cultural norms may intensify stigma around diseases like TB. In contrast, Punjab and Sindh show lower levels of stigma, especially among female family members. In Punjab, only 18.7% of females experience stigma, compared to 81.3% of males. Sindh also has a lower stigma incidence among females (33.3%). This suggests that regional variations in stigma perception could be influenced by cultural or social attitudes.

Stigma experienced by family when they supported their PWTB family member on their TB Journey under different settings

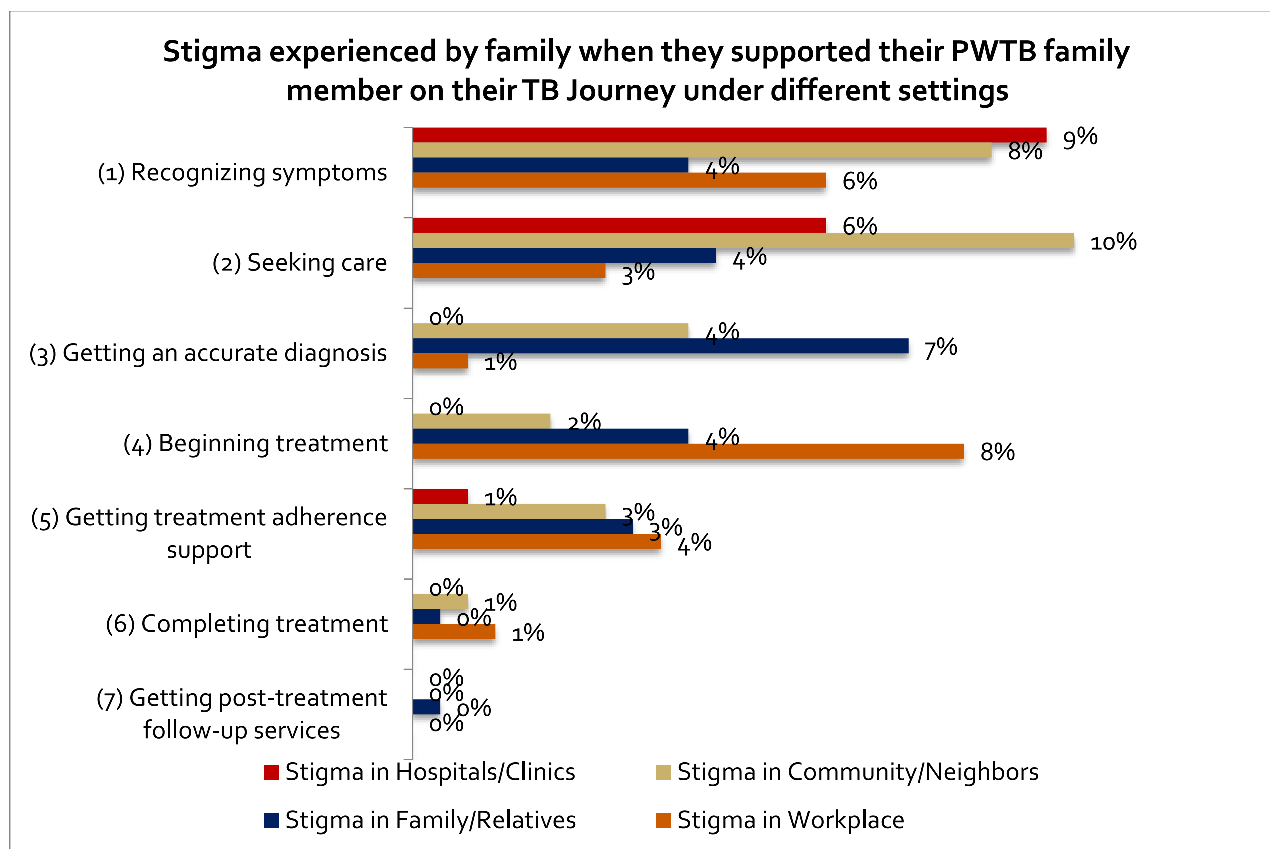
Family members who supported their loved ones with TB (PWTB) reported encountering stigma at various stages of the TB care journey across different settings, including healthcare facilities, the community, and the workplace.

a. **Healthcare Facilities**: The highest levels of stigma in healthcare settings were experienced during the **initial recognition of symptoms** and **seeking care** stages. Family members noted that during these early stages, they felt judged or stigmatized when accompanying the PWTB to healthcare facilities. However, once a diagnosis was established and treatment was initiated, the stigma in healthcare settings appeared to lessen significantly. This reduction in stigma may be attributed to the specialized care provided at TB DOTS units, where staff are accustomed to working with PWTB and likely exhibit greater sensitivity and understanding.

b. **Community Setting**: At the community level, family members experienced the highest levels of stigma while **seeking care** for their PWTB relative. This stigma was followed closely by the stage of **recognizing symptoms**. The fear of being stigmatized by neighbors and community members led many family members to keep the symptoms and TB management process hidden. The social pressures and potential judgment from the community make families hesitant to disclose the condition, thereby intensifying feelings of isolation and fear.

c. **Workplace Setting**: In the workplace, stigma was most commonly reported during the **beginning of treatment**, **recognition of symptoms**, and **support for treatment adherence** stages. Family members supporting a PWTB often faced challenges and negative perceptions from colleagues and supervisors, particularly when their support role required them to take time off work or when the nature of TB as an infectious disease became known. This stigma in the workplace setting highlights the need for better workplace policies and support systems to reduce discrimination against family members who are involved in the care and support of PWTB.

This analysis shows that stigma experienced by family members supporting PWTB varies across different stages of the TB journey and is particularly high during the initial phases of symptom recognition and seeking care in healthcare and community settings. The reduction in stigma after diagnosis and initiation of treatment in healthcare settings suggests that specialized care environments, such as TB DOTS units, play a significant role in creating a more accepting atmosphere. However, community and workplace stigma remain challenging areas that need targeted interventions.



Graph 16: *Stigma experienced by family when they supported their PWTB family member on their TB Journey under different settings*

Summary:

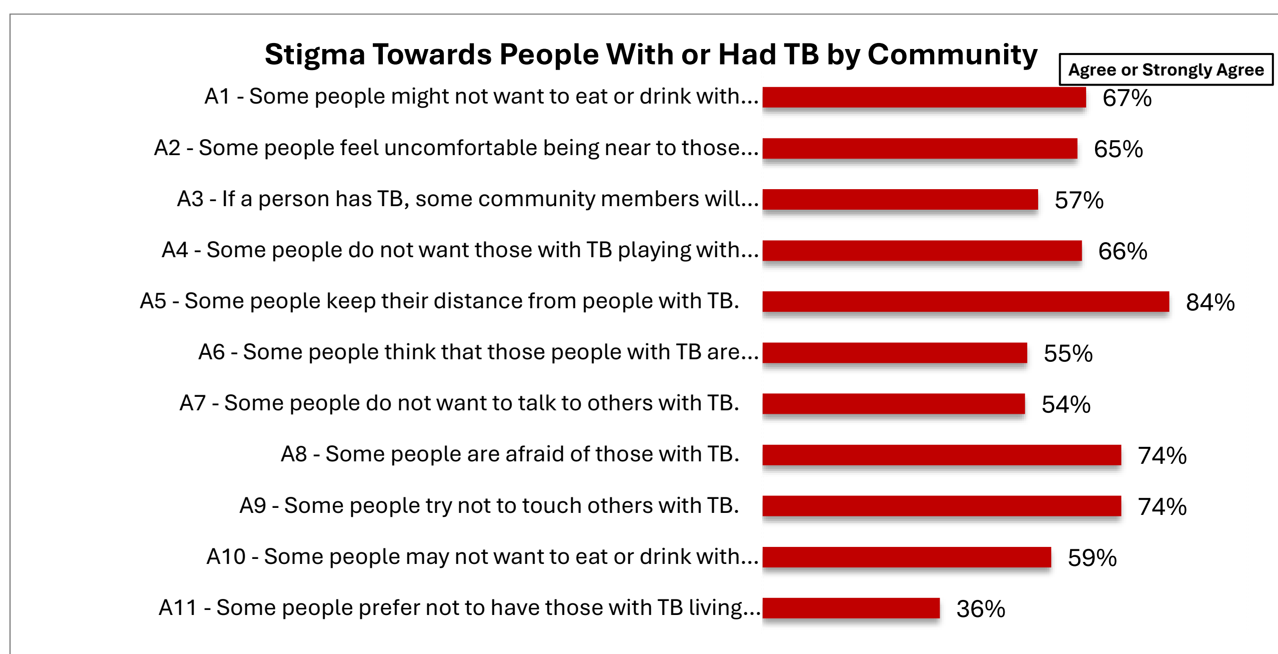
1. **Most Prevalent Stigmatizing Attitudes**:
   - **Secrecy and Concealment**: A significant proportion of families (64%) feel compelled to keep a TB diagnosis secret due to fear of judgment, with many avoiding open discussions even among relatives (59%).
   - **Fear of Infection**: Misconceptions about TB transmission lead to 68% of family members expressing concern about contracting the disease, driving social distancing and isolation within households.
   - **Shame and Social Exposure**: Feelings of guilt and shame (44%) and concerns about being seen at healthcare facilities (41%) reflect the stigma's impact on family dynamics and societal interactions.
2. **Most Relevant Setting-TB Journey Combinations**:
   - **Community Setting and Seeking Care**: Families experience the highest levels of stigma during care-seeking due to fear of community judgment.
   - **Community Setting and Symptom Recognition**: Stigma at this stage deters families from acknowledging symptoms or seeking help promptly.
   - **Healthcare Setting and Symptom Recognition**: Judgement from healthcare staff during early visits intensifies stigma for both PWTB and their families.

- **Workplace Setting and Treatment Support**: Stigma arises when families supporting PWTB face negative perceptions at work, especially during treatment initiation and adherence.
- **Healthcare Setting and Treatment Initiation**: Although stigma reduces after diagnosis, it remains a barrier in the early stages of treatment.

These findings emphasize the need for targeted community education, stigma reduction in healthcare environments, and supportive workplace policies to address these critical areas effectively.

Anticipated Stigma within community

The level of anticipated stigma within the community towards people with TB (PWTB) is alarmingly high. Nearly 90% of community representatives agreed that PWTB face social distancing behaviors, with community members often avoiding them, refusing to share food or drink, and discouraging their children from interacting with PWTB (Graph 16). Additionally, a substantial portion of respondents believes that this stigmatizing attitude is enduring; 57% stated that individuals who have had TB are likely to be treated differently by some members of society for the rest of their lives. Furthermore, over one-third of community representatives (36%) acknowledged that there are people who would prefer that PWTB not reside within their community at all. This data underscores the persistent and deeply rooted nature of TB-related stigma in community settings.



Graph – 17: *Dimensions of anticipated stigma in community: level of support for each statement which refers to living with TB, % (n=222)*

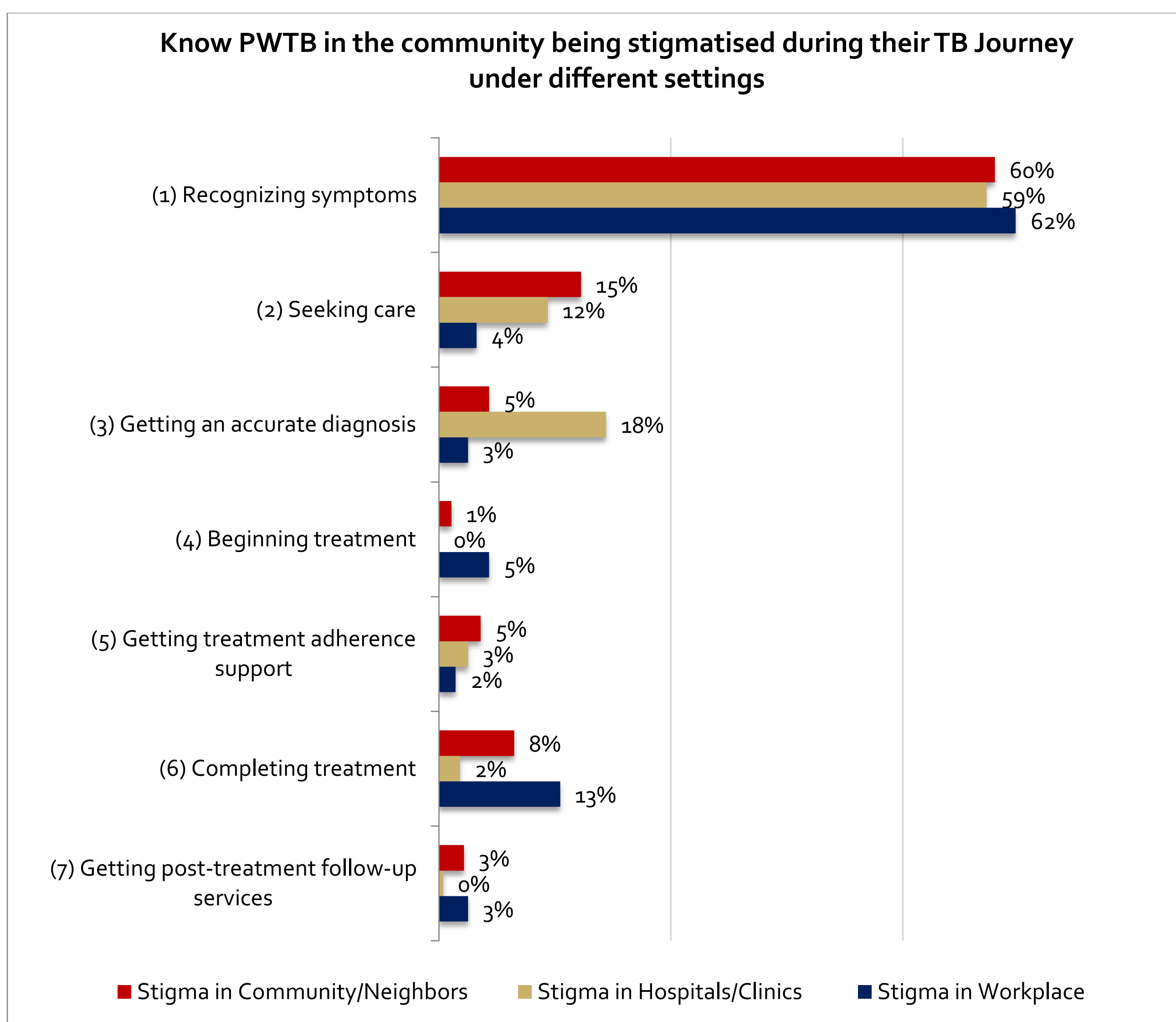
This high level of anticipated stigma was seen in all respondent populations across respect to age and gender (Table 11).

	AJK/ GB	Bal	ICT	KPK	Punjab	Sindh	Total
Gender							
Male	8 (21.6)	17 (65.4)	3 (27.3)	7 (21.2)	6 (6.7)	9 (36)	**50 (22.5%)**
Female	29 (78.4)	9 (34.6)	8 (72.7)	26 (78.8)	84 (93.3)	16 (64)	**172 (77.5%)**
Age							
18 - 24	1 (2.7)	10 (38.5)	1 (9.1)	8 (24.4)	22 (24.4)	4 (16)	**46 (20.7%)**

25 - 45	28 (75.7)	15 (57.7)	6 (54.5)	16 (48.5)	58 (64.4)	16 (64)	**139 (62.6%)**
45 - 64	6 (16.2)	1 (3.8)	3 (27.3)	5 (15.2)	10 (11.1)	5 (20)	**30 (13.5%)**
65 or older	2 (5.4)	0 (0)	1 (9.1)	4 (12.1)	0 (0)	0 (0)	**7 (3.2%)**
Personally know PWTB							
Only one	17 (45.9)	7 (26.9)	5 (45.5)	12 (36.4)	21 (23.3)	7 (28)	**24 (10.8%)**
Two or more	15 (40.5)	9 (34.6)	3 (27.3)	15 (45.5)	56 (62.2)	1 (4)	**30 (13.5%)**
None	3 (8.1)	8 (30.8)	2 (18.2)	0 (0)	1 (1.1)	16 (64)	**69 (31.1%)**
Don't Know	2 (5.4)	2 (7.7)	1 (9.1)	6 (18.2)	12 (13.3)	1 (4)	**99 (44.6%)**

Table – 13: *The general level of anticipated stigma in community representatives, per social and demographic populations, (n=222). The data with statistically significant p-values (<0.05) has been highlighted in grey.*

A large proportion of the respondents in the communities have either witnessed or heard about a person from their community who was stigmatised because of TB.



Graph – 18: *Dimensions of anticipated stigma in community: level of support for each statement which refers to living with TB, % (n=222)*

Nearly one-quarter of respondents were aware of individuals in their community who faced stigma that prevented them from accessing specialized TB care. According to community members, stigma was most intensely experienced by PWTB at the **initial recognition of symptoms**, with 60% observing stigma in community settings, 59% in hospitals or clinics, and 62% in workplaces. This early-stage stigma likely discourages individuals from acknowledging their symptoms or seeking timely medical advice.

Following symptom recognition, **seeking care** was another significant point where stigma was observed, with 15% of respondents reporting stigma in community environments, 4% in healthcare settings, and 12% in workplaces. This stigma, often stemming from misconceptions about TB transmission, contributes to social distancing and may prevent individuals from seeking proper care due to fear of community judgment.

Additionally, community members noted stigma during **getting an accurate diagnosis** (5% in the community and 18% in healthcare settings) and **completing treatment** (8% in community settings, 2% in hospitals, and 13% in workplaces). The presence of stigma at these later stages suggests a persistent societal reluctance to fully accept individuals with TB, even as they progress through their treatment journey.

Overall, the data highlights a pervasive stigma experienced by PWTB across multiple settings—community, healthcare facilities, and workplaces—especially during critical phases like recognizing symptoms and seeking care. This stigma poses a significant barrier to accessing timely and effective treatment, underscoring the need for stigma reduction initiatives within these environments to support PWTB through every stage of their journey.

Summary:

1. **Most Prevalent Stigmatizing Attitudes:**
   - **Social Distancing Behaviors**: Nearly 90% of community representatives reported that PWTB face behaviors such as being avoided, refused shared food or drink, or excluded from interactions, reflecting deep-rooted societal rejection.
   - **Fear of Lifelong Discrimination**: Over half (57%) of respondents believed that individuals who have had TB would continue to be treated differently for the rest of their lives, perpetuating stigma beyond recovery.
   - **Community Rejection**: More than one-third (36%) of respondents acknowledged that some community members prefer PWTB not reside within their locality, indicating entrenched exclusionary attitudes.
2. **Most Relevant Setting-TB Journey Combinations**:
   - **Community Setting and Symptom Recognition**: Stigma at this early stage (60%) discourages individuals from acknowledging symptoms or seeking help.
   - **Workplace Setting and Symptom Recognition**: Observed stigma (62%) hinders disclosure and early care-seeking due to fear of discrimination at work.
   - **Healthcare Setting and Seeking Care**: Stigma reported by 59% in hospitals or clinics impedes timely medical advice and care-seeking.
   - **Community Setting and Seeking Care**: Misconceptions about TB transmission drive stigma (15%), preventing individuals from accessing specialized care.
   - **Workplace Setting and Completing Treatment**: Persistent stigma (13%) during treatment completion impacts adherence and reinforces barriers to recovery.

Anticipated and experienced stigma in healthcare providers

The findings (Graph – 19) reveal a significant level of stigma among healthcare providers toward people with TB (PWTB), reflecting widespread concerns and biases within the medical community.

A substantial majority (75%) of healthcare workers believe that PWTB should be **isolated during the intensive phase of treatment**. This attitude may stem from fears about contagion but could contribute to feelings of isolation and stigma among PWTB.

Approximately 63% of healthcare providers feel that **TB treatment should be enforced if necessary**, suggesting a perception that PWTB may not adhere to treatment on their own. While this perspective may be rooted in concerns about public health, it also reflects a lack of trust and empathy toward PWTB.

A significant 66% of healthcare workers view PWTB as **dangerous**, reinforcing the perception that TB is a highly contagious threat, which likely fuels the desire for isolation and distancing measures.

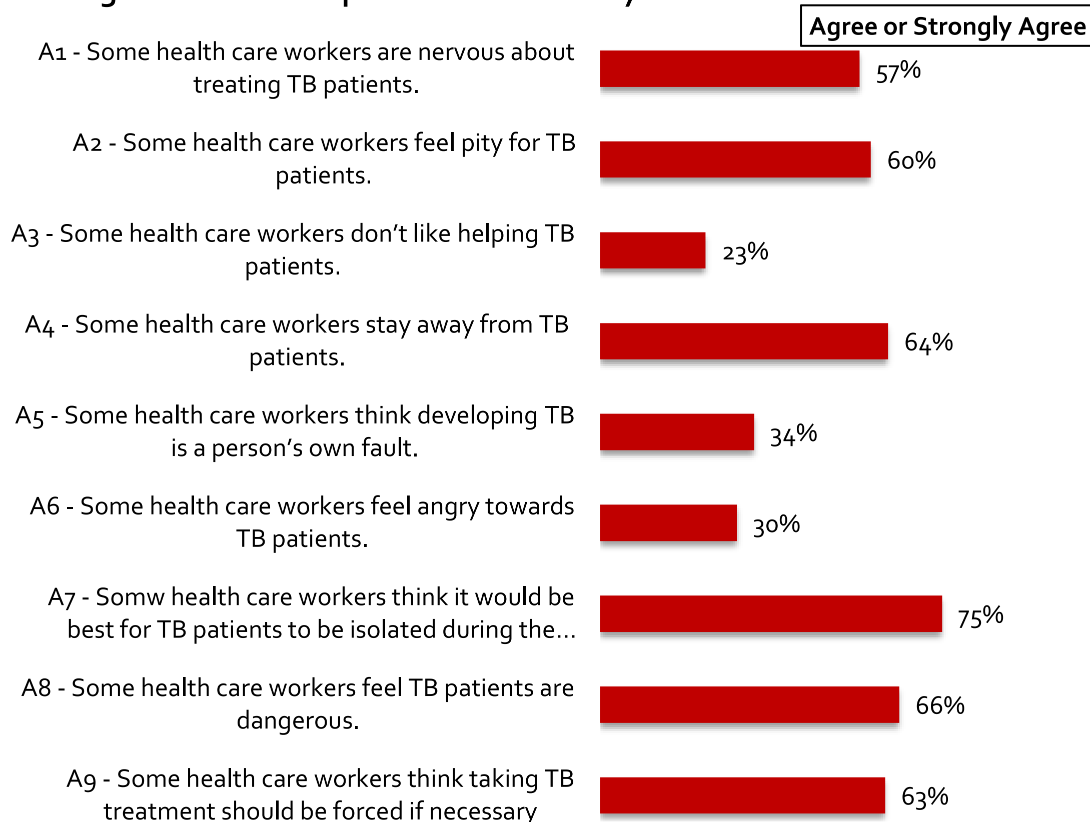
Nearly two-thirds (64%) of healthcare workers admit to **avoiding PWTB**, indicating a high level of discomfort or fear in handling PWTB. This avoidance could compromise the quality of care provided to PWTB and lead to feelings of marginalization.

About 34% of healthcare workers believe that **developing TB is the individual's own fault,** while 30% report feelings of anger toward PWTB. Such attitudes indicate that a portion of healthcare providers harbor judgmental or resentful views toward PWTB, which may impact the support and compassion offered to them.

Over half (57%) of healthcare providers **feel nervous when treating PWTB**, while 60% express pity toward them. Although pity may seem empathetic, it can also imply a sense of helplessness or inferiority in the PWTB, further contributing to stigma.

Only 23% of healthcare workers openly stated they **don't like helping PWTB**, which is relatively lower compared to other stigma indicators but still noteworthy, as it highlights some resistance within the medical community to fully support PWTB.

Overall, the data underscores a significant presence of stigma among healthcare providers, with a substantial portion advocating for isolation, compulsory treatment, and distancing from PWTB. This stigma can undermine the quality of care, discourage PWTB from seeking treatment, and perpetuate negative perceptions of TB within the healthcare setting.



Graph – 19: *Dimensions of anticipated stigma in medical care providers: level of support for each statement which refers to living with TB, % (n=159)*

	AJK/ GB	Bal	ICT	KPK	Punjab	Sindh	Total
Gender							
Male	32 (84.2)	23 (88.5)	7 (63.6)	29 (100)	26 (86.7)	20 (80)	**137 (86.2%)**
Female	6 (15.8)	3 (11.5)	4 (36.4)	0 (0)	4 (13.3)	5 (20)	**22 (13.8%)**
Age							
18 - 24	0 (0)	1 (3.8)	1 (9.1)	0 (0)	1 (3.3)	2 (8)	**5 (3.1%)**
25 - 45	36 (94.7)	19 (73.1)	10 (90.9)	23 (79.3)	22 (73.3)	21 (84)	**131 (82.4%)**
45 - 64	2 (5.3)	6 (23.1)	0 (0)	4 (13.8)	7 (23.3)	2 (8)	**21 (13.2%)**
65 or older	0 (0)	0 (0)	0 (0)	2 (6.9)	0 (0)	0 (0)	**2 (1.3%)**
Profession							
Doctor	1 (2.6)	11 (42.3)	6 (54.5)	13 (44.8)	11 (36.7)	1 (4)	**43 (27%)**
Lab Attendant	8 (21.1)	4 (15.4)	1 (9.1)	6 (20.7)	2 (6.7)	4 (16)	**25 (15.7%)**
Nurse	2 (5.3)	5 (19.2)	2 (18.2)	6 (20.7)	2 (6.7)	11 (44)	**28 (17.6%)**

Others	6 (15.8)	2 (7.7)	0 (0)	0 (0)	0 (0)	0 (0)	8 (5%)
Paramedics	21 (55.3)	4 (15.4)	2 (18.2)	4 (13.8)	15 (50)	9 (36)	**55 (34.6%)**
Provided service to PWTB before							
Yes	28 (73.7)	19 (73.1)	11 (100)	23 (79.3)	30 (100)	13 (52)	**124 (78%)**
No	10 (26.3)	7 (26.9)	0 (0)	6 (20.7)	0 (0)	12 (48)	**35 (22%)**

Table – 14: *The general level of anticipated stigma in healthcare workers, per social and demographic populations, (n=159). The data with statistically significant p-values (<0.05) has been highlighted in grey.*

Table 12 provides insights into the demographic and professional characteristics associated with anticipated stigma among healthcare workers (HCWs) toward PWTB. This analysis reveals variations in stigma based on gender, age, professional role, and previous experience in providing services to PWTB.

Representing 86.2% of the respondents, male HCWs demonstrate a significantly higher level of anticipated stigma compared to their female counterparts. This could reflect a greater presence of men in roles involving TB care, or it might indicate a stronger expression of stigma-related attitudes among male HCWs. Comprising only 13.8% of the sample, female HCWs show lower levels of stigma. This may suggest that female healthcare workers are either less involved in TB care or may approach PWTB with more empathy and less judgment.

The majority of HCWs exhibiting stigma fall within the 25-45 age range, comprising 82.4% of respondents. This age group likely includes HCWs in mid-career stages with significant person interaction but may lack extensive experience or training in TB stigma reduction. HCWs aged 45-64 represent 13.2% of respondents, while those over 65 are minimally represented (1.3%). The relatively lower levels of stigma in older age groups could suggest greater experience, increased familiarity with PWTB, or different attitudes toward infectious diseases acquired over years in practice.

Doctors constitute 27% of the sample, indicating that a significant portion of stigma originates from the physician level. This may affect the quality of care provided, as doctors are often the primary point of contact for TB diagnosis and treatment. Their attitudes could greatly influence the treatment experience and adherence of PWTB.

Paramedics, representing 34.6% of respondents, have the highest level of anticipated stigma. This group's close involvement with persons during treatment stages may expose them to misconceptions about TB transmission and lead to heightened stigma. Nurses comprise 17.6% of respondents. While not the highest, their representation indicates that nurses also encounter stigma, which could impact their willingness to fully engage with PWTB and support their treatment journey. Lab attendants represent 15.7% of respondents. Given their role in diagnostics, stigma from this group may affect how they interact with TB samples or communicate with PWTB, potentially affecting persons' perceptions of care.

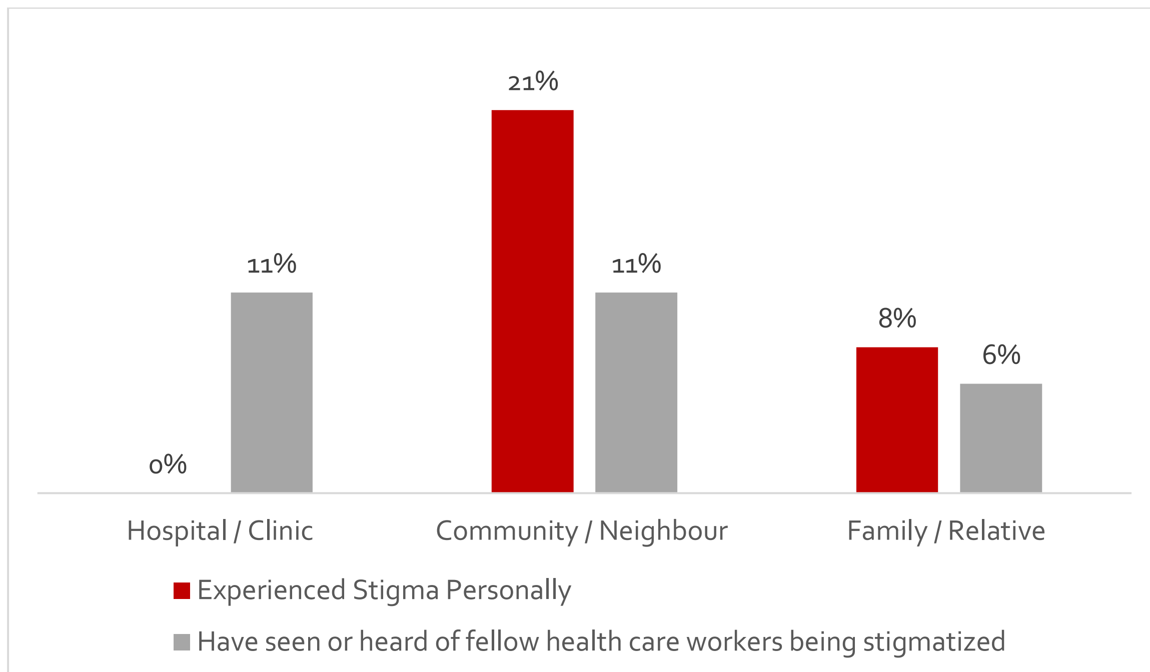
78% of HCWs have previously provided services to PWTB, suggesting that anticipated stigma exists even among those familiar with TB cases. This finding implies that experience alone does not necessarily reduce stigma and highlights the need for targeted stigma reduction training. The remaining 22% have no prior experience with PWTB. While they are a minority, their anticipated stigma may stem from lack of familiarity and a reliance on societal misconceptions about TB. Training and exposure to PWTB could help alleviate stigma in this group.

Regional Distribution of Stigma

A large percentage of respondents from Azad Jammu & Kashmir/Gilgit-Baltistan (84.2%) and Khyber Pakhtunkhwa (100%) report anticipated stigma. These regions may have cultural or societal beliefs that reinforce stigma, necessitating region-specific interventions.

HCWs from Sindh (80%) and Baluchistan (88.5%) exhibit relatively lower levels of stigma compared to other regions, though levels remain high. The presence of stigma in these regions indicates that stigma is pervasive across Pakistan, albeit with regional variations.

Graph - 18 illustrates the prevalence of stigma experienced by healthcare providers who work with PWTB, highlighting both direct experiences of stigma and observed instances affecting their colleagues. The data sheds light on the social repercussions that healthcare workers face within various settings due to their professional association with TB, an often-stigmatized disease.



Graph – 20: *Share of medical care providers who have personally experienced, witnessed or were aware of prejudice-related incidents due to working with PWTB, % (n=159)*

Direct Experiences of Stigma

The highest level of personal stigma was reported within the community or neighborhood context, where 21% of healthcare providers reported experiencing stigma. This indicates a significant level of prejudice among community members, who may associate TB with infectious risk and extend this perception to those who work with PWTB. Such experiences can lead to social isolation, discomfort, and reluctance among healthcare providers, potentially impacting their willingness to work with PWTB or discuss their work openly within their community.

Approximately 8% of healthcare workers reported experiencing stigma within their family or from relatives due to their role in TB care. This suggests that stigma permeates personal relationships, as even family members may hold biases or fears about TB transmission, influencing their view of healthcare workers in this field. This family-based stigma could result in strained family dynamics, further isolating healthcare workers and adding emotional stress to their professional responsibilities.

Interestingly, none of the healthcare workers reported experiencing direct stigma within the hospital or clinic setting. This could imply that healthcare institutions, especially those directly involved in TB care, have developed environments that are more accepting and understanding of TB. Within professional settings, there may be a greater awareness of TB's transmission, reducing fear and stigma. However, the absence of reported stigma in these settings does not necessarily reflect complete support, as there may still be unreported biases or underlying tension.

Observed or Heard Experiences of Stigma in Colleagues

In both community and hospital settings, 11% of healthcare workers reported witnessing or hearing about colleagues experiencing stigma due to their work with PWTB. This observation highlights the broader impact of TB-related stigma

within the community and healthcare environments, where even indirect association can trigger negative perceptions or prejudice.

A smaller percentage (6%) reported hearing or witnessing stigma toward colleagues in family or relative settings. This suggests that while family-based stigma is less visible, it still exists and affects healthcare workers, possibly affecting their morale and support network.

Summary:

1. Among healthcare providers, three prevalent stigmatizing attitudes stand out. A significant 75% of providers believe that PWTB should be isolated during the intensive phase of treatment, likely stemming from fears of contagion. While this may aim to protect public health, it contributes to the marginalization and emotional distress of PWTB.
2. Additionally, 63% of healthcare providers feel that TB treatment should be enforced, reflecting a lack of trust in PWTB's ability to adhere to their treatment independently. This perception undermines a supportive and person-centered approach.
3. Furthermore, 66% of healthcare workers view PWTB as dangerous, reinforcing avoidance behaviors reported by 64% of respondents. Such attitudes create barriers to compassionate care and perpetuate stigma within the healthcare system.
4. The most pressing settings for stigma reduction are community and healthcare environments. In community settings, 21% of healthcare workers report experiencing personal stigma from neighbors and community members due to their association with TB care, highlighting the pervasive fear of TB within society. Within healthcare settings, stigmatizing attitudes such as enforced treatment and the perception of PWTB as a threat erode the trust needed for effective person-provider relationships. Addressing stigma in these settings through targeted training, awareness campaigns, and supportive workplace policies is essential for fostering a more inclusive and empathetic approach to TB care.

Assessment of Legal and Policy Environment in TB

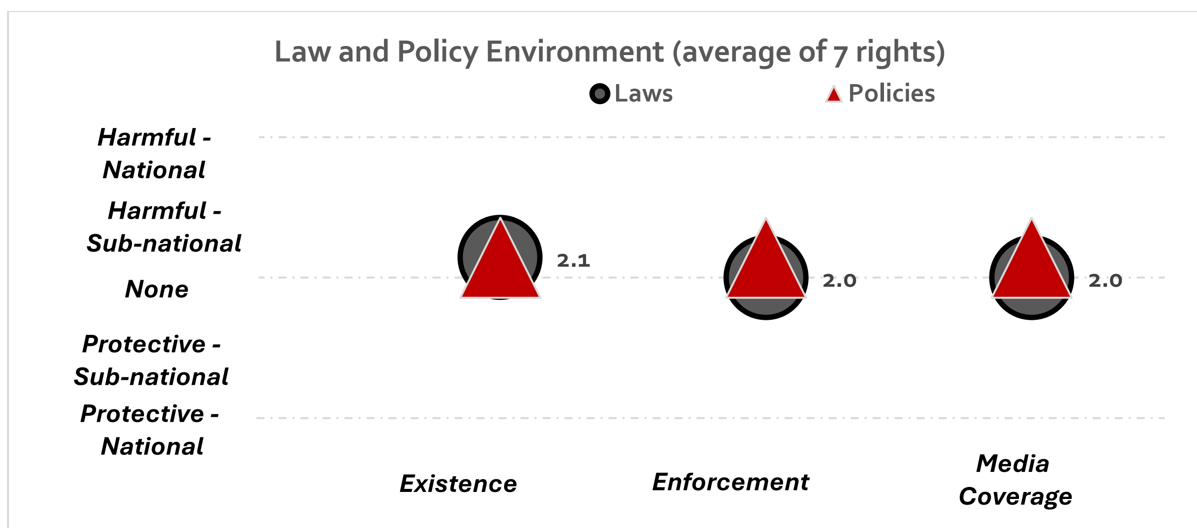
In addition to field data collection, a Focus Group Discussion (FGD) was conducted with representatives from the judiciary, legal professionals, and media to evaluate Pakistan's legal and policy environment for TB. This FGD was part of the Stigma Assessment tool developed by the Stop TB Partnership (STP) and aimed to assess the effectiveness and inclusivity of the legal and policy frameworks affecting people with TB.

According to Stop TB Partnership recommendations, assessing Pakistan’s legal and policy environment for TB control requires examining key rights most relevant to individuals affected by TB, particularly those rights frequently associated with violations. This analysis identifies areas requiring urgent policy intervention and enhanced social accountability to protect the rights and well-being of TB-affected individuals. The Dopasi Foundation also conducted a comprehensive TB Legal Environment and Human Rights Assessment aligned with the STP Tool, and the findings of that report were referenced during the FGD.

The assessment focused on the following seven rights:

1. Right to Freedom from Discrimination
2. Right to Access Information
3. Right to Access Services
4. Right to Privacy
5. Right to Informed Consent
6. Right to Freedom from Arbitrary Detention and Involuntary Isolation
7. Right to a Safe Workplace

In accordance with Stop TB Partnership recommendations, the assessment of Pakistan's legal and policy environment for TB control focuses on critical rights most relevant to TB-affected individuals, particularly those at risk of rights violations. This assessment, based on the TB Legal and Human Rights Scorecard, identifies areas requiring immediate policy interventions and social accountability measures to safeguard the rights of TB-affected individuals.



Graph – 21: *Law and policy environment scoring summary created from the FDG group works*

	Introduced		Implemented		Covered by the media	
	Legislation	Policies	Legislation	Policies	Legislation	Policies
Rights to Freedom from Discrimination (enacted stigma)	2	1	2	1	2	1
Rights to Access Information	2	2	2	2	2	2
Rights to Access Services	1	2	2	2	2	2
Rights to Privacy	2	2	2	2	2	2
Rights to Informed Consent	2	2	2	2	2	2
Rights to Freedom from Arbitrary Arrest/Detention and Involuntary Isolation	2	2	2	2	2	2
Rights to Safe Workplace	2	2	2	2	2	2

Table – 15: *Matrix for the assessment of TB-related stigma in the legislative and policy environment, per expert opinion*

Key findings and recommendations for each right are outlined below.

1. Right to Freedom from Discrimination

Essence of the Right: This right ensures that TB-affected individuals are treated equally in healthcare, employment, and social services without discrimination based on TB status.

Analysis: Although the Constitution of Pakistan provides a broad framework for equality and non-discrimination, it does not specifically address discrimination based on health status, such as tuberculosis (TB).[8] Therefore, while Article 25 supports the general right to equality, there may be a need for additional legislation or policies to explicitly prevent discrimination against individuals with TB in areas such as healthcare, employment, and education. Pakistan, therefore, lacks a formal mechanism to prevent discrimination against TB-affected individuals in various social domains, including

[8] https://download1.fbr.gov.pk/Docs/201861106324057Article-25Caselaw.pdf

employment and healthcare. Many individuals with TB face enacted stigma, particularly in the workplace, where discrimination may result in job loss or reduced opportunities. Healthcare settings are also impacted, with biases affecting the quality-of-service provision.

Recommendations:

- **Law Matrix**: Introduce explicit legal protections against TB-related discrimination and promote community support for people with TB (PWTB).
- **Policy Matrix**: Regular meetings with parliamentarians, media, and other stakeholders to update health policies, including anti-discrimination measures for TB.

2. Right to Access Information

Essence of the Right: People with TB should have access to accurate information about the disease, treatment options, preventive measures, and potential side effects. The Right to Access Information was added through the 18th Amendment to the Constitution in 2010, affirming that Pakistani citizens have a constitutional right to access information on matters of public importance.[9] While this article establishes the general right to information, further legislative or policy frameworks are often needed to ensure specific access to health-related information, including for diseases like tuberculosis (TB).

Analysis: There is a gap in providing essential information to TB-affected individuals, especially in underserved and rural areas. The lack of accessible information contributes to myths, stigma, and non-adherence to treatment.

Recommendations:

- **Law Matrix**: Enact legislation that enshrines the right to health and information, ensuring that PWTB are well-informed about their rights and treatment.
- **Policy Matrix**: Provide preventive treatment information to those closely associated with TB-affected individuals. Promote TB awareness on social media platforms such as Facebook, Twitter, and YouTube.

3. Right to Access Services

Essence of the Right: This right guarantees PWTB access to quality diagnostic and treatment services without barriers.

Analysis: The Right to Access Services is not explicitly mentioned as a standalone right in the Constitution of Pakistan. However, certain provisions indirectly support access to essential services, particularly in the realm of health, education, and social welfare. Access to TB services in Pakistan is limited, particularly in rural and marginalized communities. Issues such as medication shortages, logistical barriers, and lack of funding hinder the availability of essential TB services, impacting treatment outcomes.

Recommendations:

- **Law Matrix**: Ensure that free medications are available and consider permitting doorstep delivery of medicines to PWTB.
- **Policy Matrix**: Increase visibility of TB information on social media to raise awareness and improve access to services.

4. Right to Privacy

Essence of the Right: Privacy ensures that PWTB' health information is kept confidential, preventing unauthorized disclosure that could lead to stigma.

Analysis: Article 14 establishes the right to privacy as a fundamental right, specifically protecting the privacy of the home and the dignity of individuals. Although it does not explicitly extend to all aspects of personal data or health information, it provides a constitutional basis for privacy that can be interpreted to include personal information and medical confidentiality, especially in legal and human rights contexts. While Pakistan has some policies in place to

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[9] https://shehri.org/rti/Your%20Right%20to%20Know%20Book%20bk.pdf

protect health-related privacy, unauthorized disclosures of TB status are still reported, particularly in community health settings, leading to social stigma and discrimination.

Recommendations:

- **Law Matrix**: Strengthen legal measures to ensure that PWTB' information is kept confidential, reducing stigma and protecting their rights.
- **Policy Matrix**: Employ an activist approach to TB and stigma reduction, working with healthcare providers and communities to protect person privacy.

5. Right to Informed Consent

Essence of the Right: PWTB must fully understand medical procedures and give informed consent before beginning treatment.

Analysis: Informed consent is not consistently emphasized, particularly in low-literacy regions. Many PWTB are not fully aware of treatment regimens or potential side effects, which affects their trust in the healthcare system.

Recommendations:

- **Law Matrix**: Use electronic media and national TV to raise TB awareness and reintroduce educational programs. Conduct awareness sessions in universities.
- **Policy Matrix**: Train healthcare staff to communicate treatment information effectively, ensuring individuals understand their treatment and give informed consent.

6. Right to Freedom from Arbitrary Detention and Involuntary Isolation

Essence of the Right: PWTB should not face detention or isolation unless absolutely necessary for public health and in line with legal protections.

Analysis: Pakistan currently lacks a clear legal framework governing involuntary isolation for TB, which could lead to rights violations for those with drug-resistant TB or individuals not adhering to treatment. The Right to Freedom from Arbitrary Detention and Involuntary Isolation is not explicitly mentioned as such in the Constitution of Pakistan. However, protections against arbitrary detention and restrictions on personal liberty can be found in several constitutional provisions, primarily under Articles 9 and 10.

Recommendations:

- **Law Matrix**: Develop guidelines to regulate involuntary isolation and ensure it is only used in extreme public health cases.
- **Policy Matrix**: Provide healthcare staff with training on respecting PWTB' rights and implementing non-coercive measures.

7. Right to a Safe Workplace

Essence of the Right: PWTB should have the right to safe working conditions, free from discrimination and health risks related to TB.

Analysis: Pakistan lacks workplace policies specific to TB, leaving many PWTB vulnerable to job loss or discrimination due to their health status. This is particularly problematic in high-risk sectors where physical proximity is necessary.

Recommendations:

- **Law Matrix**: Create labor laws that support the employment continuity of PWTB and offer financial support where needed.

- **Policy Matrix**: Develop policies that provide PWTB with reasonable workplace accommodations and reduce occupational risk of TB transmission.

Summary:

1. **Rights Needing Urgent Attention**:

   - Right to Freedom from Discrimination: Requires enactment of explicit anti-discrimination laws for TB-affected individuals, enforcement in workplaces and healthcare settings, and media coverage to raise awareness and promote acceptance.
   - Right to Access Information: Needs enactment of legislation guaranteeing health-related information dissemination, enforcement through proactive government campaigns, and media coverage via social and electronic platforms to debunk myths and improve adherence.
   - Right to Privacy: Requires strengthening enforcement of confidentiality laws, particularly in healthcare, and media advocacy to build awareness about person privacy.

2. **Actions Needed for Specific Rights:**

   - Right to Access Services: Urgent enforcement of equitable access policies, including free medications and home delivery options, supported by media campaigns to inform the public.
   - Right to a Safe Workplace: Needs enactment of workplace safety and anti-discrimination laws, enforcement of employment protections, and media engagement to highlight challenges faced by TB-affected workers and advocate for inclusive practices.

Key Findings and discussions

The TB Stigma Assessment in Pakistan provides a comprehensive view of the stigma faced by PWTB and their families across multiple settings. The findings highlight systemic challenges that hinder TB care and emphasize the need for targeted interventions. Below, the key findings are detailed alongside discussions on statistically significant differences by region, gender, key populations (KPs), and DR-TB diagnosis:

Community stigma emerged as the most severe, with 60% of PWTB reporting experiences of discrimination and isolation in their neighborhoods or social circles. Misconceptions about TB's contagiousness and its perceived links to socially undesirable behaviors fueled this stigma. AJK/GB reported the highest stigma levels (95%), followed by KPK (90%), where cultural norms and limited awareness exacerbate stigma. Sindh (10%) and Punjab (44%) exhibited significantly lower and moderate stigma, potentially reflecting better TB awareness and access to healthcare services in urbanized areas (p-*value* < 0.05). Women (65%) faced higher stigma than men (58%) due to societal pressures, restricted mobility, and greater vulnerability to judgment. Transgender individuals experienced the highest levels of community stigma (78%), highlighting the compounded challenges of gender identity and TB-related stigma. Vulnerable groups such as the rural poor (65%), people who use drugs (67%), and persons with disabilities (72%) experienced heightened community stigma. For these groups, TB stigma intersects with social and economic marginalization. Indigenous populations (71%) and urban slum residents (51%) also reported significant stigma, driven by poor living conditions and restricted access to health education. People with Extra-pulmonary TB (74%) experienced higher stigma compared to those with pulmonary TB (58%), as misconceptions about disease severity and transmission risks are more pronounced for less common TB types.

Community stigma profoundly affects PWTB mental health and willingness to seek care. High stigma in regions like AJK/GB and KPK underscores the importance of region-specific community engagement programs. Public awareness campaigns tailored to local cultural contexts can address misconceptions and promote acceptance.

Stigma in healthcare environments was reported by 53% of PWTB. People frequently cited judgmental attitudes from healthcare providers, breaches of confidentiality, and isolation practices as key contributors. AJK/GB (86%) and KPK (77%) showed the highest healthcare stigma, reflecting gaps in healthcare worker training and person-centered care. ICT (38%) and Sindh (35%) reported the lowest stigma levels, likely due to better infrastructure and sensitization efforts in urban areas (p-*value* < 0.05). Women (57%) faced slightly higher stigma than men (50%), likely due to greater cultural expectations for modesty and fear of judgment in public spaces. Transgender individuals (56%) faced significant stigma, often linked to systemic discrimination in healthcare settings. Healthcare worker stigma was particularly severe for

persons with disabilities (66.7%) and those who use drugs (72.2%). These groups face compounded biases, with healthcare providers often attributing their illness to personal failings. Refugees (50%) and miners (44.9%) also reported notable stigma in healthcare, reflecting barriers to equitable care. People with Extra-pulmonary TB (65%) reported higher stigma compared to people with pulmonary TB (51%). Persons with drug-resistant TB experienced mixed outcomes: XDR-TB (55%) faced higher stigma than MDR-PWTB (41%), possibly due to fears of prolonged transmission risks.

Stigma in healthcare undermines trust in the system, leading to delayed care and poor adherence to treatment. Comprehensive training programs for healthcare workers, focused on individual's confidentiality, empathetic communication, and stigma-free care, are essential to reversing this trend.

Self-stigma, reported by 44% of PWTB, is characterized by feelings of shame, guilt, and withdrawal from social interactions. Many respondents expressed fear of disclosure and internalized blame for their illness. AJK/GB and KPK reported the highest self-stigma levels (20%), significantly more than Sindh, ICT, and Punjab (14% each) (*p-value* < *0.05*). These variations may reflect stronger cultural taboos and limited access to mental health support in rural regions. Women exhibited higher self-stigma, influenced by societal expectations, caregiving roles, and fear of exclusion. Transgender individuals also showed high self-stigma, driven by the dual burden of societal rejection and TB-related discrimination. The rural poor (50.3%) and prisoners (11.4%) experienced the highest self-stigma, reflecting compounded marginalization. Urban slum residents (6%) and miners (4.7%) reported moderate self-stigma, influenced by challenging living and working conditions. People with Pulmonary TB (81%) reported significantly higher self-stigma compared to those with extra-pulmonary TB (12%). Drug-resistant TB cases (MDR-TB: 2%, XDR-TB: 1%) showed lower self-stigma, potentially due to ongoing support in specialized treatment settings.

Self-stigma poses a substantial barrier to accessing care and maintaining treatment adherence. Counseling services, peer support groups, and educational campaigns that emphasize the treatability of TB are critical to mitigating self-stigma and empowering PWTB.

These findings underscore the pervasive and multifaceted nature of TB stigma in Pakistan. The significant regional, gender, and population-based disparities indicate the need for tailored interventions. High levels of stigma in regions like AJK/GB and KPK demand localized approaches, incorporating cultural nuances to address stigma effectively.

Intersectionality of Vulnerabilities: Gender disparities and the challenges faced by KPs highlight the intersectionality of stigma. For instance, transgender individuals and persons with disabilities consistently reported high stigma levels across all settings, indicating the compounded impact of overlapping identities.

Policy and Structural Gaps: The absence of legal protections and stigma-reduction policies perpetuates discriminatory practices in workplaces, healthcare facilities, and communities. Advocacy for anti-discrimination laws and enforcement mechanisms must be a priority.

Call for Holistic Solutions: Addressing TB stigma requires a multi-sectoral approach involving government agencies, civil society, healthcare providers, and communities. Integrating stigma-reduction strategies into existing TB control programs and leveraging tools like Dopasi's digital platforms for community monitoring can ensure sustainable progress.

Recommendations Suggested by Respondents

The study gathered insights and recommendations from key populations involved in TB care, including people with TB (PWTB), their families, community members, and medical care providers. These recommendations aim to address and reduce TB-related stigma. Additionally, the research team developed general recommendations based on the findings.

Recommendations by People with TB (PWTB):

PWTB highlighted the need for privacy and the right to control the disclosure of their TB status. They also urged healthcare providers to adopt a more empathetic and respectful approach, emphasizing clear communication, avoidance of condescension, and meaningful involvement of persons in their own healthcare decisions. Many PWTB requested expanded access to psychological and social support services, particularly during in-patient treatment. They also called for increased media coverage on the social impact of TB to promote understanding. Additionally, PWTB

recommended improved living conditions and nutritional standards in TB clinics, ensuring access to basic facilities like hot water and clean lavatories. Some also suggested better management of flow of people in clinics to separate individuals at different stages of TB and those with high-risk behaviors, such as substance use, to prevent potential disruptions in care.

Recommendations by Families of PWTB:

Family members echoed many of the recommendations provided by PWTB, emphasizing the importance of compassionate, person-centered care from healthcare providers. They suggested that medical staff receive training to foster a more supportive and friendly attitude toward PWTB. Families also advocated for access to psychological support not only for the PWTB but also for the family as a whole, recognizing the emotional toll that TB can take on households. Many families stressed the need to enhance in-patient facilities, particularly regarding diet and overall living conditions, to support better health outcomes for their loved ones.

Recommendations by Community Members:

Community members strongly recommended large-scale awareness campaigns to be conducted in various settings, such as healthcare facilities, schools, public transportation networks, social media, and mainstream media. These campaigns should aim to improve public understanding of TB, dispel myths, and reduce stigma within society and the healthcare community. Many respondents considered this recommendation a priority, believing it would significantly change societal attitudes toward TB. Additionally, some community members suggested establishing a TB helpline to offer telephone counseling for PWTB and their families. Although a TB notification line currently exists in Islamabad, expanding it nationwide could increase accessibility for those affected by TB across Pakistan.

Recommendations by Medical Care Providers:

Medical care providers recommended increasing TB awareness within society, especially through Public-Private Mix (PPM) partnerships. They highlighted the importance of educating the public to foster a better understanding of TB and reduce stigma. This awareness could also address misconceptions within the healthcare sector, contributing to more supportive and effective care environments for PWTB.

General Recommendations:

Based on the findings of the stigma assessment, both short-term and long-term strategies are essential to address TB-related stigma in Pakistan and ensure sustained impact. These recommendations focus on reducing stigma at multiple levels while improving access to TB services for people with TB (PWTB) and key vulnerable populations (KVPs). Specific attention is given to addressing stigma during the first two stages of the TB journey (recognizing symptoms and seeking care) and targeting statistically significant differences by region, gender, KVPs, and disease type.

1. Strengthen Awareness and Education Efforts

Addressing Specific Stigmatizing Attitudes:

- Misconceptions about TB contagiousness.
- Associations of TB with moral failings or personal shortcomings.
- Gendered stereotypes that limit women's and KVP's ability to seek care.
- Fears of association with HIV/AIDS and its compounded stigma.

Community Awareness Campaigns:

- **Nationwide Public Education Campaigns**: Develop large-scale, multi-platform campaigns to educate the public on TB transmission, prevention, and treatment. Highlight personal testimonies from TB survivors, especially from high-stigma regions like AJK/GB and KPK, to counteract stigma in communities with high prevalence. Messaging focusing on destigmatizing especially with regard to KVPs, Transgenders and women
- **Targeted Education in Schools and Workplaces**: Implement TB awareness modules in schools and workplaces, particularly in rural and urban slum areas with statistically significant stigma levels among KVPs, including rural poor and miners. Address specific misconceptions around TB and transmission risks.

- **Engagement of Religious and Community Leaders**: Collaborate with influential community leaders to promote TB awareness in culturally sensitive ways, especially in regions where community stigma is high, and particularly for women, Transgenders, and KVPs. These efforts should prioritize addressing fears of social exposure during the initial stages of recognizing symptoms and seeking care.

Healthcare Worker Training and Sensitization:

- **Comprehensive Stigma Reduction Training**: Develop stigma-reduction training for healthcare workers, focusing on person-centered care and the specific needs of vulnerable groups such as women, transgender individuals, prisoners, miners, Healthcare workers, people who use drugs and persons with disabilities, etc.
- **Ongoing Sensitization Sessions**: Regularly update healthcare workers on TB, to reduce stigmatizing attitudes like fears of infection and bias toward PWTB.
- **Integration of Stigma Reduction in Medical Curricula**: Incorporate stigma awareness training into medical and nursing programs to ensure future generations provide compassionate, stigma-free care.

2. Enhance Person-Centered Support Systems

Increase Mental Health and Psychosocial Support:

- **Counseling and Mental Health Services**: Provide counseling at TB clinics to address self-stigma among PWTB and secondary stigma among family members. Focus these services on the first two stages of the TB journey to support individuals who may delay care-seeking due to internalized stigma.
- **Peer Support Groups**: Establish peer support groups in high-stigma regions such as AJK/GB and among marginalized populations like the rural poor, ensuring emotional support for recognizing symptoms and seeking care.

Confidentiality and Non-Disclosure Protections:

- **Strengthened Privacy Policies**: Enforce confidentiality measures in TB clinics to protect person privacy and reduce fears of stigma in healthcare settings.
- **Anonymized Support Systems**: Provide anonymous counseling services through national helplines to support PWTB particularly those from highly stigmatized groups, during the early stages of care-seeking.

3. Address Structural and Institutional Stigma

Policy Reforms for Rights Protection:

- **Anti-Discrimination Policies**: Develop and implement policies prohibiting TB-related discrimination in healthcare, employment, and education, with mechanisms to hold violators accountable. Ensure these policies address statistically significant stigma experienced by people with DR-TB and vulnerable KPs, like transgender individuals and refugees.
- **Workplace Protections**: Advocate for labor protections to prevent job loss and discrimination against PWTB and their family members, particularly in regions with high workplace stigma.

Legal Protections and Advocacy:

- **Legal Awareness for PWTB and KPs**: Establish community-based legal literacy programs targeting KPs like miners, urban slum residents, and people who use drugs, focusing on the rights of people experiencing stigma.
- **Policy Advocacy for Legal Reform**: Collaborate with policymakers to strengthen legal protections specifically addressing TB stigma and include TB as a protected condition in anti-discrimination laws.

4. Community and Workplace Initiatives to Combat Stigma

Community Stigma Reduction Programs:

- **Community-Based Support Groups**: Set up peer support groups in communities with high TB prevalence to provide support for PWTB and reduce stigma. Emphasize their role during the first stages of the TB journey, ensuring individuals recognize symptoms without fear of judgment.
- **Public-Private Partnerships (PPM)**: Collaborate with private healthcare providers to engage communities, particularly in underserved regions, to ensure stigma-free access to TB services.

Workplace Stigma Reduction Policies:

- **Anti-Stigma Workshops**: Encourage employers to provide TB awareness workshops, particularly for HR and management, to ensure non-discriminatory practices.
- **Incentives for Inclusive Work Environments**: Introduce incentives for organizations that create stigma-free workplaces, providing job security and acceptance for PWTB.

5. Tailored TB Services for Key Populations

Service Accessibility for Key Populations:

- **Mobile Clinics and Tailored Services**: Establish mobile health clinics to provide confidential TB services to key populations in hard-to-reach areas, such as women, transgender individuals, prisoners, miners, Healthcare workers, people who use drugs and persons with disabilities, etc. Prioritize regions where stigma significantly delays care-seeking behaviors.
- **Community-Led Monitoring**: Train and Empower community groups to monitor the quality of TB services to ensure KPs receive appropriate care without discrimination.

Self-stigma and healthcare stigma were notably higher among persons with disabilities and drug users. Interventions should address these disparities during the recognition of symptoms and care-seeking stages.

6. Implement Stigma Reduction Monitoring and Accountability

Monitoring and Evaluation:

- **Data Collection and Community Feedback**: Develop M&E frameworks that incorporate feedback from high-stigma regions and track service improvements for KVPs and PWTB.
- **Regular Assessments**: Conduct semi-annual reviews to evaluate the effectiveness of interventions, using indicators like increased treatment adherence, fewer reports of stigma, and enhanced legal recourse for PWTB. Repeat the full stigma assessment every 2-3 years to track progress and adapt interventions as needed.

Action Plan

An action plan is being developed in alignment with the findings and recommendations of the Stigma Assessment Report. This comprehensive plan aims to address TB-related stigma across multiple levels, focusing on key areas such as community engagement, healthcare system improvements, policy reform, and support for people with TB (PWTB) and key populations (KPs). Following the final dissemination of the Stigma Assessment Report, Dopasi Foundation, in collaboration with the Stop TB Partnership and other key stakeholders, will initiate the implementation of this action plan.

The action plan will adopt a phased approach, beginning with short-term strategies to tackle immediate challenges, such as raising awareness and enhancing healthcare worker training, while simultaneously laying the groundwork for long-term, sustainable interventions like legal reforms and integration of stigma-reduction measures into national health strategies. The implementation will prioritize regions and populations identified in the report as experiencing the highest levels of stigma, such as AJK, KPK, women, transgender individuals, and those diagnosed with drug-resistant TB.

To ensure the action plan is impactful and inclusive, Dopasi Foundation will engage a broad range of stakeholders, including government health departments, civil society organizations, local communities, healthcare providers, and representatives from marginalized groups. This collaborative approach will help design interventions that are contextually relevant, gender-responsive, and culturally sensitive.

With the support of the Stop TB Partnership, Dopasi Foundation will focus on mobilizing resources, building capacity at all levels, and monitoring progress against clear, measurable indicators. This collaborative effort aims to create a stigma-free environment that encourages early diagnosis, treatment adherence, and equitable access to care for all affected individuals, ultimately contributing to the broader goal of ending TB in Pakistan.

A tentative and in-process action plan is attached as **Annex-2.**

Conclusion

The TB Stigma Assessment in Pakistan highlights the pervasive and multifaceted nature of stigma experienced by people with TB (PWTB), their families, and key populations (KPs). The findings underscore that stigma is not confined to individual attitudes but is deeply rooted in community norms, healthcare settings, workplaces, and structural barriers, such as the absence of legal protections. It is evident that TB stigma significantly impacts the early stages of the TB journey, particularly in recognizing symptoms and seeking care, leading to delayed diagnosis and treatment.

Key findings from this assessment reveal statistically significant variations in stigma levels by region, gender, and among specific vulnerable groups, such as women, transgender individuals, persons with disabilities, and individuals with drug-resistant TB (DR-TB). These disparities highlight the urgent need for targeted and context-sensitive interventions to address stigma at its core.

The assessment emphasizes that stigma reduction requires a multi-pronged approach that involves raising awareness, sensitizing healthcare workers, providing psychosocial support, advocating for legal reforms, and empowering communities to combat stigma. Community leaders, healthcare professionals, policymakers, and PWTB themselves must collectively drive efforts to reduce stigma and create an enabling environment for TB prevention and care.

Looking ahead, the development of a comprehensive action plan, led by Dopasi Foundation with support from the Stop TB Partnership, represents a critical step toward operationalizing the recommendations of this assessment. This action plan will prioritize addressing stigma during the early stages of the TB journey, while ensuring interventions are gender- and KPs-responsive, culturally relevant, and sustainable. By focusing on regions and groups with the highest stigma levels, this plan aims to create an equitable healthcare system where no one is denied care or support due to stigma.

The findings of this assessment serve as a catalyst for collective action, urging stakeholders across sectors to prioritize stigma reduction as a central pillar of TB care and control. Only through sustained, collaborative, and evidence-driven efforts can we ensure that stigma no longer hinders progress in the fight against TB in Pakistan. Together, we can foster a society where TB is no longer a source of shame or discrimination, but a challenge that is met with compassion, understanding, and a commitment to ending the epidemic.

Acknowledgements

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- TB survivors and community members for their openness and essential contributions.
- The Dopasi Foundation's field and Head Quarter team for data collection, compilation, analysis and report writing

We would like to extend a special word of appreciation to the Stop TB Partnership for their support and guidance in adapting the assessment tool to align with Pakistan's unique needs and context.

Feelings expressed by various respondents during interviews

People with TB

"I wasn't just battling TB; I was battling the stares, whispers, and judgments that came with it."

"I imprisoned myself in my room which felt safer than the outside world—at least here, no one called me contagious."

"My family's silence was louder than any words. It told me I was a burden they didn't want to carry."

"At work, my colleagues avoided me as if I was the disease itself. Their fear hurt more than the illness."

"I started hating myself because the world made me feel unworthy of love and respect."

"They told me TB was curable, but no one told me how to cure the shame I felt when my marriage proposal was rejected due to the disease I had"

"I stopped seeking treatment because every visit to the clinic reminded me of how society saw me—unclean."

"My friends disappeared one by one, leaving me alone to face this battle with no allies."

"The hardest part wasn't the medicine or the isolation—it was losing my identity to the stigma."

Families of People with TB

"When my husband was diagnosed with TB, the neighborhood treated us as if we were all infected."

"We avoided telling anyone about my son's illness because we feared losing our place in the community."

"The hardest part was not knowing how to support my sister while carrying the weight of others' judgment."

"Every day, we fought not only the disease but also the isolation from those we once called friends."

"People in the village told us to move away. It was as if they wanted to erase us because of my child's illness."

"We kept my father's TB a secret even from relatives, afraid they'd stop visiting us forever."

Key Vulnerable Populations

Transgender individuals

"As a transgender person, I was already invisible, but TB made me untouchable."

"The clinic wouldn't even let me sit in the waiting area because of who I am and my illness."

"I fought for my identity all my life, but TB stripped me of the little dignity I had left."

"I went to the hospital seeking care, but all I received were glances filled with fear and disgust."

Previous prisoner

"I kept my illness a secret because I knew TB in prison meant being abandoned, even by the guards."

Coal miner

"The mine was my lifeline, but the moment they found out about my TB, they cut me loose."

Healthcare Workers

"I feel pride in saving lives, but the whispers behind my back often drown out my accomplishments."

"Some people refuse treatment because they think I judge them, but all I see are people in need."

"Even among healthcare workers, there's stigma against those of us who dedicate our lives to PWTB."

"The hardest part isn't the long hours or the difficult cases—it's seeing the walls society builds around my patients and me."

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29	Farnaz Naseer		TB Survivor

Annextures

Annex-1 - Table 5: Factors associated with self-stigma

PWTB Self Stigma 5 +	N=2392	Number experienced Stigma	%age experienced stigma	P-Value
Province				
AJK/ GB	58	4	7%	-
Bal	146	23	16%	**0.926**
ICT	23	6	26%	**0.186**
KPK	394	74	19%	**0.104**
Punjab	1234	224	18%	**0.003**
Sindh	537	52	10%	**0.000**
Gender				
Male	1483	187	13%	**0.000**
Female	791	120	15%	**0.412**
Transgender	118	76	64%	**0.000**
Age				

18-24	413	85	21%	**0.006**
25-44	1150	178	15%	**0.517**
45-64	694	106	15%	**0.518**
65 or older	135	14	10%	**0.065**
Localization of TB				
Pulmonary	2163	341	16%	**0.221**
Extra Pulmonary	123	23	19%	**0.359**
Extensively Drug-Resistant TB	11	5	45%	**-**
Multi Drug Resistant TB	43	6	14%	**0.709**
Others	52	8	15%	**0.899**
Self Identify as				
Person living with HIV	68	8	12%	**0.355**
Miner	125	11	9%	**0.026**
HCW	123	29	24%	**0.019**
Refugee	56	15	27%	**0.026**
Urban Slums	197	23	12%	**0.077**
Rural Poor	1042	174	17%	**0.430**
Person who uses drugs	37	7	19%	**0.629**
Person with disability	43	27	63%	**0.000**
Indigenous Person	140	20	14%	**0.563**
Former Prisoner	321	44	14%	**0.222**
Transgender	118	76	64%	**0.000**

Table 4: *Factors associated with self-stigma (n=2392)*

Annex-2 Action Plan to address TB-related Stigma

Pakistan	**Tentative / In-process Action Plan to Address TB-related Stigma**
Date Action Plan Endorsed: (day, month, year)	**Proposed date - June - 2025**
Implementation Period of the Action Plan (start month/year, end month/year, e.g., Jan 2020 - Dec 2021)	**Dec 2025 - Dec 2028**
Endorsed by: (government ministries, civil society organizations, health care professional organizations, private sector, etc.)	**Department of Health - CMU/PTPs**

Obj. Sr #	*Objectives*	*Intervention Sr.#*	*Interventions*	**Priority** 1=short term (implementation within 2 years) 2=longer term, (implelmentation 3-5 years)	(A) **Target settings for this intervention?** (select ✓ if Yes)						(B) **Which of the stages of the TB Journey would this intervention contribute towards reducing stigma?** (select ✓ if Yes)							(C) **Details of Interventions**		(D) **Alignment with National Strategic Plan** (specify which NSP goals the proposed intervention would contribute towards)	(E) **Which key findings and recommendations of the stigma assessment do this intervention address?**	(F) **Costs** (estimates in local currency, based on country's existing similar programme unit costs)	(G) **Focal Point** (person/ organisation)
					PWTB	Family of PWTB	Community	Health Care	Law and Policy	Media	(1) Recognizing symptoms	(2) Seeking care	(3) Getting an accurate diagnosis	(4) Beginning treatment	(5) Getting treatment adherence support	(6) Completing treatment	(7) Getting post-treatment follow-up services	How would the intervention be gender- and KVPs-responsive?	Who, when, where and how many? What are the source and unit costs of existing or similar programmes in the country?				
1	Reduce Community Stigma	1.1	Nationwide Public Education Campaigns	1 - Short Term	✓	✓	✓			✓	✓	✓	✓			✓		Incorporate testimonials from gender-diverse TB survivors. Prioritize outreach to rural women and transgender individuals in high-burden areas.	Nationwide campaigns over 3 years in all provinces.	Increase awareness about TB to enhance early case detection and reduce stigma	Community stigma, delayed care-seeking, regional differences	TBD	Ministry of Health and National TB Control Program (NTP)
1	Reduce Community Stigma	1.2	Engagement of Religious and Community Leaders	1 - Short Term	✓	✓	✓				✓	✓						Collaborate with local community leaders to address culturally sensitive issues, including gender-specific barriers to accessing care.	3-year intervention in high-burden regions (KPK, AJK/GB). Partner with 100+ local leaders.	Promote community engagement to address TB-related stigma	Fear of contagiousness and stigma in early TB stages	TBD	Religious Affairs Ministry and Community-Based Organizations, Implementing partners
1	Reduce Community Stigma	1.3	Targeted TB Awareness in Schools and Workplaces	2 - Longer Term	✓		✓				✓	✓	✓					Design school and workplace programs that include specific modules on gender roles and stigma faced by KPs.	Target 500 schools and 200 workplaces in Punjab and Sindh.	Integrate TB education into non-health sectors to normalize TB discussions	Lack of TB education in schools and workplaces contributing to stigma	TBD	Education Boards and Private Sector Employers, implementing partners
1	Reduce Community Stigma	1.4	Community Awareness Campaigns Led by TB Survivors	1 - Short Term	✓		✓			✓	✓	✓				✓		Engage TB survivors from diverse backgrounds to lead awareness campaigns in high-stigma regions.	Provide counseling in 100 clinics annually, prioritizing AJK and KPK.	Utilize TB survivors to promote person-centered stigma reduction strategies	Limited inclusion of TB survivors in stigma reduction efforts	TBD	TB Survivor Networks and Local NGOs, implementing partners
1	Reduce Community Stigma	1.5	Stigma Resilience Messaging	1 - Short Term	✓		✓			✓	✓	✓				✓		Share testimonials from TB survivors, particularly women and KVPs, to normalize TB and reduce self-stigma.	Develop stigma resilience campaigns across five provinces within 2 years.	Encourage stigma-free attitudes through survivor testimonials	Self-stigma and lack of resilience among PWTB and KVPs	TBD	National and Provincial Health Departments, implementing partners
1	Reduce Community Stigma	1.6	Use of OneImpact for Community Reporting	2 - Longer Term	✓		✓			✓	✓	✓	✓			✓		Train communities on using OneImpact for anonymous stigma reporting, ensuring inclusivity for women and KVPs.	Train 200 community members annually in using OneImpact for stigma reporting.	Enhance data collection and accountability for stigma reduction	Absence of real-time stigma reporting systems	TBD	Stop TB Partnership and Community Monitoring Teams, implementing partners
1	Reduce Community Stigma	1.7	Digital Awareness Campaigns via Social Media	1 - Short Term	✓		✓			✓	✓	✓				✓		Use social media to develop gender-specific messaging addressing misconceptions and stigma.	Launch campaigns targeting 1M social media users annually.	Leverage digital platforms to target stigma among youth and urban populations	Low awareness among youth and urban populations	TBD	Social Media Influencers and Health Communication Agencies, implementing partners
1	Reduce Community Stigma	1.8	Storytelling Campaigns via Radio	2 - Longer Term	✓		✓			✓	✓	✓	✓	✓	✓	✓	✓	Share diverse survivor stories on radio to address stigma in high-prevalence regions.	Broadcast weekly survivor stories via local radio in three high-prevalence provinces.	Increase public awareness using accessible media formats	Community myths and misinformation about TB	TBD	National Radio Broadcasters and Community Radio Stations, implementing partners

Obj. Sr #	Objectives	Intervention Sr.#	Interventions	Priority 1=short term (implementation within 2 years) 2=longer term, (implelmentation 3-5 years)	(A) Target settings for this intervention? (select ✓ if Yes)						(B) Which of the stages of the TB Journey would this intervention contribute towards reducing stigma? (select ✓ if Yes)							(C) Details of Interventions		(D) Alignment with National Strategic Plan (specify which NSP goals the proposed intervention would contribute towards)	(E) Which key findings and recommendations of the stigma assessment do this intervention address?	(F) Costs (estimates in local currency, based on country's existing similar programme unit costs)	(G) Focal Point (person/ organisation)
					PWTB	Family of PWTB	Community	Health Care	Law and Policy	Media	(1) Recognizing symptoms	(2) Seeking care	(3) Getting an accurate diagnosis	(4) Beginning treatment	(5) Getting treatment adherence support	(6) Completing treatment	(7) Getting post-treatment follow-up services	How would the intervention be gender- and KVPs-responsive?	Who, when, where and how many? What are the source and unit costs of existing or similar programmes in the country?				
2	Address Healthcare Stigma	2.1	Comprehensive Stigma-Reduction Training for Healthcare Workers	1 - Short Term				✓			✓	✓						Ensure training covers specific biases and stigma faced by women, transgender individuals, and other marginalized groups.	Train 5,000 healthcare workers annually across all provinces.	Train healthcare workers to provide stigma-free and person-centered care	Stigma within healthcare settings due to poor provider attitudes	TBD	Medical Training Institutes and Health Workforce Departments, implementing partners
2	Address Healthcare Stigma	2.2	Integration of Stigma Awareness into Medical Curricula	2 - Longer Term				✓				✓						Include case studies and scenarios that address gender disparities in accessing healthcare.	Revise medical curricula across 50 institutions over 5 years.	Incorporate stigma-reduction training into formal healthcare education	Lack of stigma awareness in formal medical training	TBD	National Medical and Nursing Councils, implementing partners
2	Address Healthcare Stigma	2.3	Enhanced Confidentiality Measures in Clinics	1 - Short Term				✓				✓						Redesign clinic spaces to ensure privacy for PWTB during consultations and treatment.	Redesign clinic spaces to ensure privacy for PWTB during consultations and treatment.	Ensure privacy and reduce enacted stigma in healthcare settings	Fear of disclosure and lack of confidentiality in healthcare settings	TBD	National TB Control Program and Hospital Administration, implementing partners
2	Address Healthcare Stigma	2.4	Task Shifting to Community Health Workers	1 - Short Term			✓	✓			✓	✓						Train CHWs to provide basic TB care and support, reducing stigma in clinical settings	Train 200 CHWs annually to support TB care in underserved areas.	Decentralize TB care to reduce stigma associated with clinical settings	High levels of stigma associated with clinical visits	TBD	Provincial Health Departments and Community Health Worker Programs, implementing partners
2	Address Healthcare Stigma	2.5	Mystery Patient Surveys	1 - Short Term				✓			✓	✓	✓	✓	✓	✓	✓	Evaluate stigma through surveys, focusing on biases faced by women and KVPs in healthcare settings.	Survey 500 healthcare facilities nationwide within 3 years.	Measure and address biases in healthcare settings systematically	Provider bias and gender-specific stigma in healthcare settings	TBD	Independent Monitoring and Evaluation Teams, implementing partners
2	Address Healthcare Stigma	2.6	Stigma-Free Facility Certification	2 - Longer Term				✓				✓						Acknowledge and Certify healthcare facilities that provide gender-sensitive and stigma-free care.	Certify 50 facilities as stigma-free annually.	Certify and reward stigma-free healthcare facilities	Limited incentives for healthcare facilities to adopt stigma-free practices	TBD	National TB Control Program and Accreditation Bodies, implementing partners
2	Address Healthcare Stigma	2.7	Healthcare Champions Program	2 - Longer Term				✓				✓						Train TB survivors from diverse genders and KVPs to act as stigma-reduction advocates.	Train 300 TB survivors annually to serve as stigma champions.	Empower survivors to advocate for stigma-free healthcare environments	Need for survivor advocacy to address stigma in healthcare	TBD	TB Survivor Networks and Provincial Health Departments, implementing partners

Obj. Sr #	Objectives	Intervention Sr.#	Interventions	Priority 1=short term (implementation within 2 years) 2=longer term, (implementation 3-5 years)	(A) Target settings for this intervention? (select ✓ if Yes)						(B) Which of the stages of the TB Journey would this intervention contribute towards reducing stigma? (select ✓ if Yes)							(C) Details of Interventions		(D) Alignment with National Strategic Plan (specify which NSP goals the proposed intervention would contribute towards)	(E) Which key findings and recommendations of the stigma assessment do this intervention address?	(F) Costs (estimates in local currency, based on country's existing similar programme unit costs)	(G) Focal Point (person/ organisation)
					PWTB	Family of PWTB	Community	Health Care	Law and Policy	Media	(1) Recognizing symptoms	(2) Seeking care	(3) Getting an accurate diagnosis	(4) Beginning treatment	(5) Getting treatment adherence support	(6) Completing treatment	(7) Getting post-treatment follow-up services	How would the intervention be gender- and KVPs-responsive?	Who, when, where and how many? What are the source and unit costs of existing or similar programmes in the country?				
3	Enhance Person-Centered Support	3.1	Counseling and Mental Health Services in TB Clinics	1 - Short Term	✓	✓					✓	✓						Provide gender-sensitive counseling and mental health services, particularly targeting rural women and transgender individuals.	Deploy counselors in 50 TB clinics in AJK/GB and KPK within 2 years.	Provide accessible mental health support to address self-stigma	High prevalence of self-stigma and limited access to counseling	TBD	Regional Mental Health Departments and TB Clinics, implementing partners
3	Enhance Person-Centered Support	3.2	Peer Support Groups for PWTB and Families	1 - Short Term	✓	✓					✓	✓						Ensure peer groups include representatives from all genders and KVPs to foster inclusivity and shared experiences.	Set up 100 peer support groups across high-burden districts in 2 years.	Foster inclusive support networks for PWTB and families	Social isolation and secondary stigma in families	TBD	Community-Based Organizations and Local Health Authorities, implementing partners
3	Enhance Person-Centered Support	3.3	OneImpact Peer Support Groups	1 - Short Term	✓	✓	✓				✓	✓	✓			✓		Use OneImpact to connect users with gender-specific peer support groups.	Create 20 peer groups annually through OneImpact.	Use digital platforms to facilitate stigma-free peer interactions	Limited access to peer support for gender and KVPs	TBD	Stop TB Partnership and Digital Health Teams, implementing partners
3	Enhance Person-Centered Support	3.4	Support Helpline via OneImpact	2 - Longer Term	✓	✓	✓					✓						Enable helpline services through OneImpact, offering immediate support for gender and KVP-specific needs.	Handle 2000 helpline cases annually via OneImpact.	Provide real-time support to PWTB and KVPs for stigma-related issues	Unavailability of immediate support for stigma-related issues	TBD	National TB Control Program and Helpline Operators, implementing partners
3	Enhance Person-Centered Support	3.5	Family Workshops on Reducing Secondary Stigma	2 - Longer Term	✓	✓						✓		✓	✓			Organize family workshops addressing stigma faced by women and KVPs within households.	Conduct 12 family workshops annually in high-stigma regions.	Educate families to reduce secondary stigma within households	Secondary stigma perpetuated by family members	TBD	Provincial Health Departments and Family Counseling Centers, implementing partners
3	Enhance Person-Centered Support	3.6	Recognition Programs for Supportive Families	2 - Longer Term	✓	✓						✓						Highlight supportive families in campaigns, focusing on diverse family structures.	Recognize 50 families annually through community programs.	Celebrate supportive families to normalize stigma-free behavior	Lack of recognition for stigma-free family behaviors	TBD	Local Health Authorities and Community Leaders, implementing partners

Obj. Sr #	Objectives	Intervention Sr.#	Interventions	Priority 1=short term (implementation within 2 years) 2=longer term, (implelmentation 3-5 years)	(A) Target settings for this intervention? (select ✓ if Yes)						(B) Which of the stages of the TB Journey would this intervention contribute towards reducing stigma? (select ✓ if Yes)							(C) Details of Interventions		(D) Alignment with National Strategic Plan (specify which NSP goals the proposed intervention would contribute towards)	(E) Which key findings and recommendations of the stigma assessment do this intervention address?	(F) Costs (estimates in local currency, based on country's existing similar programme unit costs)	(G) Focal Point (person/ organisation)
					PWTB	Family of PWTB	Community	Health Care	Law and Policy	Media	(1) Recognizing symptoms	(2) Seeking care	(3) Getting an accurate diagnosis	(4) Beginning treatment	(5) Getting treatment adherence support	(6) Completing treatment	(7) Getting post-treatment follow-up services	How would the intervention be gender- and KVPs-responsive?	Who, when, where and how many? What are the source and unit costs of existing or similar programmes in the country?				
4	Build Structural Protections	4.1	Anti-Discrimination Policies	2 - Longer Term					✓			✓			✓			Advocate for gender-neutral legal protections and policies that prioritize vulnerable groups, including women and transgender persons.	Legal drafting and advocacy campaigns targeting 4 major provinces within 3 years.	Advocate for laws protecting PWTB from discrimination	Systemic discrimination against PWTB in various settings	TBD	Ministry of Law and Justice, CMU, implementing partners
4	Build Structural Protections	4.2	Legal Literacy Programs	2 - Longer Term	✓		✓		✓			✓	✓					Develop literacy programs focused on the rights of women, transgender individuals, and other marginalized KVPs.	Conduct 100 workshops across all provinces in 3 years.	Educate marginalized populations on their legal rights	Lack of legal awareness among KVPs and marginalized groups	TBD	Legal Aid Organizations and Advocacy Networks, implementing partners
4	Build Structural Protections	4.3	TB Stigma Grievance System	2 - Longer Term			✓		✓			✓			✓			Launch grievance systems on OneImpact to report and track gender-specific discrimination cases.	Handle 50 grievances annually via OneImpact.	Provide mechanisms for reporting and addressing stigma-related grievances	No formal grievance mechanisms for stigma-related cases	TBD	Stop TB Partnership and Legal Aid Organizations, implementing partners
4	Build Structural Protections	4.4	Anti-Stigma Policy Advocacy Workshops	2 - Longer Term					✓						✓			Conduct advocacy workshops addressing the unique legal needs of KVPs.	Conduct 50 workshops annually focusing on legal reforms.	Promote policy changes to institutionalize stigma reduction	Limited policy focus on stigma reduction	TBD	Advocacy Teams and National TB Control Program, implementing partners
4	Build Structural Protections	4.5	Youth-Led Advocacy Groups	2 - Longer Term			✓			✓	✓	✓			✓			Engage youth advocacy groups to address TB stigma, focusing on gender and diversity.	Establish 100 youth advocacy groups annually in schools and colleges.	Engage youth to challenge stigma through creative and advocacy activities	Youth involvement in stigma reduction is minimal	TBD	Schools, Colleges, and Youth Organizations, implementing partners