

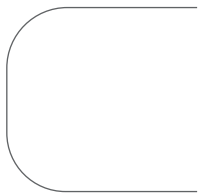
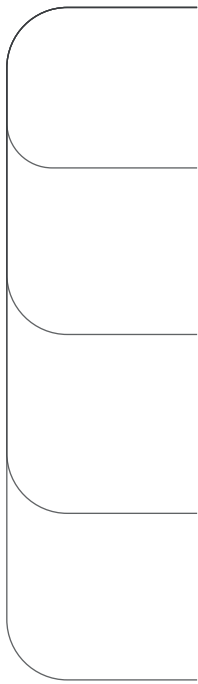


Stop TB Partnership hosted by  **UNOPS**

TB STIGMA ASSESSMENT **DATA COLLECTION INSTRUMENTS**

KEY INFORMANT SEMI-STRUCTURED INTERVIEW
& FOCUS GROUP DISCUSSION GUIDES

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SAMPLE CONSENT FORM

INTRODUCTION

Hello, my name is _____, and I work with _____ (NGO's name), an independent nongovernmental organization working with people affected by tuberculosis (TB), which includes people with or who have had TB, their family, their neighbours in the community where they live and health care workers who provide TB-related services. Today, we are conducting a community study on TB-related stigma among _____ (people with or who have had TB, family of people with or who have had TB, community/neighbours of people with or who have had TB, health care workers) who are 18 years of age or older.

We would like to learn from you about your experience with TB-related stigma, as well as if you have heard or seen others being stigmatized. We are particularly interested in how stigma acts as a barrier to accessing TB services. We also welcome your input on how TB services, laws and policies could be enhanced. Your responses will help to improve TB services in _____ (country X).

For the purpose of this interview, when we refer to stigma, we include both stigma and discrimination:

Stigma originates from the ancient practice of branding or marking someone who is thought to be “morally flawed” or to have behaved badly. The person therefore ought to be avoided by other members of society. Stigma is often described as a process of devaluation, whereby a person is discredited, seen as a disgrace, or perceived to have less value or worth in the eyes of others. Some common examples of stigma related to TB include assuming that someone with TB also has HIV, that he/she must be a drug user, and that he/she must have done something bad to deserve the punishment of having TB. This devaluation is then used to justify social isolation and discrimination against the person with TB.

Discrimination involves treating someone in a different, unjust, unfair or prejudicial manner, often on the basis of his/her belonging – or perceived belonging – to a particular group. Discrimination is often viewed as the end result of the process of stigmatization. In other words, when stigma is acted upon – sometimes called “enacted stigma” – the result is discrimination. Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized. TB-related discrimination occurs when someone is treated differently and to his/her disadvantage. This is because the person is known to have or have had TB or be closely associated with people with TB, such as their spouse or other members of their household. Some TB-related discrimination examples include: not being attended to at hospitals or clinics after TB was diagnosed; being given inferior medical treatment; being kicked out of home by family members upon knowledge of TB diagnosis; being asked not to attend religious services or community events despite being on treatment without any coughing; not being served by neighbourhood market vendors; being fired by employers upon knowledge of TB diagnosis; and being refused to return to school despite being on treatment without any coughing.

This interview should take 30 to 45 minutes. You are free to leave the interview any time without any consequences. You are also free to not answer any of the questions that you don't feel comfortable answering. Just let me know.

Your participation will not affect your or others' access to TB treatment. This survey is completely anonymous. No record of your name or any other personal information relating to you will be linked to your response. Interview notes will be analysed only by the research team. Results of the survey will not disclose any information specific to you. The research methodology has been approved by (name of national ethics review board).

Do you have any questions? Are you happy for us to proceed with this interview?

We thank you for your time to help us with this important work. Before we start, I must ask you to state that you have understood everything that I just explained and that I answered all the questions you had. I would appreciate it if you could sign the consent form before we proceed with the interview.

I, _____, hereby confirm I am aged 18 or over and give my consent to participate in the TB Stigma Community Study interview being run by _____ (NGO name).

INTERVIEWEE'S DECLARATION OF INFORMED CONSENT:

1. I have been informed about the specified and additional purpose(s) for which my opinions will be collected, used and disclosed, as described above.
2. I understand that my opinions may be used and disclosed for secondary purposes that are necessary to achieve the above-described specified purpose.
3. I voluntarily make this declaration and freely consent to the participation in the interview.

Signature

Signed at (place)

on (date)

QUESTIONNAIRE 1: FOR PEOPLE WITH OR WHO HAVE HAD TB (AGED 18 OR OVER)

Interviews should be conducted by trained people who have had TB.

Interviewer's Initials	(e.g., "AS" for Alice Smith)
Questionnaire Type	(e.g., "PA" for People with or who have had TB)
Interviewee No.	(e.g., "001", "002" & "003" for the 1 st , 2 nd & 3 rd Alice Smith, respectively)
Interview Location	(e.g., district name, village name)
Interview Date	(day-month-year e.g., 14 July 2018)

- A. I am going to read you a few statements that describe how you may feel about tuberculosis (TB). Please tell me on a 5-point scale how much you disagree or agree with each of the following statements, where "0" indicates you "Strongly Disagree", "1" you "Disagree", "2" you "Have No Opinion", "3" you "Agree", or "4" you "Strongly Agree". If you don't want to respond to a statement or think the statement is not applicable to you, just let me know and we can skip to the next statement. *[CHECK ONLY ONE BOX FOR EACH STATEMENT]*

		0 Strongly Disagree	1 Disagree	2 No Opinion	3 Agree	4 Strongly Agree
A1	I feel hurt how others react to knowing I have TB.					
A2	I lose friends when I share with them that I have TB.					
A3	I feel alone.					
A4	I keep a distance from others to avoid spreading TB germs.					
A5	I am afraid to tell those outside my family that I have TB.					
A6	I am afraid of going to TB clinics because other people might see me there.					
A7	I am afraid to tell others that I have TB because they may think that I also have HIV/AIDS.					
A8	I feel guilty because my family has the burden of caring for me.					
A9	I choose carefully who I tell about having TB.					
A10	I feel guilty for getting TB because of my smoking, drinking, or other careless behaviours.					
A11	I am worried about having HIV/AIDS.					
A12	I am afraid to tell my family that I have TB.					

Adapted from Van Rie TB Patient Stigma Scale. Tropical Medicine and International Health 2008;13(1):20–30.

a1 Do any of the above 12 statements also describe how you feel about TB yourself? *[CHECK ONLY ONE BOX BELOW]*

Yes, at least one statement.

No, none of the 12 statements *[Skip to Question B]*.

a2 Have any of these feelings you have about TB inhibited you from seeking and accessing TB services? *[CHECK ONLY ONE BOX BELOW]*

Yes

No

B. Have you ever felt you were stigmatized because of your TB status? *[CHECK ONLY ONE BOX BELOW]*

Yes

No *[Skip to Question E]*

b1 Have you experienced stigma in hospitals or clinics that inhibited you from continuing to seek and access TB services? *[CHECK ONLY ONE BOX BELOW]*

Yes

No

b2 Have you experienced stigma from your neighbours in your community where you live that inhibited you from seeking and accessing TB services? *[CHECK ONLY ONE BOX BELOW]*

Yes

No

b3 Have you experienced stigma at home that inhibited you from seeking and accessing TB services? *[CHECK ONLY ONE BOX BELOW]*

Yes

No

b4 Have you experienced stigma at work that inhibited you from seeking and accessing TB services? *[CHECK ONLY ONE BOX BELOW]*

Yes

No

- C. Please tell me more about when you **experienced stigma**? Have you experienced stigma **that inhibited you from** seeking timely care, going to a DOTS facility, getting an accurate diagnosis, beginning treatment, adhering to treatment or completing treatment in hospitals/clinics, community/neighbours, home/family, workplace, [insert other setting 1 (e.g., school, church) chosen by Core Group], or [insert other setting 2 (e.g., school, church) chosen by Core Group]? *[CHECK ALL BOXES THAT ARE APPLICABLE]*

Have you experienced stigma in these settings (right) that inhibited you from (below)...	Settings					
	C1 Hospitals/ Clinics	C2 Community/ Neighbours	C3 Home/ Family	C4 Workplace	C5 [Other Setting 1]	C6 [Other Setting 2]
Recognizing symptoms?						
Seeking care?						
Getting an accurate diagnosis?						
Beginning treatment?						
Getting treatment adherence support?						
Completing treatment?						
Getting post-treatment follow-up services?						

- D. Can you tell me more about the TB-related stigma you have experienced (e.g., TB/HIV coinfection, public messages on TB, laws and policies of those laws and policies)? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

- E. Do you know of other people with or who have had TB being stigmatized because of their TB status? *[CHECK ONE BOX ONLY]*

Yes

No *[Skip to Question H]*

- F. Do you know of other people with or who have had TB experiencing stigma in hospitals/clinics, community/neighbours, home/family, workplace, [insert other setting 1 (e.g., school, church) chosen by Core Group], and [insert other setting 2 (e.g., school, church) chosen by Core Group] that inhibited them from seeking timely care, going to a DOTS facility, getting an accurate diagnosis, beginning treatment, adhering to treatment or completing treatment? *[CHECK ALL BOXES THAT ARE APPLICABLE]*

Have you experienced stigma in these settings (right) that inhibited you from (below)...	Settings					
	C1 Hospitals/ Clinics	C2 Community/ Neighbours	C3 Home/ Family	C4 Workplace	C5 [Other Setting 1]	C6 [Other Setting 2]
Recognizing symptoms?						
Seeking care?						
Getting an accurate diagnosis?						
Beginning treatment?						
Getting treatment adherence support?						
Completing treatment?						
Getting post-treatment follow-up services?						

- G. Can you tell me more about the TB-related stigma you have seen or heard of (e.g., somebody was refused access to services due to his/her TB status, a woman was divorced due to her TB status, or a family member with TB refused to disclose his/her status)? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

- H. **What would you like to see changed in TB services, laws and policies to address TB-related stigma** (e.g., in hospital/clinics, community, family, workplace)? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*
-

- I. Do you have further comments you would like to share with us? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*
-

- J. What is your gender? *[CHECK ONE BOX ONLY]*

Female

Male

Transgender

Other

- K. How old are you? *[CHECK ONE BOX ONLY]*

18-24

25-44

45-64

65 or older

L. Do you self-identify as any of the following? *[CHECK AS MANY BOXES AS APPROPRIATE, AND IF NONE, CHECK NONE]*

Person living with HIV

Miner

Health care worker

Refugee

Urban slum dweller

Rural poor

Person who uses drugs

Person who has a disability

Indigenous person

Former prisoner

None

M. Which of the following statements is accurate about you? *[CHECK ONE BOX ONLY]*

Completed TB treatment over one year ago

Completed TB treatment within the last year

Currently on TB treatment

Never had TB treatment

N. What type of TB were you last diagnosed with? *[CHECK ONE BOX ONLY]*

Pulmonary TB

Multidrug-Resistant TB

Extensively Drug-Resistant TB

Extrapulmonary TB

Don't Know



Thank you very much for your time today and for sharing so generously with us both your experiences and insights.

QUESTIONNAIRE 2: FOR FAMILY MEMBERS LIVING IN THE SAME HOUSE AS PEOPLE WITH OR WHO HAVE HAD TB (AGED 18 OR OVER)

Interviews should be conducted by trained people who have had TB.

Interviewer's Initials (e.g., "AS" for Alice Smith)
 Questionnaire Type (e.g., "FA" for Family)
 Interviewee No. (e.g., "001", "002" & "003" for the 1st, 2nd & 3rd Alice Smith, respectively)
 Interview Location (e.g., district name, village name)
 Interview Date (day-month-year e.g., 14 July 2018)

- A. I am going to read you a few statements that describe how you may feel about tuberculosis (TB). Please tell me on a 5-point scale how much you disagree or agree with each of the following statements, where "0" indicates you "Strongly Disagree", "1" you "Disagree", "2" you "Have No Opinion", "3" you "Agree", or "4" you "Strongly Agree". If you don't want to respond to a statement or feel the statement is not applicable to you, just let me know and we can skip to the next statement. *[CHECK ONLY ONE BOX FOR EACH STATEMENT]*

		0 Strongly Disagree	1 Disagree	2 No Opinion	3 Agree	4 Strongly Agree
A1	My family member asks me to keep the TB a secret.					
A2	I feel ashamed because my family member has TB.					
A3	I hide the fact that my family member has TB from the community.					
A4	My family member hides his/her TB diagnosis from the community.					
A5	I avoid talking about TB in the presence of other family members or neighbours.					
A6	I'm afraid that someone will see me at the health care clinic where my relative is being treated.					
A7	I substitute another word for TB in conversations with my family member.					
A8	I substitute another word for TB in conversations with my friends.					
A9	I've noticed changes in my family member since the TB diagnosis.					
A10	I am worried about becoming infected.					

Arcencio TB Stigma Scale, Public Health Action 2014;4(3):195–200.

B Have you ever felt you were stigmatized because of your family member's TB status? *[CHECK ONLY ONE BOX]*

Yes

No *[Skip to Question E].*

C. Have you **experienced stigma** in hospitals/clinics, community/neighbours, extended family/relatives, workplace, [insert other setting 1 (e.g., school, church) chosen by Core Group], and [insert other setting 2 (e.g., school, church) chosen by Core Group] **that inhibited you from supporting your family member with TB to go to a DOTS centre, begin treatment, adhere to treatment or complete treatment?** *[CHECK ALL BOXES THAT ARE APPLICABLE]*

<i>Have you experienced stigma in these settings (right) that inhibited you from (below)...</i>	Settings					
	C1 Hospitals/ Clinics	C2 Community/ Neighbours	C3 Home/ Family	C4 Workplace	C5 [Other Setting 1]	C6 [Other Setting 2]
Recognizing symptoms?						
Seeking care?						
Getting an accurate diagnosis?						
Beginning treatment?						
Getting treatment adherence support?						
Completing treatment?						
Getting post-treatment follow-up services?						

D. Can you tell me more about the TB-related stigma you have experienced (e.g., being refused services by neighbourhood market vendors, being refused to attend community events)? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

- E. Have you seen or heard of other families being stigmatized because of their family member's TB status? *[CHECK ONE BOX ONLY]*

Yes

No *[Skip to Question H]*

- F. Do you **know of other families experiencing stigma** in hospitals/clinics, community/neighbours, extended family/relatives, workplace, [insert other setting 1 (e.g., school, church) chosen by Core Group], and [insert other setting 2 (e.g., school, church) chosen by Core Group] **that inhibited them from supporting their family members with TB** to go to a DOTS centre, begin treatment, adhere to treatment or complete treatment? *[CHECK ALL BOXES THAT ARE APPLICABLE]*

<i>Do you know of other families experiencing stigma in these settings (right) that inhibited them from supporting their family members with TB to (below)...</i>	Settings					
	C1 Hospitals/ Clinics	C2 Community/ Neighbours	C3 Home/ Family	C4 Workplace	C5 [Other Setting 1]	C6 [Other Setting 2]
Seek care?						
Get an accurate diagnosis?						
Begin treatment?						
Get treatment adherence support?						
Complete treatment?						
Get post-treatment follow-up services?						

- G. Can you tell me more about the TB-related stigma you have seen or heard of (e.g., being refused services by neighbourhood market vendors, being refused to attend community events)? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

- H. What would you like to see changed in TB services, laws and policies to address TB-related stigma (e.g., in hospital/clinics, community, family, workplace)? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*
-

- I. Do you have further comments you would like to share with us? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*
-

- J. What is your gender? *[CHECK ONE BOX ONLY]*

Female

Male

Transgender

Other

K. What is your age? *[CHECK ONE BOX ONLY]*

18–24

25–44

45–64

65 or older

L. How are you related to the person with TB in your family? Are you a parent, grandparent, child, grandchild, sibling or other relative of the person with TB in your family? *[CHECK ONE BOX ONLY]*

Parent

Grandparent

Child

Grandchild

Sibling

Other relative



Thank you very much for your time today and for sharing so generously with us both your experiences and insights.

QUESTIONNAIRE 3: FOR COMMUNITY (RESIDENTS/NEIGHBOURS OF PEOPLE WITH OR WHO HAVE HAD TB, AGED 18 OR OVER)

Interviews should be conducted by trained people who have had TB.

Interviewer's Initials	(e.g., "AS" for Alice Smith)
Questionnaire Type	(e.g., "CO" for Community)
Interviewee No.	(e.g., "001", "002" & "003" for the 1 st , 2 nd & 3 rd Alice Smith, respectively)
Interview Location	(e.g., district name, village name)
Interview Date	(day-month-year e.g., 14 July 2018)

- A. I am going to read you a few statements that describe how you may feel about tuberculosis (TB). Please tell me on a 5-point scale how much you disagree or agree with each of the following statements, where "0" indicates you "Strongly Disagree", "1" you "Disagree", "2" you "Have No Opinion", "3" you "Agree", or "4" you "Strongly Agree". If you don't want to respond to a statement or feel the statement is not applicable to you, just let me know and we can skip to the next statement. *[CHECK ONLY ONE BOX FOR EACH STATEMENT]*

		0 Strongly Disagree	1 Disagree	2 No Opinion	3 Agree	4 Strongly Agree
A1	Some people might not want to eat or drink with friends who have TB.					
A2	Some people feel uncomfortable being near those who have TB.					
A3	If a person has TB, some community members will behave differently towards that person for the rest of their life.					
A4	Some people do not want those with TB playing with their children.					
A5	Some people keep their distance from people with TB.					
A6	Some people think that people with TB are disgusting.					
A7	Some people do not want to talk to others with TB.					
A8	Some people are afraid of those with TB.					
A9	Some people try not to touch others with TB.					
A10	Some people may not want to eat or drink with relatives who have TB.					
A11	Some people prefer not to have those with TB living in their community.					

- B. Have you seen or heard of a member in your community who has TB being stigmatized because of his or her TB status? *[CHECK ONE BOX ONLY]*

Yes

No *[Skip to Question E]*

- C. Do you **know of community members with TB experiencing stigma** in different settings (community/neighbours, hospitals/clinics, workplace) **that inhibited them from** going to a DOTS centre, beginning treatment, adhering to treatment or completing treatment? *[CHECK ALL BOXES THAT ARE APPLICABLE]*

<i>Do you know of community members with TB experiencing stigma in these settings (right) that inhibited them from (below)...</i>	Settings		
	C1 Community/ Neighbours	C2 Hospitals/ Clinics	C3 Workplace
Recognizing symptoms?			
Seeking care?			
Getting an accurate diagnosis?			
Beginning treatment?			
Getting treatment adherence support?			
Completing treatment?			
Getting post-treatment follow-up services?			

- D. What stigma have you seen or heard of being experienced by a person with TB in your community (e.g., somebody was refused access to services due to his/her TB status, a woman was divorced due to her TB status, or a family member with TB refused to disclose his/her status)? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

E. What do you think the community can do to help address TB-related stigma? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

F. Do you have further comments that you would like to share with us? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

J. What is your gender? *[CHECK ONE BOX ONLY]*

Female

Male

Transgender

Other

K. What is your age? *[CHECK ONE BOX ONLY]*

18–24

25–44

45–64

65 or older

L. How many people with or who have had TB in your community do you know personally? *[CHECK ONE BOX ONLY]*

None

One only

Two or more

Don't know



Thank you very much for your time today and for sharing so generously with us both your experiences and insights.

QUESTIONNAIRE 4: FOR HEALTH CARE WORKERS (HOSPITAL OR CLINIC STAFF WHO PROVIDE TB SERVICES, AGED 18 OR OVER)

Interviews should be conducted by trained people who have had TB.

Interviewer's Initials	(e.g., "AS" for Alice Smith)
Questionnaire Type	(e.g., "CO" for Community)
Interviewee No.	(e.g., "001", "002" & "003" for the 1 st , 2 nd & 3 rd Alice Smith, respectively)
Interview Location	(e.g., district name, village name)
Interview Date	(day-month-year e.g., 14 July 2018)

- A. I am going to read you a few statements that describe how you may feel about tuberculosis (TB). Please tell me on a 5-point scale how much you disagree or agree with each of the following statements, where "0" indicates you "Strongly Disagree", "1" you "Disagree", "2" you "Have No Opinion", "3" you "Agree", or "4" you "Strongly Agree". If you don't want to respond to a statement or feel the statement is not applicable to you, just let me know and we can skip to the next statement. *[CHECK ONLY ONE BOX FOR EACH STATEMENT]*

		0 Strongly Disagree	1 Disagree	2 No Opinion	3 Agree	4 Strongly Agree
A1	Some health care workers are nervous about treating TB patients.					
A2	Some health care workers feel pity for TB patients.					
A3	Some health care workers don't like helping TB patients.					
A4	Some health care workers stay away from TB patients.					
A5	Some health care workers think developing TB is the person's own fault.					
A6	Some health care workers feel angry towards TB patients.					
A7	Some health care workers think it would be best for TB patients to be isolated during the intensive phase of treatment.					
A8	Some health care workers feel TB patients are dangerous.					
A9	Some health care workers think taking TB treatment should be forced if necessary.					

Adapted from Corrigan 9 Stigma Domains (AQ-9), KNCV Stigma Measurement Guidance, Chapter 5, Table 3 (2018) https://www.challenge.tb.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.

- B. Have you ever felt you were stigmatized because your work involves interacting with people with or who have had TB? *[CHECK ONE BOX ONLY]*

Yes

No *[Skip to Question E]*

- C. Have you experienced stigma in hospitals/clinics where you work, from the community/neighbours where you live, and from your family/relatives? *[CHECK ALL BOXES THAT ARE APPLICABLE]*

Hospitals/clinics where you work

Community where you live

Your family/relatives

- D. Can you tell me more about the TB-related stigma that you have experienced (e.g., being refused services by neighbourhood market vendors due to your work with people with TB, not being invited to family gatherings due to your work with people with TB, being refused to attend religious gatherings)?
[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]
-

- E. Have you seen or heard of your fellow health care workers being stigmatized because their work involves interacting with people with or who have had TB? *[CHECK ONE BOX ONLY]*

Yes

No *[Skip to Question H]*

- F. Do you know of any of your fellow health care workers being stigmatized in hospitals/clinics where they work, by community/neighbours where they live or by their family/relatives? *[CHECK ALL BOXES THAT ARE APPLICABLE]*

Hospitals/clinics where they work

Community where they live

Their family/relatives

E. What do you think the community can do to help address TB-related stigma? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

F. Do you have further comments that you would like to share with us? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

J. What is your gender? *[CHECK ONE BOX ONLY]*

Female

Male

Transgender

Other

K. What is your age? *[CHECK ONE BOX ONLY]*

18–24

25–44

45–64

65 or older

- G.** Can you tell me more about TB-related stigma experienced by fellow health workers (e.g., being refused services by neighbourhood market vendors due to their work with people with TB, not being invited to family gatherings due to their work with people with TB, being refused to attend religious gatherings)? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*
-

- H.** What do you think health care workers can do to help address TB-related stigma? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*
-

- I.** Do you have further comments that you would like to share with us? *[SUMMARIZE INTERVIEWEE'S KEY POINTS IN SPACE BELOW]*

J. What is your gender? *[CHECK ONE BOX ONLY]*

Female

Male

Transgender

Other

K. How old are you? *[CHECK ONE BOX ONLY]*

18-24

25-44

45-64

65 or older

L. How old are you? *[CHECK ONE BOX ONLY]*

Doctor

Nurse

Other

M. Have you provided services to people with TB before? *[CHECK ONE BOX ONLY]*

Yes

No



Thank you very much for your time today and for sharing so generously with us both your experiences and insights.

LAW AND POLICY ENVIRONMENT SCORING MATRICES

The Law and Policy Scoring Matrices should be completed by the Core Group in a focus group discussion (FGD) with policy and other decision makers who are familiar with TB and human rights–related laws and policies.

1. **All participants will need to read the following documents before attending the Law and Policy Matrices Scoring meeting to discuss the extent to which existing laws and policies harm or protect people with TB:**

- [Legal Environment Assessments \(LEA\) for Tuberculosis – An Operational Guide](http://www.stoptb.org/assets/documents/communities/StopTB_TB%20LEA%20DRAFT_FINAL_Sept%2027.pdf), section “Defining Human Rights Framework for TB” on pp. 12–28 (http://www.stoptb.org/assets/documents/communities/StopTB_TB%20LEA%20DRAFT_FINAL_Sept%2027.pdf)
- [Health and Human Rights Resource Guide](https://cdn2.sph.harvard.edu/wp-content/uploads/sites/25/2014/03/HHRRG-master.pdf), Chapter 3 “Tuberculosis and Human Rights” on pp. 3.1–3.85 (<https://cdn2.sph.harvard.edu/wp-content/uploads/sites/25/2014/03/HHRRG-master.pdf>)
- Other national and local TB-related laws and policies compiled by the Stigma Expert

2. **Rights most related to TB to be discussed and scored by the Core Group**

Right	What is this right?	Examples of violation of this right
A Right to Freedom from Discrimination (enacted stigma)	All persons are equal before the law. Legal frameworks should exist that prohibit unequal treatment against someone with TB in both public and private settings, including, but not limited to, health care, employment, education, and access to social services.	<ul style="list-style-type: none"> • Persons with TB are refused medical treatment or given a lower standard of care. • Persons with TB are denied or fired from jobs based on their TB status or TB history.
B Right to Access Information	People with TB shall have access to information about the nature of the disease, its transmission and contagiousness, effective preventive measures, and treatment availability and options, including the duration of treatment, the names and kinds of medicines involved, the nature of side effects, and the risks of treatment non-adherence.	<ul style="list-style-type: none"> • People who are illiterate may have less knowledge of TB and its signs and symptoms. Health care workers fail to adequately explain to persons with TB why adherence to TB medicine is important.
C Right to Access Services	People with TB have the right to available, accessible and acceptable good-quality diagnostics and treatment on a non-discriminatory basis.	<ul style="list-style-type: none"> • Persons with TB are denied access to quality TB treatment and care in prison. • Persons with MDR-TB are denied tailored therapies with second-line medicines. • Governments fail to utilize donor resources to construct isolation wards. • People with TB who belong to additionally marginalized groups are discriminated against in TB care and given subpar treatment or denied care.
D Right to Privacy	Information related to an individual’s TB status and treatment must be kept private and shall not be disclosed to any party, unless approved by appropriate medical professionals under narrowly and expressly tailored circumstances enumerated in law, including to protect third parties who are at serious and imminent risk of infection and to share essential health information with medical professionals providing care to the person with TB.	<ul style="list-style-type: none"> • Information about a person’s TB status is disclosed through provider breach of confidentiality, flawed contact investigations, or poor data protections in surveillance systems. • An individual’s migrant, HIV, drug use, or other status is disclosed in a TB diagnostic setting.
E Right to Informed Consent	People with TB shall have the right to informed consent prior to treatment for TB and the right to be free from non-consensual, compulsory treatment under all circumstances.	<ul style="list-style-type: none"> • People with TB are involuntarily tested for HIV. • Unapproved medication regimens are used to treat people with TB without informing them. • People with TB are involuntarily summoned for treatment.

Right	What is this right?	Examples of violation of this right
F Right to Freedom from Arbitrary Arrest/Detention and Involuntary Isolation	People with TB shall have the right to liberty and to freedom from arbitrary detention, including involuntary detention or isolation of contagious persons, except in exceptional circumstances enumerated in law and proportional to what is strictly necessary, using the least restrictive and intrusive means available to achieve legitimate public health aims (e.g., when a person is known to be contagious and is likely to transmit the disease, but refuses treatment, and all reasonable measures to ensure adherence have been attempted and proven unsuccessful). People with TB should not be detained or imprisoned in non-medical facilities for failure to adhere to treatment.	<ul style="list-style-type: none"> • Persons diagnosed with TB, who have been declared to be noncompliant with TB treatment, are arrested. • Persons arrested for noncompliance with TB treatment are not provided with treatment while in detention or detained in environments that are non-medical settings (prisons, holding cells, detention centres).
G Right to a Safe Workplace	Workers have the right to operate in an environment that does not pose undue hazards to health, and employers have the responsibility to implement measures that decrease the occupational risk of TB.	<ul style="list-style-type: none"> • Poor ventilation in health care settings • Poor ventilation in prison settings

3. The participants then deliberate on the extent to which the country's existing laws and policies harm or protect people with TB.

- **Laws and policies that harm people with TB:** This refers to the legal and policy basis that allows violations of the rights of people with TB to take place without legal or administrative consequences.
- **Laws and policies that protect people with TB:** This refers to the legal and policy basis that allows violations of the rights of people with TB to be redressed through legal or administrative channels.

For each of the seven TB-related rights listed above, the Core Group would score the **Existence** of laws (or policies), **Enforcement** of laws (or policies) and **Media Coverage** of the enforcement of laws (or policies) according to the following 5-point system in the Law and Policy Matrices (below).

Existence of Laws/Policies	
Score	Description
0	Laws/policies that <u>harm</u> people with TB exist at <u>national level</u>
1	Laws/policies that <u>harm</u> people with TB exist only at <u>subnational level</u>
2	No laws/policies relevant to people with TB exist
3	Laws/policies that <u>protect</u> people with TB exist only at <u>subnational level</u>
4	Laws/policies that <u>protect</u> people with TB exist at <u>national level</u>

Enforcement of Laws/Policies	
Score	Description
0	Laws/policies that <u>harm</u> people with TB are enforced at <u>national level</u>
1	Laws /policies that <u>harm</u> people with TB are enforced only at <u>subnational level</u>
2	No laws/policies relevant to people with TB
3	Laws/policies that <u>protect</u> people with TB are enforced only at <u>subnational level</u>
4	Laws/policies that <u>protect</u> people with TB are enforced at <u>national level</u>

Media Coverage of Enforcement of Laws/Policies	
Score	Description
0	Enforcement of laws/policies that <u>harm</u> people with TB is supported in <u>national media coverage</u>
1	Enforcement of laws/policies that <u>harm</u> people with TB is supported only in <u>subnational media coverage</u>
2	No media coverage
3	Enforcement of laws/policies that <u>protect</u> people with TB is supported only in <u>subnational media coverage</u>
4	Enforcement of laws/policies that <u>protect</u> people with TB is supported in <u>national media coverage</u>

4. Law Matrix – Scoring and Recommendations for the Action Plan

	L1	L2	L3	
	Existence of Laws	Enforcement of Laws	Media Coverage of Law Enforcement	
<p>Law Matrix</p> <p>Outcome of Core Group’s discussion on the country’s current laws, law enforcements and corresponding media coverage in relation to protecting individuals against TB-related ...</p> <p>(Fill in ALL cells colored in grey and choose from the pull-down menu for L1-L3 & provide comments/recommendations to the right)</p>	0 Laws that <u>harm</u> people with TB exist at <u>national level</u>	0 Laws that <u>harm</u> people with TB are enforced at <u>national level</u>	0 Enforcement of laws that <u>harm</u> people with TB is supported in <u>national media coverage</u>	Comments and Key Recommendations for the Action Plan
	1 Laws that <u>harm</u> people with TB exist only at <u>subnational level</u>	1 Laws that <u>harm</u> people with TB are enforced only at <u>subnational level</u>	1 Enforcement of laws that <u>harm</u> people with TB is supported only in <u>subnational media coverage</u>	
	2 No laws relevant to people with TB exist	2 No laws relevant to people with TB exist	2 No media coverage	
	3 Laws that <u>protect</u> people with TB exist only at <u>subnational level</u>	3 Laws that <u>protect</u> people with TB are enforced only at <u>subnational level</u>	3 Enforcement of laws that <u>protect</u> people with TB is supported only in <u>subnational media coverage</u>	
	4 Laws that <u>protect</u> people with TB exist at <u>national level</u>	4 Laws that <u>protect</u> people with TB are enforced at <u>national level</u>	4 Enforcement of laws that <u>protect</u> people with TB is supported in <u>national media coverage</u>	
Rights to Freedom from Discrimination				
Rights to Access Information				
Rights to Access Services				
Rights to Privacy				
Rights to Informed Consent				
Rights to Freedom from Arbitrary Arrest/Detention and Involuntary Isolation				
Rights to Safe Workplace				

5. Policy Matrix – Scoring and Recommendations for the Action Plan

	L1	L2	L3	
	Existence of Policies	Enforcement of Policies	Media Coverage of Policy Enforcement	
<p>Policy Matrix</p> <p>Outcome of Core Group’s discussion on the country’s current policies, policy enforcements and corresponding media coverage in relation to protecting individuals against TB-related ...</p> <p>(Fill in ALL cells colored in grey and choose from the pull-down menu for P1-P3 & provide comments/ recommendations to the right)</p>	<p>0 Policies that <u>harm</u> people with TB exist at <u>national level</u></p> <p>1 Policies that <u>harm</u> people with TB exist only at <u>subnational level</u></p> <p>2 No policies relevant to people with TB exist</p> <p>3 Policies that <u>protect</u> people with TB exist only at <u>subnational level</u></p> <p>4 Policies that <u>protect</u> people with TB exist at <u>national level</u></p>	<p>0 Policies that <u>harm</u> people with TB are enforced at <u>national level</u></p> <p>1 Policies that <u>harm</u> people with TB are enforced only at <u>subnational level</u></p> <p>2 No policies relevant to people with TB</p> <p>3 Policies that <u>protect</u> people with TB are enforced only at <u>subnational level</u></p> <p>4 Policies that <u>protect</u> people with TB are enforced at <u>national level</u></p>	<p>0 Enforcement of policies that <u>harm</u> people with TB is supported in <u>national media coverage</u></p> <p>1 Enforcement of policies that <u>harm</u> people with TB is supported only in <u>subnational media coverage</u></p> <p>2 No media coverage</p> <p>3 Enforcement of policies that <u>protect</u> people with TB is supported only in <u>subnational media coverage</u></p> <p>4 Enforcement of policies that <u>protect</u> people with TB is supported in <u>national media coverage</u></p>	Comments and Key Recommendations for the Action Plan
Rights to Freedom from Discrimination				
Rights to Access Information				
Rights to Access Services				
Rights to Privacy				
Rights to Informed Consent				
Rights to Freedom from Arbitrary Arrest/Detention and Involuntary Isolation				
Rights to Safe Workplace				



TB Stigma Assessment - Data Collection Instruments

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