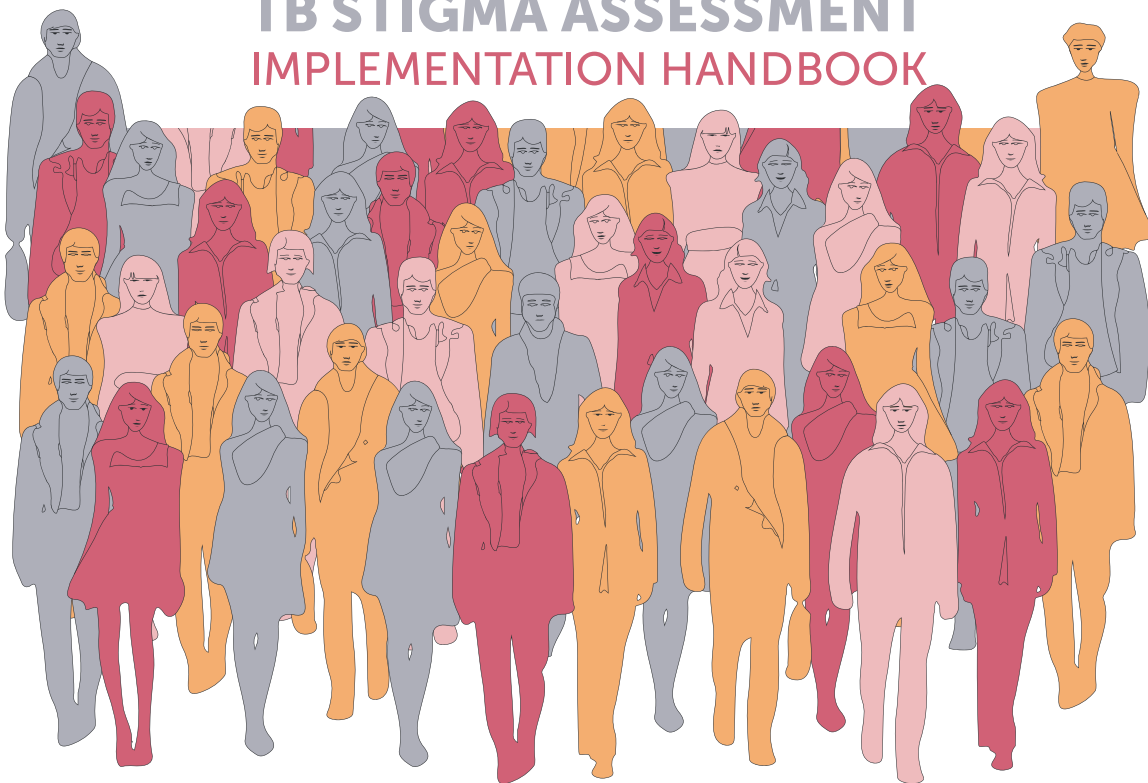


## **TB STIGMA ASSESSMENT IMPLEMENTATION HANDBOOK**



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## ACRONYMS

**CBO**

Community-based  
organization

**CRG**

Community, Rights and  
Gender

**FGD**

Focus group discussion

**ICF**

Informed consent form

**IEC**

Information, Education  
and Communication

**NGO**

Nongovernmental  
organization

**NTP**

National TB Programme

**STP**

Stop TB Partnership

**TB**

Tuberculosis

**UN**

United Nations

**UNAIDS**

Joint United Nations  
Programme on HIV/AIDS

**UNOPS**

United Nations Office for  
Project Services

**USAID**

United States Agency for  
International Development

**WHO**

World Health  
Organization

## DEFINITIONS OF TYPES OF TB STIGMA<sup>1</sup>

**Internalized or self-stigma** captures the idea that individuals may come to endorse negative stereotypes, and therefore behave or think according to false portrayals and negative messages.

**Anticipated stigma (perceived stigma)** is the worry that one will be devalued after a TB diagnosis. For the person with a TB diagnosis, this is the fear (often the result of observing others being stigmatized) that the stigma against the person will be so bad that will affect access to TB services. It may delay people from seeking and returning for care, or impact adherence to the prescribed medicines. Whether or not stigma actually occurs, anticipated stigma may interfere with care seeking and treatment adherence.

**Enacted or experienced stigma** reflects the range of stigmatizing behaviours, messages, and effects that are either directly experienced by the person with TB or by their families and/or that drive others to acts of discrimination, rejection, or isolation in different settings (family, community, health care, workplace, in particular). Enacted and experienced stigma are two sides of the same coin, either seen from the perspective of the stigmatizer (enacted) or the stigmatized (experienced).

**Secondary stigma** refers to the idea that caregivers, friends or family members may expect negative attitudes or rejection because of their association with the disease and/or TB patients. Furthermore, this may dictate their behaviours or beliefs, regardless of whether stigmatizing attitudes or reactions actually occur.

**Community/public stigma** describes negative attitudes, beliefs and behaviours held by the wider community (neighbours in particular) or general public. This is closely related to anticipated stigma.

**Structural stigma** describes the laws, policies, media and institutional architecture that may be stigmatizing or alternatively protective against stigma. This includes societal level conditions, cultural norms and institutional practices that constrain the opportunities, resources and wellbeing of stigmatized populations.

<sup>1</sup> Challenge TB. TB stigma measurement guidance. The Hague: KNCV; 2018  
[https://www.challenge4tb.org/publications/tools/ua/TB\\_Stigma\\_Measurement\\_Guidance.pdf](https://www.challenge4tb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf)

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### CORE TB STIGMA TECHNICAL TEAM

- Abdulai Abubakarr Sesay, Civil Society Movement Against TB Sierra Leone (CISMAT-SL)
- Allan Maleche, The Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN)
- Caoimhe Smyth, Stop TB Partnership (and Coordinator)
- Charlotte Colvin, USAID
- James Malar, Stop TB Partnership
- Kathy Fiekert, KNCV
- Nadine Ferris France, The Work for Change
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- Thandi Katlholo, Stop TB Partnership
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- Timur Abdullaev, TBpeople
- Virginia Nagy, United States Agency for International Development (USAID)
- Yuliya Chorna, TB Europe Coalition (TBEC)

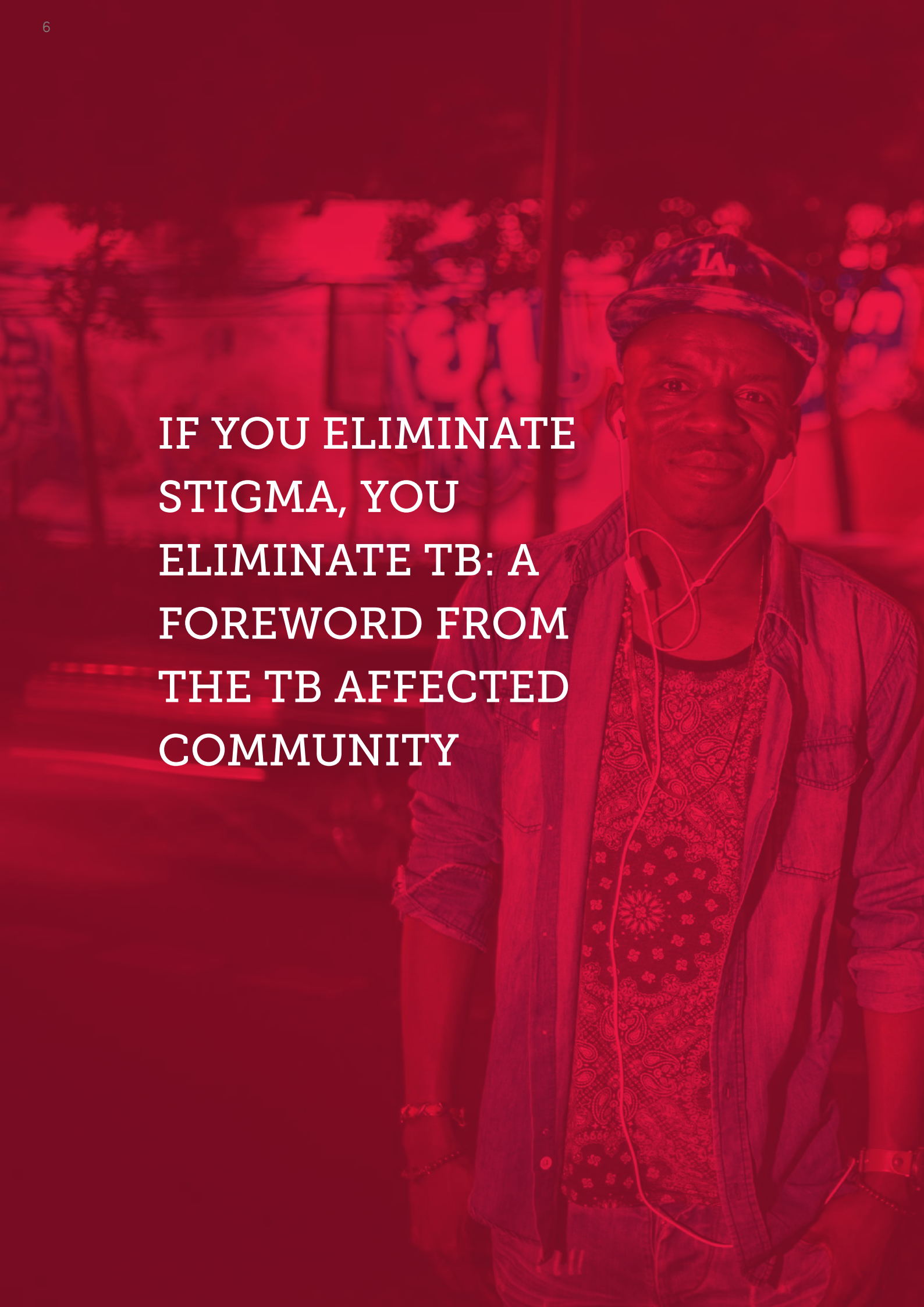
### FACILITATORS OF THE PRE-TEST

- REACH India, Ramya Ananthakrishnan and Anupama Srinivasan
- Civil Society Movement Against TB Sierra Leone, Abdulai Abubakarr Sesay

STP would like to extend a special word of thanks to KNCV, namely, Kitty van Weezenbeek, Kathy Fiekert, Ellen Mitchell, and Susan Bergson in particular. The vast body of work that KNCV is doing on TB stigma has informed the TB Stigma Assessment.

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A photograph of a man in an urban setting, wearing a cap and headphones, with a red overlay. The man is looking directly at the camera with a slight smile. He is wearing a dark cap with a logo, a patterned t-shirt, and a denim jacket. The background shows a street scene with buildings and trees, all tinted in a deep red color.

IF YOU ELIMINATE  
STIGMA, YOU  
ELIMINATE TB: A  
FOREWORD FROM  
THE TB AFFECTED  
COMMUNITY

Tuberculosis (TB) is curable but it still kills more people globally than any other single infectious disease. This is mainly due to challenges in accessing quality, affordable and equitable TB services and care. Millions of people affected by TB endure its hardships and manage to survive despite these barriers, which are driven by and heightened by TB stigma. Put simply, to end TB, we must end TB stigma.

Drawing on our experiences of TB and those of our community, we, the representatives of people affected by TB on the Stop TB Partnership Board, join these efforts to eliminate TB stigma, and here's why.

Throughout the TB journey, our community experiences rejection, hopelessness, loneliness, societal shame, broken relationships, self-pity and job losses, all as a direct or indirect result of TB stigma. The degree of stigma's impact varies from society to society. People avoid accessing TB services as a result of stigma or fear of it. People interrupt treatment because of inadequate or a lack of care, counselling, social support or economic assistance. In worst case scenarios, this loneliness, guilt and isolation can lead to degrees of or permanent mental trauma and even suicidal feelings. After TB, believe us, lives are never the same. Our aim, therefore, is to make sure that no one that has been, is, or will be affected by TB experiences TB stigma ever again. So, inasmuch as we are putting efforts into developing new and advanced medical TB interventions to end TB (as we should), we must also look at the social drivers to ensure that our community realizes their rights to accessing essential TB services. In the voice of our community:

At first, I was told "You are not sick, you are pretending so you will be released by the Magistrate." I was then told "You will not get cured of TB – it is your punishment from God". If we are unable to break stigma around access to TB and health services in prisons, we will never end TB.

 Karabo, South Africa

People told me I would infect them, and they would die. I was on my treatment – so these claims were incorrect. To be told this though is a horrible and demeaning sentiment that should not have to be carried by people with TB.

 Naomi, Kenya

My community still does not know much about TB. They do not know what having TB means, that it can be treated. They think anyone who has TB has HIV. A person with TB is not allowed to share food plates or participate in other social activities with people who do not have TB. People need to know the symptoms, the names of medicines and why it is important to take them. My community must be empowered with knowledge. It is through this knowledge we can defeat stigma.

 Ntahonde, United Republic of Tanzania

I am a dentist. When people found out that I had TB, clients no longer wanted to come to me for services and my peers avoided me. As such, I could not do my job and it made me question my value and place in society.

 Mileni, Bolivarian Republic of Venezuela

TB impeded my studies and cost me my hearing. The effects of TB can remain after treatment has concluded, and so can the stigma.

 Phumeza, South Africa

For some people, like me, stigma is internalized. I doubted myself, I felt a sense of shame or guilt and so I ended up isolating myself from others, even from family and friends.

 Rogerio, Mozambique

Because of the stigma associated with TB, my family and I hid my illness, which made it much harder to seek care. My own self-stigma tore me up inside and made me want to give up and quit the fight. If we don't eliminate the stigma, we will not be able to eliminate TB.

 Melquiades, Peru

Stigma is also a product of the community. People judge you or fear you for something you cannot control.

 Paul, United Kingdom of Great Britain and Northern Ireland


For me, the stigma was linked to gender identity. For friends, it was a reason to stop or avoid treatment. Other friends lost their personal relationships and even their jobs. To overcome stigma, policies and programmes must be gender responsive and health care providers must offer inclusive services irrespective of gender.

 Kiran Danish, Pakistan

TB stigma drives silence, and silence is responsible for all those lives we've lost – through our experience counselling those affected by TB through Bolo Didi (Say sister) we've seen how women sometimes don't confide in their own families for fear of being ostracized.

 Rhea, India


Stigma is compounded when you identify as an already marginalized and criminalized population – people living with HIV, men who have sex with men, sex workers, people who use drugs, and undocumented migrants, among others. This has negative implications on a health system response. To address stigma, we must work for a more inclusive society and address the underlying inequities, discrimination and fear that are the true drivers of stigma.

 Harry, Indonesia


I lost my home, my job, my family and my friends as a result of TB stigma. We must take steps to reduce and ultimately eliminate stigma, but first we need to show where it exists and how it manifests. This tool can help us do just that.

 Abdulai, Sierra Leone

People with and affected by TB have every right to access safe, supportive, affordable, and quality TB and TB-related health care services free from stigma and discrimination, regardless of where they are from, what they do, their sexual orientation or gender identity, ethnicity, belief system, citizenship, and health status.

 Jeff, Philippines


We must create legal and policy environments that ensure that families, communities and health service providers do not stigmatize people affected by TB. We also need legal and policy environments that protect TB key populations and other vulnerable populations including prisoners, people who use drugs, people living with HIV, mobile and migrant populations, homeless people, urban poor, indigenous populations, children and people with disabilities, from stigma and discrimination.

 Olya, Ukraine

Working and engaging with TB survivors across the globe we understand that stigma is the biggest barrier to accessing treatment, care and support, and so we need to assess and address the stigma that relentlessly undermines the response. Every one of our stories tells us this.

 Blessi, India

We must invest in engaging and capacitating community networks of people that have survived TB. These networks can provide the support and care needed for people to get diagnosed, to get treated, and importantly to regain confidence and control of their lives after TB.

 Safar, Tajikistan

We have everything to beat TB. Still, it kills millions of people. New medicines may offer safer more effective treatments, but that will not matter if people feel the need to hide themselves and their disease. Our main enemy is STIGMA. If we beat stigma, we will beat TB.

 Paulina, Russian Federation



This is our global call to the broader TB community for your commitment and support to end TB stigma and achieve universal access to TB services. Yes, we can end TB by 2030. To do so, we must adopt a human rights-based, people-centred and gender transformative response to TB and we must, as noted in the United Nations High-Level Meeting on TB Key Targets, promote and support an end to TB stigma.

We wish to congratulate the entire TB community, particularly our fellow TB survivors, for raising their voices, and the Stop TB Partnership for initiating this journey and for developing this TB Stigma Assessment with us. This is a collective responsibility and so, as equal partners on this journey to end TB, we the TB affected community will work tirelessly with you all to prioritize the elimination of TB stigma. Now, the work begins.

**Thokozile Phiri Nkhoma, Malawi & Timur Abdullaev, Uzbekistan**  
TB Affected Community Representatives to the Stop TB Partnership Board





**FOREWORD:  
EXECUTIVE  
DIRECTOR STOP TB  
PARTNERSHIP**

# IT'S TIME! TO END TB STIGMA.

As a friend once said, "I have TB. I need care and support. Not stigma".

Today, no matter who we are, we all, for one reason or another, have experienced stigma, whether it's because of our height, our weight, our colour, our gender, our profession, our sexuality, our nationality, our religion, among other things; and we have felt the helplessness, frustration, loneliness, stain and shame associated with it. TB stigma is the same. It impacts people, families, friends; it is responsible for delays in seeking a diagnosis and care, treatment interruptions, poor treatment outcomes; it breaks hearts, destroys relationships and families, leads to unemployment, desperation, even suicide.

But there is genuine hope for enduring change. On 26 September 2018, at the first-ever United Nations (UN) High-Level Meeting (HLM) on Ending Tuberculosis (TB), Heads of State endorsed a historic Political Declaration on TB with specific, measurable targets to achieve by 2022. The Declaration specifically calls for an end to stigma and all forms of discrimination associated with TB, a clear testimony to the collective resolve to unite against it. Unquestionably, it was a watershed moment for the TB community.

So, now is the time to multiply our efforts. Country programmes should, in alignment with the Political Declaration and in partnership with the affected TB community, intensify their actions to eliminate TB stigma. Protective laws and protocols, as well as legal, social and policy frameworks, must be put in place. Tools and resources to assess and measure the burden and impact of stigma must be utilized, and interventions, such as anti-discrimination advocacy, must be funded, monitored and ramped up. We each have a role. It is our global and shared responsibility.

I am proud of the journey we have taken together with you, our partners, especially those mentioned in the Acknowledgements and in the Foreword from the TB Affected Community. With support from USAID, we were able to bring brilliant hearts and minds to this collective effort, and by creating spaces in Liverpool, Geneva, Bangkok, The Hague and Guadalajara, we were able to capture personal experiences, innovate ideas and generate plans to develop a tool that would support country efforts to assess the burden of TB stigma and its manifestations that relies on rigorous research methods and community-driven strategies. Here, within these pages, is the fruit of our work, and while I sincerely congratulate our efforts so far, I also encourage us to seize the moment to keep the promises of the UN Political Declaration by taking concrete action to end TB stigma. Having declarations, commitments, guidelines, policies and tools mean nothing to me, unless they are used to support, protect and help those who are affected by, vulnerable to, underserved and at risk for TB. We have a tool now; let's use it and end TB stigma in our programmes, services, homes, communities and selves. It's time to end TB stigma.

Much love,  
**Dr. Lucica Ditiu**



# PREAMBLE

## ENDING TB USING A COMMUNITY, RIGHTS AND GENDER APPROACH

The Stop TB Partnership (STP), hosted by UNOPS, is leading the way to a world without tuberculosis (TB), a disease that is curable but still kills three people every minute. Founded in 2001, STP's mission is to serve every person who is vulnerable to TB and ensure that high-quality diagnosis, treatment and care are available to all who need it.

To find and treat all people with TB and thus reach the World Health Organization (WHO) End TB Strategy<sup>1</sup> targets, countries must abandon the passive, top-down disease programmes of the past and adopt a radical new approach. According to STP, and as articulated in the Global Plan to End TB 2016–2020<sup>2</sup>, this approach should strive for equity; address the structural, social, socioeconomic, human rights and gender drivers of the disease; and ensure the meaningful engagement of empowered TB survivors and affected communities in the response. This Community, Rights and Gender (CRG) approach aligns with the WHO End TB Strategy, which calls for due attention to equity, human rights and ethics as one of the four principles of the strategy. This also aligns with the international human rights framework, the principles of universal health coverage and Sustainable Development Goal 3, which all aim to ensure that everyone everywhere can access quality, affordable health services.

STP is a global leader in advancing a CRG approach to TB. This has been demonstrated through the establishment of a CRG unit and comprehensive port-

folio of CRG work. Collaborative CRG initiatives include the development of the Nairobi Strategy on TB & Human Rights<sup>3</sup>, the Declaration of the Rights of People of Affected by TB<sup>4</sup>, key population briefs, and a digital platform (OneImpact) that facilitates community-based monitoring of the TB response. STP has also developed a suite of CRG qualitative assessment tools: the Legal Environment Assessments for TB<sup>5</sup>, the Gender Assessment Tool for National HIV and TB Responses<sup>6</sup> and the Data for Action for TB Key, Vulnerable and Underserved Populations<sup>7</sup>. Across the three thematic areas of these assessments, the joint aim is to develop recommendations for improving the TB response so that quality TB services are available, accessible and acceptable to all. These assessments have been rolled out in several countries, and findings indicate that TB stigma exacerbates the medical, social and economic hardships of TB and is a cross-cutting barrier to accessing quality, affordable and timely TB care and support services.

Stigma and discrimination are recognized among the most commonly identified human rights-related barriers hindering the fight against the TB epidemic.<sup>8</sup> In September 2018, Heads of State and Government at the United Nations (UN) High-Level Meeting on TB, and in the resulting Political Declaration on the Fight to End TB<sup>9</sup>, committed to promoting and supporting an end to TB stigma and all forms of discrimination.<sup>10</sup> This commitment demonstrates recognition at the highest level that to end TB, we must eliminate TB stigma.

<sup>1</sup> World Health Organization. The End TB Strategy <https://www.who.int/tb/strategy/end-tb/en/>

<sup>2</sup> The Global Plan to End TB: the paradigm shift 2016–2020. Geneva: Stop TB Partnership; 2015 <http://www.stoptb.org/global/plan/plan2/>

<sup>3</sup> Stop TB Partnership, International Human Rights Clinic, University of Chicago Law School, Kenya Ethical, Legal Information Network for HIV (KELIN). The Nairobi Strategy: a human rights-based approach to tuberculosis. Geneva: Stop TB Partnership; 2017 <http://www.stoptb.org/assets/documents/communities/NairobiTBStrategyFINAL.pdf>

<sup>4</sup> TBpeople, Stop TB Partnership. Declaration of the rights of people affected by tuberculosis. Geneva: Stop TB Partnership; 2019 [http://www.stoptb.org/assets/documents/communities/SUPER%20FINAL%20Declaration%20\\_for%20website-A4-biggerletters-nrs.pdf](http://www.stoptb.org/assets/documents/communities/SUPER%20FINAL%20Declaration%20_for%20website-A4-biggerletters-nrs.pdf)

<sup>5</sup> Legal environment assessments for tuberculosis: an operational guide. Geneva: Stop TB Partnership; 2017 [http://www.stoptb.org/assets/documents/communities/StopTB\\_TB%20LEA%20DRAFT\\_FINAL\\_Sept%202017.pdf](http://www.stoptb.org/assets/documents/communities/StopTB_TB%20LEA%20DRAFT_FINAL_Sept%202017.pdf)

<sup>6</sup> Gender assessment tool for national HIV and TB responses. Geneva: Stop TB Partnership; 2016 [http://www.stoptb.org/assets/documents/resources/publications/acsm/Gender\\_Assessment\\_Tool\\_TB\\_HIV\\_UNAIDS\\_FINAL\\_2016%20ENG.pdf](http://www.stoptb.org/assets/documents/resources/publications/acsm/Gender_Assessment_Tool_TB_HIV_UNAIDS_FINAL_2016%20ENG.pdf)

<sup>7</sup> Data for action for tuberculosis key, vulnerable and underserved populations. Geneva: Stop TB Partnership; 2017 <http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key,%20Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf>

<sup>8</sup> Ethics guidance for the implementation of the End TB Strategy. Geneva: World Health Organization; 2017 <https://www.who.int/tb/publications/2017/ethics-guidance/en/>

<sup>9</sup> Political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis (A/RES/73/3). New York: United Nations General Assembly; 2018 [https://www.un.org/en/ga/search/view\\_doc.asp?symbol=A/RES/73/3](https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/73/3)

<sup>10</sup> UN High-Level Meeting on TB key targets and commitments for 2022. Geneva: Stop TB Partnership; 2018 [http://www.stoptb.org/assets/documents/global/advocacy/unhlm/UNHLM\\_Targets&Commitments.pdf](http://www.stoptb.org/assets/documents/global/advocacy/unhlm/UNHLM_Targets&Commitments.pdf)

## THE LINKS BETWEEN TB AND STIGMA

Stigma is frequently described as a process of devaluation, whereby stigmatized people are discredited, seen as a disgrace, perceived to have less value or worth, or even seen as a danger. Stigmatized people are therefore often avoided by other members of society. Stigma is also a significant social determinant of health because of its ubiquity, its disruption of several life necessities (e.g., resources, social relationships, and coping behaviours), and its destructive impact on the health of populations. As such, stigma is a fundamental cause of health inequality.<sup>11</sup> When it comes to understanding stigma in relation to a social disease such as TB, the dimensions of stigma are not exhaustive or mutually exclusive. Rather, they are inextricably linked to many aspects of peoples' lives. Those who are considered key populations in TB<sup>12</sup> often face double or multiple reinforcing stigmas associated with TB. These include gender, sexual orientation, identity (e.g., people who use drugs), citizenship/legal status (e.g., undocumented migrants, people with refugee status), financial status (e.g., the urban poor), profession (e.g., miners, health care workers), and the presence of other illnesses (e.g., HIV, silicosis).

## RATIONALE FOR ASSESSING AND ADDRESSING TB STIGMA

Research highlights that stigma and its manifestations (e.g., discrimination<sup>13</sup>) limit access to TB services<sup>14,15</sup> and have an impact on the quality of life for people with TB<sup>16</sup>. As such, it is essential for countries to understand the levels and dimensions of TB stigma in order to address the health disparities experienced by people with TB, inform interventions to end TB stigma and implement a CRG approach to TB. The qualitative assessments conducted by countries in 2017–2019, with support from STP, built an understanding of the human rights barriers in the context of TB and revealed that TB stigma has a cross-cutting influence on health-seeking behaviour and peoples' ability to access TB services. Therefore to respond to the findings of the CRG assessments and the advocacy efforts of the affected TB community and relying on the vast body of work done by KNCV to measure TB stigma, STP developed the STP TB Stigma Assessment. It aims to support countries to assess the extent to which and how TB stigma acts as a barrier to both accessing and providing services, and to support the development of recommendations to address TB stigma so that quality TB services are available, accessible and acceptable to all.

<sup>11</sup> Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health*. 2013;103(5):813–21 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3682466/>

<sup>12</sup> Stop TB Partnership's definition of key populations, Chapter 3 in The Global Plan to End TB: the paradigm shift 2016–2020. Geneva: Stop TB Partnership; 2015 [http://www.stoptb.org/assets/documents/global/plan/GlobalPlanToEndTB\\_TheParadigmShift\\_2016-2020\\_StopTBPartnership.pdf](http://www.stoptb.org/assets/documents/global/plan/GlobalPlanToEndTB_TheParadigmShift_2016-2020_StopTBPartnership.pdf)

<sup>13</sup> Discrimination involves treating someone in a different and 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.

<sup>14</sup> Craig GM, Daffary A, Engel N, O'Driscoll S, Ionnaki A. TB stigma as a social determinant of health: a systematic mapping review of research in low incidence countries. *Int J Infect Dis*. 2017;56:90–100 <https://www.ncbi.nlm.nih.gov/pubmed/27810521>

<sup>15</sup> Yang WT, Gounder CR, Akande T, De Neve JW, McIntire KN, Chandrasekhar A, et al. Barriers and delays in tuberculosis diagnosis and treatment services: does gender matter? *Tuberc Res Treat*. 2014;2014:461935 <https://www.ncbi.nlm.nih.gov/pubmed/24876956>


<sup>16</sup> Moya EM, Biswas A, Chavez Baray SM, Martinez O, Lomeli B. Assessment of stigma associated with tuberculosis in Mexico. *Public Health Action*. 2014;4(4):226–32 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4286806/>

<sup>17</sup> Challenge TB. TB stigma measurement guidance. The Hague: KNCV; 2018 [https://www.challengetb.org/publications/tools/ua/TB\\_Stigma\\_Measurement\\_Guidance.pdf](https://www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf)

<sup>18</sup> From the inside out: dealing with TB-related self-stigma and shame. A pilot toolkit for people with TB to deal with self-stigma and shame. The Hague: KNCV; 2018 <https://www.kncvtbc.org/en/stigma-3/>

<sup>19</sup> Lemaine I, Mitchell EMH, van de Berg S, Mirtskhulava V. Tuberculosis stigma reduction for health care institutions. Intervention package – allies approach. The Hague: KNCV; 2018 <https://www.kncvtbc.org/en/stigma-3>

<sup>20</sup> Challenge TB. TB stigma measurement guidance. The Hague: KNCV; 2018 [https://www.challengetb.org/publications/tools/ua/TB\\_Stigma\\_Measurement\\_Guidance.pdf](https://www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf)

A woman in a blue uniform is holding a clipboard and looking towards the camera. She is standing in a park-like setting with a large tree and a bench in the background. The entire image has a green tint.

# PURPOSE OF THE IMPLEMENTATION HANDBOOK

The Implementation Handbook provides guidance to countries on how to design and conduct an assessment using quantitative and qualitative research methods. Such an assessment will help countries to develop new insights into the ways in which TB vulnerability, treatment availability, accessibility and acceptability, and the quality of TB care are shaped by stigma, and inform the design of stigma reduction interventions to transform TB responses at country level.



# OBJECTIVES

PROTECTING  
ENDANGERED SPECIES

## OVERALL OBJECTIVE



To assess to the extent to which and how TB stigma acts as a barrier to both accessing and providing services, and to support the development of recommendations to address TB stigma so that quality TB services are available, accessible and acceptable to all, with special considerations given to the needs of key, vulnerable and underserved populations.

## SPECIFIC OBJECTIVES

1. To understand the level and dimensions of **anticipated stigma, self-stigma, enacted stigma** (stigma directly experienced) and **observed stigma** among people diagnosed with TB:

  - a. To understand how and the extent to which self-stigma manifests among people diagnosed with TB;
  - b. To understand the settings and stages of care in which TB stigma is being experienced and observed by people diagnosed with TB.
2. To understand the level and dimensions of **secondary TB stigma**, stigma directly experienced, and stigma observed by family members / primary carers of people diagnosed with TB:

  - a. To understand how and the extent to which secondary stigma manifests among family members / primary carers of people diagnosed with TB;
  - b. To understand the settings and stages of care in which secondary TB stigma is being experienced and observed by family members / primary carers of people diagnosed with TB.
3. To understand the level of perceived TB **stigma against people diagnosed with TB in communities** and stigma observed by the community:

  - a. To understand how and the extent to which stigma against people diagnosed with TB takes place in communities;
  - b. To understand the settings and stages of care in which TB stigma against people diagnosed with TB is being observed by community members.
4. To understand the level and dimensions of perceived **TB stigma against people diagnosed with TB in health care settings**<sup>21</sup> and stigma against health care workers:

  - a. To understand how and the extent to which perceived stigma against people diagnosed with TB manifests in health care facilities;
  - b. To understand the settings in which TB stigma is experienced by TB health care workers;
  - c. To understand the settings in which TB stigma against health care workers is observed by other TB health care workers.
5. To understand the extent to which structural stigma (any existing laws/policies, the enforcement of those laws/policies and the corresponding media coverage) could harm or protect people diagnosed with TB.
6. To support the development of recommendations to **address TB stigma** in order to reduce peoples' vulnerability to TB infection, increase peoples' access to TB services and improve treatment outcomes.

<sup>21</sup> Includes both government and private health care settings



TARGET AUDIENCE  
AND KEY HUMAN  
RESOURCES

## TARGET AUDIENCE

The Assessment is community-driven with strategic guidance from the National TB Programme (NTP). The TB Stigma Assessment follows the same process as all other assessments developed by STP, i.e., it uses a multi-stakeholder approach to ensure broad buy-in and uptake of recommendations at the highest level, while ensuring that the approach is community-driven.

## KEY HUMAN RESOURCES AND THEIR ROLES

### 1 NATIONAL TB PROGRAMME

**Role:** To provide strategic and technical guidance to the TB Stigma Assessment and process.



### 2 TB AFFECTED COMMUNITY

**Role:** To inform the design and development of the Assessment Protocol, collect data, be key informants, and support the analysis of the results and the development and validation of the recommendations and Action Plan.



### 3 LEAD COMMUNITY-BASED ORGANIZATION (CBO)

**Role:** To recruit the TB Stigma Expert (with support from the NTP) and data collectors and to support the coordination of the TB Stigma Assessment, including the organization of orientation meetings, training sessions, Core Group discussions and validation meetings.



### 4 TB STIGMA CORE GROUP

**Role:** To provide technical guidance and oversight to the TB Stigma Assessment and process.



### 5 TB STIGMA MULTI-STAKEHOLDER GROUP

**Role:** To ensure broad engagement and uptake of recommendations.



### 6 TB STIGMA EXPERT (TECHNICAL LEAD)

**Role:** To be the technical focal point and lead coordinator of the TB Stigma Assessment (See [Annex A: Sample Terms of Reference for TB Stigma Expert](#)). The Stigma Expert will report to the lead CBO and be accountable to the Core Group. The Expert will train data collectors, analyse results, and produce a consensus-driven narrative report analysing and summarizing draft findings and recommendations, as well as an Action Plan to address the findings and recommendations.



### 7 STATISTICIAN

**Role:** To conduct and calculate population sampling / frame. (See [Annex B: Sample Terms of Reference for Statistician](#))



### 8 TB STIGMA (TRAINED) DATA COLLECTORS FOR THE SEMI-STRUCTURED INTERVIEWS

**Role:** To collect the stigma-related data and give it to the Stigma Expert. The data collectors will be trained by the Stigma Expert.



### 9 REPRESENTATIVES FROM NATIONAL AND SUB-NATIONAL TB PROGRAMMES, JUDICIARY AND LEGAL COMMUNITIES, LEGISLATORS, MEDIA WORKERS AND POLICY MAKERS

**Role:** To deliberate (in a focus group discussion [FGD]) and score the extent to which any existing laws/policies, the enforcement of those laws/policies and the corresponding media coverage could harm or protect people with or who have had TB. Based on the analysis, they will draft law/policy-related recommendations, which will be included in the Action Plan (when validated).



A close-up portrait of a woman with dark, wavy hair, smiling warmly. She is wearing a light-colored top with a dark, intricate floral pattern. The entire image is overlaid with a semi-transparent blue filter. The word 'METHODOLOGY' is centered in white, bold, uppercase letters.

# METHODOLOGY

## TB SURVEY RESEARCH USING QUALITATIVE AND QUANTITATIVE METHODS



### SEMI-STRUCTURED QUESTIONNAIRES

In total, there are four interviewer-administered semi-structured questionnaires, guided by validated and adapted TB stigma scales presented in the KNCV Stigma Measurement Guidance. The questionnaires are complemented by additional questions to better understand the point(s) at which stigma is being experienced /observed and how it manifests along the TB journey. See Table 1 for an overview of the questions to be administered. See Diagrams 1 and 2 for more information on the TB journey stages and settings. For more information on the assessment questions, see *TB Stigma Assessment, Data Collection Instruments, Key Informant Semi-Structured Interview and Focus Group Guides*.



### DESK REVIEW

In addition to the questionnaires, a desk review will provide additional information to inform the TB Stigma Assessment. The review will include scanning the literature, analysing secondary data, and creating a reference list so that all documents are organized and easily accessible to all stakeholders. The purpose of the desk review is to understand the country context in relation to TB stigma; identify key themes, gaps and opportunities by analysing available secondary data; and gather data and information to inform the final report, which will outline gaps and possible opportunities presented by the TB Stigma Assessment.



### FOCUS GROUP DISCUSSION (FGD)

Finally, an FGD with a multi-stakeholder group (TB programme staff, representatives from judiciary and legal communities, legislators, media workers, policy makers, funders, and implementing organizations) will help build an understanding of the extent to which any existing laws/policies, the enforcement of those laws and policies and corresponding media coverage could harm or protect people with TB.

## The survey research will target five sets of respondents:

**1. People diagnosed with TB** to understand the levels and dimensions of anticipated stigma, self-stigma, enacted stigma and observed stigma among people diagnosed with TB. The Statistician will calculate the necessary sample size and determine the sampling method to ensure that the number of respondents is representative of the target population. The target population is here defined as *the total number of new and previously treated TB cases registered during the year preceding the interviews (or assessment) as per the Global TB database (WHO)*. People from the current and previous TB cohorts over the last 12 months from available registers will be interviewed using a semi-structured questionnaire (See *Questionnaire 1, TB Stigma Assessment, Data Collection Instruments, Key Informant Semi-Structured Interview*) until the calculated sample size is reached.

**2. Family members / primary carers of people diagnosed with TB** to understand the levels and dimensions of secondary stigma, stigma directly experienced, and stigma observed. The household members should be individuals who supported the person with TB throughout his or her TB journey. They will be interviewed using a semi-structured questionnaire (See *Questionnaire 2, TB Stigma Assessment, Data Collection Instruments, Key Informant Semi-Structured Interview*). The sample size should be between 20 and 30 people, paying special attention to the demographic and geographic profiles of the research recruits<sup>22</sup>.

**3. Community** to understand the level of perceived TB stigma against people diagnosed with TB in communities and stigma observed by the community. The community should be community leaders, defined by the assessment settings where people diagnosed with TB (who were interviewed) reside. They will be interviewed using a semi-structured questionnaire (See *Questionnaire 3, TB Stigma Assessment, Data Collection Instruments, Key Informant Semi-Structured Interview*). The sample size should be between 20 and 30 people, paying special attention to the demographic and geographic profiles of the research recruits.

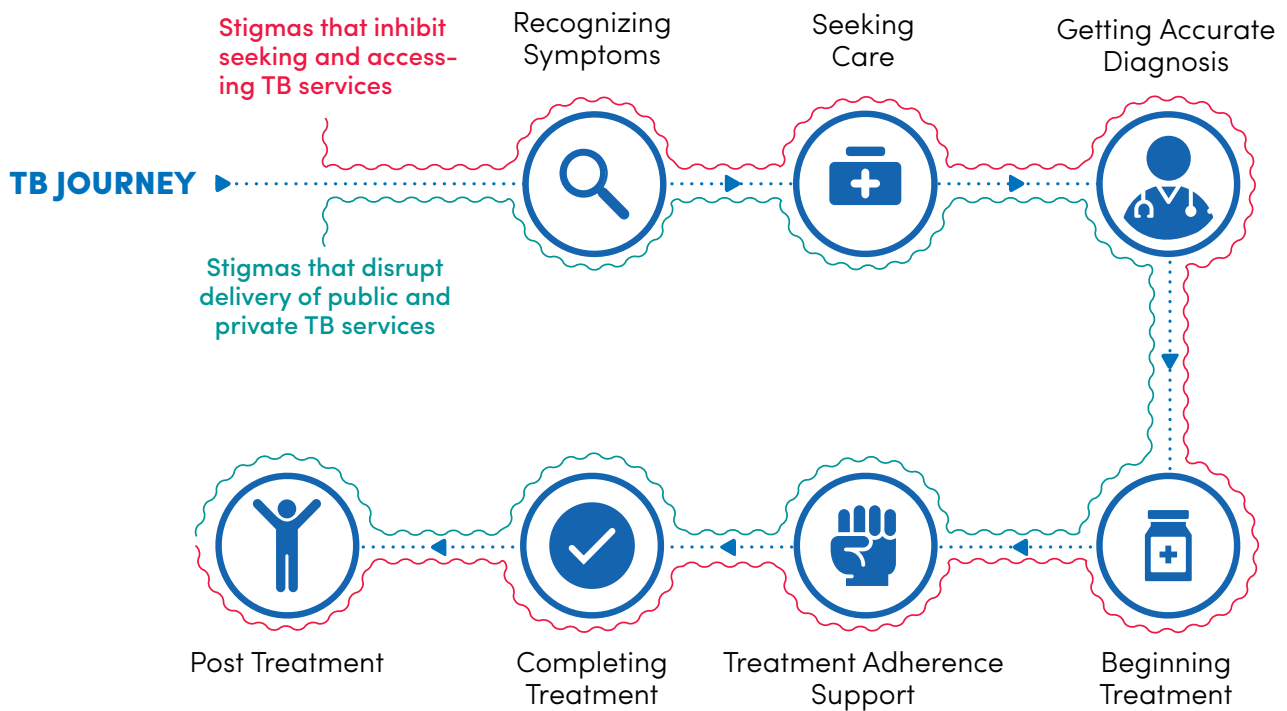
<sup>22</sup> Cresswell JW. *Qualitative inquiry and research design: choosing among five traditions*. Thousand Oaks: Sage; 1998.

**4. Health care workers** to understand the level and dimensions of perceived TB stigma against people diagnosed with TB and stigma against health care workers. The health care workers should be TB nurses or facility managers linked to people diagnosed with TB who were interviewed. They will be interviewed using a semi-structured questionnaire (See *Questionnaire 4, TB Stigma Assessment, Data Collection Instruments, Key Informant Semi-Structured Interview*). The sample size should be between 20 and 30 people, paying special attention to the demographic and geographic profiles of the research recruits.

**5. Multi-stakeholder group** (TB programme staff (national and subnational), representatives from judiciary and legal communities, legislators, media workers, policy makers, funders, and implementing organizations) to understand the extent to which any existing **laws/policies**, the enforcement of those laws/policies and the corresponding media coverage could harm or protect people with TB. They will be interviewed using an FGD Guide (See *Law and Policy Environment Scoring Matrices, TB Stigma Assessment, Data Collection Instruments, Key Informant Semi-Structured Interview*). The sample size should be between 20 and 30 people, paying special attention to the demographic and geographic profiles of the research recruits.

The Assessment can also be done at subnational level, following the requirements for calculating the representative sample size.

**Diagram 1:** STP AED Cough to Cure Pathway / TB Journey (Adapted)



**Diagram 2:** WHO Social Ecological Model of Stigma

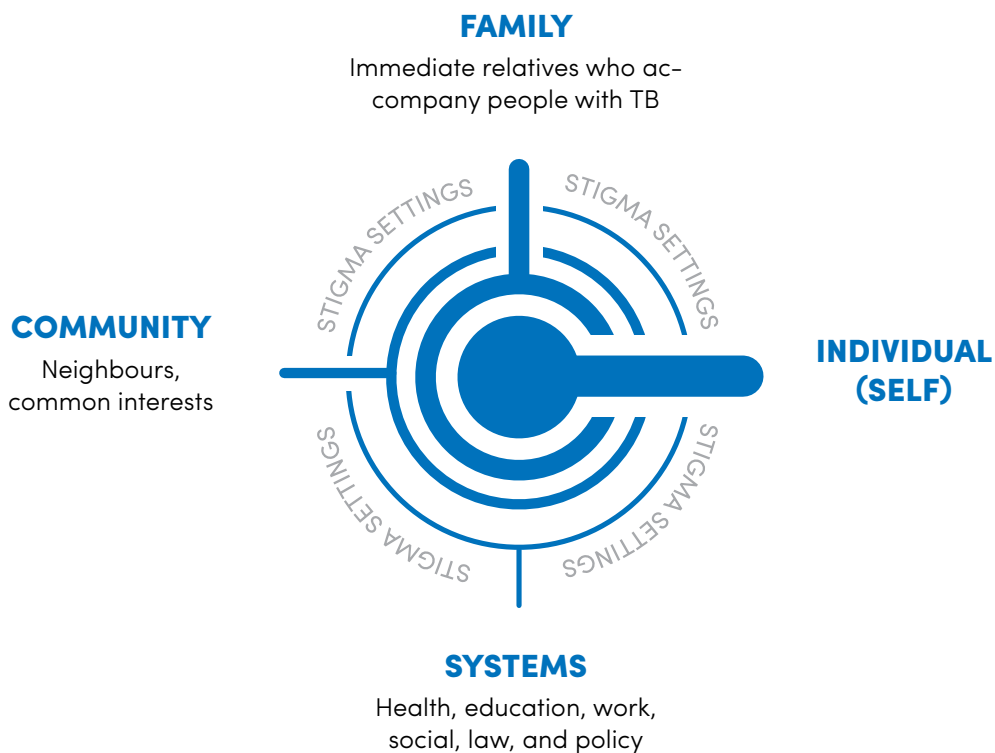




Table 1: Overview of semi-structured interviews and focus group discussion

| Stigma Questionnaires  | Assessment Objectives  | Setting  | Stigma Scale <sup>23</sup> (quantitative)   | Experienced Stigma/ Discrimination (quantitative and qualitative)   | Observed Stigma/ Discrimination (quantitative and qualitative)   | Demographics (quantitative)  |
|--|--|--|---|---|--|--|
| 1. People diagnosed with TB                                    | To understand the level and dimensions of perceived self-stigma, and stigma directly experienced and observed among people with or who have had TB   | <b>Self-stigma, stigma experienced within people with or who have had TB</b> | Self-stigma among individuals who have been diagnosed with TB (adapted from <b>Van Rie TB Patient Stigma Scale</b> , Tropical Medicine and International Health 2008;13(1):20–30)   | <b>Along seven stages of the TB journey</b> in six settings (hospitals/clinics, community/neighbours, home/family, workplace, and two other settings chosen by the country) | Along seven stages of the TB journey in six settings (hospitals/clinics, community/neighbours, home/family, workplace, and two other settings chosen by the country) | Gender, age, key population, TB treatment status, TB type  |
| 2. Family members / primary carers of people diagnosed with TB | To understand the level and dimensions of secondary TB stigma, stigma directly experienced, and stigma observed by family members / primary carers of people diagnosed with TB                               | <b>Stigma in family settings</b>   | Secondary stigma experienced by family members at time of diagnosis of a family member ( <b>Arcencio TB Stigma Scale</b> , Public Health Action 2014;4(3):195–200)  | <b>Along seven stages of the TB journey</b> in six settings (hospitals/clinics, community/neighbours, home/family, workplace, and two other settings chosen by the country) | Along seven stages of the TB journey in six settings (hospitals/clinics, community/neighbours, home/family, workplace, and two other settings chosen by the country) | Gender, age, relationship to the person with TB  |
| 3. Community   | To understand the level of perceived TB stigma against people diagnosed with TB in communities and stigma observed by community  | <b>Stigma in local community/ neighbourhood settings</b>                     | Perceived stigma by neighbours against people with or who have had TB ( <b>Van Rie TB Community Stigma Scale</b> , Tropical Medicine and International Health 2008;13(1):20–30)   | No questions  | Along seven stages of the TB journey in three settings (community/neighbours, hospitals/clinics, workplace)  | Gender, age, number of people diagnosed with TB in the community they know personally            |
| 4. Health care workers   | To understand the level and dimensions of perceived TB stigma against people diagnosed with TB in health care settings and stigma against health care workers  | <b>Stigma in health care settings</b>  | Perceived stigma by health care workers against people with or who have had TB (adapted from <b>Corrigan 9 Stigma Domains (AQ-9)</b> , KNCV Stigma Measurement Guidance Chapter 5 Table 3 (2018), Psychiatry Research 2014;215:466–70), Community Mental Health Journal 2004;40(4):297–307, Journal of Family Psychology 2006;20(2):239–46)   | Stigma experienced in three settings (hospitals/clinics, community/neighbours, family/relatives)  | Stigma observed in three settings (hospitals/clinics, community/neighbours, family/relatives)  | Gender, age, role in hospital/clinic, experience of service provided to people diagnosed with TB |
| <b>5. Legal and Policy Environment Matrix</b>                  | <b>Assessment Objectives</b>   | <b>Setting</b>   | <b>How the country's laws/policies, their enforcement and media coverage protect or harm people diagnosed with TB</b>   |   |  |  |
| Input by legal and policy experts in the Core Group            | To understand the extent to which structural stigma (any existing laws/policies, the enforcement of those laws/policies and the corresponding media coverage) could harm or protect people diagnosed with TB | <b>Society at large</b>  | Country's existing laws/policies, law/policy enforcement and corresponding media coverage that protect or harm people diagnosed with TB in relation to seven TB-related rights: <ul style="list-style-type: none"> <li>• Right to Freedom from Discrimination</li> <li>• Right to Access Information</li> <li>• Right to Access Services</li> <li>• Right to Privacy</li> <li>• Right to Informed Consent</li> <li>• Right to Freedom from Arbitrary Arrest/Detention and Involuntary Isolation</li> <li>• Right to a Safe Workplace</li> </ul> |   |  |  |

<sup>23</sup> Additional social desirability scales can be added during national roll-out of stigma measurement.

## OVERVIEW OF FGD

The law and policy environment matrices focus on the following seven rights most relevant to TB:

- Right to Freedom from Discrimination
- Right to Access Information
- Right to Access Services
- Right to Privacy
- Right to Informed Consent
- Right to Freedom from Arbitrary Arrest/Detention and Involuntary Isolation
- Right to a Safe Workplace

Definitions and examples of these rights are included in the “Data Collection Instrument” tool. An FGD with expertise and representatives from the national and subnational TB programmes, judiciary and legal communities, legislators, media workers and policy makers will deliberate and score the extent to which any existing laws/policies, the enforcement of those laws/policies and the corresponding media coverage could harm or protect people with or who have had TB. Based on the analysis, the TB Stigma Expert will draft law-/policy-related recommendations, which will be included in the Action Plan. Once the Action Plan has been endorsed at the validation workshop, the recommendations will be incorporated into the costed Action Plan.



A man in a dark suit, white shirt, and patterned tie is speaking into a microphone. He is wearing a white wristband with the number '3' on it. The background is a blurred indoor setting with a circular light fixture. The entire image is overlaid with a semi-transparent green filter.

# THE ASSESSMENT APPROACH AND PROCESS



## THE APPROACH


The overall process adopts an implementation research approach, which aims to address implementation bottlenecks, identify optimal approaches for specific settings, and promote the uptake of the assessment findings – ultimately leading to improved TB prevention, care and support. It also requires multi-stakeholder involvement to ensure that there is broad buy-in and uptake of the recommendations at the highest level and that the approach is community-driven.





## THE PROCESS


The recommended process is community-driven with strategic guidance from the NTP, with people affected by TB as equal partners in the process. The Assessment's delivery will be guided by the human rights principles of universality, indivisibility and interdependence, equality, non-discrimination, accountability, and participation, which guide other human rights interventions. The timeline, key steps and details of the process to roll out the TB Stigma Assessment are outlined below.




| STEPS  | DETAILS   | STATUS  |  |
|--|---|---|--|
|  <b>MONTH 1</b> |   |   |  |
| <b>1</b>   | <p><b>Lead CBO recruits the TB Stigma Expert.</b></p>   | <ul style="list-style-type: none"> <li>• Lead CBO appoints the TB Stigma Expert, Statistician and Administrative Assistant.</li> <li>• See <a href="#">Annex A</a>: Sample Terms of Reference for TB Stigma Expert</li> <li>• See <a href="#">Annex B</a>: Sample Terms of Reference for TB Stigma Statistician</li> </ul>  |  |
| <b>2</b>   | <p><b>Lead CBO and NTP mobilize Core Group (Technical Working Group / oversight).</b></p>                                 | <ul style="list-style-type: none"> <li>• Lead CBO, in collaboration with the NTP, sends an email with Terms of Reference to the selected organizations to appoint focal people to the Core Group.</li> <li>• Lead CBO convenes and facilitates the first meeting of the Core Group, co-facilitated by the NTP, to present the concept note and agree on the project workplan.</li> </ul>  |  |
| <b>3</b>   | <p><b>Lead CBO and TB Stigma Expert convene the Core Group and prepare the multi-stakeholder orientation meeting.</b></p> | <ul style="list-style-type: none"> <li>• TB Stigma Expert conducts a desk review and maps the stakeholders who will be engaged in the process (informed by the desk review).</li> <li>• TB Stigma Expert drafts the agenda for the Core Group meeting.</li> <li>• Lead CBO convenes the Core Group to present and agree upon the protocol (draft 1) for the TB Stigma Assessment. See <a href="#">Annex C</a> for sample Protocol, list of stakeholders and the agenda for the orientation meeting. <ul style="list-style-type: none"> <li>• Cultural adaptation of the scales is an important part of this process. See Other Resources “Cultural adaptation of the TB-related stigma scale”, which outlines the stages of the process to culturally adapt the scales, which involves translation/back-translation with semantic validation. The same approach should be used for all questions.</li> <li>• As part of the Protocol adaptation process, attention should be paid to minimizing social desirability bias. Additional social desirability scales can be added during the national roll-out of stigma measurement.</li> </ul> </li> <li>• The TB Stigma Expert produces the second draft of the TB Stigma Assessment Protocol, based on the Core Group feedback.</li> </ul> |  |


| STEPS   | DETAILS   | STATUS |
|---|---|--------|
|  <b>MONTH 2</b>  |   |        |
| <b>4</b><br>Lead CBO, with strategic guidance from the NTP, convenes the multi-stakeholder meeting facilitated by the TB Stigma Expert. | <ul style="list-style-type: none"> <li>Lead CBO convenes the multi-stakeholder meeting with strategic guidance from the NTP. <ul style="list-style-type: none"> <li>The meeting orients people to stigma in TB and the rationale for conducting the TB Stigma Assessment.</li> <li>The meeting seeks consensus on the second draft of the TB Stigma Assessment Protocol.</li> </ul> </li> </ul>   |        |
| <b>5</b><br>TB Stigma Expert finalizes the Protocol, and lead CBO / NTP submits it for ethics approval.                                 | <ul style="list-style-type: none"> <li>The TB Stigma Expert consolidates input from the orientation meeting and finalizes the TB Stigma Assessment Protocol (draft 3).</li> <li>The Statistician develops the sampling methods and calculates sample sizes.</li> <li>The lead CBO / NTP submits the Protocol to the ethics committee.</li> </ul>  |        |
| <b>6</b><br>Lead CBO and TB Stigma Expert prepare for data collection.  | <ul style="list-style-type: none"> <li>TB Stigma Expert drafts the job description for TB Stigma research assistants. See <a href="#">Annex D</a> for sample Terms of Reference for research assistants/data collectors.</li> <li>Lead CBO recruits TB Stigma research assistants/data collectors.</li> <li>TB Stigma Expert prepares training materials for TB Stigma research assistants/data collectors.</li> <li>TB Stigma Expert trains TB Stigma research assistants. See <a href="#">Annex E</a> for sample training outline for research assistants/data collectors.</li> </ul> |        |
| <b>7</b><br>Lead CBO informs and seeks approval from respective assessment sites.   | <ul style="list-style-type: none"> <li>Lead CBO shares ethical clearance approval with targeted audiences from respective sites to seek approval to collect data.</li> </ul>  |        |

| STEPS  | DETAILS  | STATUS   |  |
|--|--|--|--|
|  <b>MONTH 3</b> |  |  |  |
| 8  | <b>Data collection commences.</b>  | <ul style="list-style-type: none"> <li>• TB Stigma research assistants collect data.</li> </ul>  |  |
|  |  | <ul style="list-style-type: none"> <li>• TB Stigma research assistants send data immediately to the TB Stigma Expert to start analysis.</li> </ul>   |  |
|  |  | <ul style="list-style-type: none"> <li>• TB Stigma Expert leads and monitors the data collection.</li> </ul>   |  |
| 9  | <b>TB Stigma Expert conducts FGD with representatives from the national and subnational TB programme, judiciary and legal communities, legislators, media workers and policy makers.</b> | <ul style="list-style-type: none"> <li>• Experts deliberate and score the extent to which any existing laws/policies, the enforcement of those laws/policies and the corresponding media coverage could harm or protect people with or who have had TB. See <a href="#">Annex F</a> for Sample agenda – Core Group results meeting.</li> </ul> |  |
|  |  | <ul style="list-style-type: none"> <li>• Based on the analysis, the experts, facilitated by the TB Stigma Expert, draft law-/policy-related recommendations.</li> </ul>  |  |
| 10   | <b>TB Stigma Expert conducts the data analysis and drafts the findings and recommendations.</b>  | <ul style="list-style-type: none"> <li>• Lead CBO convenes the Core Group.</li> </ul>  |  |
|  |  | <ul style="list-style-type: none"> <li>• TB Stigma Expert presents preliminary findings and recommendations (first draft) to the Core Group for input and endorsement.</li> </ul>  |  |
|  |  | <ul style="list-style-type: none"> <li>• The multi-stakeholder participant list for the validation workshop should be revised based on the findings and recommendations of the report.</li> </ul>  |  |

| STEPS  | DETAILS  | STATUS |
|--|--|--------|
|  <b>MONTH 4</b> |  |        |
| 11   | <p><b>Lead CBO informs and seeks approval from respective assessment sites.</b></p> <ul style="list-style-type: none"> <li>The TB Stigma Expert incorporates comments from the Core Group to produce a second draft.</li> <li>The lead CBO shares the second draft with the NTP for input and approval.</li> <li>The TB Stigma Expert produces a third draft based on NTP feedback.</li> <li>Invitations are sent to the revised multi-stakeholder group to attend the validation workshop (ideally sent by the NTP).</li> <li>Led by the NTP, the lead CBO organizes the validation workshop with support from the TB Stigma Expert.</li> </ul> |        |



| STEPS   | DETAILS  | STATUS |
|---|--|--------|
|  <b>MONTH 5</b>                  |  |        |
| <b>12</b><br><b>Lead CBO and NTP convene the validation workshop of the fourth draft of the TB Stigma Report.</b> | <ul style="list-style-type: none"> <li>• NTP and person affected by TB open and close the meeting.</li> <li>• If other ministries should be there (based on findings), e.g., Ministry of labour, mines, poverty, refugees, gender, human rights, they should also be part of the agenda.</li> <li>• Donors should be part of the agenda.</li> <li>• Project team (led by the TB Stigma Expert) and the NTP present the findings and recommendations.</li> <li>• Break-out groups review and provide input on respective areas of the report.</li> <li>• Key recommendations are prioritized.</li> <li>• NTP shares next steps regarding the implementation of the key recommendations.</li> <li>• TB Stigma Expert incorporates validation workshop outcomes, including the agreed and endorsed action plan, into the fourth draft of the report for the Core Group's review.</li> </ul> |        |
| <b>13</b><br><b>Communications strategy developed, IEC materials developed and disseminated.</b>                  | <ul style="list-style-type: none"> <li>• TB Stigma Expert incorporates Core Group's final comments and finalizes the report (draft 5).</li> <li>• Lead CBO recruits a communications consultant.</li> <li>• Communications consultant develops communications strategy including dissemination plan.</li> <li>• Communications consultant develops Information, Education and Communication (IEC) materials.</li> <li>• Key messages disseminated to different actors.</li> </ul>  |        |

| STEPS  | DETAILS   | STATUS  |  |
|--|---|---|--|
|  <b>MONTH 6</b> |   |   |  |
| 14   | TB Stigma Expert and costing consultant develop costed Action Plan. | <ul style="list-style-type: none"> <li>• Lead CBO recruits a costing consultant to inform the TB Stigma Action Plan.</li> </ul>   |  |
|  |   | <ul style="list-style-type: none"> <li>• Costing consultant and TB Stigma Expert develop first draft of the Action Plan based on the action plan endorsed at the validation workshop.</li> </ul>            |  |
|  |   | <ul style="list-style-type: none"> <li>• Lead CBO hosts a multi-stakeholder (NTP, action implementers) costing meeting to elaborate actions / activities to implement the recommendations.</li> </ul>       |  |
|  |   | <ul style="list-style-type: none"> <li>• TB Stigma Expert and costing consultant produce second draft (including estimated costs), based on feedback from the multi-stakeholder costing meeting.</li> </ul> |  |
|  |   | <ul style="list-style-type: none"> <li>• Lead CBO sends second draft of TB Stigma Action Plan to Core Group for input and approval.</li> </ul>  |  |
|  |   | <ul style="list-style-type: none"> <li>• TB Stigma Expert and costing consultant produce third draft of the TB Stigma Action Plan.</li> </ul>   |  |
|  |   | <ul style="list-style-type: none"> <li>• Lead CBO sends third draft to NTP for approval.</li> </ul>   |  |

A man in a dark suit and light-colored shirt is seated and speaking into a microphone. He is gesturing with his hands as he speaks. The entire image is overlaid with a semi-transparent red color. The text 'DATA ENTRY & ANALYSIS' is positioned on the left side of the image.

**DATA ENTRY  
& ANALYSIS**

## DATA ENTRY

The TB Stigma Assessment Data Entry and Analysis Workbook is used by the Stigma Expert to enter and analyse data, develop a narrative report, compile findings, develop recommendations, and develop a draft Action Plan to address TB stigma. The Excel Workbook has a number of tabs:

- **Basic information: country, location of assessment, and assessment period**
- **Data from people with or who have had TB: respondents' unique confidential ID and responses**
- **Family data: respondents' unique confidential ID and responses**
- **Community data: respondents' unique confidential ID and responses**
- **Health care worker data: respondents' unique confidential ID and responses**
- **Law and policy environment matrices**
- **Results**
- **Action Plan**



## ANALYSIS

|   | Charts  | Rows in "Results" Sheet | Description  | Interpretation Examples and Analysis Guidance  |
|---|---|-------------------------|--|--|
| 1 | Stigma Radar  | Key Assessment Results  | <p>Big picture of the extent of stigma in five different settings:</p> <ol style="list-style-type: none"> <li>1. Self-stigma experienced by people with TB or who have had TB (people diagnosed with TB)</li> <li>2. Family</li> <li>3. Community/neighbours</li> <li>4. Health care</li> <li>5. Law/policy environment</li> </ol> | <ul style="list-style-type: none"> <li>• (1-a) <b>People diagnosed with TB anticipated self-stigma</b> level (0–100%)</li> <li>• (1-b) % <b>People diagnosed with TB</b> reporting that <b>self-stigma</b> inhibited them from seeking and accessing TB services</li> <li>• (2-a) <b>Family secondary stigma</b> level (0–100%)</li> <li>• (2-b) % <b>People diagnosed with TB</b> reporting that <b>stigma experienced in their family/home setting</b> inhibited them from seeking and accessing TB services</li> <li>• (3-a) Level of <b>community/neighbours' perceived stigma</b> towards PWTB (0–100%)</li> <li>• (3-b) % <b>People diagnosed with TB</b> reporting that <b>stigma in their community/neighbourhood</b> inhibited them from seeking and accessing TB services</li> <li>• (4-a) Level of <b>health care workers' perceived stigma</b> towards PWTB (0–100%)</li> <li>• (4-b) % <b>People diagnosed with TB</b> reporting that <b>stigma in a health care setting</b> inhibited them from seeking and accessing TB services</li> <li>• (5) % <b>People diagnosed with TB</b> reporting that <b>stigma in the workplace</b> inhibited them from seeking and accessing TB services</li> <li>• (6-a) <b>Harmful law environment</b> level (0–100%)</li> <li>• (6-b) <b>Harmful policy environment</b> level (0–100%)</li> </ul> <p><b>NB.</b> The larger the radar web, the more likely PWTB will face barriers in seeking and accessing TB services, and likewise for government and private service providers in delivering services.</p> <p><b>NB.</b> Indicators 1b, 3b and 4b are core TB indicators in the Global Fund Modular Framework.</p> |
| 2 | Stigma Details (manifestations)                               | Stigma Dimensions       | % of respondents who agreed or strongly agreed to each of the items in the stigma scale  | <ul style="list-style-type: none"> <li>• The horizontal bar labelled "A1" on the y-axis in "People with or who have had TB self-stigma" shows the percentage of respondents who agreed or strongly agreed to the question "I feel hurt how others react to knowing I have TB".</li> <li>• The horizontal bar labelled "A6" on the y-axis shows the percentage of respondents who agreed or strongly agreed to the question "I am afraid of going to TB clinics because other people might see me there".</li> <li>• Relatively higher percentages on items describe more frequent manifestations of stigma than lower percentages.</li> </ul>  |
| 3 | Stigma Experienced Along the TB Journey in Different Settings | Stigma Experienced      | % of respondents reporting that they experienced stigma that inhibited them from seeking and accessing care in a setting at a stage of the TB journey  | <ul style="list-style-type: none"> <li>• The horizontal blue bar labelled "(2) – Seeking Care" on the y-axis in "Stigma experienced by PWTB" shows the percentage of respondents who reported experiencing stigma in a health care setting that inhibited them from seeking and accessing TB services.</li> <li>• The horizontal green bar labelled "(6) – Completing Treatment" on the y-axis shows the percentage of respondents who reported experiencing stigma at home that inhibited them from completing their TB treatment.</li> <li>• Relatively higher percentages in the horizontal bars indicate the TB journey stages and settings in which the stigma experienced has a more negative impact on individuals seeking and accessing TB services.</li> </ul>  |
| 4 | Stigma Observed Along the TB Journey in Different Settings    | Stigma Observed         | % of respondents reporting that they have seen/heard stigma experienced by other PWTB that inhibited them from seeking and accessing care in a setting at a stage of the TB journey  | <ul style="list-style-type: none"> <li>• The horizontal blue bar labelled "(2) – Seeking Care" on the y-axis in "Stigma experienced by PWTB" shows the percentage of respondents reporting that they have seen/heard other PWTB experiencing stigma in a health care setting that prevented them from seeking and accessing care.</li> <li>• The horizontal green bar labelled "(6) – Completing Treatment" on the y-axis shows the percentage of respondents reporting that they have seen/heard other PWTB experiencing stigma at home that prevented them from completing their TB treatment.</li> <li>• Relatively higher percentages in the horizontal bars indicate the TB journey stages and settings in which stigma seen/heard has a more negative impact on individuals' access to TB services.</li> </ul>   |

| Charts   | Rows in "Results" Sheet                  | Description   | Interpretation Examples and Analysis Guidance  |
|--|--|---|--|
| 5<br>Summary of Open-Ended Qualitative Questions on Further Details on Stigma Experienced and Observed | Stigma as a Barrier to Accessing Service | Core Group's analysis of the most commonly mentioned stigma issues (nature, setting) for each of the seven stages of the TB journey | <ul style="list-style-type: none"> <li>These qualitative results will be triangulated with the above quantitative results to identify the most critical stigma issues (which stages of the TB journey and which settings) that need to be urgently addressed.</li> </ul> |
| 6<br>Summary of Changes (TB Services, Laws/ Policies) Suggested by Respondents                         | Suggested Changes                        | Core Group's analysis of the most commonly mentioned changes suggested for each of the seven stages of the TB journey               | <ul style="list-style-type: none"> <li>These suggested changes will provide ideas on how to address the critical stigma issues identified through the triangulation of quantitative and qualitative results.</li> </ul>  |
| 7<br>Summary of Further Comments by Respondents  | Comments                                 | Core Group's analysis of the most commonly mentioned comments   | <ul style="list-style-type: none"> <li>These most commonly mentioned comments will serve as checks of the robustness of the quantitative and qualitative analysis and generate further ideas on how to address critical stigma issues.</li> </ul>                        |
| 8<br>Respondents' Background   | Demographics                             | Background of respondents   | <ul style="list-style-type: none"> <li>Demographic data will support the data collection process by ensuring that respondents' profiles match the expectations and gender balance in particular.</li> </ul>  |



A photograph of a middle-aged man with a shaved head, wearing a dark grey suit jacket over a light blue button-down shirt. He is sitting at a table with his hands clasped in front of him, looking off to the side with a serious expression. The background is a plain, light-colored wall.

# ANNEXES

## ANNEX A: SAMPLE TERMS OF REFERENCE FOR TB STIGMA EXPERT

### BACKGROUND

Assessing tuberculosis (TB) stigma is essential to addressing health disparities. Drawing from the vast body of work done by KNCV<sup>24,25,26</sup> to measure and reduce TB stigma, Stop TB Partnership (STP) has developed the TB Stigma Assessment, with support from USAID and in collaboration with KNCV, a core team of TB stigma experts and a technical committee. The TB Stigma Assessment supports countries to assess the burden of TB stigma and to develop recommendations for reducing the burden of TB stigma so that quality TB services are available, accessible and acceptable to all, with special considerations given to the needs of key, vulnerable and underserved populations. The TB Stigma Expert will provide technical guidance to the assessment process. He or she will be accountable to the Core Group and will report directly to the community-based organization [insert name] in charge of planning and implementing the assessment, under the strategic guidance of the National TB Programme (NTP).

### OVERALL OBJECTIVE

To assess the extent to which and how TB stigma acts as a barrier to both accessing and providing services, and to support the development of recommendations to address TB stigma so that quality TB services are available, accessible and acceptable to all, with special considerations given to the needs of key, vulnerable and underserved populations.

### ASSESSMENT AREA

The TB Stigma Assessment (informed by the desk review) can be done at the national or subnational level or targeting certain TB key populations.

### SPECIFIC OBJECTIVES

1. To understand the level and dimensions of perceived self-stigma, and stigma directly experienced and observed by people diagnosed with TB:
  - a. To understand how and the extent to which perceived self-stigma manifests among people diagnosed with TB;
  - b. To understand the settings and stages of care in which TB stigma is being experienced and observed by people diagnosed with TB.
2. To understand the level and dimensions of secondary TB stigma, stigma directly experienced, and stigma observed by family members / primary carers of people diagnosed with TB:
  - a. To understand how and the extent to which secondary stigma manifests among family members / primary carers of people diagnosed with TB;
  - b. To understand the settings and stages of care in which secondary TB stigma is being experienced and observed by family /primary carers of people diagnosed with TB.
3. To understand the level of perceived TB stigma against people diagnosed with TB in communities and stigma observed by the community:
  - a. To understand how and the extent to which stigma against people diagnosed with TB takes place in communities;
  - b. To understand the settings and stages of care in which TB stigma against people diagnosed with TB is being observed by community members.

<sup>24</sup> Challenge TB. TB stigma measurement guidance. The Hague: KNCV; 2018 [https://www.challengebtb.org/publications/tools/ua/TB\\_Stigma\\_Measurement\\_Guidance.pdf](https://www.challengebtb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf)

<sup>25</sup> From the inside out: dealing with TB-related self-stigma and shame. A pilot toolkit for people with TB to deal with self-stigma and shame. The Hague: KNCV; 2018 <https://www.kncvtbc.org/en/stigma-3/>

<sup>26</sup> Lemaine I, Mitchell EMH, van de Berg S, Mirtskhulava V. Tuberculosis stigma reduction for health care institutions. Intervention package – allies approach. The Hague: KNCV; 2018 <https://www.kncvtbc.org/en/stigma-3/>

<sup>27</sup> Includes both government and private health care settings.



4. To understand the level and dimensions of perceived TB stigma against people diagnosed with TB in health care settings<sup>27</sup> and stigma against health care workers:
  - a. To understand how and the extent to which perceived stigma against people diagnosed with TB manifests in health care facilities;
  - b. To understand the settings in which TB stigma is experienced by TB health care workers;
  - c. To understand the settings in which TB stigma against health care workers is observed by other TB health care workers.
5. To support the development of recommendations to address TB stigma in order to reduce peoples' vulnerability to TB infection, increase peoples' access to TB services and improve treatment outcomes.

## **RESPONSIBILITIES**

1. Conduct the stigma desk review that will inform the development of the TB Stigma Assessment Protocol.
2. Map all the stigma stakeholders who should engage in the process.
3. Develop draft 1 of the TB Stigma Assessment Protocol.
4. Draft the agenda for the Core Group meeting.
5. Co-facilitate the Core Group meeting.
6. Develop draft 2 of the TB Stigma Assessment Protocol based on feedback from the Core Group.
7. Present draft 2 at the multi-stakeholder orientation meeting.
8. Develop draft 3 of the TB Stigma Assessment Protocol based on feedback from the orientation meeting.
9. Develop Terms of Reference for the TB Stigma research assistants/data collectors.
10. Develop training materials for the TB Stigma research assistants/data collectors.
11. Train the TB Stigma research assistants/data collectors.
12. Oversee the data collection process.
13. Facilitate a focus group discussion (FGD) to score the extent to which any existing laws/policies, the enforcement of those laws/policies and the corresponding media coverage could harm or protect people with or who have had TB.
14. Draft law/policy recommendations based on the FGD.
15. Draft report (draft 1) with preliminary findings and recommendations for the Core Group to review.
16. Incorporate Core Group inputs to produce draft 2 of the report.
17. Share draft 2 of the report with the NTP for review.
18. Incorporate NTP inputs to produce draft 3 of the report.
19. Support the planning of the validation meeting.
20. Facilitate discussions at the validation meeting.
21. Incorporate feedback from the validation meeting to produce the final report.
22. Work with the costing consultant to develop the first draft of the TB Stigma Action Plan.
23. Facilitate discussions on the Action Plan at the multi-stakeholder meeting.
24. Incorporate feedback from the multi-stakeholder meeting to produce draft 2 of the TB Stigma Action Plan.
25. Share draft 2 of the TB Stigma Action Plan with the Core Group.
26. Incorporate feedback from the Core Group to produce draft 3 of the TB Stigma Action Plan.
27. Share draft 3 of the TB Stigma Action Plan with the Ministry of Health.
28. Incorporate Ministry of Health feedback and finalize the TB Stigma Action Plan.

**REQUIREMENTS AND COMPETENCIES**

1. Advanced university degree in social science and/or policy research disciplines
2. Demonstrated expertise in stigma measurement methodologies, as well as their implementation, analysis and publication
3. A qualitative and quantitative researcher with experience in statistical sampling and analysis
4. Demonstrated in-depth knowledge of TB and TB programmatic responses
5. Demonstrated experience of stigma in the context of TB
6. Familiarity with the country's ethics review process and the documentation needed
7. Demonstrated experience in analysis and report writing, as well as policy advocacy
8. Strong analytical skills
9. Ability to research, analyse and present complex information
10. Excellent planning and facilitation skills

## ANNEX B: SAMPLE TERMS OF REFERENCE FOR STATISTICIAN

### BACKGROUND

Assessing tuberculosis (TB) stigma is essential to addressing health disparities. Drawing from the vast body of work done by KNCV<sup>28, 29, 30</sup> to measure and reduce TB stigma, Stop TB Partnership (STP) has developed the TB Stigma Assessment, with support from USAID and in collaboration with KNCV, a core team of TB stigma experts and a technical committee. The TB Stigma Assessment supports countries to assess the burden of TB stigma and develop recommendations for reducing the burden of TB stigma so that quality TB services are available, accessible and acceptable to all, with special considerations given to the needs of key, vulnerable and underserved populations.

### OVERALL OBJECTIVE

The Statistician will provide technical guidance to the assessment process. He or she will be accountable to the Core Group and will report directly to the community-based organization [insert name] in charge of planning and implementing the assessment, under the strategic guidance of the National TB Programme (NTP).

### RESPONSIBILITIES

To design samples and sampling methods and calculate and create sample sizes to fulfil the specific assessment objectives.

### REQUIREMENTS AND COMPETENCIES

1. Demonstrated expertise in quantitative survey methodologies, including creation of population frames and drawing random samples from population frames
2. Bachelor's degree in statistics or quantitative social science
3. Demonstrated experience in creating population frames, drawing random samples from population frames, calculating sample sizes, sampling weights for analysis, the power of statistical tests from sample size and performing univariate/multivariate statistical analysis
4. Demonstrated experience in data analysis using advanced statistical software packages (SPSS, SAS, Python, Matlab, R, Julia), including disaggregated analysis

<sup>28</sup> Challenge TB. TB stigma measurement guidance. The Hague: KNCV; 2018 [https://www.challengetb.org/publications/tools/ua/TB\\_Stigma\\_Measurement\\_Guidance.pdf](https://www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf)

<sup>29</sup> From the inside out: dealing with TB-related self-stigma and shame. A pilot toolkit for people with TB to deal with self-stigma and shame. The Hague: KNCV; 2018 <https://www.kncvtbc.org/en/stigma-3/>

<sup>30</sup> Lemaine I, Mitchell EMH, van de Berg S, Mirtskhulava V. Tuberculosis stigma reduction for health care institutions. Intervention package – allies approach. The Hague: KNCV; 2018 <https://www.kncvtbc.org/en/stigma-3/>

## ANNEX C: SAMPLE ASSESSMENT PROTOCOL

The Stigma Expert can adapt the following Protocol.<sup>31</sup> The lead community-based organization (CBO) will then submit the Protocol to the ethics committee.

- **Project summary:** The Protocol should include a summary section outlining the central elements of the Protocol, for example, the rationale, objectives, methods, populations, time frame, and expected outcomes.
- **Rationale and background information:** This section should provide the reasons for conducting the Assessment considering current knowledge. It should include a well-documented statement of the need/problem that forms the basis of the project, the cause of this problem and its possible solutions. It should answer the questions of why and what, namely, why the Assessment is necessary and what its relevance will be. The magnitude, frequency, affected geographical areas, key populations and gender considerations, etc. of the problem should be followed by a brief description of the most relevant studies published on the subject to date (with references).
- **Assessment goals and objectives:** Goals are broad statements of what the Assessment hopes to accomplish. These goals establish a context for the proposal. Specific objectives are statements of the Assessment question(s). Objectives should be simple (not complex), specific (not vague), and stated in advance (not after the research is done).
- **Assessment design:** The design of the Assessment should include information on the type of assessment, the assessment population or sampling frame, who can take part (e.g., inclusion and exclusion criteria, withdrawal criteria, etc.), and the expected duration of the assessment.
- **Methodology:** The methodology section is the most important part of the Protocol. It should include detailed information on the interventions (e.g., training) planned, procedures (e.g., focus group discussion / in-depth Interviews, etc.) to be used, and so on.
- **Data management and analysis:** The Protocol should provide information on how the data will be managed, including monitoring and verification. The methods proposed for analysing the data should be clearly outlined, including reasons for the sample size selected, level of significance, etc. Sufficient details on how the qualitative data will be analysed should also be included.
- **Quality assurance:** The Protocol should describe the quality control and quality assurance system for the Assessment.
- **Expected outcomes of the Assessment:** The Protocol should indicate how the Assessment will contribute to the advancement of knowledge, and how the results will likely affect health care, health systems or health policies.
- **Dissemination of results:** The Protocol should specify how results will be disseminated among all relevant stakeholders (also to enhance the uptake of results and accountability).
- **Duration of the Assessment:** The Protocol should specify the time frame for each phase of the project, along with a detailed month by month timeline for each activity to be undertaken.
- **Assessment management:** This section should describe the roles and responsibilities of each member of the Assessment team.
- **Ethics:** The Protocol should describe any ethical considerations related to the Assessment. This section should not only provide information on how or from whom the ethics approval will be requested, but also document the issues that are likely to raise ethical concerns. It should also describe how the investigator(s) plan to obtain informed consent from the research participants.
- **Informed consent forms:** The approved version of the Protocol must include copies of informed consent forms (ICFs), both in English and in the local language in which they are going to be administered. If the Assessment involves more than

<sup>31</sup> Recommended format for a Research Protocol [Internet]. Geneva: World Health Organization [https://www.who.int/rpc/research\\_ethics/format\\_rp/en/](https://www.who.int/rpc/research_ethics/format_rp/en/)

one group of individuals, for example health care users and health care providers, specifically tailored ICFs must be included for each group. See document *TB Stigma Assessment Data Collection Instruments* for sample ICFs.

- **Budget:** See [Annex G](#): Sample budget.

## ANNEX D: SAMPLE TERMS OF REFERENCE FOR RESEARCH ASSISTANTS/DATA COLLECTORS

### LEVEL OF EFFORT

Each interviewer is expected to spend approximately 40 hours in total (4 hours per day, 10 days over a 3-week period) to interview approximately 10 respondents from the sample drawn up by the Stigma Expert, who will assign the interviewer to specific respondents.

### GENDER

Consideration should be given to the gender of the interviewer in relation to the person being interviewed. Depending on the context, this might be an important consideration.

### INTERVIEW PROCESS

- Each interviewer will be given blank questionnaires based on the number of people he/she will interview, consent forms, envelopes and token incentives, when possible.
- Interviews will take place on weekdays or weekends, day or evening, depending on the availability of interviewees.
- Interviews may take place outside office hours in order to allow maximum flexibility for interviewees.
- Interviewers will follow the interviewee recruitment method they were trained on.
- Once an interviewee agrees to do the interview, the interviewer will set up an appointment to conduct the face-to-face interview at a time/place convenient for the interviewee.
- The interviewer will start the interview with an introduction and ask the interviewee if he/she has any questions.
- The interviewer will ask the interviewee to read, ask any questions and sign the consent form (if in agreement).
- The interviewer will fill in the top box on the first page of the questionnaire (interviewer's initials, the 1st, 2nd, 3rd... interview of the interviewer, interview location, interview date).
- The interviewer will conduct the interview by following the sequence of questions in the questionnaire and note the respondent's response on the form (i.e., ticking the appropriate boxes for multiple-choice questions, writing down the respondent's responses to open-ended questions).
- At the end of the interview, the interviewer will check to make sure the questionnaire is complete, and then place the completed questionnaire and consent form in an envelope and seal the envelope in front of the interviewee.
- The interviewer will thank the interviewee for their participation in the TB Stigma Assessment.
- The interviewer will then pass the sealed envelope to the Stigma Expert in person at the end of the day (when possible).
- The interviewer will also discuss with the Stigma Expert at the end of each day (if possible) how the day went (including challenges faced) and receive any support for the day's work.
- The Stigma Expert will support the interviewers by discussing ways to manage challenges, including difficulties in contacting the assigned interviewees.
- All completed questionnaires and consent forms will be secured in sealed envelopes and handed to the Stigma Expert at the end of each day.
- In the event an interviewee chooses to terminate the interview before it is finished, the interviewer should ask the interviewee if there would be another more convenient time to continue the interview. If so, the interviewer should then reschedule the interview. If not, the interviewer should thank the interviewee and not push further for the interviewee to complete the interview. Then, the interviewer should return the incomplete interview to the Stigma Expert who will then determine whether the incomplete interview should be included in the analysis (i.e., entered into the Workbook) or not. Interviews with less than two thirds of the questions completed will normally be discarded.

## REPORTING TO THE STIGMA EXPERT

- The Stigma Expert will track and manage the number of assigned interviews each interviewer has completed.
- The Stigma Expert may decide to drop an interviewer due to confidentiality breaches, or their inability to follow questionnaires or adhere to the interview principles and processes taught during the 2-day training. In the event that an interviewer is dropped, the Stigma Expert should report his/her decision and rationale to the Core Group in person and in writing.

## DATA ENTRY TIPS

- At the end of each day, the Stigma Expert will transfer information on each completed questionnaire (10 questionnaires per day) into the Excel Workbook: five sheets – “Basic Info”, “(1) People with or who have had TB Data”, “(2) Family Data”, “(3) Community Data”, “(4) Health Care Worker Data”.
- For each of the five sheets, the Stigma Expert will enter information only in the grey-coloured cells (i.e., NOT in any other cells, as doing so may alter the formulae that auto-calculate to generate the graphics in the “RESULTS” sheet).
- For multiple-choice questions with boxes, the Stigma Expert will select the appropriate data from the pull-down menu for each cell.
- For open-ended questions, the Stigma Expert will enter the text.
- The Stigma Expert will follow up with the interviewer if a pattern of inconsistency is observed or further clarifications are needed.
- The Stigma Expert will ensure that the confidential respondents’ IDs are unique among all respondents across all four questionnaires.
- The Stigma Expert should watch out for patterns of identical completed questionnaires (e.g., same responses for over half of the questions). If noted, he or she should raise concerns about the validity of the data with the data collector.

- The Stigma Expert should also watch out for erroneous data entry, e.g., data that have been recorded where blanks should be.

## SUPPORT

Interviewers should have contact details of a help centre/peer counsellor in case they confront a situation where they find it difficult to cope with the effects of stigma.

## ANNEX E: SAMPLE TRAINING OUTLINE FOR RESEARCH ASSISTANTS/DATA COLLECTORS

\*The training should be developed and adapted by the Stigma Expert. There should be gender balance among all trainees.

### DAY 1 Background, Confidentiality, Recruiting Interviewees

#### Session 1: Background

🕒 2 hours

- Importance of transforming the TB response into one that is community-driven, rights-based and gender responsive in order to reach the targets of the End TB Strategy, the Global Plan to End TB and the United Nations Political Declaration on TB
- TB basics
- TB stigma
- The TB Stigma Assessment
- The role of the research assistant / data collector (ideally a TB survivor)

#### Session 2: Confidentiality

🕒 1 hour

##### Examples of breach of confidentiality

- Zero tolerance (immediate dismissal) for breach of confidentiality
- Not discussing with anyone (including fellow interviewers) the identity of the interviewee or linking any information to an identified interviewee (e.g., "the person I interviewed yesterday in XXX said....." that would expose the interviewee's identity. This would be a confidentiality breach. The best practice is to not discuss any of the interviews with anyone.
- When in doubt about a potential confidentiality breach, check with the Stigma Expert.

#### Session 4 Interviewing skills

🕒 1 hour

##### Interview Skills

- The interviewer should never express an opinion to any response. The job of the interviewer is to ask the question, clarify the response (when the response is unclear) and note the response on the questionnaire.
- The interviewer should reinforce the message that all responses are important.
- The interviewer should always be patient and never challenge the respondent.
- The interviewer should use phrases like the following when answers are unclear: "I am so sorry I did not quite understand what you just told me. I know the question is a bit confusing. Do you mind if I repeat the question?"
- The interviewer should not rush or pressure the respondent to finish their response to the question.
- The interviewer should always use eye contact, as it is critical to building the respondent's trust.
- The interviewer should minimize distractions to ensure the interview is completed in a timely fashion, e.g., silencing or turning off cell phones to avoid interruptions.
- The interviewer should inform the respondent that they can withdraw consent/stop the interview at any point.

#### Session 3: Contacting assigned interviewees

🕒 1 hour

##### Principles for recruiting interviewees

- People who have had TB (TB survivors) should be directly involved in the data collection (participatory research).
- Maximize the chance to achieve a statistically representative sample of interviewees with a >60% response rate (% of sampled respondents who complete the interview).

##### Methods

- Interviewers will need to spend time on the phone or in person to reach the assigned interviewees. Multiple phone calls may be needed to build trust before the assigned interviewee agrees to be interviewed. In the case of initial refusal, the interviewer should discuss with the Stigma Expert strategies to convince

the assigned interviewees to participate in the assessment (e.g., by explaining the important role of this study in improving the situation of people with TB like him/herself, reinforcing that participation is completely confidential and will not affect his/her current treatment, or simply asking the interviewee about his/her concerns).

- Except for the health care worker questionnaire (which will be administered by trained health care worker interviewers), the other three questionnaires should be administered by trained people who have had TB (i.e., TB survivors). In the case that the TB survivors available do not have the skillset or there are not sufficient numbers to engage, other people with appropriate backgrounds in data collection should be trained to collect the data.



## DAY 2 Interview Questionnaires, Selection of Interviewers & Next Steps

### Session 1: Practice interview questionnaires and provide feedback 4 hours

- Trainees become familiar with all questions in each of the four questionnaires.
- In pairs, trainees use the questionnaires to practice on each other (switching roles between interviewer and interviewee).
- In plenary, trainees provide feedback on questionnaires (e.g., how to change the wording etc.).
- Each pair uses the TB Survivor Questionnaire (including introduction and consent) to perform the role of the interviewer and interviewee during the first round (15 min).
- The pair then switches roles and repeats the task using the same questionnaire (15 min).
- In plenary, trainees report back and make suggestions on how to improve the questionnaire content and adapt it to local cultural context (15 min).
- The Stigma Expert repeats the process for the other three questionnaires (family, community/ neighbours, health care workers).

#### Tips for trainers

- The Stigma Expert walks all trainees through each of the four questionnaires – introduction, consent, questions (1 hour)
- The Stigma Expert randomly mixes TB survivors and health care workers (25–30) and groups them into pairs (12–15).

### Session 2: Selection of interviewers 1 hour

The Stigma Expert informs those trainees who have been selected to participate in the Assessment as interviewers and those who have not been selected will be asked to leave. The selection criteria are based on performance during the training (i.e.,

the trainee has demonstrated an understanding of interview principles and did well in the questionnaire role plays). The number of people selected will be determined by the size of the Assessment.

### Session 3: Preparation for selected interviewers 1 hour

#### The Stigma Expert will explain the following:

- The Terms of Reference
- The number of interviews that should be conducted
- How interviewees will be assigned to the interviewers

- Before going out to recruit interviewees, all chosen interviewers should continue practicing with each other (using the questionnaires) and let the Stigma Expert know if they have any questions or need any clarifications.

## ANNEX F: SAMPLE AGENDA – CORE GROUP RESULTS MEETING

### MEETING OBJECTIVES

- To discuss and score the law and policy environment matrices and formulate recommendations for the Action Plan.
- To review responses to the four open-ended questions – (a) experience of stigma, (b) observations of stigma, (c) suggestions for changes in TB services, and (d) further comments – for each of the four questionnaires (people with or who have had TB, family, community/neighbours, health care workers), analyse them along the seven stages of the TB journey and formulate recommendations for the Action Plan.
- To complete the Action Plan.

### DAY 1

#### Morning Session (scoring law and policy environment matrices)

- The Core Group scores the “Law and Policy Environment Matrices” sheet of the Workbook.
- Scoring is based on the extent to which existing laws/policies, law/policy enforcement and corresponding media coverage are protective or harmful for people with, who have had or who are vulnerable to TB. Scoring is done against the main (7) TB-related human rights issues (right to freedom from non-discrimination [enacted stigma], right to access information, right to access services, right to privacy, right to informed consent, right to freedom from involuntary isolation, right to a safe workplace).
- The Core Group agrees on scoring and provides recommendations for the Action Plan.

#### Afternoon (analysing results)

- The Core Group splits into four groups, with each group focusing on one questionnaire. Each group reviews the responses of the three open-ended questions for the questionnaire assigned to the group.
- Each group summarizes the most frequently mentioned stigma issues/manifestations and stigma mitigation measures suggested by the respondents.
- Each group reports back in a plenary session (facilitated by the Stigma Expert).
- The Project Manager/Stigma Expert summarizes the key issues by questionnaire, as agreed upon by the end of Day 1, for each of the seven stages of the TB journey.

## DAY 2 AGENDA

### Morning Session (Action Plan development)

- The Project Manager/Stigma Expert presents a summary of Day 1, the Stigma Radar and other charts in the “Results” sheet of the Workbook.
- The Core Group splits into seven groups, with each group focusing on one of the seven stages of the TB journey:
  - Recognize symptoms
  - Seek timely care
  - Get accurate diagnosis
  - Begin treatment
  - Get treatment adherence support
  - Complete treatment
  - Get post-treatment follow-up services
- Each of the seven groups then discusses:
  - What aspects of stigma and its manifestations need to be addressed most urgently/prioritized to maximize impact?
  - What interventions are needed?
  - How do these priority interventions align with the National Strategic Plan?
  - Where and when should the interventions be implemented?
  - Which organization should be the focal point to monitor the implementation of the Action Plan?

### Afternoon (reporting back and drafting the Action Plan)

- Each group reports back in the plenary (facilitated by the Project Manager/Stigma Expert).
- The Project Manager/Stigma Expert summarizes the priority interventions agreed (endorsed) by the end of Day 2 for each of the seven stages of TB journey.
- The Project Manager/Stigma Expert enters summaries from both days into the Workbook.
- Subject to approval, the Core Group endorses the draft Action Plan to be submitted to the multi-stakeholder validation workshop for final endorsement.

## ANNEX G: SAMPLE BUDGET TEMPLATE

This template can be adapted to draw up a budget for the TB Stigma Assessment to be submitted to the Core Group for approval.

| (A)  | (B)   | (C)         | (D)             | (E)               | (F)                     |
|--|---|-------------|-----------------|-------------------|-------------------------|
| Item   | Details   | Unit        | Number of Units | Unit Costs (US\$) | Amount (US\$) (D) x (E) |
| (1) <b>Stigma Expert compensation</b>  | Full-time compensation  | Months      | X               | Xx                | Xx                      |
| (2) <b>Training</b> - Interviewer training workshop (2-day workshop for X people)  | Venue (e.g., local community hall or NGO office) hire per day (trainees return home at the end of Day 1, no hotel needed)     | Days        | X               | Xx                | Xx                      |
|  | Lunch and refreshments  | Person-days | X x X           | Xx                | Xx                      |
|  | Public transportation   | Person-days | X x X           | Xx                | Xx                      |
| (3) <b>Data Collection</b> - x interviewers, each spending x hours in x days over an X-week period                                       | Lunch   | Person-days | X               | Xx                | Xx                      |
|  | Public transportation (to conduct interviews & end-of-day meeting with Project Manager)                                       | Person-days | X               | Xx                | Xx                      |
|  | Token non-monetary gifts for interviewees who complete interview  | Interviews  | X               | Xx                | Xx                      |
| (4) <b>Law and Policy Environment Scoring and Analysis FGD Meeting</b>   | Venue (e.g., local community hall or NGO office)  | Days        | X               | Xx                | Xx                      |
|  | Lunch and refreshments  | Person-days | X x X           | Xx                | Xx                      |
|  | Public transportation   | Person-days | X x X           | Xx                | Xx                      |
| (5) <b>Results dissemination</b>   | Report writing and design (graphics, Action Plan)   | Consultancy | X               | Xx                | Xx                      |
|  | Printing of report  | Reports     | X               | Xx                | Xx                      |
| (6) <b>Multi-stakeholder meetings</b> (two 2-day meetings, "Orientation" at the beginning and "Validation" at the end of the Assessment) | Venue (e.g., local community hall or NGO office) hire per day (participants return home at the end of Day 1, no hotel needed) | Days        | X x X           | Xx                | Xx                      |
|  | Lunch and refreshments  | Person-days | X x X x X       | Xx                | Xx                      |
|  | Public transportation   | Person-days | X x X x X       | Xx                | Xx                      |
|  |   |             |                 | <b>TOTAL</b>      | <b>XXXX</b>             |

## ANNEX H: OTHER RESOURCES

### **KNCV - Stigma Measurement Guidance**

[https://www.challengetb.org/publications/tools/ua/TB\\_Stigma\\_Measurement\\_Guidance.pdf](https://www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf)

A collection of validated tools and strategies for planning TB stigma baseline measurements and monitoring trends in order to capture the outcomes of TB stigma reduction efforts.

### **KNCV - The Work for Change Self-Stigma Toolkit**

<https://www.kncvtbc.org/uploaded/2018/10/From-the-Inside-out-stigma-compressed.pdf>

A framework and tools to reduce self-stigma in people with TB.

### **KNCV - Health Care Setting Stigma Toolkit**

[https://www.kncvtbc.org/uploaded/2018/10/Allies\\_Approach\\_V4.pdf](https://www.kncvtbc.org/uploaded/2018/10/Allies_Approach_V4.pdf)

A package of self-learning modules to change the attitudes and workplace conditions of health care workers in order to enable them to provide empathetic, non-stigmatizing care to all people with TB.

**Stop TB Partnership - Legal Environment Assessments (LEA) for Tuberculosis: An Operational Guide** (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](http://www.stoptb.org/assets/documents/communities/StopTB_TB%20LEA%20DRAFT_FINAL_Sept%2027.pdf)

A guide for countries to document issues relevant to TB and human rights and to foster national dialogue around TB laws.

**FXB Center for Human Rights - Health and Human Rights Resource Guide** (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>

This chapter covers key issues and resources in TB and human rights – international human rights standards and rights-based approach to advocacy, litigation and programming.

### **Sampling methods**

Chapter 9 (Sampling methods for measuring TB stigma in hard-to-reach populations without sampling frames) in KNCV Measurement Guidance

[https://www.challengetb.org/publications/tools/ua/TB\\_Stigma\\_Measurement\\_Guidance.pdf](https://www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf)

An overview of scientific sampling methods for collecting data among hard to reach populations.

### **Cultural adaptation of the TB-related stigma scale in Brazil**

[http://www.scielo.br/scielo.php?pid=S1413-81232016000702233&script=sci\\_arttext&tlng=en](http://www.scielo.br/scielo.php?pid=S1413-81232016000702233&script=sci_arttext&tlng=en)



## **TB Stigma Assessment - Implementation Handbook**

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