# TB Stigma
## Measurement Guidance

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# Guidance

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# Acknowledgements

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# Acronyms

| | |
|---|---|
| ACT | African Coalition on TB |
| AIDS | Acquired Immune Deficiency Syndrome |
| CAB | Community Advisory Boards |
| CBO | Community Based Organization |
| CBPR | Community-based Participatory Research |
| CDC | U.S. Centers for Disease Control and Prevention |
| CEA | Cost-effectiveness Analysis |
| CISNAT-SL | Civil Society Movement Against Tuberculosis in Sierra Leone |
| CRAG | Community Research Advisory Group |
| CUA | Cost-utility Analysis |
| DALY | Disability-adjusted Life Years |
| DOTS | Directly Observed Treatment Shortcourse |
| DS-TB | Drug-sensitive TB |
| GDP | Gross Domestic Product |
| GIPA | Greater Involvement of People Living with HIV and AIDS |
| GNP+ | Global Network of People Living with HIV |
| HCW | Healthcare Worker |
| HIV | Human Immunodeficiency Virus |
| ICER | Incremental Cost-effectiveness Ratio |
| JE | Justice Enhanced |
| LAM | Lipoarabinomannan |
| LED | Light-Emitting Diode |
| LGBT | Lesbian, Gay, Bisexual and Transgender |
| LTBI | Latent TB Infection |
| MDR-TB | Multi-drug Resistant TB |
| M&E | Monitoring and Evaluation |
| NGO | Non-governmental Organization |
| NIAID | National Institute of Allergy and Infectious Diseases |
| NIH | National Institutes of Health |
| NTP | National TB Program |
| PLTB | Person Living With TB |
| PWTB | Person with TB |
| QALY | Quality-Adjusted Life Year |
| REDTBLAC | Red de Personas Afectadas por Tuberculosis en Latino América y El Caribe |
| RDS | Respondent-Driven Sampling |
| SOP | Standard Operating Procedure |
| SSM | Sputum Smear Microscopy |
| TAG | Treatment Action Group |
| TB | Tuberculosis |
| TB CAB | The Global TB Community Advisory Board |
| TBEC | TB Europe Coalition |
| TLS | Time Location Sampling |
| TSMG | TB Stigma Measurement Group |
| UNDP | United Nations Development Programme |
| USAID | United States Agency for International Development |
| VDT | Venues, Days and Times |
| WHO | World Health Organization |

# Introduction

The word stigma is derived from the Greek word for a mark or a stain. Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Within particular cultures or settings, certain attributes are defined by others as discreditable or unworthy. When stigma is acted upon, discrimination may result.

Stigma related to tuberculosis (TB) is receiving well-deserved attention at the policy level.[1] Zero suffering is one of the three aims of the WHO's End TB strategy, and stigma is commonly referenced in key implementation documents.[2–4] The Global Fund has declared it one of the most commonly identified barriers to fighting the TB epidemic,[5] and The United Nations agencies have called for an end to discrimination in health care.[1] People with TB are also making their rejection of TB stigma a cornerstone of organizing efforts.[6] By demanding respect and dignity in health care, employment, education, and the justice system, TB survivors and their families are signaling a new era in power relations between programs and patients.

We have always acknowledged that TB stigma represented a significant challenge, but we have traditionally framed TB stigma as either natural[7] and intractable[3], or easily overcome with a general improvement in quality or access to care.[8]

Recent studies have shown that both frames are inaccurate.[9] TB stigma is not as unyielding as previously suggested.[10] It can be reduced with well-designed efforts.[10,11] However, stigma does not simply fade away as a result of small changes, nor is it a collateral result of improving the clinical standard of care or access.[6,9]

This measurement guidance was born from the deliberations of a three-day TB Stigma Measurement Experts meeting in May of 2016 in the Hague, the Netherlands, organized by the KNCV Tuberculosis Foundation and supported through USAID's flagship project Challenge TB.[12] Attended by over 50 Social Scientists, NGOs, donors, and technical partner agencies, the meeting brought stakeholders from across the world to debate TB stigma measurement papers and to grapple with the best way to define, capture, and report TB stigma in a variety of settings and populations.

Their conclusion was that, with proper guidance, TB stigma measurement can be carried out by community-based organizations with research backgrounds and national TB program staff.[12] Each chapter of this guide attempts to balance ambition and pragmatism. It offers step-by-step instructions and limited jargon and intuitive graphics. This book and the accompanying curriculum will not make readers into TB stigma measurement experts, but will enable users to conduct assessments in a timely, systematic, and pragmatic manner according to well-established research standards.

Many people default to doing surveys when they want to measure attitudes or behaviors, but that is not always appropriate with stigma. This manual is intended for National TB program staff, implementing agencies, NGOs, CBOs, donors, WHO, technical partners, and TB advocates to understand the range of options and to make appropriate methodological choices. All of these stakeholders may have distinct reasons to measure TB stigma.

The goal of this manual is to help busy people generate enough information about stigma issues to design and monitor and evaluate (M&E) stigma reduction efforts. We adhere to some basic M&E principles familiar to many readers. This manual is not for academics or theorists, but rather for health workers, professional or management staff, people who advocate for those with TB, and all who need to understand stigma and respond to TB stigma.

The guidance is designed to be user-friendly and appropriate for a broad audience, and it contains concrete examples and tools that are easy to adapt and use. We offer validated tools and strategies where they exist and recommend ways to experiment and innovate where they do not. This guide is appropriate for planning TB stigma baseline measurements and monitoring trends to capture the outcomes of TB stigma reduction efforts.

Readers should also consult the Companion Curriculum of this manual to fortify their skills and core competencies in TB stigma measurement.

The training materials include exercises and offer more in-depth coverage of challenging topics that require strong research skills. The Companion Curriculum to this guide can be downloaded here:

http://www.challengetb.org/publications/tools/ua/TB_Stigma_Companion_ Curriculum.pdf

The curricula include ready-to-use PowerPoints, training exercises, and pre/ post-tests. Like the guidance, it can be used in a modular way (i.e., face to face course, webinar, or combined with an M&E workshop). We hope to have a training of trainers to create a pool of professionals in each region (activists, nurses, providers, and researchers) that can help countries implement these tools.

# How should this book be used?

It is not necessary to read the whole book. Chapters 1 and 2 are sufficient to give an overview, and then read only the chapters that are relevant for the particular stigma problem you are measuring. The glossary provides useful definitions of core concepts. This is a technical guide to help TB programs and partners measure levels of TB stigma in specific settings and populations. The Companion Curriculum is designed to build the skills and core competencies in TB stigma measurement that you will need to successfully undertake the TB stigma studies recommended in this book.

# Overview of the contents

**Chapter 1** introduces readers to stigma theory and some basic definitions of types of stigma. **Chapter 2 (methodology)** offers an overview of the scientific and operational considerations for matching your stigma measurement method to your question. **Chapter 3** teaches formative qualitative research techniques to find out why the TB stigma takes a particular form, where the stigma comes from, and how stigma operates in your setting. **Chapter 4** focuses on the measurement of TB stigma at the community level. This chapter details special considerations for embedding TB stigma measures in household surveys (e.g., scale length), and in settings with concentrated vs. generalized HIV epidemics. **Chapter 5** focuses on measurement of TB discriminatory attitudes and behaviors in institutions such as prisons, schools, and health facilities, and has a special focus on measuring enacted TB stigma (discriminatory behaviors) through observational methods. The TB stigma literature has focused more on discrimination and disparagement of individual TB patients and less on the structural forms of discrimination.[13–17]

**Chapter 6** covers the measurement of structural stigma. **Chapter 7** teaches the basic principles of TB stigma measurement among TB patients. This is a relatively well-developed field with validated TB stigma scales robust in a variety of settings. Nevertheless, there are statistical and sampling challenges that require special consideration. Techniques for measuring secondary stigma are introduced in **Chapter 8**. This chapter describes the best practices for measuring stigma among healthcare workers (HCW), family members, and those in TB-affected industries. HCW stigma measurement is a high priority because HCW are often stigmatized for their vital TB care work, and yet may simultaneously mistreat TB patients.

**Chapter 9** explores how to measure TB stigma among socially networked populations who are already marginalized and socially excluded for other reasons. It outlines the efforts required to obtain reliable and unbiased estimates. State-of-the-art methods for capturing self-stigma, resilience, and self-efficacy are covered in **Chapter 10**. It is vital to measure the strengths and forms of

resistance of people affected by TB. Documenting how some groups successfully deflect stigma can inform interventions. **Chapter 11** teaches how to deconstruct the language of TB programs to identify stigmatizing rhetoric and discourse. This chapter explores methods for policy analysis to pinpoint stigma embedded in norms and guidelines.

**Chapter 12** describes how to engage civil society and TB patients meaningfully in TB stigma measurement efforts. This text provides useful tips on participatory strategies that prevent further stigmatization and ensure dignity. **Chapter 13** lays out the methodological foundations for incorporating the costs of TB stigma and social disadvantage into a cost-effectiveness analysis. Policy and strategy debates in TB control may have unintended consequences that should be anticipated. **Chapter 14** involves intersectional and compound stigmas, such as the double stigma of TB/HIV. It is widely understood that TB stigma can be enmeshed with other kinds of social exclusions and marginalities. This creates analytical challenges that must be managed carefully to prevent bias and confusion. **Chapter 15** describes how to study the impact of TB on complex behaviors, such as health-seeking, adherence, and mortality. This is a field of particular interest to TB programs seeking to understand the impact of TB stigma on their program. **Chapter 16** gives concrete advice for those who want to develop and validate their own TB stigma scales. **Chapter 17** gives step-by-step instructions for analyzing qualitative data from formative stigma research.

## Table 1. Overview of the Questions Answered in this Book

| Research Questions/ Research Topics | Chapter |
| --- | --- |
| 1. How do I meaningfully engage people with TB in this work? | Chapters 1, 2, and 14 (Stigma theory, Methods, and Advocacy) |
| 2. How does stigma operate in my setting? What are the underlying ideas behind this stigma? | Chapter 3 (Drivers) |
| 3. How do I organize a TB stigma study? | Chapter 2 (Methods) |
| 4. Does stigma hamper TB screening/diagnosis? | Chapter 4 (Measuring TB stigma at the Community level) |
| 5. How do healthcare workers experience TB stigma when they provide TB services? Does this impact care? | Chapter 8 (Measuring TB stigma among healthcare workers) |
| 6. Does stigma hamper the quality and completeness of contact and outbreak investigations? Does stigma reduce willingness to disclose TB disease to contacts? | Chapter 7 (Measuring TB stigma among TB patients) |
| 7. Does stigma contribute to the erosion of social capital and social networks (social impacts)? | Chapters 7 and 10 (Measuring stigma among TB patients, Measuring Self-Stigma) |
| 8. Do our laws and policies stigmatize or discriminate? | Chapters 6 and 11 (Measuring structural stigma and Discourse analysis) |
| 9. How do I measure someone's discriminatory beliefs or actions accurately? | Chapter 5 (Stigmatizing behaviors) |

| | |
|---|---|
| 10. How do to know if TB stigma is really the cause of low health service utilization by key populations? | Chapter 9 (Measuring TB stigma in hard-to-reach populations), Chapter 14 (Intersectional stigma) |
| 11. Does TB stigma contribute to poor adherence or treatment outcomes? Does TB stigma hamper treatment initiation? | Chapter 15 (Measuring the impact of stigma on treatment adherence) |
| 12. Does TB stigma(s) worsen TB outcomes, via poor adherence or loss to follow up? | Chapter 15 (Measuring the impact of stigma on behavior) |
| 13. Is stigma limiting the returns from other TB investments? | Chapter 13 (Measuring the cost of stigma) |
| 14. Does stigma contribute to death and disability? | Chapter 15 (Measuring the impact of TB stigma on TB mortality) |
| 15. Does stigma contribute to catastrophic costs for patients? | Chapter 13 (Measuring the cost of stigma) |
| 16. Are we communicating in ways that stigmatize? | Chapter 11 (Discourse analysis for measuring TB stigma) |
| 17. Does stigma hamper recovery and long term wellness (mental health and quality of life)? | Chapter 10 (Measuring resilience, resistance, coping, and countering) |

We invite you to focus on the chapters you need and adapt the tools and techniques to your unique setting. There is a companion curriculum to help implement the techniques recommended here. We invite you to share feedback on what you learn to strengthen the global efforts to measure and reduce TB stigma.

## Acknowledgements

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# Chapter 1

# TB Stigma Theory and Measurement

*"Defeating racism, tribalism, intolerance, and all forms of discrimination will liberate us all, victim and perpetrator alike." Ban Ki-moon*

*Kate Macintyre, Ellen M.H. Mitchell, Amrita Daftary, and Gill Craig*

## Abstract

There is a science to stigma measurement that brings TB stigma into focus. This book will orient the reader to the basics of TB stigma measurement. Mapping stigma becomes feasible once its underlying mechanisms are understood. The means by which bias and social exclusion are created is well understood. This chapter outlines the common architecture upon which different types of bias and hate are built by illustrating the basic process of "othering".

## Objectives

1. To explain why we must measure TB stigma, and who should be involved in this process.
2. To introduce the elements of stigma theory.
3. To present a basic typology of stigma.

## Target Audience

This chapter is for people intending to measure TB stigma who lack an in-depth understanding of stigma theory. It is for community-based organizations, TB program staff, M&E officers, and others who have not studied discrimination or marginalization in an academic setting.

## Introduction

Many experts believe that it will be necessary to address TB stigma in order to diagnose and treat the 4 million TB cases that are currently unidentified.[1,2] Similarly, the life-saving potential of new multi-drug resistant TB (MDR-TB), pediatric, and latent TB drugs and regimens cannot be realized without first addressing TB stigma.[3]

Increasingly, countries are attempting to reduce TB stigma and discrimination across and within elements of their TB programs. However, the capacity to measure and evaluate the success of these interventions must be fostered through capacity building.[4–7]

This chapter introduces stigma theory and identifies and defines the basic vocabulary of stigma.

## Why do we need to measure TB stigma?

There is increasing recognition that TB stigma continues to be a major barrier for some people (patients, families, caregivers, and communities).[8–11]

Figure 1 exemplifies how TB stigma delays treatment, hinders recovery, and increases the suffering of some people with TB.

**Figure 1. Potential Impacts of Stigma along a Person's TB Care Itinerary or Trajectory (Artist: Retsu Takahashi).**

Stigma reduces or improves health-seeking behavior

Stigma undermines full recovery and sense of self, affects contact tracing

Fear of stigmatization reduces use of masks/ separation infection control contributing to transmission?

Stigma lowers MD's index of suspicion for some groups

Stigma reduces or improves health seeking behavior

Stigma undermines the patient provider partnership

Stigma obstructs accurate recording and reporting - impact disease and mortality estimates

Stigma causes stress which contributes to breakdown to disease

Stigma leads to aggressive screening in some groups and no screening in other at-risk communities

Reducing TB stigma to facilitate early diagnosis and full recovery is increasingly a priority of national TB programs. Patient groups and groups representing those who suffer from the stigma of TB, such as miners and healthcare workers, are also calling for concerted efforts to reduce stigma.[12,13]

Several donors and governments are asking TB programs to further reduce barriers to TB services. The Global Fund is asking countries to improve their analysis of the human rights barriers to TB services, but some TB programs lack the skills necessary to do this.[14,15] One of the ways to help these programs is to demonstrate how to measure stigma and discrimination to reveal how it impairs health care seeking, quality of care, and recovery.

## Participatory approaches to TB Stigma measurement

Participatory research was developed in response to concerns that traditional forms of research conferred too much power on researchers to set research agendas and provide solutions.[5,6] Participatory TB stigma research recognizes that communities have expertise in identifying the drivers of stigma and in creating solutions.

TB stigma knowledge should thus be co-produced with and co-owned by those most affected by TB.[5,7] Participatory research aims to democratize the research process and challenges traditional power relations in the 'smash and grab' approaches to research. Historically, research was conducted without involving those most affected, and recommendations were made with little sensitivity to the impacts of implementation.[5,8] Table 1 lists ways to engage people in the stigma measurement process.

**Table 1. Ways to Engage People with TB in the Stigma Measurement Process**

| Participating in Research | Managing Research |
|---|---|
| • Setting the research agenda by deciding on topics for research. <br> • Sitting on recruitment panels for the appointment of research staff. <br> • Acting as researchers/peer researchers following training. <br> • Conducting fieldwork and collecting data. <br> • Assisting with the analysis and interpretation of data. <br> • Devising recommendations. <br> • Writing or coauthoring research reports. <br> • Disseminating findings. <br> • Serving as interpreters or cultural ambassadors. | • Acting as co-applicants on research proposals. <br> • Chairing or participating in project advisory groups/ steering committees. <br> • Chairing or participating in research implementation groups and ethical review committees. <br> • Monitoring the implementation of recommendations. |

There are many different ways of conducting participatory research with affected communities that go beyond interviews or focus groups. Some have been used in the field of TB. These are described in Chapter 12. We believe that there is plenty of room to incorporate the full range of stakeholders, disciplines, and experiences. Diversity can strengthen the process and outcomes as TB stigma

measures are advanced. Survivors, families, friends, caretakers, healthcare workers, and other TB-associated occupations also witness and suffer from stigma, and stigmatize. Many perspectives are needed to develop comprehensive tools.[16,17]

Engaging communities in owning the problem of TB stigmas and crafting the solutions is essential. The following resources detail how to address the challenges associated with engaging communities in this process:

Van der Werf, Mitchell, and Heumann. Community Engagement in TB Research. STOP TB Partnership Research Movement. Community involvement in tuberculosis care and prevention. Towards partnerships for health. Guiding principles and recommendations based on a WHO review WHO/HTM/ TB/2008.397.

Somesh Kumar. 2002. Methods for Community Participation: A Complete Guide for Practitioners London:ITDG

Parks et al. Communications for Social Change Consortium. 2005. Who measures change? An introduction to participatory monitoring and evaluation of communication for social change.
Available at: http://www.comminit/en/node/70592/347
(Document can be downloaded from a link at the bottom of the web page)

Guy Bessette. Involving the Community: A Guide to Participatory Development Communication. http://web.idrc.ca/en/ev-52226-201-1-DO_TOPIC.html

# Conceptualizing TB stigma and its measurement

There has been considerable work on measuring TB stigma over the past 20 years. Link and Phelan's 2001 publication *Conceptualizing Stigma* helps in the understanding and measurement of TB stigma.[18] They show that while the process of stigmatization (for multiple conditions or illnesses) is complex, it can be untangled by following a clear framework.

# TB Stigma is not natural

Understanding the way that stigma is constructed is important for its measurement and reduction. Once thought to be evolutionarily advantageous, most theorists now see stigma as a maladaptive social structure.[19,20]

TB stigma is neither a natural nor inevitable part of having TB.[18] It needs to be enabled and nurtured to exist.[21] Figuring out what ideas, legal, social and cultural norms, rhetoric, and routines fuel and sustain particular stigmas requires detailed

inquiry. However, there are some hallmarks of stigma production that have been defined over the years.[18,20,22] These include conscious and unconscious processes that generate prejudice. They can be envisioned as a series of progressive, sequential steps, and conditions under which it may become socially permissible to reclassify a person as somehow less valuable.

Link & Phelan give a framework of defined components that make up the "stigmatizing process" and show that people construct categories around people with conditions or differences. These categories then get linked to stereotypical beliefs, which can lead to discrimination or other forms of behavior change that affect the patient or their family. The different types of stigma are described below. The group of sufferers (or patients) that is stereotyped with negative attributes either think they are going to be stigmatized, or they are made to feel stigmatized. Link and Phelan describe this process in the following way:

"In our conceptualization, stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them." In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes.

## Effective stigmatization requires power

Finally, stigmatization is highly contingent upon access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination. Thus, we apply the term stigma when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold."[18]

Stigmatization, and the discrimination that can result from it, are only possible when there are differences in power between the group being stigmatized and the so-called mainstream group (the powerful).[20]

They use politicians as an example. In many societies, people attach negative attributes to "politicians." But few would consider them to be stigmatized because of the influence they wield.

Figure 2 shows how stigma creation begins innocuously with the recognition of difference, and the gradual insidious process of exaggerating difference to the point of dehumanization. Stigma theorists find commonalities in this process across countries and across stigmatized identities.

**Figure 2. A typical stigma-building Cascade (Link & Phelan)**

**Mark differences as "not normal"**
- Create new language and terms to connote otherness
- Medicalize and pathologize difference
- Dehumanize
- Infantilize

**Rhetorically linked to deviance, negative traits**
- Create stereotypes (e.g., dangerous, unpredictable, untrustworthy, noncompliant, secretive)
- Link to other disparaged groups/identities OR recast as "victims" - without agency

**Establish responsibility for TB to blame**
- Blame
- Shame
- Punish

**Emphasize the peril of TB to normalize exclusion**
- Rationalize, legitimize, normalize disparities in access, care, empathy, and protection
- Render unworthy of consideration, investment, or engagement

**Curtail rights and other harms**
- Ghettoize, quarantine
- Discriminate
- Microaggressive acts
- Disparage, malign
- Create failure loops

Almost all stigma involves the social construction of dangerousness.[22] The social creation of a different, dangerous identity creates fear. Generating fear of the 'marked' person is an essential step in creating stigma. Many times this requires amplifying or exaggerating the risk that a disease or condition poses to society.[23]

## Unpacking Stigma

To understand TB stigma, the first task is to clearly separate stigma drivers, domains, and consequences in your mind. This will help you to pose and answer the right questions.

**Figure 3. Unpacking Stigma**



- Drivers of TB stigma
- Domains of TB stigma
- Consequences of TB stigma
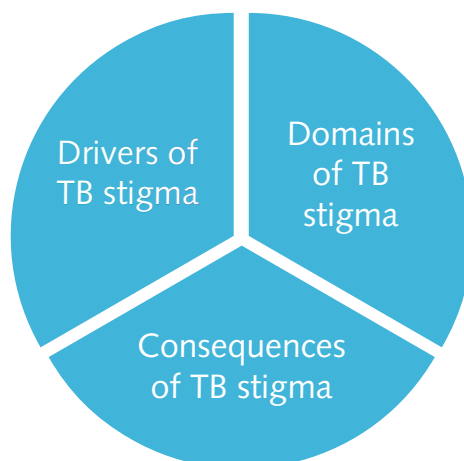
# Domains of Stigma

If you think of stigma as a puzzle, then domains would be the individual pieces of the puzzle.

Pescosolido and Martin (2015) identified seven domains of public stigma: social distance, traditional prejudice, exclusionary sentiments, negative affect, treatment carryover, disclosure carryover and perceptions of dangerousness.[1]

**Figure 4. Common domains of Public Stigma[2]**
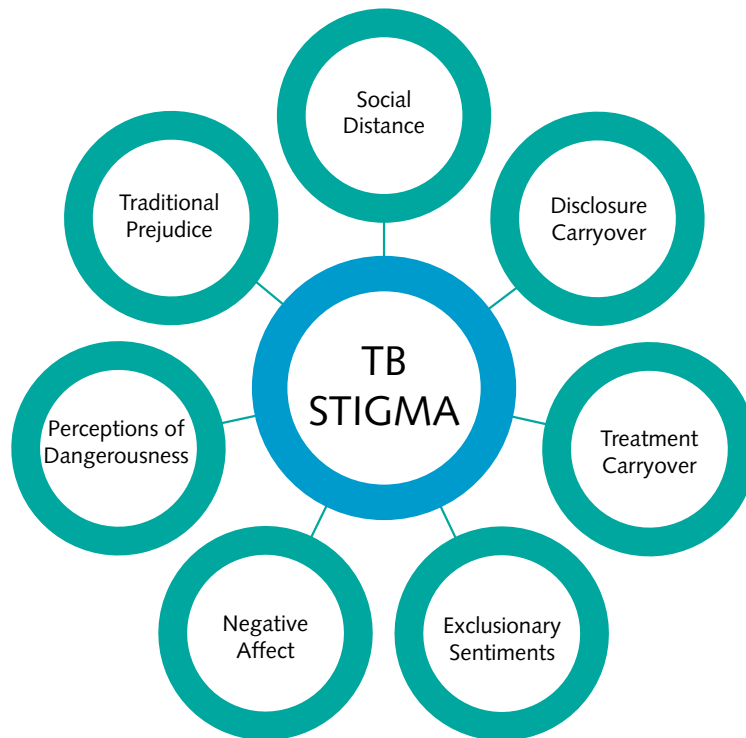


These seven domains may sound abstract but when explained in terms of TB patients they become recognizable as commonly understood parts of stigmatization.

1. "Social distance" is when someone tries to avoid a person with TB (PWTB).
2. "Traditional prejudice" is when someone stereotypes people with TB believing all people with TB are less valuable
3. "Exclusionary sentiments" refers to the wish to separate PWTB from everyone else, or deny them their rights.
4. "Negative affect" refers to emotional reactions such as disgust or hatred toward PWTB,
5. "Treatment carryover" is when people are afraid of people knowing they were treated for TB in the past. This is the perceived need for secrecy that may linger after a person recovers.
6. "Disclosure carryover" is when people are afraid of the reactions they would get if they were known to have TB.
7. "Perceptions of dangerousness"[1] is the idea that PWTB somehow represent a risk to society.

## Universal and local

Almost all stigmas are made by attaching negative ideas, labels, and behaviors, to a person. The process of 'sticking' labels onto marked people involves making rhetorical links and associations. This can be a conscious or an unconscious process. While negative labeling and linking are part of the 'stigma backbone' all over the world, the specific labels, links, and stereotypes vary by context. In some communities in Africa, TB is frequently linked to abortion or associated transgression of sexual mores.[24,25] In Asia, TB can be linked to dependency on tobacco and alcohol.[26] Among drug users in a treatment program in urban Chicago, having TB was rhetorically associated with selfishness, greed, and a lack of street ethics and solidarity.[27] People who used drugs who developed TB were said to engage in deception, cheating, and failure to uphold community norms around drug sharing.[27]

**Figure 5. Illustrative Negative TB Stereotypes by Setting**
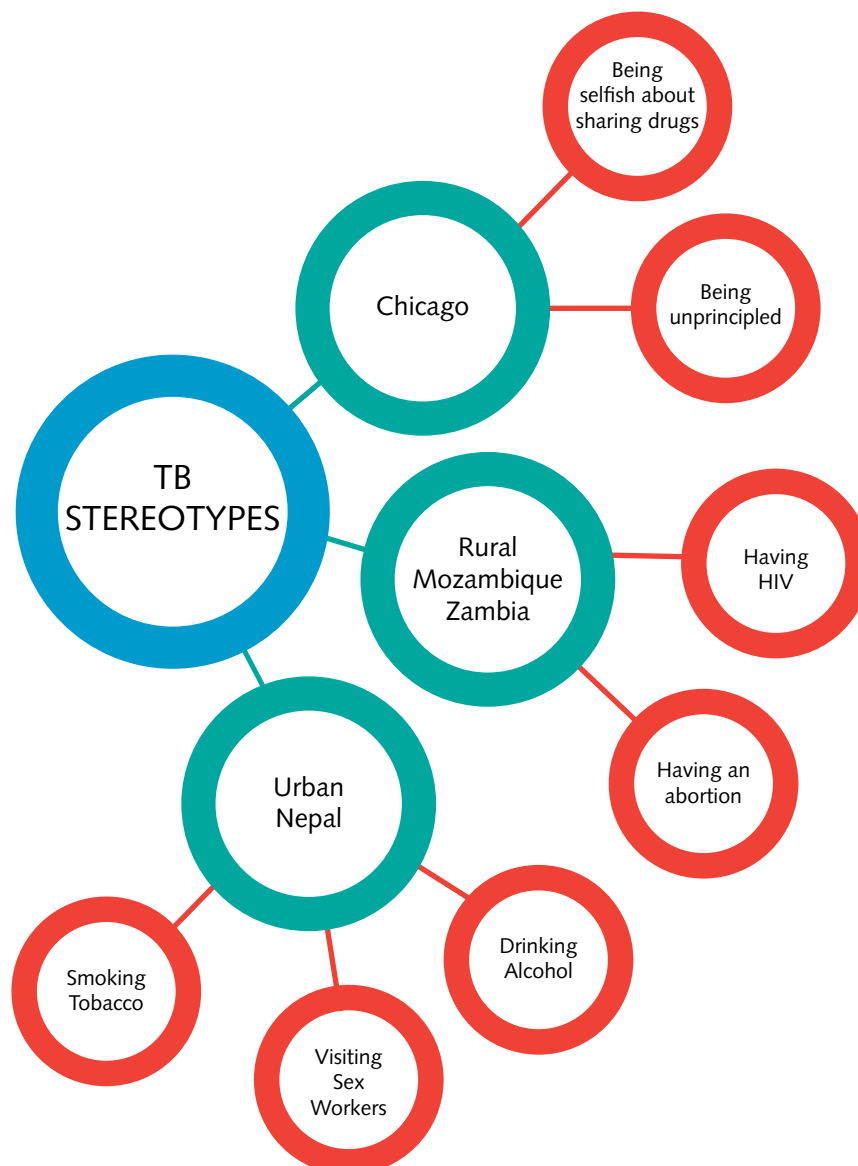
## Definition of types of TB stigma and populations to measure it

**Public stigma** describes negative attitudes, beliefs, and behaviors held by the wider community or general public. This is closely related to anticipated stigma.

**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 that the stigma against the person will be so bad that it affects treatment. It may delay people from returning for care, or impact adherence to the prescribed drugs. Whether or not stigma actually occurs, anticipated stigma may interfere with care seeking and treatment adherence.

**Secondary stigma**[28] refers to the idea that caregivers, friends, family members, or health workers may expect negative attitudes or rejection because of their association with the disease and/or TB patients. (See also courtesy stigma). Further, this may dictate their behavior or beliefs, regardless of whether the stigmatizing attitudes or reactions actually occur.[29]

**Internalized or self-stigma** captures the idea that individuals may come to endorse negative stereotypes, and therefore behave or think according to these false portrayals and negative messages.[20,30]

**Enacted or experienced stigma** reflects the range of stigmatizing behaviors, messages, and effects that are either directly experienced by the person with TB or their families and/or that drive others to acts of discrimination, rejection, or isolation. It is useful to distinguish between enacted and experienced stigma as two sides of the same coin, either seen from the perspective of the stigmatizer (enacted) or the stigmatized (experienced).

**Structural stigma** describes the laws, policies, 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."[31,32]

Table 2 highlights the fact that most research to date has focused on those on the receiving end of discrimination as opposed to those perpetrating it. To reduce stigma, it will be important to focus on understanding the attitudes and behaviors of those who stigmatize.

**Table 2. Matrix to Delineate Types of Stigma by Main Population Groups**

| Population Group | Anticipated stigma | Internalized/self stigma | Enacted or experienced stigma (≈discrimination) |
|---|---|---|---|
| General Public | (Jaramillo, 1999; Aaron M Kipp et al., 2011; Murray et al., 2013; Rood, Mergenthaler, Bakker, Redwood, & Mitchell, 2017; Van Rie et al., 2008) (Sagili, Satyanarayana, and Chadha 2016) | | (Dodor and Kelly 2009; Møller et al. 2011) |
| Vulnerable groups at higher risk of TB | (Adams et al., 2017; Colvin, 2005, Godfrey-Fausset, 2002) (Chikovore et al. 2017; de Vries et al. 2017) | | (Adams et al. 2017) |
| Members of TB-affected families | (Arcêncio et al., 2014) (Coreil et al. 2010) | | (de Almeida Crispim et al. 2017; Bond et al. 2017; Touso et al. 2014) |
| People with TB | (Cremers et al., 2016; Murray et al., 2013) | (Jittimanee et al., 2009; A.M. Kipp et al., 2011; Macq, Solis, Martinez, & Martiny, 2008; Somma, Gosoniu, et al., 2008) | (Bond et al., 2017; Somma, D., et al., 2008)(Daftary and Padayatchi 2012; Miller et al. 2017) |
| Healthcare workers | (Buregyeya et al., 2012; Sommerland et al., 2017; E Wouters et al., 2017; Edwin Wouters et al., 2016,(Tudor et al. 2013) (Coreil, Lauzardo, and Heurtelou 2012) | (Sommerland et al., 2017; E Wouters et al., 2017; Edwin Wouters et al., 2016) | (Straetemans, Bakker, & Mitchell, 2017) (Dodor, Kelly, and Neal 2009; Nottingham and User 2009) |
| Media | (Smith, 2016; Soffer, 2011a, 2011b) | | |

Moreover, we will need to expand our focus beyond individual bad behavior to the societal structures that enable stigma to persist.[33]

## Conclusion

While we hope this book spurs robust measurement of TB stigma, measurement itself is not the goal. We hope to catalyze intervention and prompt additional resources to end discrimination and prejudice against people with TB. Moreover, only by improving the well-being and quality of life of those at risk for TB, and the family and caregivers that surround them, can we reach this aim. Valid stigma measurement is necessary to kick-start the kind of transformational work that is needed to end TB.

## Acknowledgements

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# Chapter 2

# Overview of Methodological Considerations for Measuring TB Stigma

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## Abstract

TB stigma is embedded in social structures, human behavior, and belief systems. In addition to a diversity of types of stigma, there are also a wide range of vital questions to be answered about its severity, scope, and impact. TB stigma measurement methods should be adapted to specific goals. This chapter will help researchers select the method best suited for their question.

## Objectives

1. To provide an overview of the general principles of TB stigma measurement.
2. To guide readers in assessing their options and selecting the methodology best suited to their study aims.
3. To lay out the operational steps and considerations when measuring stigma.

## Target audience

This chapter is essential reading for all persons who want to measure TB stigma and need an overview of basic principles. TB program staff and non-governmental organization staff will benefit from the chapter's pragmatic and stepwise approach to TB stigma measurement.

## Introduction

TB stigma is embedded in law text, dialog, behavior, attitudes, and even in architecture.[1] It includes anticipated and actual discrimination. Crucially, it can be measured both from the point of view of the stigmatizer or the stigmatized. TB stigma measurement methods should adapt to exercise goals. Measuring different manifestations and impacts of TB stigma involves a range of data collection and analysis methods, including direct and participant

observation, structured and unstructured interviews, discourse analysis, cost-effectiveness analysis, and non-traditional sampling and statistical approaches. Stigma measurement can also be an advocacy effort where primacy is given to amplifying compelling narratives and authentic voices. This chapter helps researchers to pick the method best suited for their needs and provides general advice for stigma measurement efforts.

For some readers with a clinical background, an accessible analogy may be to compare the challenges associated with TB stigma measurement to challenges associated with TB diagnostics. Different types of TB stigma are analogous to different types of TB. Some are easier to detect than others. The challenge is to select the methodology that is sufficiently accurate to assess the type of stigma you are looking for within a reasonable time limit and budget.

**Table 1. Analogies between the TB Stigma Studies and the Challenges of TB Diagnoses**

| Type of Stigma | Analogous to Diagnosis of | Rationale |
|---|---|---|
| Enacted stigma against patients | Pulmonary TB in adults | Methods well established, validated tools available. |
| Secondary stigma of families and care workers | Extra-pulmonary TB | Manifestations vary widely, methods not well standardized, few tools. |
| Self-stigma | Childhood TB | Hard to differentiate from other health issues, requires skill, experience, methods under development. |

As with TB, TB stigma tests are not always performed the same way in all circumstances. Methods will often require local adaptation. This is analogous to 'calibration' of laboratory or radiological equipment. This chapter introduces standardized operating procedures (SOPS) for measuring stigma, which should be adjusted for local conditions.

The methods of stigma measurement vary depending on the goal. Some common reasons for measuring stigma include:

1. Because you want to know whether TB stigma is causing additional suffering or sequelae for people with TB (Chapters 7, 10, 15)[2]
2. Because you want to know if TB patients' rights are being violated (Chapter 6)[3]
3. Because you wish to discern if TB stigma is deterring health seeking generally or for specific groups (Chapters 9, 15)[4–6]
4. Because you want to know if TB stigma is the biggest problem for patients, or do they face exclusion due to other stigmas as well. (Chapter 14)
5. Because you want to know if stigma is causing recruitment or retention challenges for healthcare workers (HCW). (Chapter 8)[6–8]

It is important to understand why you are measuring TB stigma. This will help you to identify the right tools and people to help you. Often you already know or suspect TB stigma is a problem, so you plan to do a baseline measurement to develop your intervention.

The method of TB stigma measurement should be based on the following criteria:

1. The rationale for stigma measurement (see examples above).
2. The inherent potential bias in a particular method.
3. The available resources (e.g., time, expertise, financial).

TB stigma can be difficult to measure because few people will openly admit to discriminating. TB stigma may operate at a subconscious level so typically it can be best captured through observations, vignettes, indirect questions, and thought experiments. Each method has advantages and disadvantages, which are discussed in the chapters that follow. One has to weigh the potential bias from self-report in surveys against the potential risk of reactivity (aka observer effect)from observational studies. These decisions are consequential and cannot be made on scientific criteria alone. Often the budgetary resources available for reducing stigma are competing against resources for diagnosing and treating TB, so feasibility and efficiency are critical elements in deciding methodology. The majority of scarce resources must go towards stigma reduction, not measurement.

## Choosing a stigma measurement method

If you seek to measure the "footprint" or extent of stigma, use of locally validated scales is necessary. However, surveys seldom provide enough information, and may not tell you why TB stigma is a problem or *what can be done about it*. These *"how"* and *"why"* questions require a qualitative approach.

Figure 1 depicts the cascade of questions that a TB program manager might have about TB stigma. Each of these questions lends itself to a different methodology.

## Figure 1. Matching Method to Mission



Figure 1. Matching Method to Mission

**What do you want to know about TB stigma?**

**How does 'TB stigma' operate in my setting?**

**Qualitative (Ch.3,17)**

**How does 'TB stigma' operate in my setting?**
- ...across the globe? (Ch.4,16)
- ...in health care settings? (Ch.5)
- ...in my community? (Ch.4)
- ...in TB-affected families, healthcare workers, and industries? (Ch.8)
- ...among people with TB (PWTB) and survivors? ( Ch.7,10)

**Why is there so much TB stigma?**
- What are the drivers of TB stigma? (Ch.3,11,17)

**What is the impact of all this TB stigma...**
- ...on health-seeking? (Ch.4)
- ...on people's health? (Ch.15)
- ...on people's lived experiences? (Ch.3,10)
- ...on investment decisions (Ch.13)

**Where and how is TB stigma embedded?**
- ...in our laws and policies? (Ch.6)
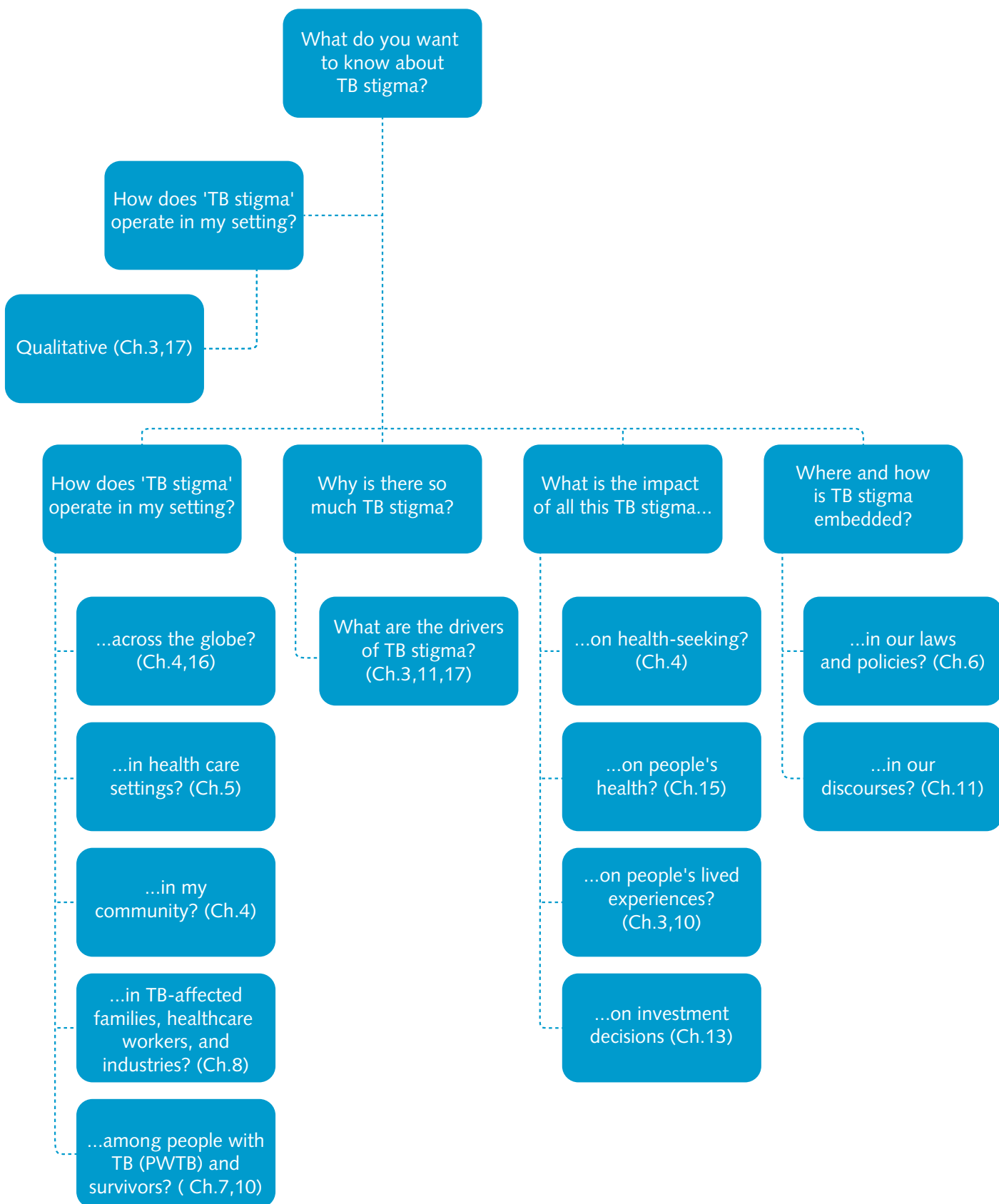- ...in our discourses? (Ch.11)

Table 2 outlines the situations where quantitative and qualitative methods may be applied. It also shows some respective advantages and limitations. We do not recommend choosing between them, but rather combining them to leverage their respective strengths.

**Table 2. Comparison of Qualitative and Quantitative Methods**

| Measurement tools to assess TB stigma | | | |
|---|---|---|---|
| | When to use | Advantages | Limitations |
| Quantitative | Measuring general prevalence and severity of stigma. | 1. Easily applied to large groups. 2. Easy to train staff to administer the tools. 3. Comparisons across contexts. | 1. Fixed outputs with data quality reliant on good question design. 2. Does not clarify how to intervene. |
| | Assessment of stigma levels pre- and post-intervention. | | |
| Qualitative | Identifying drivers and core beliefs underlying stigma. | 1. Can feed into targeted survey design. 2. Flexibility allows for the discovery of new and unpredicted domains. 3. Helps assess and design interventions. | 1. Difficult to apply to large groups. 2. Skilled facilitators and analysts needed. 3. Comparisons across settings may not always be possible. |
| | Build understanding of stigmatizing mechanism and ways to address them. | | |

The full range of TB stigma measurement methods are explored in more detail in the chapters that follow. Qualitative techniques, structured observation, and participatory approaches are particularly valuable in beginning stigma-reduction interventions shortly after measurement.

## Operational Issues in Measuring TB Stigma

Here we present an overview of activities and illustrative flow of workshops to develop and implement a TB stigma study. Table 3 includes an illustrative timeline, with sequence and approximate duration of the respective activities. TB stigma measurement has two phases, a formative qualitative research phase and a latter phase where the structured tools and methods are developed and applied. A TB stigma study implementation process can be divided into 11 sequential steps.

**Table 3. Overview of Activities to Develop a Valid TB Stigma Measure**

| Step | Timeline |
| --- | --- |
| 1. Orientation workshop - Engagement | One day |
| 2. Workshop 2: Capacity building methodologies | One to two days |
| 3. Formative research (i.e., qualitative field work) | One to two months |
| 4. Workshop 3: Selection of stigma domains | Two to three days |
| 5. Workshop 4: Construction of TB stigma methodology | Two to five days |
| 6. Protocol development | Two to five days |
| 7. Field testing of TB stigma measure | Two weeks |
| 8. Workshop 5: Revise method based on pilot results | Two to five days |
| 9. Study Implementation | Two to six months |
| 10. Workshop 6: Analysis | Five to seven days |
| 11. Workshop 7: Results dissemination and development of action plan | Two days |

# STEP 1. Community engagement and stakeholder mobilization

The first step in planning involves a dialog with the national health authorities, research bodies, technical partners, and activists and advocates to create political commitment, co-ownership, and shared expectations of stigma measurement. It is important to involve NTP managers, Ministry of Health representatives, and members of affected communities in study design, measurement, and data analysis. Without their input, the whole process will have limited impact.

**Methods of involving these partners include:**

- Hold a stakeholders orientation workshop.
- Establish a diverse TB stigma measurement committee. Define roles and responsibilities in writing, including its composition, terms of reference, and frequency of meetings.
- Include a TB stigma measurement activity in the national TB strategy, concept note, or project work plan.
- Develop a costed operational plan in close collaboration with all partners.

Engaging communities in identifying TB stigma and the searching for solutions is very important. A participatory approach to stigma measurement is very helpful. For hints on how to address the challenges this entails, see the following resources:

Van der Werf, Mitchell, and Heumann. Community Engagement in TB Research. STOP TB Partnership Research Movement .Community involvement in tuberculosis care and prevention. Towards partnerships for health. Guiding principles and recommendations based on a WHO review WHO/HTM/TB/2008.397.

Somesh Kumar (2002) Methods for Community Participation: A Complete Guide for Practitioners London:ITDG

Parks et al. Communications for Social Change Consortium. 2005. Who measures change? An introduction to participatory monitoring and evaluation of communication for social change.
Available at http://www.comminit/en/node/70592/347
(Document can be downloaded from a link at the bottom of this page)

Guy Bessette. Involving the Community: A Guide to Participatory Development Communication. http://web.idrc.ca/en/ev-52226-201-1-DO_TOPIC.html
http://web.idrc.ca/en/ev-52226-201-1-DO_TOPIC.html

## STEP 2. Formative research

A formative research workshop should be held at the outset. The objectives of the workshop are to:

- Familiarize participants with qualitative research and methodology.
- Build skills in qualitative data collection techniques.
- Develop topic guides for focus group discussions and in-depth interviews.
- Develop formative SOPS and protocols.

The study team is oriented on basic TB stigma terms, concepts, and jargon. It is essential to have a general consensus on what stigma is before studying it in depth. Study staff need basic stigma theory to be able to differentiate among:

- Actionable Drivers of TB stigma.
- Manifestations of TB stigma.
- Facilitators of TB Stigma.

The workshop should consist of interactive introductory sessions on qualitative research issues and group work to develop the proposal. The participants should become familiar with research ethics, in-depth interviews, focus group discussions, and observation methods. If participants have some social science background, plan a one or two-day event. If they do not, plan for a three to five-day workshop. (See Chapter 3 for formative research methods).

## STEP 3. Qualitative fieldwork to study stigma drivers and domains

Chapter 3 has detailed steps on ways to unpack stigma. A range of qualitative methods are needed to identify how stigma manifests locally, what sustains it, how it operates, and where it 'lives'. Formative stages should minimally include the literature review and some qualitative research (focus group discussions,

in-depth interviews, participant observation). How much formative research is needed depends on how much is already known about TB stigma in the context.

## STEP 4. Workshop 2 to analyze the data and select TB stigma domains

A thematic analysis is one in which data are sifted to identify words, themes, behaviors, to develop potential items for a structured instrument. Each transcript has to be coded and analyzed to draw out the themes, terms, framings, and attributions. Data analysis involves triangulation of data from different sources. Chapter 17 offers step-wise guidance on how to analyze specific types of qualitative data. Once the data are organized into themes and patterns, it is possible to interpret meanings and derive a conceptual framework of TB stigma for that population, and build skills in data analysis techniques.

Salient behaviors, terms, phrases, and frames from the transcripts have to be identified and used in the analysis. The data are analyzed in a participatory workshop involving all members of the study teams. The results are used to develop a quantitative instrument to measure TB stigma.

## STEP 5. Workshop 3 to choose study methodology and draft instruments

The main objective of this workshop is to decide on a study methodology and mode of data collection (observation vs. self-report, online vs. in person, self-administered vs. interview, digital vs. paper, etc.)

Many people default to doing surveys when they want to measure stigma. However, the choices are much broader and indeed the strengths and limitations of each merit a thorough debate. Figure 2 provides examples of the decisions that must be made at this stage.

**Figure 2. Illustrative Methodological Choices**

| Method? | Mode? | Means? | Data? | Consent? |
|---|---|---|---|---|
| Observation | Online | Self-administered | Digital | Oral |
| Self-report | Individual | Interview | Paper | Written |
| | Group | | Video | |
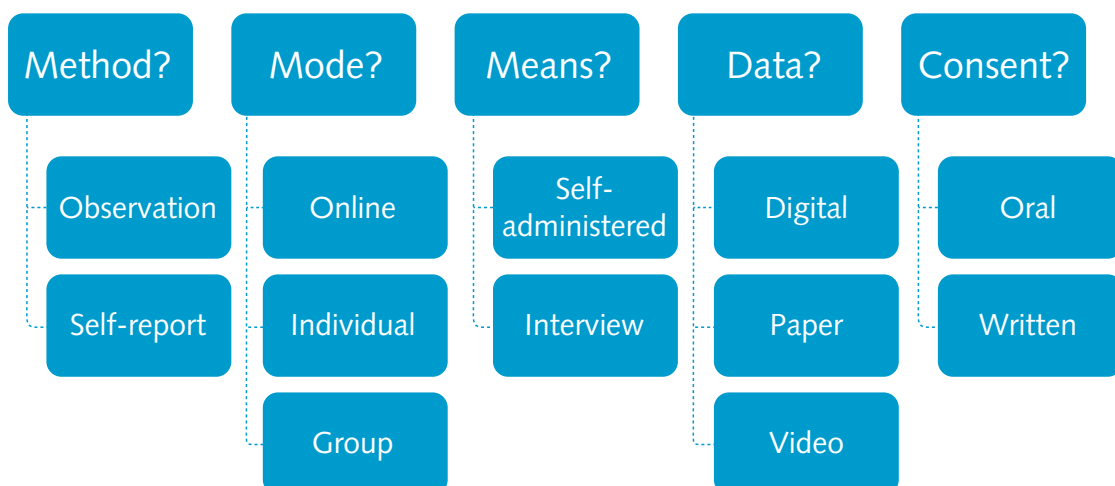
**Issues to discuss include:**

- How reliable are self-reports of discriminatory acts, and how can they be queried without being accusatory or offensive?
- How does one craft observational tools to minimize bias reactivity due to being observed?
- Do patients prefer to answer quantitative questionnaires in a group setting, or as individuals?
- Do groups increase the risk of their conferring or agreeing on responses instead of giving their own personal answers? Are confidential interviews or group discussions more suitable?

People who have had TB have lived experience and practical knowledge of how stigma manifests and how it can be discussed. People from the National TB Program are also helpful, and they can keep the study grounded in national practice and policy. Often stigma researchers from other fields (e.g., mental health, substance use) add value, but they should have a firm understanding of TB.

## Developing the first draft of TB stigma measurement tools

Once a method is chosen, the TB stigma measurement tools are drafted. The research findings from the formative phase should be used to inform a first draft of TB stigma measurement.

If you do a survey, you may combine a mix of validated sub-scales with new items derived from your formative research. Existing TB stigma scales and instruments are described in Chapters 4, 5, 7, 8, and 10. These chapters help you decide between the range of methodological options and questions to consider, including:

- What actions am I trying to measure specifically? How are we defining discrimination? Shaming? Blaming? Stereotyping?
- Are they more comfortable answering questions in the first-person or third-person? (e.g., "I feel ashamed" may be changed to "Some people feel ashamed")
- Are questions worded appropriately to elicit the correct responses and avoid bias?
- How should you take into local idiom and cultural interpretations if implementing across diverse regions?
- How can you balance negatively and positively worded items?
- What is the best flow of stems and items?
- How can you best prepare a research plan for field testing, with an adequate pilot sample size and data entry templates?

## STEP 6. Writing a protocol, SOPs and undergoing ethical review

For each data collection method, there are unique sampling, staffing, and ethical issues to consider.

Statistical formulas sample size calculations for different study designs are explained in Chapters 4, 7, and 9. Ensure social validity by engaging TB-affected people in protocol development. Ensure content validity by basing the measures on thorough qualitative/formative research, and ensure construct validity by engaging sufficient social scientific and statistical experts. TB stigma measurement may involve risk of social harms for the people observed, interviewed, or surveyed, and these risks should be mitigated. Informed consent processes have to be developed. A thorough ethical review helps ensure protection for participants and investigators alike.

## STEP 7: Piloting of TB stigma methodology and measurement

The research team, under the guidance of social scientists, should train research assistants to administer the measurement instrument. Training and SOP guidelines are necessary. Data collectors will need specific skills depending on the type of TB stigma and where it is being measured. They will need sufficient training and practice to succeed. During this period, it is important to:

- Pre-test with cognitive interviewing to explore understanding, feasibility, and translation.
- Pre-test ethics and informed consent.
- Pre-test all aspects of data collection, data management, and security.

## STEP 8. Revision workshop to address pilot results

At this stage, it is important to use the pilot data in order to:

- Conduct reliability testing (scaling) and validation through correlation, factor analysis, and data reduction of any scales. (See Chapter 16 for more on scale validation).
- Adjust the instruments and SOPs.
- Re-train the data collectors if inter-rater reliability is low or ethical lapses occur.

If surveys using scales are being developed, the piloting (validation) is very formal. Chapter 16 explains these steps in detail. Participants who are familiar with statistical concepts, statistical software, and techniques such as correlation analysis, factor analysis and data reduction (scaling) require three to five-days. If experienced local statisticians are not available, the workshop should be five to seven-days, and external technical assistance is recommended.

## STEP 9: Implementation

Once the methods and tools are deemed robust, they can be applied with the population of interest in the chosen settings.

## STEP 10: Analysis and dissemination

Analysis should be conducted immediately, and results shared widely. Participants who are familiar with correlation analysis and factor analysis may require as little as three to five days to do the analysis. If the local team needs more support, a longer workshop of five to seven days (with external technical assistance) is recommended. Typically, an additional two-weeks is needed to write-up the results.

## STEP 11: Action plan

The results should be used to set priorities for stigma reduction. Dissemination can begin by organizing a meeting, with representation from TB patients, the TB program, health service providers, their managers, and community leaders, to discuss feedback on the interviews, set priorities, and to formulate interventions to address the problems.

An action plan will need to set intervention priorities. If several interventions have been proposed, but not all can be implemented, additional selection criteria can be used for further prioritization.

**The action plan needs to include the following components:**

- Intervention topic;
- Reasons why this intervention is believed to be successful;
- Intervention objective;
- Theory of change (conceptual framework, logic model);
- Strategies;
- Activities; projects;
- Team members (champions, early adopters, M&E);
- Time frame for implementation;
- Financial, material, and human resources required; and
- Indicators for monitoring and evaluating change.

All TB stakeholders can play a role in implementing the action plan.

- **Community members** can support and monitor the implementation of the change process in facilities and provide feedback on local perceptions of the changes.

- **Activists** can hold stakeholders accountable for changes and push for scale-up of successful efforts.
- **National, regional, and international decision-makers** support these changes in health delivery practices. They act as matchmakers, marrying effective practices for clinical and programmatic work and strategies for implementing change and scale-up.
- **Researchers** can help to resolve issues revealed by the study.
- **Clinicians** apply effective practices to save lives and reduce the impact of stigma on treatment experiences.
- **Mid-level managers** can lead and champion changes in health delivery practices.
- **Senior management** needs to visibly support the changes and those who are leading the change process.
- **Members of the legal community** can push for an end to discriminatory laws and policies.

## Conclusion

Measuring different manifestations and impacts of TB stigma can involve a range of methods, including directed and participant observation, structured and unstructured interviews, discourse analysis, cost-effectiveness analysis, and non-traditional sampling and statistical approaches. The subsequent chapters introduce readers to these methods and help clarify how to choose among them.

## Acknowledgements

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# Chapter 3

# Qualitative Methods for Identifying Domains (roots) of TB Stigma

*Amrita Daftary, and Gill Craig*

## Abstract

This chapter offers guidance on how to do formative research using qualitative methods to unpack the drivers (causes) and dimensions (forms) of TB stigma. Formative research must be conducted prior to any survey or other structured stigma measurement.

## Objectives

1. To understand the role and relevance of qualitative methods in TB stigma assessment
2. To learn how to deconstruct (unpack) the drivers (causes) and dimensions (forms) of TB stigma
3. To be aware of ethical considerations, limitations, and challenges of qualitative methods

## Target Audience

This chapter is for anyone seeking to understand how stigma operates and wishing to understand the ideas that nurture and sustain it in different settings. People without a social science background will benefit from the comprehensive explanation of why and how to engage people in talking about stigma.
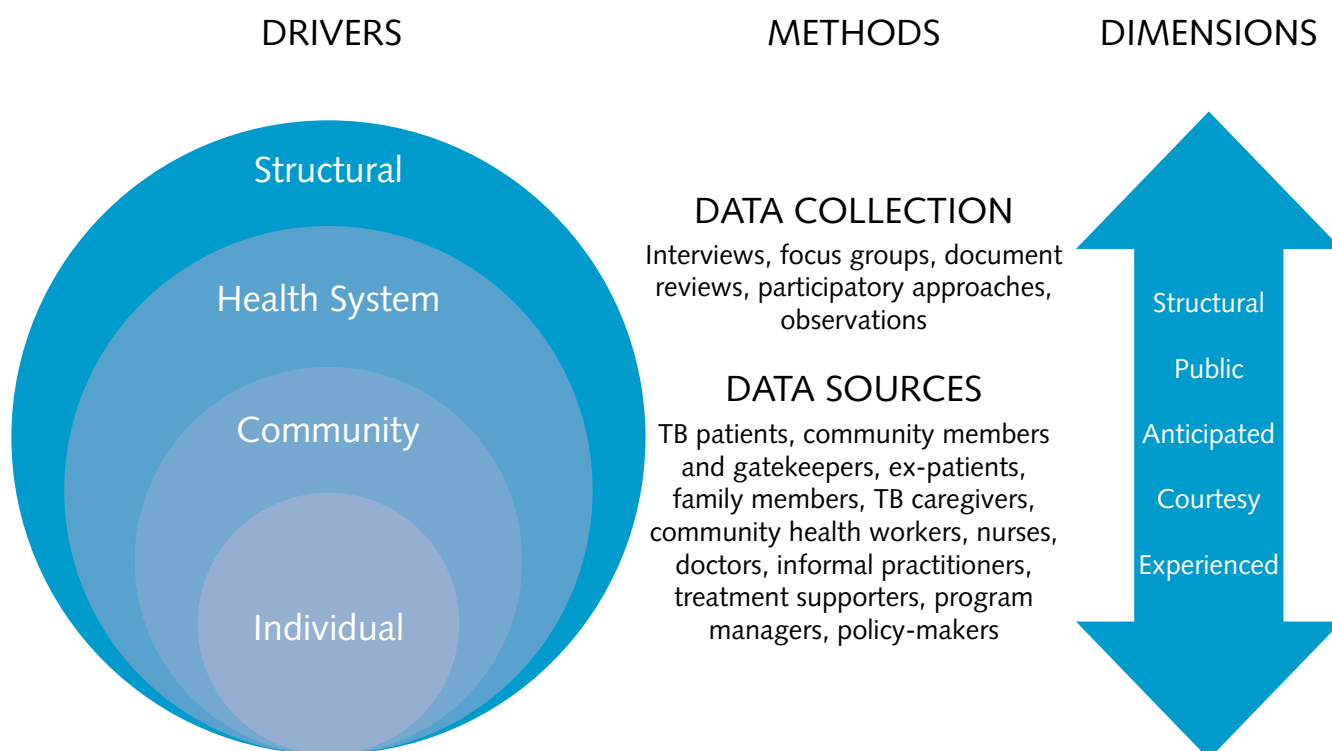
## Introduction

Context is key to understanding, assessing and measuring TB stigma. Individual, patient, household, family, community, economic, historical, socio-political, health facility, and health systems circumstances collectively illuminate why, how and in what forms stigma is perceived, experienced and understood by particular

populations in particular settings. Qualitative research methods can help us to understand these varied contexts in a more nuanced and deeper way. This chapter offers guidance on how to use qualitative methods to conduct formative studies that unpack the drivers (causes) and dimensions (forms) of TB stigma.

## The social dimensions of TB stigma

Although stigma is often conceived of at the individual level, tied to a particular immutable characteristic such as infectivity of the TB bacillus, it is important to recognize its mutable social dimensions. For instance, TB is stigmatized due to its relative deviance from that which is considered to be normal. But the assumptions or norms that govern what is acceptable (normal) or unacceptable (abnormal) are created by society and not by individuals alone.[31] Stigma may thus be encountered in multiple ways, ways that may coexist and be contradictory. An act or symbol that is stigmatizing to one person or community may be perceived or experienced in an entirely different way by another. For example, healthcare workers may wear face masks to protect themselves and consider this action to be normal, but PWTB may perceive it to be exclusionary and stigmatizing. Once on treatment, people with TB usually recover, their visible symptoms fade and they may more easily pass as normal[14] – experienced stigma may fade with or without commensurate changes in self or internalized stigma. When developing a stigma measurement scale, these contextual considerations are key to scale validity and analysis. A qualitative approach is the optimal way to deconstruct the local drivers (causes) and dimensions (forms) of TB stigma, or what we refer to as the TB stigma complex (see Figure 1).

### Figure 1. Deconstructing the Stigma Complex



DRIVERS

Structural

Health System

Community

Individual

METHODS

DATA COLLECTION
Interviews, focus groups, document reviews, participatory approaches, observations

DATA SOURCES
TB patients, community members and gatekeepers, ex-patients, family members, TB caregivers, community health workers, nurses, doctors, informal practitioners, treatment supporters, program managers, policy-makers

DIMENSIONS

Structural

Public

Anticipated

Courtesy

Experienced

# Qualitative methods to identify the dimensions and drivers of TB stigma

A qualitative approach is grounded in the experience and perspectives of those most intimately affected, that is, the persons who perceive and experience stigma as well as the persons, communities, interactions, and contexts that produce and sustain stigma. We summarize its tenets in Table 1. We then offer guidance on main steps in the design and implementation of qualitative studies aimed to identify the drivers and dimensions of TB stigma.

**Table 1. Tenets of qualitative methods**

| | |
|---|---|
| Premise | There are multiple ways of building and sustaining TB stigma and these operate consciously and unconsciously |
| Goal | To explore how TB stigma is produced and sustained (social construction); to understand its drivers (causes) and dimensions (forms) |
| Researcher(s) | Situated and reflexive, fair dealing (non-judgmental) |
| Sample | Purposive samples (principle of maximum variation to gain diverse perspectives); with those who directly experience, perceive or produce TB stigma (e.g., people with TB, persons considered to be at risk for TB, community members, providers) |
| Approach | Semi-structured, open-ended questioning and probing; flexible, spontaneous, iterative and analytic approaches; participatory approaches |
| Data collection | Interviews; focus groups; observations; document review; ethnography; participatory techniques (e.g., theater, diaries, photography, action-oriented community groups, use of visual aids, charting, ranking) |
| Data format | Textual (audio and video transcripts, field notes), non-numerical |
| Analysis | Staying close to the data but does not accept it at face value; drawing on participants' own words before developing higher order constructs; moving beyond descriptive (realist) summaries to in-depth (critical) interpretations |

## Asking a formative research question

Qualitative studies to discover the drivers and dimensions of TB stigma are primarily exploratory. As far as possible, the approach to deriving root causes of stigma should be broad and devoid of assumptions.

Although qualitative researchers start off with a research question there is flexibility in tailoring the research questions, as the open-ended nature of qualitative inquiry allows for interesting issues to arise that had not been initially considered. Indeed, many qualitative studies that report on TB stigma have begun with research questions that were not focused on stigma (including studies described in Table 2). Findings related to TB stigma were incidental – an unanticipated discovery while addressing a distinct research problem, for example, to examine the lived experience of people with TB or challenges to TB health care seeking more broadly.

# Selecting and recruiting samples

The strength of qualitative data comes from its richness and ability to tap into new and unanticipated areas of interest through in-depth inquiry with "information-rich" [Patton 1990; p169] participants.[40] In studies seeking to identify the drivers and dimensions of TB stigma, this includes a wide range of people with detailed knowledge of or direct experience with TB stigma, as well as persons who may not directly encounter TB stigma to understand its buffers and hidden drivers. See Chapter 1 and Chapter 12 on how to engage populations in the design and implementation of stigma studies.

**Table 2: Samples to Consider for Unpacking Specific Drivers of Stigma**

| Types of Stigmas | Whom to interview | Illustrative empirical qualitative studies and normative papers |
|---|---|---|
| Structural | Policy makers, government officials, journalists, bureaucrats, people with TB/ communities affected by TB | Coreil et al. 2010; Farmer 1996; Farmer 1997[2-4] |
| Public stigma | Persons deemed to be 'at risk' for TB (e.g., migrant mine workers in sub-Saharan Africa, slum dwellers in South Asia, homeless persons in North America). | Daftary et al. 2007; Macq et al. 2005; Ngamvithyapong et al. 2000; Senthilingham et al. 2015; Waisbord 2007[5-9] |
| Enacted TB stigma against people with TB (e.g. people) | People with TB, service providers (e.g., nurses, doctors, social workers, counsellors, community case/field workers), | Bond & Nyblade 2006; Daftary & Padayatchi 2012; Daftary 2015; Kelly 1999,[10-13] |
| Self-stigma | People with TB | |
| Secondary stigma | Caregivers, TB care providers, persons deemed to be 'at risk' for TB service providers (e.g., nurses, doctors, social workers, counsellors, community case/ field workers), | Baral 2007, Buregyeya, 2012, Adams et al 2017 |
| Compound stigmas in key populations affected by TB | People with TB, persons deemed to be 'at risk' for TB (e.g., smokers, slum dwellers homeless persons, HIV), | Atre et al. 2004; Atre et al. 2011; Chikovore et al. 2014; Craig et al. 2007; Gosoniu et al. 2008; Hayes-Larson et al. 2017; Moller et al. 2007; Moller at al. 2011; Ngamvithyapong et al. 2000[10,14-22] Daftary 2012 |
| MDR-TB stigma | People with MDR-TB, Caregivers | Daftary 2014; Daftary & Padayatchi 2016; Engel 2013; Senthilingham 2015[8,12,23,24] |
| Drivers of TB stigma across varied contexts and dimensions | Board members of local, national and international guideline/recommendation committees and advisory groups). | Baral et al. 2007; Craig et al. 2016; Courtwright & Turner 2010; Coreil et al. 2010[2,25-27] |

Qualitative sampling is purposive rather than random.[1,38] **Purposive sampling** is a type of non-probability sampling where the researcher selects participants according to specific characteristics of interest at the study outset.[41,42] For example, in order to understand why patients are failing to attend clinic appointments at a newly developed program, the researcher may interview 20 women and 20 men to ascertain influences on attendance. Within this sample, the researcher may then select five people aged 20-30 years and another five aged 30-40 years to identify if there were certain (stigmatizing) practices of program arrangements that contributed to perceptions of poor care. The researcher may also purposively interview 5-10 people who demonstrate poor adherence (e.g., miss an appointment or report barriers to clinic staff) or represent marginalized sub-groups within a given population (e.g. people with HIV) to understand local drivers and dimensions of stigma. Participants of a purposive sample therefore need to meet specific criteria. This is distinct from convenience sampling where the researcher has no control over the type of participants in a study, and is often considered a weaker form of sampling.

**Maximum variation sampling** is the most common form of purposive sampling that seeks to include the full spectrum of cases and reflect the diversity within a given population by including extreme or negative cases.[1] Because we want to learn how and why stigma is produced and sustained, or what are the possible drivers and dimensions in a setting, as opposed to learning how frequently or intensely these occur, we want to capture the widest range of perspectives rather than the most common perspective. Accordingly, we give equal attention or importance to the perspectives of people who have experienced the most overt forms of discrimination on account of having TB (e.g., job loss, family abandonment) and those who perceive no stigma.

At other times, we may be interested in how stigma is shaped and experienced against the axis of gender or immigration status. We would then recruit a good balance of men and women or refugees/immigrants and locally born participants to analyze the role of gender or immigration status in TB stigma. The goal would be to achieve qualitative rather than equal representation, where issues likely to affect TB stigma in the study context are adequately included.

**Theoretical sampling** is an iterative form of purposive sampling that "is dictated by the data and the emerging theory" [Coyne 1997; p 629].[41] Early interviews may suggest important characteristics of interest that were not unanticipated at the study outset but could be explored to yield a richer understanding of the research problem. For example, a researcher may learn that participant's marital status or area of residence drives their health-seeking behaviors and perceptions of stigma in unanticipated ways. The researcher can explore this further through subsequent recruitment of participants deemed to have rich information about these unanticipated characteristics of interest (e.g., by proceeding to interview people who are married/single, or those who live in urban as well as rural areas).

## Sample size

Samples are generally smaller than those used in quantitative studies. Adequacy of the sample size is determined by the principle of theoretical saturation, whereby data collection ends once no new concepts or theoretical insights emerge following review and analysis of all data.[38,43] Thus, sampling is most successful when done in conjunction with data collection and analysis, that is, an iterative approach. Although it is not possible to define the number of participants in advance, a range of 20 to 30 interviews[1,44] or 4 to 6 focus groups[45,46] with a purposeful sample is usually sufficient to achieve saturation.

## Collecting qualitative data

There are many methods for capturing in-depth qualitative data about the drivers and dimensions of TB stigma. In this chapter, we focus on two common methods that may be applied across most settings, interviews and focus groups, and briefly discuss observations. Where feasible, these methods can be concurrently applied to facilitate triangulation and attain more comprehensive insights into the drivers and dimensions of TB stigma.

## Interviews

As discussed earlier, what it means for people to perceive, experience or produce TB stigma is inextricably related to their social contexts. However, these meanings are generally subconscious or hidden; that is, in their day-to-day actions and interactions, people may not consciously think about the history, culture, medical or social structures within which their perceptions and experiences of stigma are shaped.[47] A dynamic interaction between a researcher and participant can facilitate a rich account of the participant's lived experience, and uncover the subjective (conscious and subconscious) meanings attached to it.[1,48,49] Semi-structured interviews that allow for open-ended questioning and invite rich, narrative, explanatory responses (thick descriptions) through active listening and probing can offer a vivid picture of participants' personal experiences and perspectives about TB stigma. They are optimal tools to identify and examine the drivers and dimensions of stigma among TB patients, key populations, community gatekeepers, and policy/program managers.

A **Semi-structured interview** is a guided conversation, where the participant is considered the expert and is given the opportunity to talk about his/her experiences and feelings.

A typical **semi-structured interview**[49] is a guided conversation, where the participant is considered the expert and is given the opportunity to talk freely about their experiences and feelings. Because the interview is semi-structured it allows flexibility so that departures from the interview are permitted and even encouraged, to introduce important insights into participants' experiences. Questions are broad, exploratory and open-ended to capture participant's thoughts and perspectives based on his/her first-hand experience (i.e., what

happened to them) and personal interpretations of those experiences (i.e., how they understood this experience or event, how it made them feel).[1] Main questions may be comprised in an Interview Guide, but the wording and sequence of these questions would shift from interview to interview depending on the participants' unique responses and circumstances. Key to qualitative interviewing is to learn about TB stigma without asking about stigma outright, so that ensuing understandings about stigma are rooted in participants' own characterization of this research problem (rather than the researcher's preconceived ideas). It is only through this manner of questioning that the continuous and dynamic discovery of new and unanticipated themes related to stigma drivers and dimensions will be possible. For example, a typical interview guide may include casual questions related to a persons' diagnostic journey, experiences in treatment and care, interactions with providers, general perceptions about TB and how these may have changed with time, general experiences in their home, experiences with disclosure, relationships with others (e.g., family, partner, children, employer), financial obligations and circumstances, major life events concurrent with TB (e.g., job loss, change in residence, relationship with family, access to income or emotional support). Participants would be asked to describe day-to-day events and probed on how they navigated or responded to these events to learn about potential sources of stigma in their particular illness experience. See Tables 3 and 4 for a sample of questions that researchers may draw upon to develop interview guides (while listed in clusters, questions should be broken down and asked one at a time to avoid confusing the participant). It is in the analysis stage (see Chapter 17) that the researcher would compare these narratives and link them to broader concepts such as drivers and dimensions.

Throughout the interview, the role of the interviewer is to gently guide the participant to talk about the topics in the Interview Guide, and ask follow-up questions (probes, e.g., asking: "Can you give me an example?" or "Can you tell me what you mean by that?") to clarify a point, open new themes for discussion, or encourage elaboration[49]; it is not a question and answer session. The interviewer tries not to lead or influence participants via their body language, tone of voice, or by casting judgment or opinions according to their values or assumptions about the research problem[49], including preconceived notions about stigma. Note that questions barely mention stigma overtly (Table 3). Qualitative interviews can thus be considered active tools of data collection and analysis, where data are co-produced by both the participant as well as the researcher.

**Table 3. Sample topic guide for qualitative interviews with people on TB treatment**

**Perceptions and attitudes about TB**

– What are your thoughts about TB, how has this changed over time (since being diagnosed, starting treatment)?
– What do you think others (your community) think or feel about TB patients?
– Do you know other people with TB, what is your relationship with them now?

**TB diagnostic journey, disclosure and contact tracing**

– What were your symptoms, how did you get diagnosed, what challenges did you have?
– What were your support systems, who did you tell when you were diagnosed, what was the response, how has this changed over time?
– Was there any follow-up for your family or household contacts, how was this handled?

**Experiences in treatment and care**

– How are you coping with treatment, side effects, access to medicines?
– Where do you receive your medicines, how do you make it to your clinic appointments (how often and for what – DOT/monitoring, with who, cost/time to commute)?
– How do you take your medicines every day, who reminds you?
– What are your experiences at the clinic, how is your relationship with providers, what do you think about the quality of care you receive?
– If hospitalized, how was this experience, how were the interactions with patients and providers, how did you communicate with family or confidantes?
– What other co-morbid conditions or medical problems do you have?
– What other medical support have you received and how have you experienced these supports (e.g., counseling, grant support, food or transport assistance, community health worker, social work, etc.)?
– What barriers have you faced and how have you dealt with them?
– Probe for positive and negative experiences, always ask for examples
– Do you have any preferences or suggestions going forward, if you could change something what would it be?

**Social support and financial issues**

– Who do you live with, how is your household situation, who have you told about your illness, what did they say and what was the response?
– What social and financial obligations/priorities do you have, how are you dealing with them, who helps?
– What major life events have ensued since diagnosis (e.g., change in residence, relationship with family, access to income or emotional support), how has this affected you?
– Who do you talk to for comfort or support, who do you go to for financial assistance, who looks after your dependents when you are being treated or at the clinic, who are your close confidantes, what do they know, and how have those relationships changed?

**Table 4. Sample topic guide for qualitative interviews with healthcare workers on TB stigma**

**General experiences in health care delivery**

– What is your role, what are your day-to-day activities?
– What types of patients do you typically see, what are the common medical issues and how has this changed over the time you have been working?
– How would your peers describe your TB patients?

**Perceptions and attitudes about TB**

– What are your thoughts about TB, how has this changed over time (e.g., experience working with TB patients)?
– What do you think others (your community) think or feel about TB patients?

**Patient interactions**

– What are your experiences with patients in general, what is your relationship?
– What has been your experience with TB patients, what do you think are your most common problems and needs (start with medical, as discussed earlier, and move into social)?
– How do you respond to these needs, what difficulties have you faced, ask for examples?

**Workplace**

– How are you supported at work, what is your relationship with colleagues, senior staff, other cadres of health workers, support staff?
– How do you feel working at this site, with TB patients, what do your family and co-workers think?
– How do you perceive risk for TB infection, what countermeasures (e.g., infection control practices) do you take and how do you feel about these measures?
– Given your work day, described earlier, how else could you be supported, what are your preferences?
– Where else have you worked and how would you compare those work experiences?

**TB service delivery**

– What TB specific activities do you participate, what types of health care tasks are you directly involved in (e.g., testing, counseling, contact tracing, treatment initiation, treatment observation or monitoring, adherence support, outreach)?
– How do you enjoy these activities, what challenges have you faced and how did you deal with them, ask for examples of specific interactions with patients?
– How do you make medical decisions for each of these activities (e.g., how do you decide which patients to test for TB, how do you decide which medicines to prescribe, how do you go about performing contact tracing, ask to be walked through the decision-making process which can illuminate underlying assumptions and practices)?
– How else do you think your patients can be supported?
– How else can you be supported in accomplishing your duties, what would be your preference?

## Focus Groups

Focus groups comprise a group of interacting participants convened by a facilitator who uses natural group interactions to learn about social and cultural norms, and how pervasive they may be in a given community. Participants may share some characteristics but the richness of a focus group discussion comes from the diversity of participants' experiences; that is, the ability to capture points of group convergence as well as deviations from group norms (e.g., different experiences that may underlie participants' shared perspectives, or different perspectives among those who otherwise appear to share a similar reality).[46,51] When conducted soundly, focus groups can be highly efficient tools as rich insights may be captured from a large number of participants in a relatively short period of time.[52] Focus groups have much in common with interviews, and the recommendations shared for interviews would apply to the implementation of focus groups. The main difference is the strength of interaction and exchange between participants of a focus group over a particular issue. As Morgan (1996) notes, "what makes the discussion in focus groups more than the sum of separate individual interviews is the fact that the participants both query each other and explain themselves to each other."[46] This allows participants themselves to compare experiences and offer explanations for those differences as opposed to the researcher hypothesizing why those differences exist on the basis of separate interviews.

Focus groups with health providers, community members or key populations can be optimal tools to understand community norms around TB stigma and identify the drivers of structural and public stigma. Focus groups may also serve as tools for advocacy by channeling participants (e.g., TB patients) into a collective dialogue about a shared reality. For this reason, focus groups are a useful participatory tool, where group opinions, rankings, and preferences may be used to develop more comprehensive insights into the drivers and dimensions of TB stigma (see Chapter 7 and 12).

In focus groups, the discussion is led to a greater degree by participants compared to in an in-depth interview.[1] The facilitator's role is to guide the discussion, manage group dynamics, encourage participants to share their thoughts, and probe group consensus to identify points of divergence, all without influencing the discussion or skewing responses a particular way.[32,53] The difficulty with focus groups is that if participants share many of the same assumptions about TB patients, then they may not feel the need to make those links explicit to the underlying associations and mechanisms may remain hidden. For example, patient participants may not open up about their stigmatizing experiences in a group environment.[46] Healthcare workers may not openly express negative attitudes about people with TB, fearing judgment from their peers or the researcher. In such instances, the burden falls heavily on the skills of the facilitator to encourage the articulation of underlying assumptions, and at times introduce leading statements (e.g., asking: "I have heard that some people are reluctant to work in a TB ward", What do you think?") that encourage the group to share opinions that would be otherwise embarrassing or awkward to voice in a group environment.

Well-facilitated focus groups can be excellent ways to collect data on contentious topics, even with persons prone to give socially desirable responses, or disinclined to open up on socially sensitive subject matters.[54] Small focus groups comprising 4-5 participants have been successfully conducted with XDR-TB patients as well as TB health care providers and led to the discovery of novel dimensions and drivers of TB stigma.[12,46]

Ideally, a focus group should include 6-8 participants but the composition would depend highly on the research situation; for example, larger groups would be feasible to understand perceptions about TB stigma with community members but smaller groups may be optimal when recruiting patients who may not open up about their personal experiences with a large audience. Furthermore, as gender, immigration status, and severity of disease are understood to be critical determinants of TB stigma[27], it would be ideal to stratify focus groups accordingly. However, there is no hard-and-fast rule about focus group composition. It is the role of the researcher and focus group facilitator to consider these issues prior to organizing the focus group and tailor them to the local context.

# Observations

Naming, blaming and shaming are behaviors that can be observed. Many aggressive acts reflective of enacted and public stigma can take place in the public sphere. Field observations can provide a first-hand or insider's perspective on the physical and social environment in which TB stigma is produced and experienced.[32] Observations can illuminate deep knowledge about the sociocultural norms and practices of a study setting and may also enhance analytic credibility.[33,34] For example, clinic observations may allow for a witnessed account of the social contexts in which patients attend clinics and access TB-related services, insight to their interactions between clinic staff and with other patients, and norms and actions practiced within the clinic environment that could affect patients' overall experiences with health care. These observations may guide questions in subsequent interviews or focus groups, and allow researchers to situate their analysis of TB stigma more wholly in participants' social contexts. For more on structured and unstructured observations, see Chapter 5.

Ethical considerations. As with other studies, stigma research mandates abidance to procedural ethics at the study outset, or receipt of institutional ethics approvals, site permissions, participants' informed consent (written or verbal, depending on the situation), and developing secure mechanisms for data protection and sharing.[36] Ongoing ethical considerations, which mandate researchers to reflect on ethical decisions beyond procedural ethics include: situational ethics or unpredictable ethically relevant moments that may arise during the conduct of research activities (e.g., establishing a plan to counsel patient participants who become emotional during an interview, or to address accounts of illegal practices); relational ethics where researchers are continually mindful of their character, actions, and influence on others (e.g., drawing on the principle of reciprocity to balance a researcher's desire to publicize an evocative narrative against a participant's preference to minimize it); and exiting ethics, where researchers reflect on the manner in which they share research findings to avoid unjust or unintended consequences (e.g., representing participants who may be poor or marginalized in ways that do not portray them in a negative light and inadvertently compound their marginalization).[36]

Readers are encouraged to refer to Chapter 17 for approaches to qualitative analysis and research rigor.

## Conclusion

This chapter has laid out the rationale and fundamental considerations of using qualitative methods to identify and examine the drivers and dimensions of TB stigma. Qualitative research helps us to understand these varied contexts of TB stigma in a more nuanced and deeper way, and is thus essential to the process of developing and validating a stigma measurement scale. In-depth exploratory inquiry into the socio-medical environment in which TB stigma is produced, and with those who encounter or contribute to stigma, can result in a more humanistic[1] conceptualization of TB stigma, and uncover its building blocks in a given setting.

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# Chapter 4

# Conducting valid surveys of TB stigma and health seeking

*Lisa Redwood and Ellen M.H. Mitchell*

## Abstract

This chapter covers the main drivers and domains of TB stigma in the population. It outlines the considerations for measuring TB stigma in communities and nationwide. We introduce the available validated scales and explain the relative advantages of indirect questions and/or hypothetical questions to tap social norms. The chapter explains how to craft a high quality survey of the role of stigma in health seeking for TB symptoms. Finally, we discuss a comparative ecological analysis of anticipated stigma across settings.

## Objectives

1. The typical domains and drivers of TB stigma in the general public
2. How to measure TB stigma to assess its impact on health seeking behavior
3. How to embed studies into larger national household surveys
4. How to compare stigma in the community across settings using ecological analysis.

## Target Audience

The intended audience for this chapter is people wanting to measure TB stigma in their communities, regions, countrywide or among countries. This may include research institutions, national TB program staff, MoH or other government organizations, non-governmental organizations (NGOs), donors, and technical assistants implementing social surveys.

## Introduction

Measuring TB stigma at the community level is crucial to shift societal treatment of people with TB. Stigma in the population is also known as social stigma, public

stigma or cultural stigma. Community attitudes toward people with TB influence their support for public policies designed to ease their financial, social, and physical burdens.[1] People with more accepting views toward PWTB are more likely to support the use of public monies for TB research and anti-discrimination efforts.[1] Societies which blame PWTB for developing TB disease are less likely to support the provision of public assistance, such as disability grants.[1,2] This is important as provision of public assistance is associated with improved survival of TB patients.[3]

Community fears and prejudices about TB can also deter health care seeking for TB symptoms.[4–13] Programs and communities need to know how TB stigma operates at the community level and crucially whether it discourages health care seeking. Accurate measurement of TB stigma in the community is therefore a necessary first step in the development of effective social mobilization to increase use of TB services.

## Drivers of stigma at community level

There are many potential drivers of anticipated stigma in the general population. Stigma in the general population can be influenced by social characteristics, knowledge, national epidemiological context and structural drivers of TB stigma. Some authors have argued that lack of understanding of TB transmission increases TB stigma.[9,14] In some settings an increased understanding of the treatability of TB reduced stigma.[15,16] However levels of TB knowledge often have no consistent relationship with levels of TB stigma.[2,16,17] Indeed TB stigma can even increase with levels of education and social class.[15] At the national level, TB stigma is correlated with incarceration rates.[15] This suggests that a country's general approach to blaming and punishment can also color the country's view of PWTB.

**Figure 1. Illustrative Influences upon societal TB stigma.**
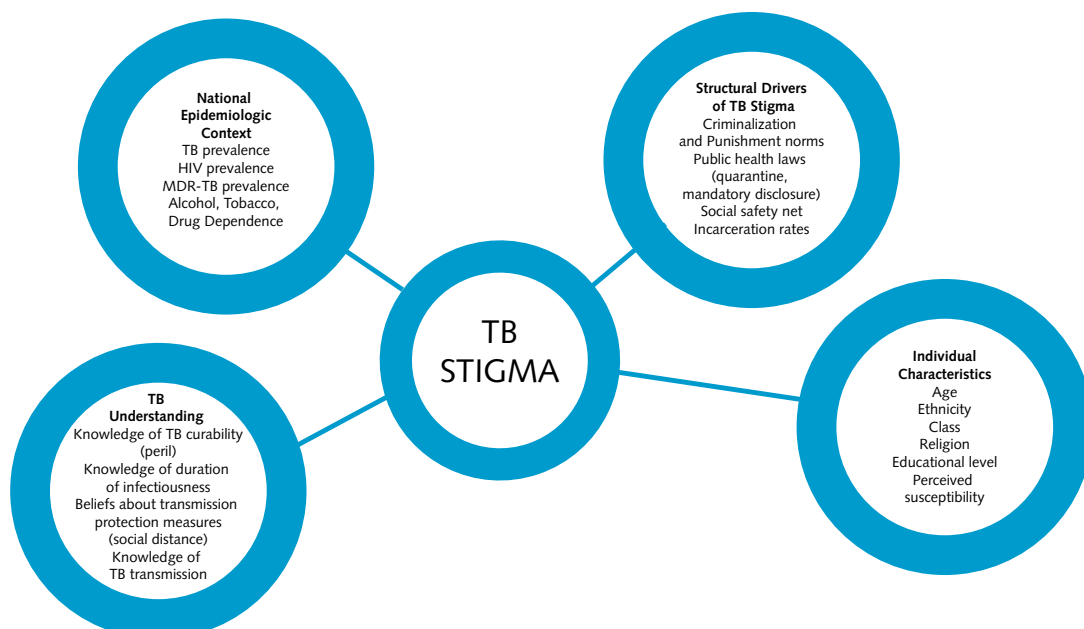
## Domains of stigma to measure

The context in which you work will impact the items and the scales you should use. The aim of the study needs to be clear to allow the questionnaire content be tailored to the need and therefore deliver the desired data.

Formative research in your setting will reveal the domains most relevant, but Pescosolido and Martin (2015) identified seven domains of public stigma that you may wish to explore. These include: social distance, traditional prejudice, exclusionary sentiments, negative affect, treatment carryover, disclosure carryover and perceptions of dangerousness.[18] These domains are defined with TB examples in Chapter 1.

**Figure 2. Seven Domains of Public Stigma[18]**
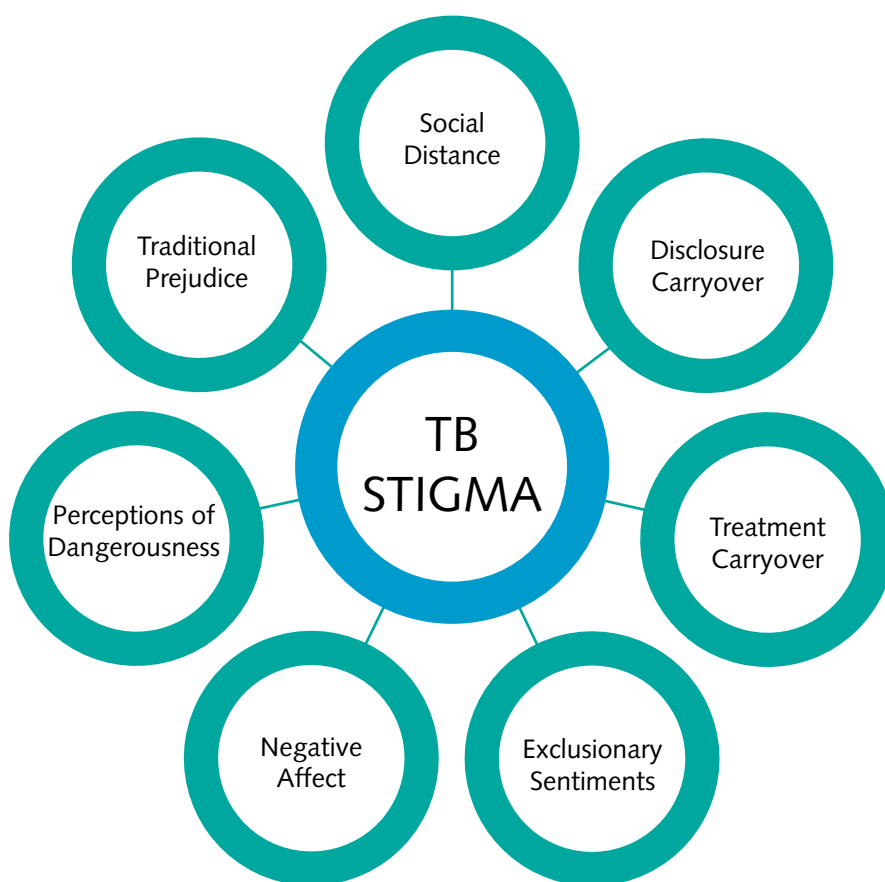


Corrigan adds two dimensions "pity" and "treatment coercion" to measure public stigma.

## Attitudinal Scales for Measuring TB Stigma at the Community Level

Once you have determined through formative research which domains are relevant in your setting, you can choose to adapt an existing scale or build a new one. There are several scales for community measurement, ranging in size from 5 to 11 items. There are non-disease specific scales and TB scales derived from HIV

scales. Each has strengths and weaknesses for you to weigh.

## Generic Scales for Measuring Discriminatory Attitudes

There are a variety of validated scales for measuring discriminatory attitudes that have been adapted for TB (See Table 1). The Bogardus Social Distance Scale is one of the oldest psychological attitude scales and it has been adapted many times and to many contexts.[19]

The social distance scales from the nineteen twenties informed the development of the Jaramillo and Mak TB stigma scales.[1,14] They have items like these:

1. Would marry a person who had had [insert stigmatized condition]
2. Would have as regular friends a person who had had [insert stigmatized condition]
3. Would work in an office beside a person who had had [insert stigmatized condition]
4. Would have several families who had had [insert stigmatized condition] in my neighborhood
5. Would have a person who had had [insert stigmatized condition] merely as speaking acquaintances
6. Would prefer a person who had had [insert stigmatized condition] live outside my neighborhood
7. Would prefer a person who had had [insert stigmatized condition] live outside my country.

The Bogardus Social distance scale was first designed to measure racism and xenophobia and some of the behaviors may be setting specific. The Social Distance Scale (SDS) by Kelly and colleagues is also widely used as a basis for disease-specific stigma scales.[20,21] The SDS questions are preceded by vignettes which is particularly effective if you want to understand how multiple types of prejudices (for example xenophobia) exacerbate TB stigmas. For guidance on the use of vignettes and the SDS items read Chapter 14.

Probably the most well-known of these non-condition specific stigma scales is the Explanatory Model Interview Catalog (EMIC) scale which has been used extensively for stigma of leprosy, mental health and TB.[20,22–27] The EMIC scale is described in more detail in Chapter 7 and its potential for gender bias is discussed in Chapter 14.

# Table 1: Overview of validated scales for health-related community stigma applied or applicable to TB

| First author | Country | Content validity | Construct validity | Reliability | No. of items | Domains (if identified) |
|---|---|---|---|---|---|---|
| Mak (2006) | Hong Kong | Literature Focus groups | CFA SEM | $\alpha = 0.83$ | 14 | Public stigma (prejudice/ discrimination) |
| Jaramillo (1999)[14] | Colombia | Literature | n/a | n/a | 5 | Social distance-intimacy |
| Sermrittirong (2015)[28] | Thailand | FGD,(EMIC-CSS | SEM | $\alpha = 0.87$ | 15 | Concealment, avoidance, pity, shame, being made fun of, respect and marriage (prospects) |
| Bogardus Social Distance (1925) | USA | | CFA | $\alpha = 0.75\text{-}0.9^{29}$ | 8 | Social distance |
| Atre[27] | India | EMIC | n/a | n/a | 15 | Concealment, avoidance, pity, shame, being made fun of, respect and marriage (prospects) |
| Coreil (2010b)[30] | US and Haiti | EMIC stigma scale Local interviews | EFA | $\alpha = 0.80$ for both | 21 (US) 20 (H) | US (4 sub-scales): internal shame; external problems; disclosure, communicability Haiti (5 sub-scales): internal shame; external problems; disclosure; family reputation; other illness |

SEM - structural equation modeling, CFA - confirmatory factor analysis, EFA – exploratory factor analysis, FGD – focus group discussion.

The Mak and Jaramillo scales are general stigma scales applied to TB. The Jaramillo scale is primarily a measure of the social distance domain and asks about five specific behaviors (i.e. kiss, share meals, have sex, work/study, hugging). Given the specificity of these behaviors, it may not be appropriate for all settings. Scales that were specifically designed for TB and informed by formative work on TB are summarized in Table 2.

# Table 2: Validated TB Stigma Scales for Public Stigma

| First author | Country | Content validity | Construct validity | Reliability | No. of items | Domains (if identified) |
|---|---|---|---|---|---|---|
| Cramm & Nieboer (2010)[31,32] | South Africa | Kalichman HIV stigma scale, Møller 2008 | Correlation with HIV stigma (r=0.66) | α = 0.74 | 8 | Traditional prejudice, exclusionary intent, social distance, blame |
| Van Rie (2008)[33] Kipp (2011)[34] | Thailand | Van Rie TB stigma scale | EFA | α = 0.85 | 11 | Social distance, exclusionary sentiments, treatment carryover, and negative affect |
| Crispim (2016,2017)[35,36] | Brazil | Van Rie | n/a | α = 0.70 | 11 | See Van Rie 2008 |
| Colvin (2005)[37,38] | Honduras | Literature, interviews | EFA | α = 0.71 | 7 | Stereotypes, exclusionary sentiments, social distance, discrimination |
| Sagili (2016)[39] | India | Literature | N/R | n/a | 13 | Exclusionary sentiments, social distance, intent to discriminate |
| Wu (2013)[40] | Taiwan | AQ-S8 | PCA | α = 0.80 for both | 8 | Avoidance, sympathy, fear |

N/R= not reported

## Wording of Stigma Items is Important

TB specific scales for use in behavioral surveys have been developed recently often borrowing items from HIV scales. One downside of borrowing items from a chronic disease is the tendency for items to implicitly assume TB disease results in a permanent mark.[35] Researchers should be careful when drafting items to use transitive verbs to imply a temporary state.

The Van Rie community TB stigma scale performs well, is validated, is self-weighting, and has been applied in multiple countries (See Table 3). Validated versions exist in English, Malay, Thai and Portuguese.[33,35,41,42] The Van Rie scale utilizes indirect items to measure TB stigma in the general community and in people living with TB, such as: "Some people do not want to talk to others with TB". This indirect method of inquiry taps social norms rather than personal

positions. During the social validity testing of the initial scale indirect questions were found to be more culturally appropriate and allow for more truthful answers.[43] The disadvantage of this indirect framing is that it may over-estimate the prevalence of stigma because it is easier to affirm that 'some' proportion of any population will think almost anything. Moreover high scores on such indirect mild stigma measures are seldom predictive of behavior or outcomes.[34] Hayes-Larson et al (2017) recently tested and expanded version of the Van Rie community attitudes scale that used three more direct and severe items. These three seemed to pinpoint severe TB stigma better and were highly correlated with negative coping behaviors.[44]

The Van Rie scale phrases the items all in the negative, but Crispim et al rephrased 2 items positively to give the scale better balance, with good results.[35] The apparent similarity between item 2 and item 10 can be confusing to respondents, and some researchers have combined them.

## Table 3: The Van Rie Scale for measuring TB Stigma at the Community level.

| | Strongly Agree | Agree | Don't know | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| 1. Some people may not want to eat or drink with friends who have TB | | | | | |
| 2. Some people feel uncomfortable about being near those with TB | | | | | |
| 3. If a person has TB, some community members will behave differently towards that person for the rest of their life | | | | | |
| 4. Some people do not want those with TB playing with their children | | | | | |
| 5. Some people keep their distance from people with TB | | | | | |
| 6. Some people think that those with TB are disgusting | | | | | |
| 7. Some people do not want to talk to others with TB | | | | | |
| 8. Some people are afraid of those with TB | | | | | |
| 9. Some people try not to touch others with TB | | | | | |
| 10. Some people may not want to eat or drink with relatives who have TB | | | | | |
| 11. Some people prefer not to have those with TB living in their community | | | | | |

Wu (2013) developed a 8-item scale based on Corrigan's Attribution Questionnaire for mental illness stigma (AQ-S8).[45] This short scale predicted willingness to become a DOTS provider (See Chapter 5).[40]

Cramm and Nieboer (2011) created an 8-item TB-related stigma scale, which is the shortest validated TB-stigma scale for use in the general population (see Table 4).[31] This scale is further simplified by having two possible answers to each question, agree or disagree. Sagili et al has a 13-item scale primarily querying agreement with social distance and exclusion behaviors.[39]

## Table 4: Cramm and Nieboer (2011) TB stigma scale[31]

| Scale Item | Agree | Disagree |
|---|---|---|
| 1. People who have TB are dirty | | |
| 2. People who have TB are cursed | | |
| 3. People who have TB should be ashamed | | |
| 4. People with TB must expect some restrictions on their freedom | | |
| 5. A person with TB must have done something wrong and deserves to be punished | | |
| 6. People who have TB should be isolated | | |
| 7. I do not want to be friends with someone who has TB | | |
| 8. People who have TB should not be allowed to work | | |

The wording of the items in the stigma scale can have an impact on the responses given and what you end up measuring.[43,46] These questions also pose their own challenges. They are very logical and direct, with the positive answer clearly conveying stigma. However, asking some people these strongly worded and specific questions might elicit a socially acceptable answer, rather than a truthful one. (see Chapter 5 for discussion on extreme questions). The dichotomized answer (yes or no) limits your ability to understand the intensity or distribution of opinions, reducing the utility for intervention planning.

The Colvin TB stigma scale covers four domains in only seven items (see Appendix 1.[38] Its succinctness and avoidance of disclosure items makes it a candidate for use in national surveys. High scores were correlated with longer distances for healthcare seeking for chronic cough.

## Challenges to valid measurement of TB stigma in behavioral surveys

## Social desirability

Being explicitly discriminatory is considered uncivilized in most societies. Awareness of social norms influences peoples' responses to direct questions. If

you ask someone if they possess a negative trait, such as stigmatizing attitudes, a proportion are likely to respond with a favorable, socially acceptable answer, rather than a truthful one.[47] This is known as social desirability bias. Interviews conducted in person are particularly susceptible to this bias .The Marlow-Crowne Scale is designed to measure the degree to which social desirability bias may be influencing your sample (See Appendix 2).

**Common strategies to reduce social desirability bias include:**

a) Use of self-administered surveys

b) Audio computer-assisted self-interview software (ACASI)[78]

c) Indirect or impersonal wording of the survey items

d) On-line or anonymous surveys.

Minimizing social desirability bias is a major challenge in all stigma measurement. To reduce the likelihood of this bias it is best to use self-administered surveys, ACASI or use indirect wording. Social desirability bias and strategies to mitigate it are covered in more detail in Chapter 5.

## Literacy Levels

Another challenge in measuring community TB stigma is literacy. Valid scales for low literacy groups and children are absent. The use of interviewer administered surveys or images are possible. Semantic differentials (i.e. having respondents choose between positive and negative images of TB patients) is one potential method of measuring TB stereotypes without words.[29]

To ensure understanding with lower literacy samples, it may be preferable to apply "hybrid" modes of scale administration. For example, a respondent enters their answers on a computer screen or paper questionnaire while a trained interviewer reads the questions to maximize perceived confidentiality while minimizing the risk of poor understanding or acquiescence bias ("rushing through"). Trained interviewers can carefully explain the instructions and answer questions, and read every question while still being unaware of the respondent's answers.

## Hypothetical questions

The use of hypothetical questions in stigma surveys was widely used for HIV, especially in self-stigma scales. An issue with hypothetical questions is that you are obliging conjecture., i.e. you are measuring peoples' assumptions about themselves rather than their stigmatizing behavior or their first hand experiences of stigma.[47] Hypothetical family concealment questions are problematic for this reason and should be used only if alternatives are lacking. A single question on hypothetical family secrecy (If a member of your family got TB, would you want it to remain a secret or not?") was used in 66 surveys as a TB stigma measure before validated stigma scales were available.[15,48,49] However hypothetical questions are no longer recommended because of the poor potential correlation with behavior.

## Adaptation of a published scale

Even if a scale is well validated, one cannot simply choose a pre-existing scale or set of interview questions for measuring anticipated stigma and assume that it will be applicable in all settings. Stigma in each country may be slightly (or very) different. Items that reference marriage, sexual or gendered behaviors are often setting-specific.[14,39] Ensure that a multidisciplinary team of local experts (including survivors of TB) are fully engaged so that all aspects of TB stigma are covered. (See Chapters 1 and 12 for how to engage PWTB, and Chapter 16 on scale validation steps).

## Assessing the role of community TB stigma upon health care seeking for TB symptoms

Stakeholders are not only interested in measuring levels of TB stigma in the community but also to gauge the extent to which these attitudes may contribute to delay in case detection. The impact of TB stigma on behavior is not always easy to figure out.[50] Stigma in the general population can be a deterrent to TB health seeking behaviors.[32,51,52] TB stigma appears to influence the location and type of provider, with higher stigma leading clients to seek health care farther from home.[38,53] Anticipated TB stigma may inhibit health-seeking behavior through fears of negative treatment, fear of being disparaged (gossip) or isolated by the community and fear of negative stereotypes. Care must be taken when studying the impact of stigma on health care behaviors. Health care seeking for TB symptoms is a very complex multi-step process influenced by diverse factors. There are many reasons why people with TB symptoms don't seek care.[54–56] To measure the effect of stigma on health seeking behavior you need to have:

1. A comprehensive causal theory to explain health seeking behaviors.[57]
2. A sufficiently powered sample to measure small effects (>50,000 respondents) and control for all the other influences.
3. Robust measures of all the other determinants of health seeking behavior
4. The ability to analyze the data correctly.

It is unwise to measure the role of stigma in isolation from all the other influences on health seeking. A lot of early work on TB health seeking behavior relied on Theory of Reasoned Action or Health Belief Model or similar frameworks linked to individual motivation.[58,59] These narrow frames have not always sufficiently accounted for all the societal, legal, and environmental obstacles to TB diagnosis. In the absence of a rapid point of care diagnostic, TB testing is now recognized as a multi-step process where access and other structural factors must be considered.[32,60–62]

**Figure 3. Illustrative conceptual framework for study of the influence of stigma upon health care seeking**[63]
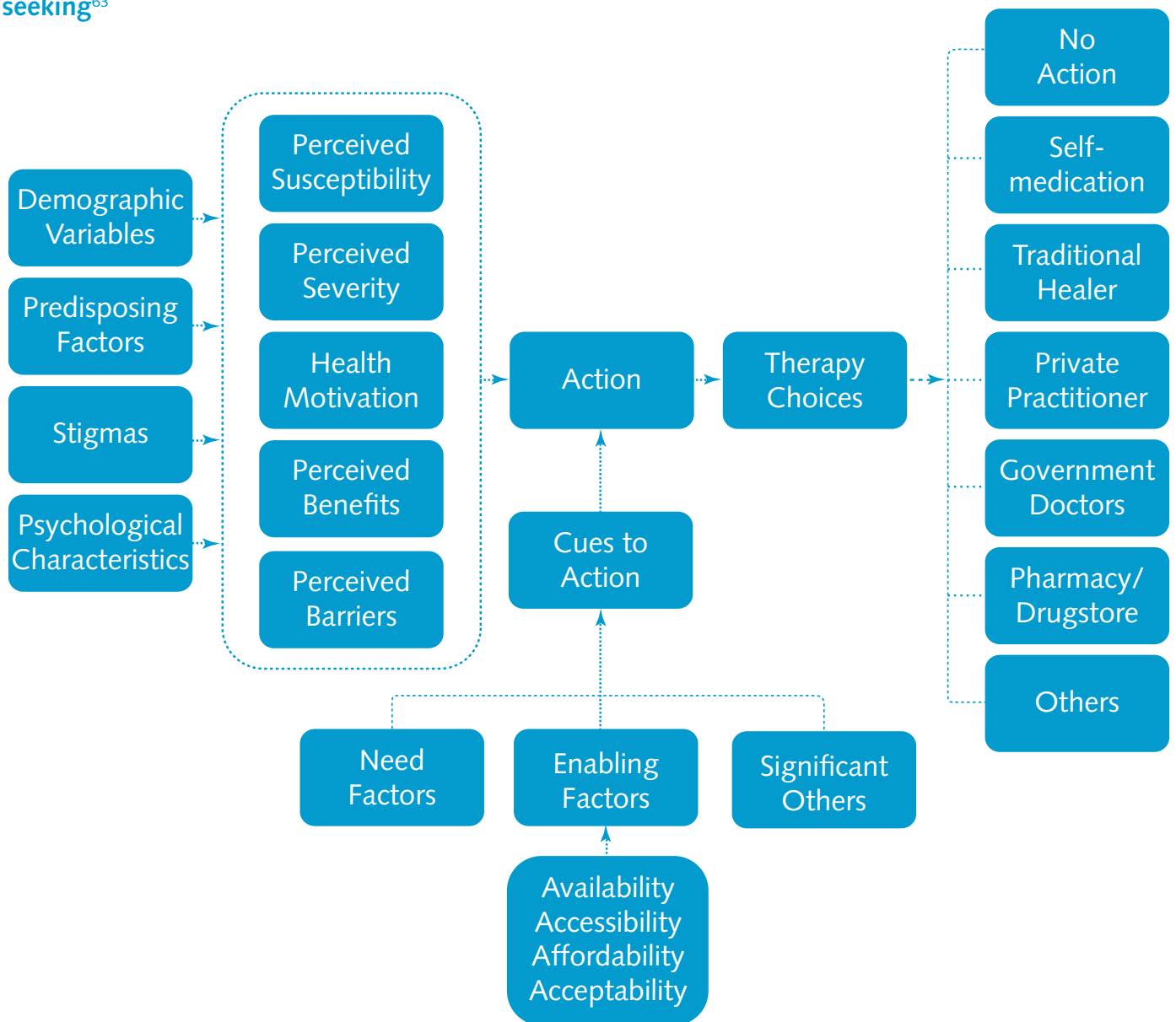


Often TB stigma can be present in high levels, but people with symptoms may deflect or overcome anticipated TB stigma if they perceive TB to be a serious threat to survival or if effective treatment is thought to avert enacted stigma.[37,67]

When a comprehensive study of determinants of health seeking is conducted and all the other contributors are taken into account, TB stigma does not always turn out to be the main obstacle to health care seeking behavior for chronic cough.[37,41,64–66] Chronic cough can conjure fears of lung cancer, HIV, and other conditions. There is evidence that the stigma of lung cancer, smoking, and HIV represent barriers to health seeking for chronic cough in some contexts.[65,72,73] Multiple stigmas can make determining the specific role of TB stigma in health care avoidance more complex.[15] The presence of other prejudices may need to be measured to improve the interpretation of health seeking behavior. See Chapter 14 for guidance on how to measure syndemic stigma.

An example from a community survey in South Africa (Figure 4) shows how fear of TB stigmatization and TB discrimination may not be the single most important impediments to care, but collectively stigmas constitute serious obstacles.[32]

**Figure 4. Reasons people delay seeking care for TB-symptoms in Eastern Cape, South Africa (n= 1020, Møller et al., 2011)**
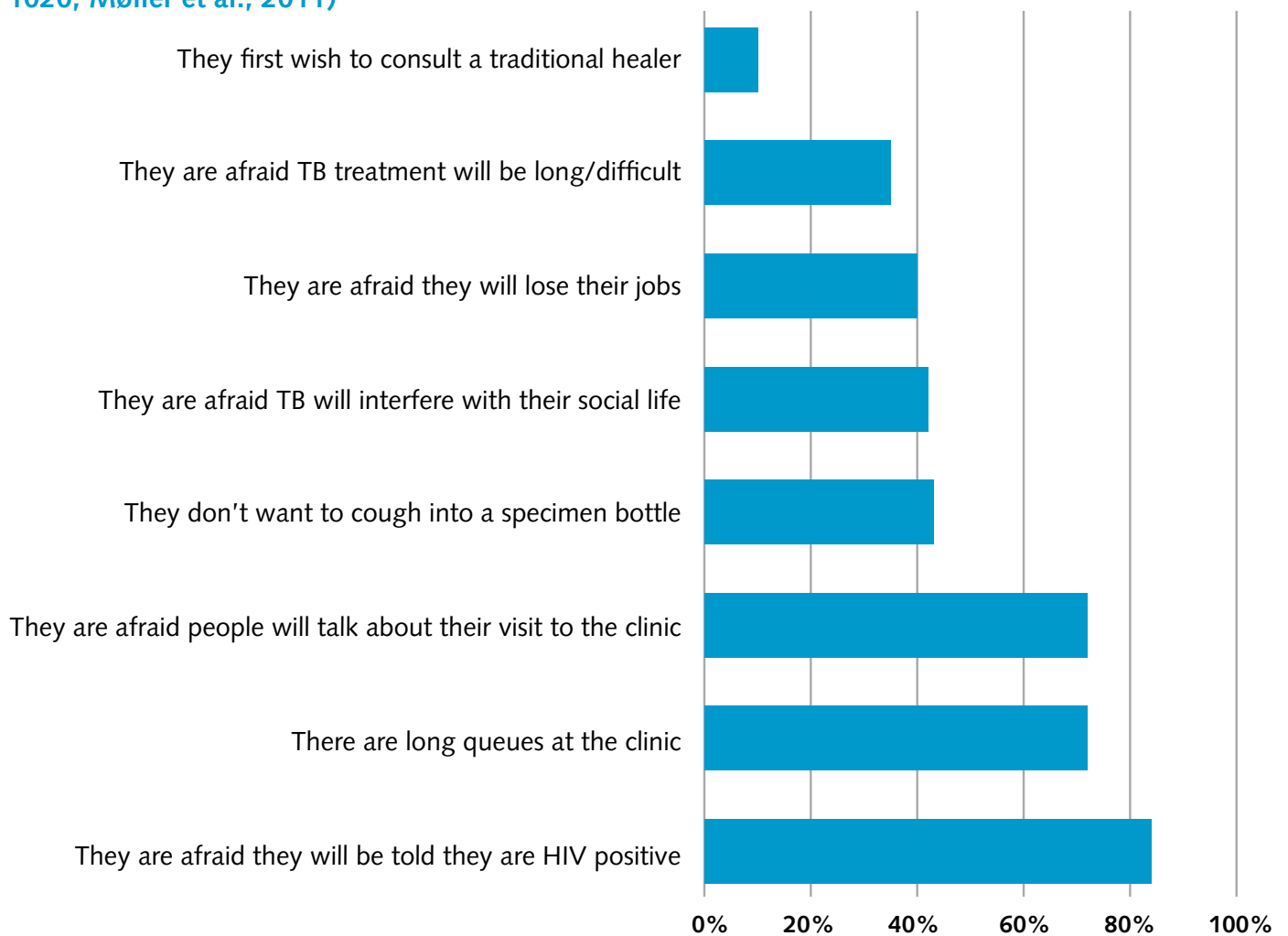


The End TB strategy will require reaching over 4 million people with TB who are currently unreached and engaging them in care.[68] For most countries, this will require a better understanding of the role of TB stigma as a deterrent to health seeking. To improve healthcare-seeking for TB, priority must be placed on addressing the specific fears and concerns of people most at risk for TB (e.g. gossip, job loss) even if these issues are not perceived as priorities by the program.

Ideally any study of healthcare-seeking behavior should recruit the study sample from outside of health facilities. Many of the studies of healthcare-seeking delay recruit only from health care facilities. By definition this biases the study by excluding people who never seek care or delay for extended periods.

When interested in stigma-related determinants on health care seeking we recommend to measure stigma domains that are susceptible to intervention. From a policy view, it makes little sense to focus on measuring TB stigma domains that are immutable or beyond your locus of control. For example, it is perhaps more important to measure negative stereotypes about people with TB than it is to focus on the role of air-borne transmission as a source of fear. The route of transmission of TB cannot be influenced whereas we can debunk myths and break down stereotypes about people.

In some settings TB is disproportionately concentrated among people and communities who are already socially excluded (See Chapter 9).[9,69,70] There is also clear variation in stigma's deterrent effect by group (e.g. pastoralists).[71]

## Planning a study on the role of stigma in health care seeking behavior

1. Identify and theorize all the major determinants of health seeking behavior in your settings ( literature review, formative interviews) and build your conceptual framework. (See Chapter 15)
2. Operationalize the framework (i.e. decide how best to measure the determinants of health care seeking).
3. Establish operational and meaningful definitions of health care seeking and 'delay'
4. Size the study (e.g. choose the sample size) based on your estimate of the relative importance of TB stigma upon health care seeking.

## National Survey Estimates of TB Stigma

Embedding a TB stigma scale into a larger nationally representative behavioral survey is the most efficient way to generate national estimates.[74] Integration of short TB stigma scales is preferable to stand alone measurement efforts because the cost and technical complexity of implementing a population-based household survey correctly are high. Imbedding TB stigma scales into health or social surveys is more feasible and cost-effective because the high implementation costs can be spread across multiple health programs. This is the most efficient approach to gather valid estimates. Moreover it allows for triangulation of the stigma findings with other attitudes and health correlates. Knowledge, attitude, and practice (KAP) surveys are also possible mechanisms for TB stigma measurement.[75,76] National surveys can reveal important sub-national differences in stigma levels (Figure 5).

**Figure 5. Variability of TB non-disclosure attitudes within India by state in the 2005 DHS[77]**



2.6-9.5%
9.6-10.9%
11-13.9%
14-20.7%
20.8-41.3%
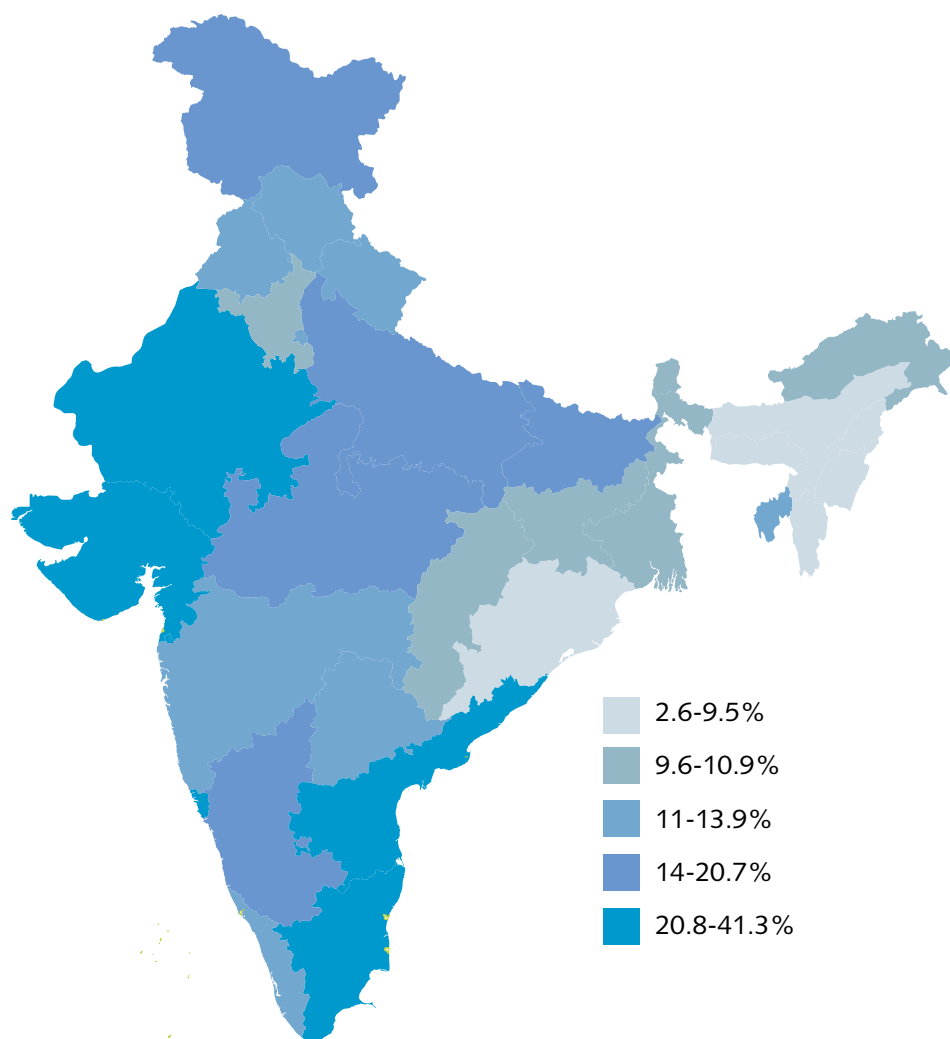
A key challenge in incorporating a stigma scale into a national health survey is the scale length. A scale with many items is hard to incorporate in behavioral surveys that do not have TB stigma measurement as their sole objective. Stigma measurement experts do not believe that a complex construct like stigma can be adequately reflected with a single item.[74] The minimum number of items required to capture a complex construct like stigma is likely to be five to seven items. Validation studies of brief TB stigma scales are on-going.[35,36]

Measures of TB stigma can be integrated into nationally-representative surveys such as a Multiple Indicator Cluster Survey (MICS), a Demographic and Health survey (DHS), TB prevalence surveys if shown to be robust across contexts. Detailed guidance on how to conduct a national household survey is beyond the scope of this Guidance. But please note that these require multi-cluster designs and usually take at least two years to plan and execute. However the United Nations, the World Bank, and the Demographic and Health Survey (DHS) implementer all offer detailed training materials to enhance local capacity to carry out rigorous national surveys:

• UNSTATS provides a 29-chapter resource that lays out the key considerations for national household surveys.
https://unstats.un.org/unsd/hhsurveys/

- The World Bank also offers an on-line course with useful capacity building exercises for national household survey planning and implementation. http://go.worldbank.org/3Q7O7NBI60
- The DHS offers this Facilitator's guide for conducting a national Demographic and Health Survey
  https://www.dhsprogram.com/pubs/pdf/DHSC4/Module_4_dhsc4.pdf
- The WHO Global TB Program also has a publication on TB prevalence surveys which describes the proper procedures of multi-cluster sampling and gives some practical tips on household survey planning and implementation.
  http://www.who.int/tb/advisory_bodies/impact_measurement_taskforce/resources_documents/thelimebook/en/
- On analysis:
  https://www.dhsprogram.com/Curriculum/index.cfm

## Conclusion

Stigma in the general population can be influenced by social characteristics, knowledge, national epidemiological context and structural drivers of TB stigma. The context in which you work will impact the items and the scales you should use. The aim of the study needs to be clear to allow the questionnaire content be tailored to the need and therefore deliver the desired data. It is best to conduct a pilot study with cognitive interviews of the stigma scale chosen to ensure that it is appropriate for the setting. This will ensure that it is contextually appropriate and minimize the misinterpretation and misunderstanding of the scale items which will inevitably lead to unusable data. You need to be aware of social desirability bias in your data collection. The most cost effective and practical way to measure stigma in the community is to imbed a TB stigma scale into a general social survey. This will allow the costs to be shared across multiple organizations and the triangulation of data from the other health areas measured. Measuring TB stigma in the community is necessary to understand how TB stigma operates, and the extent to which it discourages health seeking behaviors and to evaluate the effectiveness of stigma reduction interventions.

## Acknowledgements

# Appendix 1: Colvin Scale

1. People with TB are usually poor.
2. People with TB usually live in an unclean house.
3. People with TB do not have very much education.
4. If a friend of mine was diagnosed with TB, I would worry that s/he also has HIV/AIDS.
5. If a friend of mine had TB, people would avoid him/her.
6. If I knew a friend of mine had TB, I would no longer be friends with him/her.
7. If a friend of mine had TB, s/he would probably lose his/her job.

# Appendix 2: Marlowe-Crowne Scale for Measuring Social Desirability Bias

Use of the Marlowe-Crowne Scale for measuring social desirability bias can help to make sense of the TB stigma self-reported results.[76] Here is the scale:

## Directions:

Read each item and decide whether it is true (T) or false (F) for you. Try to work rapidly and answer each question with "true" or "false".

1. Before voting, I thoroughly investigate the qualifications of all the candidates.
2. I never hesitate to go out of my way to help someone in trouble.
3. It is sometimes hard for me to go on with my work if I am not encouraged.
4. I have never intensely disliked anyone.
5. On occasions I have had doubts about my ability to succeed in life.
6. I sometimes feel resentful when I don't get my way.
7. I am always careful about my manner of dress.
8. My table manners at home are as good as when I eat out in a restaurant.
9. If I could get into a movie without paying and be sure I was not seen, I would probably do it.
10. On a few occasions, I have given up something because I thought too little of my ability.
11. I like to gossip at times.
12. There have been times when I felt like rebelling against people in authority even though I knew they were right.
13. No matter who I'm talking to, I'm always a good listener.
14. I can remember "playing sick" to get out of something.
15. There have been occasions when I have taken advantage of someone.
16. I'm always willing to admit it when I make a mistake.
17. I always try to practice what I preach.
18. I don't find it particularly difficult to get along with loudmouthed, obnoxious people.
19. I sometimes try to get even rather than forgive and forget.
20. When I don't know something I don't mind at all admitting it.
21. I am always courteous, even to people who are disagreeable.
22. At times I have really insisted on having things my own way.
23. There have been occasions when I felt like smashing things.

24. I would never think of letting someone else be punished for my wrong-doings.

25. I never resent being asked to return a favor.

26. I have never been irked when people expressed ideas very different from my own.

27. I never make a long trip without checking the safety of my car.

28. There have been times when I was quite jealous of the good fortune of others.

29. I have almost never felt the urge to tell someone off.

30. I am sometimes irritated by people who ask favors of me.

31. I have never felt that I was punished without cause.

32. I sometimes think when people have a misfortune they only got what they deserved.

33. I have never deliberately said something that hurt someone's feelings.

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# Chapter 5

# Measuring Stigmatizing Behaviors in Health Care Facilities and other Institutions

*Ellen M.H. Mitchell, Sarah van de Berg, Julia van der Land, Amrita Daftary, Gill Craig, and Lisa Redwood*

## Abstract

Reducing stigma and discrimination in health care settings is one of most important projects of the Sustainable Development Agenda.[1–4] This chapter synthesizes the techniques and guidance presented in other chapters to show how stigma measurement could be approached in a health facility ecosystem. The same approach can be used in other institutions like courts of law, mines or prisons. The use of participatory and structured observational techniques is introduced as a way to overcome biases from reliance upon self-reported attitudes and behaviors.

## Objectives

1. To build readers' capacity to conceptualize the drivers and domains of TB stigma in institutions.
2. To make readers aware of the special challenges in measuring undesirable behaviors.
3. To build capacity in structured and unstructured observation skills for the measurement of stigma.

## Target audience

This chapter is for social scientists, M&E officers, research staff of NGOs and TB programs, activists, and health facility managers. The methods and guidance in this chapter are geared to people who want to understand the manifestations of TB stigma in their institutions.

## Introduction

TB stigma measurement has historically concentrated on those who have been

stigmatized.[5,6] Expanding the focus to document behavior of people who stigmatize is useful because those are the behaviors we seek to change.[5] One of the challenges is how to measure stigmatizing behavior in unbiased ways. Few established measurement practices exist. This chapter expands on the survey scales methods described in Chapters 4,7 and 8 to explore more innovative (and unvalidated) approaches to measure stigmatizing behavior.

Effective TB stigma reduction requires shifts in the attitudes and behaviors of healthcare workers, employers, educators, religious leaders, journalists, opinion leaders, politicians, judges, and juries.[5]

Institutions are social spaces with a specific organizational culture, architecture, and sets of norms and policies. TB stigma can thrive under enabling conditions present in institutions and be virtually absent in others.[3]

**Make sure to measure stigma domains that are susceptible to intervention if you intend to use it as a baseline**

Stigma in health care settings hampers access to, and the quality and outcomes of health service delivery.[2,4] Mistreatment of people with TB, is not only a violation of human rights, but also can contribute to mental health sequelae and other comorbidities.[6] Discrediting persons with TB is counterproductive to TB care and elimination efforts because it negatively impacts health care seeking behavior, care delivery, adherence, and recovery.[7–11] Indeed, perceptions about the way a person with TB is treated in a health care interaction influences the timing, location, and quality of care.[12] They may also impact resilience and health outcomes.[13,14] We know that when providers lack cultural competence with a wide array of client groups, their contact investigations are of lower quality and effectiveness.[15–18] Discrimination in health care thrives in settings with poor supervision and inadequate training in TB patients' rights and infection control (IC).[3,19] When healthcare workers' rights are disregarded, they tend not to prioritize patients' rights.[20]

There may be many contributors to healthcare workers' empathy fatigue (e.g., organizational hierarchies and culture, infrastructure, and policies).[21] It is helpful to map the contributors to an environment that condones or tolerates stigmatizing behaviors. The following are examples of individual behaviors and institutional practices that are stigmatizing or discriminatory:

## Provider behavior

- Human rights violations as denial of care; mandatory testing and treatment practices or use of coercion, punishment or threats; breaches in confidentiality; violence and abuse
- Negative and disparaging behavior toward TB clients[3]
- Use of value-laden terminology (see Chapters 6 and 11)
- Gossiping; breaches of trust and confidentiality

- Demeaning clients: name-calling, microaggressions
- Non-specific rudeness; insensitivity
- Authoritarian approach to treatment supervision[22,23]
- Use of coercion, punishment, and threats
- Stigmatizing policies and structures
- Unnecessary, prolonged masking[19]
- Unnecessary separation of TB clients
- Unnecessary isolation of TB clients
- Task-shifting to unqualified staff
- Over-referral to other facilities
- Denial of services
- Lack of safe waiting areas
- Lack of auditory and visual privacy

## Rational for Studying TB Stigma from an Institutional Perspective

Stigma is about interactions between people. There is much to be gained from the study of human dyads (stigmatizer-stigmatized) as a combined unit of analysis.[8] Examining stigma from multiple perspectives is more challenging than univariate measurement of the experiences of a person on the receiving end of harmful words and deeds. However, the additional investment is worthwhile because capturing aspects of TB stigma from an institutional perspective, such as the enabling environment that sustains TB stigma and the motives behind the behaviors of "perpetrators," provide insights for the appropriate design of anti-stigma interventions, and help to monitor and evaluate interventions intended to change the behavior of stigmatizers.

## Drivers of TB Stigma in Health Facilities

There are an array of factors that create an enabling environment for TB stigma.[24] Healthcare workers' educational exposures can increase or decrease their stigmatizing attitudes.[24–26] Healthcare workers who demonstrate a lack empathy and solidarity with TB clients may themselves be experiencing a heavy burden of TB "dirty work" stigma.[27,28] Healthcare workers who stigmatize may be being mistreated themselves. Healthcare workers may lack safe and decent working conditions.[29–32] TB healthcare workers often work in facilities that do not have adequate environmental and administrative infection controls needed to protect them.[31,32] They may care for TB clients in public sector facilities where salaries are paid irregularly and commodities are insufficient.[20,33–35] Healthcare workers experience a higher prevalence of workplace violence.[36–40] Poorly designed policies, guidelines, and educational messages may reinforce stigmatizing language and ideas among workers. It important to try to map the drivers of stigma in health facilities if you plan to reduce it. Chapter 3 provides guidance on how to uncover the drivers of TB stigma.

Identifying the drivers and facilitators of TB stigma through formative research makes the measurement task clearer.[20] Figure 1 is an illustrative conceptual framework for an MDR-TB stigma study in Ethiopian health care facilities. The framework maps out the structural (policy and infrastructure), organizational, and individual drivers of MDR-TB stigma so that each of the relevant drivers can be measured. The framework presents an initial hypothesis about what issues are important to measure. Some of the issues may turn out to be irrelevant. Identifying and defining all the pieces of the stigma puzzle is the first step in designing a TB stigma study.

**Figure 1. Conceptual Framework for Stigma in Health Facilities in Ethiopia**
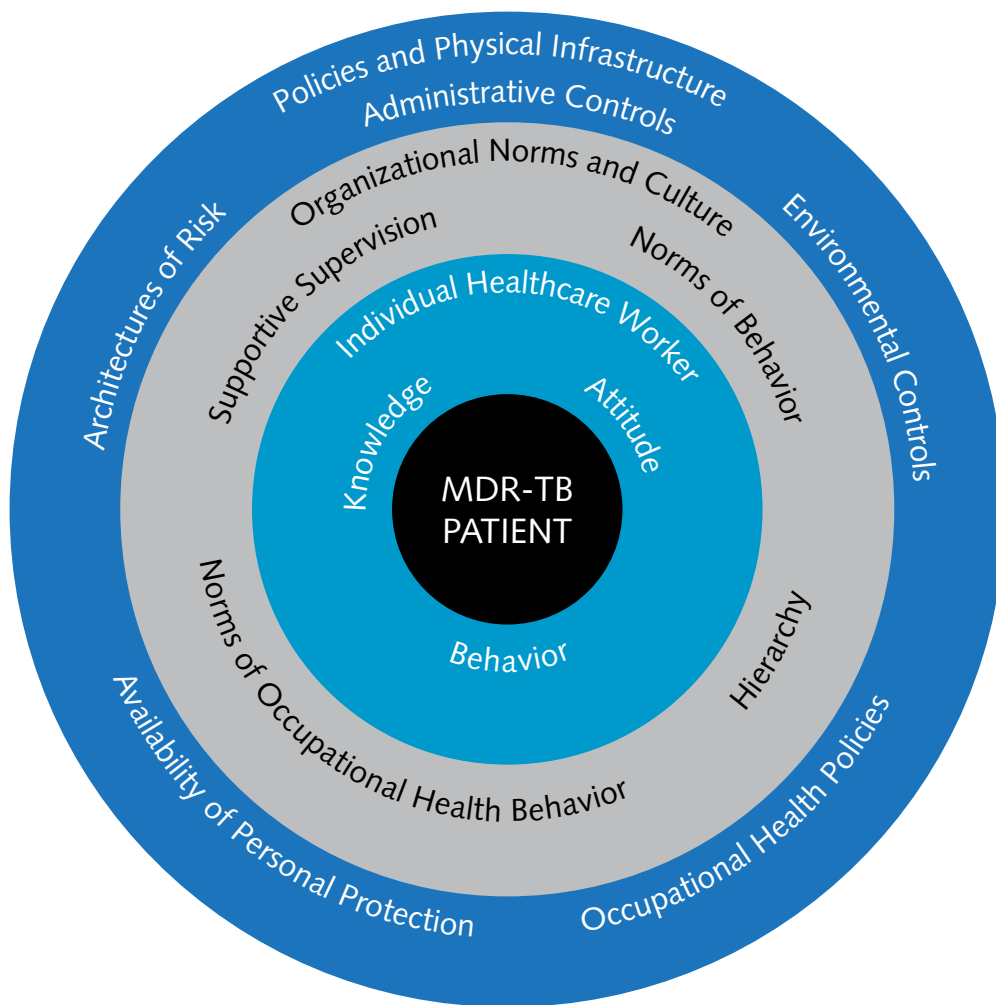


## Determining Which Domains of TB Stigma to Measure in an Institution

There are many manifestations of TB stigma that could be measured in a social space. Examples include: policies, organizational structures, management practices, health care facility (HCF infrastructure, organizational norms and culture, TB knowledge, attitudes of healthcare workers toward TB clients as well as other healthcare workers, and the behavior of healthcare workers. Measuring multiple domains and triangulating the findings can yield richer results. If resources are limited, the assessment of policies and attitudes for stigma can be inexpensively assessed. (See Chapter 11 for guidance.)

The choice of where to focus measurement is determined by both where you think the problem is and where you think opportunities for intervention lie. If your goal is to change behavior, you must measure behavior at baseline.

It is important to keep in mind that not all stigmatizing behavior is intentional. Indeed, some behaviors may be mandated. For example, standard TB control interventions, such as masking, separation, contact investigation, direct observation of treatment (DOT), can be perceived as stigmatizing and discrediting.[41–43] Figure 2 illustrates how some behaviors that may stigmatize (the segments of the circle) can have as their root causes both value-based stigma and more structural origins (the outer boxes).

## Figure 2. Indirect Causes of Stigmatizing Behaviors



Lack of auditory/visual privacy
Mandatory name-based notification

Breaches of trust
and confidentiality
(deductive disclosure)

Lack of knowledge
about the duration
of infectiousness

Neglect and
avoidance
behavior
Masking of
non-infectious
patients

Cougher
triaging
Patient
isolation

IC policies
Facility policies

Physical distancing
from TB patients

Functionality of environmental controls (e.g. locked windows)
Stockouts of IC commodities (e.g. masks)

What mask wearing means varies widely by region and by country. Wearing masks is normative in many Asian urban areas in response to air pollution or as a fashion accessory.[44–46] In health care settings, there are often many different interpretations of infection control (IC) practices.[19,41,47–49] The over-use, misuse, or prolonged use of personal protection has been a potent manifestation of stigma.[19] As IC can be conflated with stigmatization, it is important to assess the meanings attached to IC.[19]

**Table 1. Diverse Interpretations of Healthcare Worker Behavior**

| Infection control Practices | Stigmatizing Interpretation |
| --- | --- |
| Client separation | Shunning of PWTB |
| Client masking | Marking of PWTB (disclosure) |
| HCW masking | Fear of PWTB |

Noé and colleagues found that 65% of healthcare workers in Mozambique agreed that their behavior contributed to TB stigma.[50] One quarter of Ethiopian healthcare workers reported having a negative attitude toward MDR-TB patients.[51]

A comprehensive study of stigma in health care institutions should explore structural-level stigma, such as norms and policies that may mandate masking, triage, and physical separation of TB clients (Chapter 6), but also how reality may depart from official policies. The actual behaviors and interactions at a facility can belie deviations from stated policies. These unwritten (and often unspoken) norms are just as important. Observational techniques can help to tease out such issues. Secondary stigmatization of health workers by their peers should also be measured (Chapter 8). Figure 3 links the sites of stigma to the chapters that measure them.

**Figure 3. Components of the Health Care Facility that May Contribute to Stigma**



Discourses - Messages, Signage
Chapter 11

Laws, Policies, Rules, Registers
Chapter 6

Commodities, Physical Structures
Chapter 5

Community or Organizational
Norms and Behaviors
Chapters 4 & 5

Individual HCWs
and Patients
Chapters 7, 8, 10
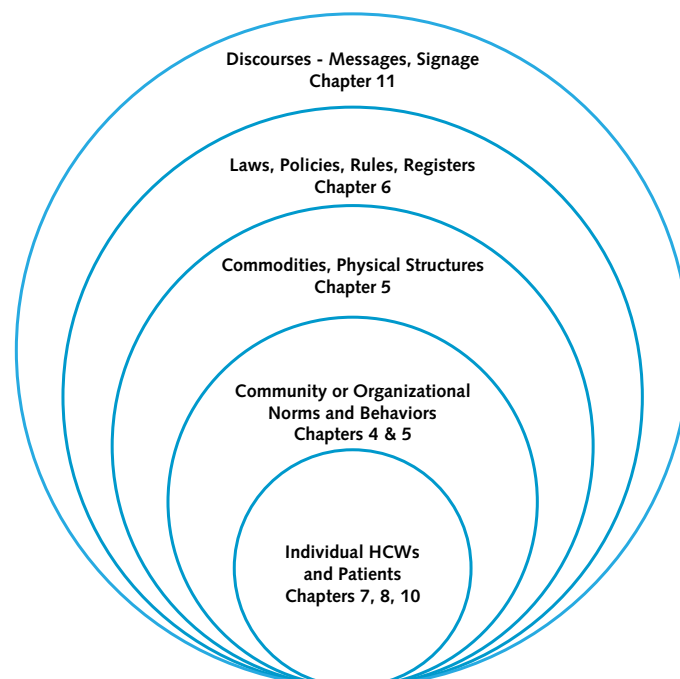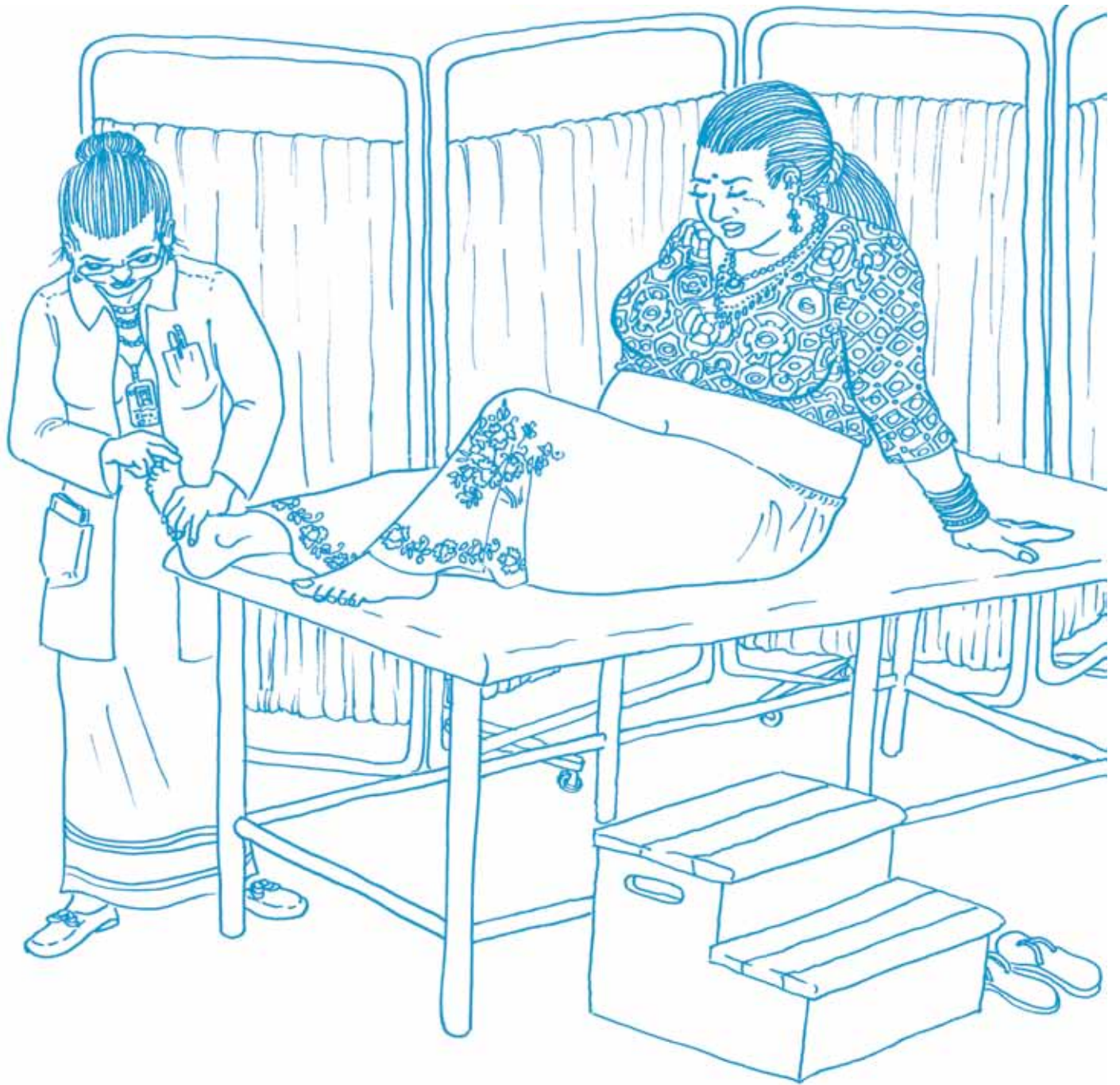
# Measuring Stigmatizing Attitudes About TB Among Healthcare Workers

Stigmatizing attitudes can be measured either with surveys or observational methods. First we review the available scales and then consider the advantages and disadvantages of different observational methods.

There are a variety of generic scales for measuring discriminatory attitudes that can be adapted to TB (See Chapters 4 and 14).

### Table 2. Stigmatizing Attitude Scales for Healthcare Workers

| First Author | Country | Population | Content Validity | Construct Validity | Reliability | Items | Domains |
|---|---|---|---|---|---|---|---|
| Wu (2013)52 | Taiwan | HCWs | Attribution Questionnaire for mental illness stigma (AQ-S8) | PCA | α=0.68 | 8 | Attribution avoidance, sympathy, |
| Respondent's external stigma toward HCWs with TB | South Africa | HCWs | | CFA | | 3 | Avoidance, fear, HIV link |

Wu et al found that answers to eight questions predicted willingness to provide directly observed therapy.[52] Corrigan's nine domain Attribution Questionnaire (AQ-9) may be more applicable to HCW because the coercion domain is closely linked to dignity and rights-based TB treatment.[53] The scale uses a ten point likert scale.

### Table 3. Illustrative items based upon Corrigan Attribution Questionnaire Short Form

| AQ-9 Domain | Illustrative Items |
|---|---|
| Fear | How nervous are you treating TB patients? |
| Pity | How much pity do you feel for TB patients? |
| Help | How likely are you to help a TB patient? |
| Avoidance | I would try to stay away from a TB patient |
| Blame | I think developing TB is a person's own fault. |
| Anger | How angry do you feel towards TB patients? |
| Segregation | I think it would be best for TB patients to be isolated in the intensive phase |
| Danger | How dangerous do you feel TB patients are? |
| Coercion | I think taking TB treatment should be forced if necessary |

In 2016, Wouters et al. validated tools to measure different levels of TB and HIV stigma in the healthcare workforce.[27,54] Wouter's External TB Stigma scale for HCWs includes three items that reflect the desire for social distance, fear of HCWs who treat TB, and linking TB care to stigmatized co-morbidities (Table 4).[27,28,54] The decision on whether to use Wouters, Wu or Corrigan may depend on available space and whether you plan to intervene narrowly on TB stigma or more broadly on a range of stigmas (e.g. TB and HIV stigma).

**Table 4. Wouter's External TB Stigma Scale Items**

| Item No. | Stigma Scale Item | Factor loadings (α reliability estimate if item was removed) |
|---|---|---|
| | Respondent's external stigma toward HCWs with TB | |
| 10 | I do not want to work together with co-workers who have TB | 0.841 (0.813) |
| 13 | I am afraid of co-workers with TB | 0.887 (0.795) |
| 14 | HCWs with TB probably also have HIV | 0.602 (0.888) |

## Biases in Self-Reporting Stigma

Self-reporting has many important limitations for the measurement of stigmatizing attitudes and behaviors. Common ways around the problems of self-reporting and social desirability are:

- To ask the HCW about the behavior of other HCWs (not themselves).
- To use computer-assisted self-interview (CASI) with highly literate, computer-savvy respondents (see Chapter 7).
- To phrase the questions in the least judgmental way possible.

It is not possible to eliminate social desirability bias completely from a survey. Therefore, the extent of social desirability among respondents should always be tested by using the Marlow-Crowne Scale. (See an explanation of the Marlow-Crowne Scale in Chapter 4.[55,56]).

## Observations

Field observations allow researchers to understand TB stigma as it is produced without asking people whether, how, or why they stigmatize.[34] Seeing daily practices can also highlight divergent interpretations of a shared reality. It is easier to measure gossip, voyeurism, taunting, scolding, and name-calling than inner thoughts. Social exclusion is quite visible and lends itself to observational measures. For example, clinic observations can allow for a witnessed account of the social contexts in which clients attend clinics and access TB-related

services, insight to their interactions with clinic staff and with other clients, and norms and actions practiced in a clinic environment that could affect clients' overall experiences with health care (Table 3). Field observations can identify architectural features or health messaging that promotes stigma. There are structured and unstructured forms of observation. This chapter describes both.

Field observations can elicit novel insights into discriminatory practices and norms that are less likely to be discussed by interview or focus group participants because they are considered socially undesirable or totally normal (Table 5). There are a variety of observational study designs, including studies in which the researcher becomes fully immersed in their research setting (assumes the role of a participant).[51]

**Table 5. Examples of What to Observe and Document at Clinics to Examine TB Stigma**

| | |
|---|---|
| Setting-architectures | Location in community/city, signposts, clinic layout, proximity between queue and provider offices, spacing/crowding, type of seating, posters/flyers, ventilation/UV lighting |
| Human behavior | Frequency and types of interactions between people (patterns/types of communication, body language/touching between clients and clients and providers), masks/cough hygiene, social distance, microaggressions, tone, eye-contact |
| Social environment | People characteristics (types of people: clients, caregivers, providers, allied workers; gender; ethnicity/race; religion, clothing; physical appearance), human traffic (numbers, entries/exits, accompanying persons, client intake/output, waiting times) |
| Clinical behavior | Clinical care provided (who receives which services, tests, treatments, advice, free samples, support, length of consultations, etc.) |
| Surprises and non-occurrences | Observations that stand out: people or activities receiving more attention; unexpected activities: expected observations that are not observed, observations that do/do not appear congruent with the literature or interview/focus group responses; and/or absence of staff/resources that are typically present |

## Unstructured Observations

Participant observation allows researchers to build familiarity and rapport with study sites, from which interview or focus group participants may subsequently be recruited, to arrive at a more sensitive and reflexive analysis.[34] Observations can inform the line of questioning during client interviews, including questions pertaining to the quality of care, interactions between clients in the clinic queue, relations between clients and providers, and a comparison of the social dynamics between multiple sites.

Non-participatory, unstructured observations identify how TB stigma may be produced or sustained in specific settings, such as health centers, prisons, mines, and other social spaces. Under this approach, the researcher serves as a bystander to the events that he or she observes, and subsequently documents and analyzes the findings through a process of reflexive practice. There is no set amount of time in which observations must be collected and analyzed. However, prolonged field engagement (e.g., a year) enhances the rigor of research.[57] Barriers to the use of observational methods are that they are time intensive, and often researchers do not have experience with or confidence in conducting them.

**Figure 4. Observations can highlight distinct social interactions and practices in TB and HIV clinics**
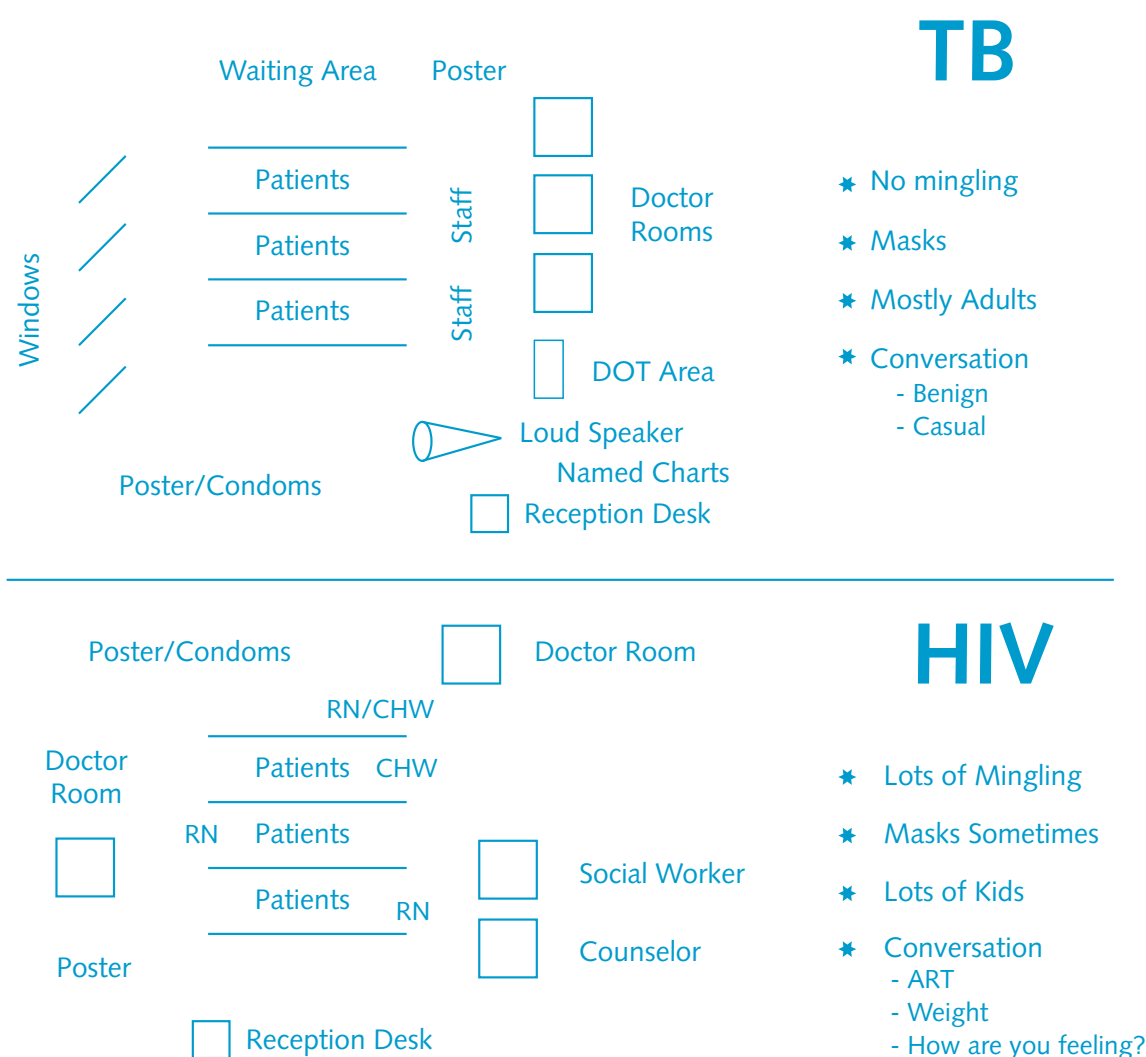


## Structured Observations

Structured (or directed) observation is a more efficient way to measure stigma in interactions if desirable and undesirable behaviors can be pre-specified.[58,59] A standardized checklist focuses the observer on discrete acts (e.g., greeting, naming, blaming, shaming). The checklist is applied in a pre-determined context or to a pre-determined group of people. The observer records the behavior and physical clues as an outsider, being as inconspicuous as possible.

Structured observation is particularly useful to measure the extent to which a particular "marker behavior" or event occurs; for example, a hand shake or a bow or other sign of mutual respect.[59] Structured observation therefore allows for the collection of broad and in-depth information on behavior. Structured observations are often used in the fields of medical education, water and sanitation, drug dispensing, and child health to study the quality of client-provider interactions.[60]

## "Marker Behaviors" of Stigma That Can Be Observed Using Structured Tools

The ability to measure stigma through structured observation is predicated on the idea that there is a specific set of observable behaviors that everyone can agree are stigmatizing and that they can be reliably coded by a trained observer. Specific and obvious acts that are also clinically contraindicated are good "marker behaviors" for stigma measurement. An appropriate marker behavior should not require the observer to infer the motives of the observed. Some thinkers argue that TB stigma marker behaviors should be the more egregious ones.[9,10] Some believe that tools should capture TB stigma in its most unambiguous aspects: discriminatory acts that are verifiably attributable to TB attitudes alone. However, focusing on the extreme tip of the stigma iceberg does make measurement more straightforward (Figure 5).

**Figure 5. Stigma Measurement Metrics**



MORE VISIBLE

STIGMA EXTREME

SHAMING, BLAMING, HARMS, DISCRIMINATION, DENIAL OF RIGHTS, DENIAL OF CARE, SOCIAL EXCLUSION

LESS VISIBLE

STIGMA SUBTLE

FEAR, SOCIAL DISTANCE, MICROAGGRESSION, LABELING
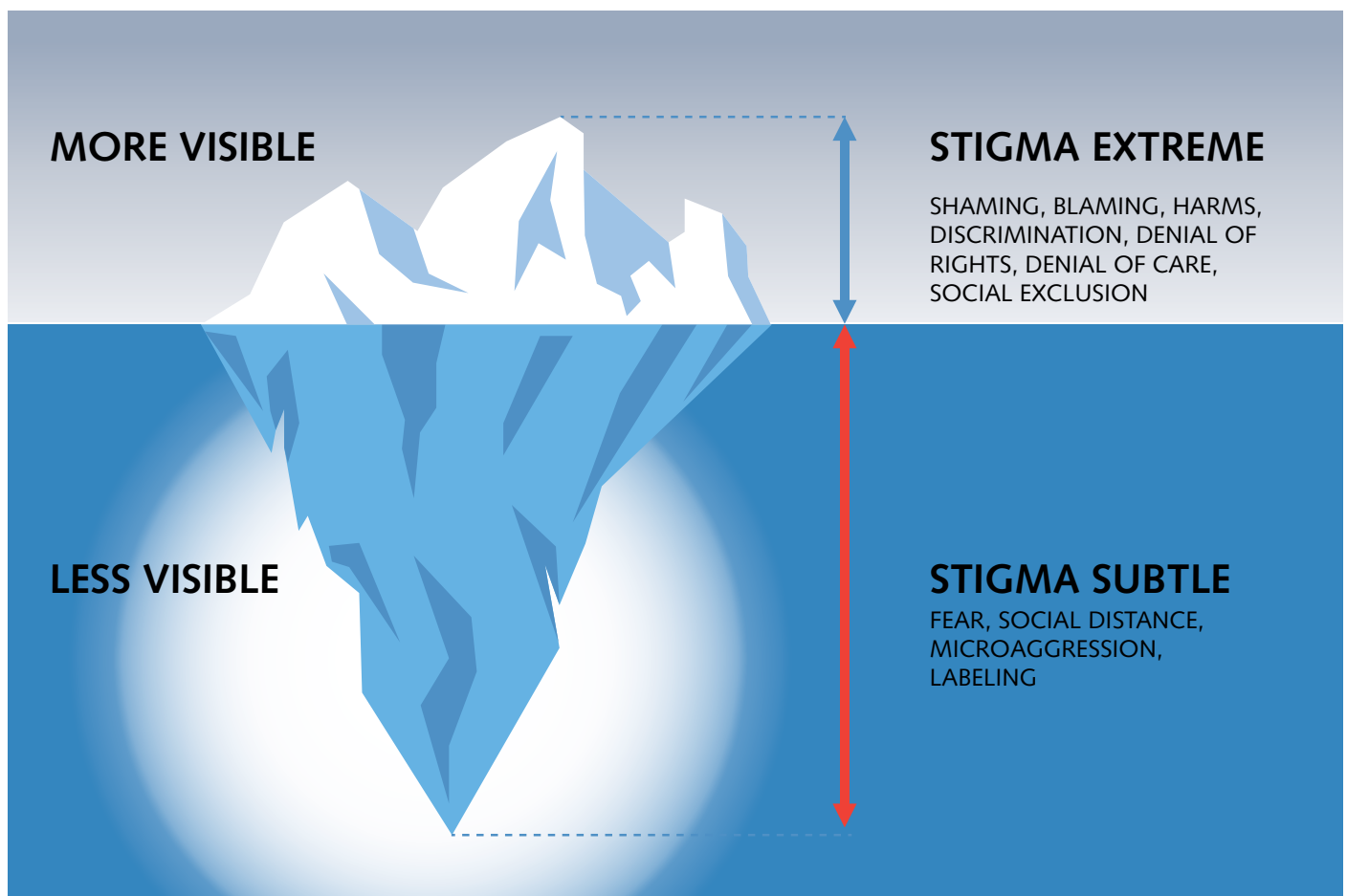
However, extreme behavioral measurement may also not reflect typical instances of stigmatization, in which stigma is likely to be displayed in more subtle ways. Measuring only the most offensive acts may not adequately capture what people with TB are experiencing. Moreover, as a policy matter, it may give false confidence. The prevalence of such distinct or extreme stigma may be "too low" and therefore policy makers may erroneously conclude that urgency to reduce stigma is lacking.

There are three types of structured observation: continuous monitoring, spot checks, and rating checks.

**Continuous monitoring** encompasses observation and recording for an extended period of time, for example, a full day or several days. The observer should randomize the time and location of observations to avoid bias. (See Chapter 9 for more information on Time Location Sampling). Note that this method would only be applicable for stigmatizing behaviors that occur frequently. **Spot checks** involve the observation of the presence or absence of a physical clue or behavior at the first moment of observation. This type of observation is especially useful to check physical clues. Its advantage is that the situation is as yet undisturbed by the presence of the observer. The third type of structured observation, **rating checks**, is similar to spot checks; however, in this case, the observed behavior or physical clue is given a value judgment by the observer. For example, while a spot check observation could be *"TB client is greeted,"* the rating check observation would be *"TB client is greeted by name and with respect."* By directly adding a judgment about the behavior (with respect), the method provides an indication of behavior more quickly, as compared to waiting for the behavior to occur. Rating checks pose a specific challenge; making continuous, consistent judgments on behavior is demanding for observers. This method should be preceded by intensive training and harmonization for the observers to ensure inter-rater reliability.[59]

## Developing Structured Observation Instruments

Formative research with people with TB provides data on marker behaviors that are locally relevant. Cognitive interviewing and other techniques should be used to refine the definition of each behavior and to enable it to be reliably coded in an observation.

The questions in Table 6 are not themselves stigma measures; rather, they allow for the collection of data on the enabling conditions. They are meant to be illustrative of the types of specific, unambiguous, observable phenomena that would need to be measured. For example, breaches in confidentiality may be facilitated by a facility infrastructure that limits privacy.

**Table 6. Example of a Structured Observation Tool to Measure the Enabling Environment for TB Stigma**

| | Yes | No |
|---|---|---|
| 1. Is there a space dedicated to TB consultations? | | |
| 2. Can conversations in the exam room be heard outside the room? | | |
| 3. Can the client be seen from outside the exam room? | | |
| 4. Are there interruptions during the TB consultation? | | |
| 5. Is there any physical wall or glass between client and provider? | | |
| 6. Is there sufficient air ventilation in the room (e.g., open window) to protect the HCW? | | |
| 7. Are there educational materials (e.g., posters, videos, pamphlets, job aids) about TB in the TB clinic? | | |
| 8. If yes, do images or text of materials convey fear, danger, pity, or death? | | |

The structured observation of conversations and interactions requires clarity and specificity about precisely which acts constitute an affirmative answer to each question. This requires thorough observer training and harmonization. Table 7 provides some examples that seem clear at first glance, but once applied, may be too ambiguously worded to yield reliable and valid results. For example, there could be different interpretations of what constitutes "listening carefully".

**Table 7. Example of a Structured Observation of a Client-Provider Encounter**

| | Yes | No |
|---|---|---|
| 1. Was the client greeted in a friendly manner by the HCW? | | |
| 2. Was the PWTB asked by the HCW if they had any questions or concerns? | | |
| 3. Did the provider listen carefully to the client? | | |
| 4. Were value-laden terms or labels used by the HCW? | | |
| 5. Were negative stereotypes or motives of clients expressed or implied? | | |
| 6. Was there any use of blaming or shaming by the HCW? | | |
| 7. Was there exaggeration of dangerousness or risk by the HCW? | | |
| 8. Were there any threats made or coercive language used by the HCW? | | |
| 9. Did HCW state that clients' health information would be protected? | | |

# Steps and Goals in the Use of Structured Observations

To implement the structured observation method, there are sequential steps to follow (adapted from Bentley et al.).[58]

1. Decide if structured observations are needed and can be done considering available resources
   a. Determine the needs of the stigma project.
   b. Determine if structured observations are necessary to meet these research needs.
   c. Decide if available resources are sufficient to do structured observations.

2. Generate a list of potential "key" or "marker" behaviors through a literature review and interviews with informants
   a. Review the literature and brainstorm.
   b. Develop a preliminary list of key behaviors.

3. Conduct formative qualitative research to identify which behaviors and how behaviors should be observed (See Chapter 3 for methods).
   a. Develop a field guide.
   b. Conduct the qualitative investigation. (See Chapter 17)

4. Refine the list of key behaviors and determine the heterogeneity of the population.
   a. Refine the list of behaviors to be observed in a structured format.
   b. Determine behavioral markers, if needed.
   c. Ascertain gender, cultural, cadre, and role heterogeneity of the study population.
   d. Check the work thus far and considering decisions made in Step 1.

5. Identify who to observe, where and when
   a. Identify who (and what) to observe.
   b. Identify locations where key behaviors occur.
   c. Identify times that key behaviors occur.

6. Choose type(s) of structured observations to conduct
   a. Use flow chart to select the type(s) of structured observations.

7. Estimate the reactivity and variability of key behaviors
   a. Select test sites.
   b. Estimate variation in key behaviors.

8. Design instruments and data sheets
   a. Operationalize and define key behaviors.
   b. Design continuous monitoring/spot check instruments.
   c. Develop ratings checklist, if required.
   d. Prepare observation summary.

9. Determine data collection schedule
   a. Determine the number of days for data collection.
   b. Determine the mean number of observational episodes that can be conducted by one observer.
   c. Determine the number of observers required to conduct structured observations.

10. Train observers and pretest instruments
    a. Involve observers in the development of structured observations.

    b.   Develop field manual and code books and carry out the training.
    c.   Pretest instruments.
    d.   Conduct reliability tests to reduce inter- and intra-observer variability.

11. Implement data collection and data management
    a.   Conduct the structured observations.
    b.   Review data sheets and store properly.

12. Clean data set(s)
    a.   Conduct range checks.
    b.   Conduct consistency checks.

13. Process the data
    a.   Determine frequencies of key behaviors.
    b.   Determine the amount of time spent on key behaviors.
    c.   Create behavioral scales or scores.

14. Conduct data analysis and use study results for project planning, implementation, or evaluation
    a.   Do descriptive analysis.
    b.   If necessary or desirable, do further statistical analysis.

A limitation of observational methods is that while they elucidate behaviors, they provide limited insight into why or what prompts such behavior. Identifying people's motives requires a more interactive approach. Many people affected by TB are managing multiple stigmatized identities (e.g., a person may have a history of incarceration).[61] This makes measurement of enacted stigma additionally challenging. Asking broad, close-ended questions about discrimination experiences, one risks conflating many different types of prejudice. Therefore, specificity of the items is essential to make sure that what you are measuring is TB stigma and not other types of prejudice. (See Chapter 14 on measurement of intersectional stigmas.) Finally, data analysis of structured observations is usually complex and often requires the assistance of a statistician.

## Bias from Being Observed

A major challenge in observational studies is that the people observed may change their behavior in response to being observed. This is known as the Hawthorne effect.[57] Researchers do not agree on the extent of the bias that may be caused by the use of observation. Some experts believe that artificial socially desirable behavior is energy-intensive to maintain over long periods of observation and, therefore, bias can be reduced through longer observation intervals. It is crucial that the observer receives proper training in order to be neutral (structured) and/or reflexive (unstructured) toward the interactions under observation.

## Additional Resources:

The World Health Organization has several handbooks in multiple languages on observation of client interactions:
http://apps.who.int/medicinedocs/en/d/Js2289e/

## Mystery Clients or Surrogate Patients for Studying Stigma in Institutions

Techniques such as "surrogate patients," "standardized patients," "simulated patients," or "mystery clients" may also be appropriate for the study of stigmatization. These terms refer to the use of trained actors to measure the quality of health care.[62] The actors are trained to follow a script, describing a series of symptoms and characteristics.[63–65] They observe and describe any stigmatizing experiences.[66] The advantage of using trained actors posing as TB clients is the ability to measure the variability of responses with a specific type of client, especially those who may be at more risk for stigmatization (e.g., female TB client who uses alcohol). Mystery clients have been used extensively in the field of family planning to measure the quality of care.

The use of mystery clients raises a host of ethical and informed consent issues. Consent is often only sought from the institution and, therefore, healthcare workers often do not realize that they are participating in research. Healthcare workers therefore need to be protected from professional harm associated with the use of such techniques.

## Exit Interviews

Exit interviews with actual TB clients is also a common approach for collecting data on the quality of interactions between providers and clients.[67–70] Exit interviews are conducted as a client is leaving a health service encounter to explore the quality of that encounter before recall bias limits the quality of the information.[71] Exit interviews have been used extensively in TB research. See Chapter 7 for a comprehensive discussion of exit interviewing people with TB about stigma.

## Considerations When Choosing a Methodology

Each of the methods presented above has advantages and disadvantages. The choice of method to use depends on your study questions, the acceptability of the method in the target group, and the resources you have available (Table 8). Unstructured observation is necessary for informing the development of structured instruments, but it is hard to operationalize across multiple settings or on a large scale.

## Table 8. Comparison of Different Methods for Quantitative Measurement of Stigma in Institutions

| | Structured Observations | Exit Interviews | Simulated Client Interviews |
|---|---|---|---|
| Ideal for measuring | • Microaggression<br>• Value-laden terms<br>• Quality of health worker-client rapport<br>• Non-verbal communication | Clients' perceptions of what occurred and how they were treated | • Healthcare worker responses to specific types of clients<br>• Microaggression<br>• Value-laden terms<br>• Quality of health worker-client rapport<br>• Non-verbal communication |
| Advantages | • More reliable than oral communication; verifies what people actually do<br>• Information can be quantified<br>• Interactions between clients and health workers can be observed in the "natural" context | • Quick way to collect data<br>• Information can be quantified<br>• Can be used in combination with observations | • Verifies what people actually do<br>• Quick way to collect data |
| Disadvantages | • Difficult not to influence the interaction because of researcher's presence<br>• Ethical question: may be impractical to ask informed consent of each new client<br>• Difficult to analyze because of researcher's own involvement in the interaction<br>• Heavily dependent on the skills of the observer<br>• Observation may alter behavior of the observed | Clients may be inclined to give socially desirable answers (to please the health workers) | Ethical question as to whether it is acceptable to collect data with only institutional (but not individual healthcare worker) informed consent |

## Sample Size Considerations

The relational nature of stigma makes considerations of sampling issues very important. Stigmatizing attitudes and behaviors are typically clustered.[3,72] There is considerable intra-country, inter-facility, and intra-facility variation.[3,73] This implies that the sample sizes for stigma surveys need to be adjusted upward by a design effect to account for the non-random distribution of stigma and the potential for selected clusters to be extreme. In practice, this means including as many facilities as logically feasible.

Figure 6 shows how exposure to stigma in a health setting is not usually randomly distributed across clients; rather, it is clustered by site and often by TB care provider. Stigma measurement in health care settings has found that stigma is clustered in facilities.[74] Similarly, there is geographic clustering.[74,75] This means that when clusters are used (i.e., specific districts or health facilities are chosen), it is vital to try to describe the nature of the specific exposures that clients have and to limit the influence that a single person with extreme behavior could have on the validity of the measurement process. For example, HCW #7 treats seven clients (patients "m" through "s" in Figure 6) and has more potential stigmatizing influence on patients than does HCW #1, who treats only two patients (a and b). Maximizing the number of clusters and decreasing their size is a good way to reduce the potential for bias.

**Figure 6. Example of how stigma may be clustered within and among facilities**

District 1 — Supervisor Q — Health Facility A — Respectful HCW 1 (Patient A, Patient B), Respectful HCW 2 (Patient C, Patient D), Stigmatizing HCW 3 (Mistreated Patient E, Mistreated Patient F); Health Facility B — Respectful HCW 4 (Patient G, Patient H), Respectful HCW 5 (Patient I, Patient J).

District 2 — Health Facility C — Respectful HCW 6 (Patient K, Patient L), Stigmatizing HCW 7 (Patient M, Patient N, Patient O, Patient P, Patient Q, Patient R, Patient S).

Statistical formulas for multi-stage cluster survey sample size calculations are explained in Chapters 4, 7, and 9. All formulas require you to input a design effect in the formula, which can only really be known after the survey is completed. In practice, this means that you should make an educated guess about how much clustering is going on based on previous studies.

## Conclusion

The study of interactions between and among people in institutions may provide the most interesting unit of analysis for the study of stigma because changing abusive dynamics is our end goal. Standardized observational techniques are not yet well-developed for measuring TB stigma in health facilities, but we can leverage established tools from other health fields. A health care facility is a complex ecosystem. In addition to the measurement of stigmatizing behaviors described here, one could measure TB stigma embedded in norms and policies (Chapter 6), discourses (Chapter 11), attitudes of HCWs (Chapter 8), and perspectives of people with TB (Chapters 7 and 10). A holistic assessment of this kind would serve as a solid basis for stigma reduction interventions and evaluation.

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# Chapter 6

# Measuring Structural Stigma - Human Rights and Legal Discrimination

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## Abstract

Measuring structural stigma against people with TB is a methodological challenge. At its core, it involves assessing whether the legal regime respects the dignity, equality and autonomy of affected communities and understanding the relationship between stigma and discrimination. Human rights law provides a useful foundation for this. Structural stigma against people with TB is most pernicious when it manifests in enacted stigma, i.e., discriminatory laws and policies or the discriminatory application of otherwise neutral laws and policies in areas of special focus. These include, but are not limited to, health care, employment, education, prisons, immigration and asylum, housing, and public benefits. The absence of legal protections and the failure to protect the human rights of people with TB are just as harmful. In order to identify and measure structural stigma, it is also critical to understand the attitudes of institutional actors and how discriminatory laws and the absence of legal protections impact affected communities.

This chapter discusses methods to assess the relationship between stigma, discrimination and law. It addresses the primary sources of law that make-up national legal regimes, including constitutions, legislation, policies and regulations, and case law. It presents a human rights-based tool to measure structural stigma against people with TB through assessment of these sources of law. Finally, it provides guidance on how to measure compliance with the legal regime on the ground.

## Objectives

This chapter aims to:
1. Examine and clarify the relationship between structural stigma, enacted stigma, and discrimination against people with TB.

2. Develop capacity in applying human rights assessment standards for measuring structural stigma against people with TB.
3. Build skills in assessing national legal regimes and gauge on-the-ground compliance to measure structural stigma against people with TB.

## Target Audience

This chapter is intended for communities, people affected by TB, national TB program staff, implementing agencies, NGOs, CBOs, USAID technical staff, WHO, and other partners and advocates. Users are not expected to be trained in law, although the concepts and tools developed in the chapter will be most easily utilized by lawyers. Familiarity researching and analyzing constitutions, legislation, policies and regulations, and case law is valuable, but the chapter provides clear guidance on how this research and analysis should be conducted.

## Introduction

**How do TB control laws and policies mitigate or sustain TB stigma?**

This chapter aims to examine, clarify, and present tools to measure structural stigma against people with TB. It focuses on assessing the components of national legal regimes (constitutions, legislation, policies and regulation, and case law) in areas of special focus, with concern for key populations at high risk of TB. The chapter provides guidance on how to assess laws and policies using human rights standards based on international human rights law.

We know that stigmatized groups experience inequities in employment, education, and health care settings, as well as poor health outcomes and challenges in their interpersonal relationships.[1] But what shape does this kind of stigma take at the societal level against people with TB?

**Structural stigma is defined by its operation at the societal level through institutions and norms. Stigmatized individuals in the society experience constrained opportunities, reduced access to resources, and negative impacts on their well-being.**

Structural stigma refers to the "legitimatization and perpetuation of a stigmatized status by society's institutions and ideological systems."[2] Another definition highlights the impact of structural stigma, defining the phenomenon as "societal-level conditions, cultural norms, and institutional practices that constrain the opportunities, resources, and well-being for stigmatized populations."[3] In both cases, structural stigma is defined by its operation at the societal level through institutions and norms. Stigmatized individuals in society experience constrained opportunities, reduced access to resources, and negative impacts on their well-being. Put simply, examining structural stigma requires us to consider "all manner of disadvantage [that] can result outside of a model in which one person does something bad to another."[4]

The impact of structural stigma occurs by way of enacted stigma: the negative treatment of a person possessing a stigmatized condition.[5] Enacted stigma comprises "instances of discrimination against people...on the grounds of their perceived unacceptability or inferiority."[6] Here we see the connection and

transformation of stigma to discrimination. Enacted stigma can occur through person-to-person treatment, but it also operates through discriminatory laws and policies, the discriminatory application of facially neutral laws and policies, the absence of legal protections, and the failure to enforce the rights of stigmatized persons.

In addition to explicitly discriminatory laws and policies and the intentional, discriminatory application of otherwise neutral laws and policies, discrimination of people with TB may be indirect. Indirect discrimination involves a law, policy or other measure that does not directly—i.e., explicitly or intentionally—discriminate on the basis of TB, but nonetheless produces a discriminatory impact.[7] For example, a public housing policy that requires all applicants to submit a full record of their medical history in order to obtain housing, may result in discrimination against people with TB if the information is used by administrators to reject their applications. There is no universal agreement on the boundaries between indirect and direct discrimination and structural and enacted stigma. Figure 1 below illustrates the overlapping relationships among the phenomena.

**Figure 1. Relationship among discrimination and stigmatization**
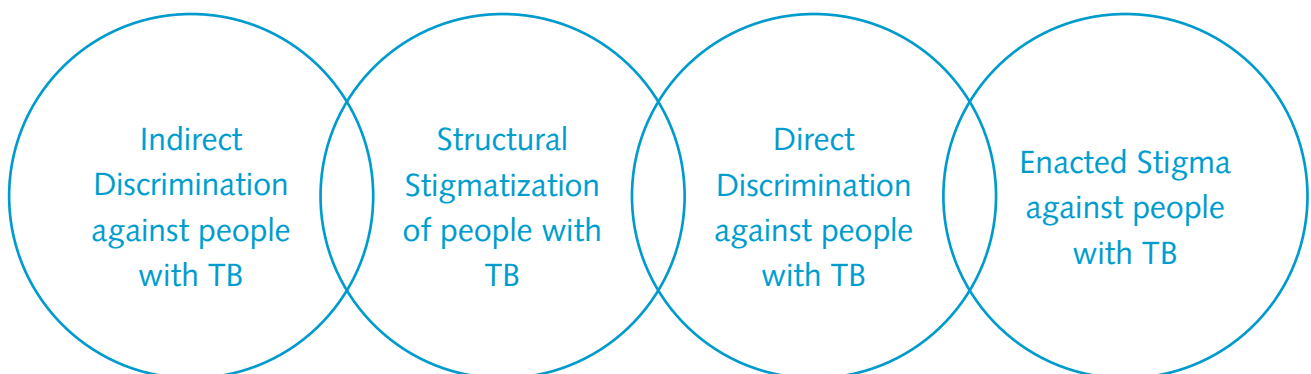


Importantly, enacted stigma excludes "fair or legitimate discrimination," whereby people are prohibited from engaging in certain kinds of activities because they are, in fact, incapable of doing so. For instance, a law that prohibits individuals with complete vision loss from driving is not an example of enacted stigma. On the other hand, a law prohibiting a person with visual impairment from using public walkways could be a form of enacted stigma. In the context of TB, for example, a law that prohibits people with TB from occupations involving customer contact during the entire period of their treatment is overly broad and a form of enacted stigma. People with TB are not contagious and thus pose no threat to customers shortly after starting appropriate treatment. In other cases, legal protections needed to prevent common forms of enacted stigma against people with TB or to provide redress for human rights violations simply do not exist. For instance, employment discrimination against people with TB and TB survivors, including dismissal and refusal to hire on the basis of TB, is rarely explicitly prohibited by law, even though such discrimination is common.

As stated in Chapter 1, enacted and structural stigma are dependent on the power to adopt and enforce discriminatory laws and policies and the power to refrain from enacting or implementing legal protections.[9] It is the power of the law that operates through national legal regime that creates, perpetuates, and exacerbates structural stigma against people with TB. This chapter will focus on the vital social institution of the law, as manifest in the text and implementation of national constitutions, legislation, policy and regulations, and case law, in areas of special focus, with concern for key populations. For more stigma analysis of texts such as health communication, see Chapter 11.

## Challenges

Measuring structural stigma against people with TB is a methodological challenge. First, there are significant research challenges. In order to identify and examine the sources of law, we must have access to the documents. Many countries make their legislation, policies and regulations, and case law available online, at government websites or in public databases, but some do not. Second, some degree of familiarity reading and interpreting legal language is very helpful. Otherwise, we may misunderstand or fail to identify important provisions or principles in the documents. Third, even when constitutions, legislation, policies and regulations, and case law are correctly interpreted, we must measure their levels of compliance and implementation to fully measure structural stigma.

## Existing Tools to Measure Structural Stigma against People with TB

No tools currently exist to measure structural stigma against people with TB. Studies have been conducted to measure other forms of stigma associated with TB,[10] but these are not helpful in developing a tool to assess legal regimes. A variety of tools have been developed to measure various kinds of stigma associated with HIV, including some examining structural stigma.[11] They also review discriminatory laws and policies and attempt to identify gaps in legal protections, but they do not present comprehensive models.

The Stop TB Partnership has developed an Operational Guide to conduct a legal environment assessment for TB.[12] The guide provides detailed direction on how to identify and analyze laws, policies, and practices that pose barriers to accessing TB services. It is founded on a human rights-based approach to prevention, treatment, and care of people with TB, and instructs users on how to advocate for TB programs to address barriers in national contexts. The guide does not provide a tool to measure structural stigma. The concept of structural stigma is not mentioned in the guide, although stigma is acknowledged as a key concern for the legal environment assessment.

# Human Rights and Structural Stigma: Developing Standards of Assessment

*"Stigma, discrimination, and human rights violations form a vicious, regenerative circle. … Condoning human rights violations can create, legitimize, and reinforce stigma that can, if left to fester, lead to discriminatory action and further human rights violations."*[13]

**Protection and fulfillment of human rights results in greater recognition and respect for the dignity, equality, and autonomy of people with TB, which in turn reduces structural stigma.**

This observation was made more than 14 years ago in an article examining HIV-related stigma and discrimination. Unfortunately, it applies with equal force today to TB. Human rights in international and regional legal instruments provide a foundation to build a robust set of standards to assess structural stigma against people with TB. Just as human rights violations create, legitimize and enable stigmatization, the incorporation of human rights principles in constitutions, legislation, policies and regulation, and case law helps protect against structural stigma. Human rights law therefore provides a universally accepted framework to develop assessment standards for measuring structural stigma, allowing us to identify priorities and develop baselines using specific legal content.

**Figure 2. Role of legal discrimination in compounding discriminatory attitudes and behaviors**

Normalization of stigmatizing attitudes and behaviors

Stigmatizing attitudes rationalize exclusion

Enactment of discriminatory laws and policies or discriminatory application of neutral laws and policies

Exclusion of stigmatized groups

## Human Dignity

**Human dignity - the inherent and equal worthiness of all human beings deserving of self-respect and the respect of others.**

The concept of human dignity acts as a nexus between human rights and structural stigma. Dignity is the backbone of human rights law. A legal system that respects and upholds human rights respects the dignity of its people. Two prominent concepts of human dignity are closely associated with stigma: dignity as the maintenance and respect of social status and dignity as the

principle of non-instrumentalization. The latter simply means that people should not be used as a means or an instrument to other people's ends. They must be respected and treated as autonomous, equal individuals.

Stigma violates human dignity. The stigma process has been described as entailing a general "downward placement of a person in a status hierarchy," thereby depreciating the person's social status.[14] The imposition of stigma through power, including structural stigma, has a significant negative impact on the life chances and opportunities of the stigmatized group,[15] thereby reducing their autonomy and equal status in their community.
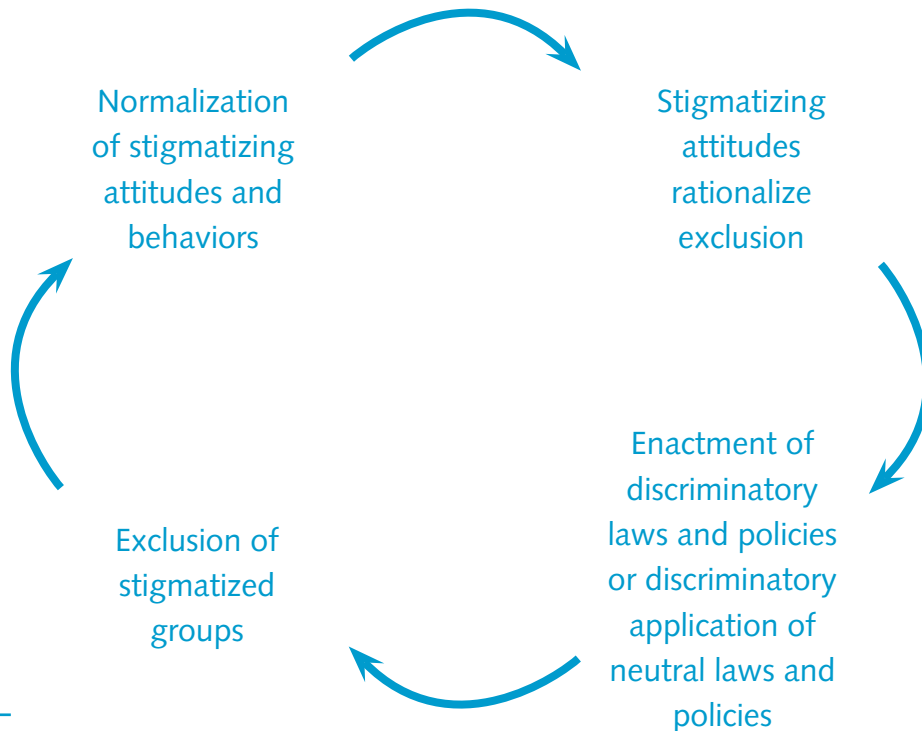
Protection and fulfillment of human rights results in greater recognition and respect for the dignity, equality and autonomy of people with TB, which in turn reduces structural stigma.

## Human Rights Assessment Standards

The content of human rights law provides standards with which to assess the level of structural stigma against people with TB in national legal contexts. Developing these standards involves three steps: (1) identify the relevant human rights and sources, (2) clarify their pertinent, health-related content and meaning, and (3) apply the rights to the context of TB as they relate to the legal regime. Table 1 contains this analysis for human rights of particular importance to people with TB and to assessing legal regimes to identify structural stigma.

The list of rights and their sources in Table 1 is not meant to be exhaustive; there are other rights important for people with TB, and the rights listed may appear in other sources. The examples of content and application are not exhaustive either, but rather highlight a critical issue related to each right for people with TB.

**Table 1. Human Rights Assessment Standards**

| Human Rights (and Sources) | Health-Related Content | Application to TB in Legal Regime |
|---|---|---|
| **Right to life**<br><br>Sources: UDHR, ICCPR, ICMW, ACHPR, IACHR, ECHR, 147 constitutions.[16] | States must adopt positive measures to protect life, to eliminate epidemics, and ensure access to medical care.[17] | States must adopt measures in law and policy to protect the lives of people with TB, including ensuring access to testing and treatment. |

| Right to health

Sources: UDHR, ICESCR, ICERD, CRC, CEDAW, ICMW, CRPD, ACHPR, 131 constitutions.[18] | States have a core obligation to provide essential medicines on the WHO Model List of Essential Medicines.[19] | Section 6.2.4 of the 19th WHO Model List of Essential Medicines includes first- and second-line anti-tuberculosis drugs, including bedaquiline and delamanid. States must adopt laws and/or policies that ensure people with TB are provided these medicines. |
|---|---|---|
| **Right to be free from discrimination**

Sources: UDHR, ICCPR, ICESCR, ICERD, CEDAW, ICMW, CRPD, ACHPR, IACHR, ECHR, 142 constitutions.[21] | Prohibition of discrimination based on "other status" includes health status and direct and indirect discrimination in the public and private spheres.[22] | People with TB must be protected by law against discrimination in both the public and private spheres, including employment, education, housing, health care settings, etc. |
| **Right to be free from torture and other cruel, inhuman or degrading treatment or punishment**

Sources: UDHR, ICCPR, CAT, ICMW, ACHPR, IACHR, ECHR, 150 constitutions.[23] | Failure to provide adequate medical care to prisoners and other people deprived of their liberty constitutes inhuman and degrading treatment.[24] | Law and policy must ensure people with TB in prisons and other detention centers are provided testing and treatment services. |
| **Right to privacy**

Source: UDHR, ICCPR, ICMW, CRPD, ACHR, ECHR, 167 constitutions.[25] | Right to privacy includes the right to keep information related to health and health status private.[26] | Law and policy must establish the right of people with TB to keep their health status and other health-related information private and confidential, except from those to whom they pose a real risk of transmission, and then only for the duration of the risk. |

| Right to liberty and security of person

Sources: UDHR, ICCPR, ICERD, ICMW, CRPD, ACHPR, IACHR, ECHR, 149 constitutions.[27] | Any deprivation of liberty must be necessary and proportionate to protecting the individual from serious harm or preventing injury to others. It must be applied only as a last resort, for the shortest period, accompanied by adequate procedural and substantive safeguards established by law.[28] | Law and policy must establish clear protections against involuntary detention or isolation of people with TB, except under exceptional circumstances, as a last resort, when a person is known to be or highly likely to be contagious but refuses treatment or testing and all reasonable measures to ensure adherence have been unsuccessful. In these cases, the least restrictive measure possible must be used, isolation must occur in an appropriate medical setting, and the individual must be provided treatment, basic necessities and the right to appeal the isolation decision.[29] |
|---|---|---|
| Right to participation (to take part in the conduct of public affairs)

Sources: UDHR, ICCPR, ICERD, ICMW, CRPD, ACHPR, IACHR, 158 constitutions.[30] | The "conduct of public affairs" is a broad concept, comprising legislative, executive, and administrative powers, and all aspects of the formulation and implementation of policy at international, national, and local levels.[31] | The law must establish and facilitate the right of people with TB and TB survivors to be involved in the formulation and implementation of law and policy implicating TB at the international, national, and local levels. |
| Right to asylum

Sources: UDHR, Convention relating to the Status of Refugees,[32] ACHPR, ADRDM, IACHR, 88 constitutions.[33] | Everyone has the right to seek and enjoy asylum from persecution in other countries without discrimination.[34] | The law must establish the right of people with TB to receive asylum without discrimination based on their health status. It should allow for asylum consideration based on a high risk of contracting TB in a person's home country, including when a person is likely to be detained in a prison with high rates of TB disease. |

| Right to adequate housing (right to shelter)<br><br>Sources: UDHR, ICESCR, ICERD, CRC, CEDAW, ICMW, CRPD, 72 constitutions.[35] | Housing must be accessible, affordable, and habitable, providing adequate space, ventilation, and protection from threats to health and disease vectors, especially for disadvantaged groups, such as people living with HIV and those with persistent medical problems.[36] | Law and policy must ensure affordable housing with adequate ventilation is accessible to the urban poor to help prevent transmission of TB in overcrowded |
|---|---|---|
| Right to food<br><br>Sources: UDHR, ICESCR, CRC, CRPD, 24 constitutions.[37] | States must ensure everyone under their jurisdiction can access minimum essential food that is sufficient, nutritious, and safe, with priority consideration given to disadvantaged groups.[38] | Law and policy must provide people with TB access to adequate, nutritious food during treatment, as under-nutrition and low body mass index are associated with poor treatment outcomes. |
| Right to education<br><br>Sources: UDHR, ICESCR, ICERD, CRC, ICMW, CRPD, 134 constitutions.[39] | Education must be accessible to all, especially the most vulnerable groups, in law and fact, without discrimination, including for persons with disabilities, children of migrants, and other disadvantaged groups.[40] | Children with TB must be protected by law against discrimination at school. They must be allowed to attend normal classes, unless and only for as long as they pose a real risk of transmission to their classmates. |

## Developing a Structural Stigma Measurement Tool

Measuring structural stigma against people with TB requires a careful assessment of a country's legal regime to identify both discriminatory laws and policies and a lack of necessary legal protections. This section lays out areas of special focus, key populations of particular concern, and the sources of law to be examined: constitutions, legislation, executive policies and regulations, and case law. It provides guidance on how to obtain and analyze the text of the sources of law to identify stigmatizing language. It utilizes the human rights assessment standards developed above to formulate key questions in assessing the legal regime. Finally, it considers how to measure compliance with the legal regime on the ground through legal implementation, the attitudes of institutional actors and experiences of affected communities, and empirical indicators.

## Areas of Special Focus

Stigma against people with TB manifests in a myriad of ways. It takes on a structural form in the laws and policies that regulate activity in certain areas of

special focus, i.e., areas in the lives of people with TB that intersect with and are regulated by the government. In these areas, people with TB are particularly vulnerable to structural stigma. Areas of special focus may depend on the country context, but often include health care, employment, education, prisons, immigration and asylum, housing, and public benefits. For more on this, see Chapter 14 on intersectional stigma.

## Key Populations

Key populations include people who have increased exposure to TB due to where they live or work, people with limited access to good quality TB services, or people at increased risk for TB due to biological or behavioral factors.[41] The Stop TB Partnership has identified 10 key populations, although more may exist depending on the country context: children, health care workers, mobile populations, miners, people who use drugs, prisoners, people living with HIV, rural poor, urban poor, and indigenous populations.[42] Special attention must be paid to the ways laws and policies impact these groups when assessing the legal regime to measure structural stigma.

## Obtaining the text of sources of law

The text of sources of law can be obtained in multiple ways. Text can be obtained by requesting the documents from the responsible government entity, such as the legislature, government agency, or court. Many sources of law can be obtained online in official government databases. For example, legislation.gov.uk, congress.gov, and indiacode.nic.in contain the texts of legislation in the United Kingdom, United States, and India, respectively.

The text of regulations and policies are often available on the website of the government agency that drafted and promulgated the regulations. For example, the regulations of the Department of Health of South Africa are available at health.gov.za. Sources of law can also be obtained in nongovernmental databases. National constitutions are available online in a free, searchable database at constituteproject.org.

Case law can also be obtained in government and nongovernmental databases online. Some countries make their case law available on their courts' government websites.[43] Several free nongovernmental databases provide access to case law. For example, the World Legal Information Institute provides free access to more than 1,000 databases covering more than 120 jurisdictions. Google Scholar provides a free database of U.S. cases. The Global Health and Human Rights Database provides free access to cases involving health and human rights from around the world. Case law is also available in databases accessible with a paid subscription, such as Westlaw, LexisNexis and Bloomberg Law.[46] Case law databases provide search functions that allow users to search for keywords, case names, and case citations.

## Analyzing the text of sources of law

The text of sources of law can be analyzed quantitatively or qualitatively. If texts are numerous and available in digital form, then quantitative content analysis may be possible.[47] In these cases,

computer software can be used to reduce the amount of human reading required. In general, choosing an analytic approach depends on how much text you have, how subtle and nuanced your examination needs to be, and whether the texts are available in a digital form.

**Table 2. Choosing an Analytic Approach to Analyze the Text of Sources of Law**

| | Advantages | Disadvantages |
|---|---|---|
| **Quantitative Content Analysis** | • Can be done in teams.<br>• Some aspects may be automated.<br>• Often seen as more legitimate by stakeholders who privilege use of data and numbers. | • Requires a very clear, replicable definition of stigma and training to ensure inter-rater reliability of coders.<br>• Difficult to ensure sufficient sample size. |
| **(Qualitative) Discourse Analysis (Ch.11)** | • Allows for unexpected forms of stigma to be discovered.<br>• Can reveal discursive frame and arguments.<br>• Can reveal what is unstated, implicit or absent. | • Large data sets require many hours to analyze.<br>• Requires skilled and meticulous analysts. |

For a detailed discussion of how to conduct discourse analysis, please see Chapter 11.

The text of sources of law may include explicit language that marks people with TB as different than people without the disease, labels people with TB using stereotypical or denigrating terms, blames people with TB for concerns related to the disease, or overemphasizes the peril people with TB represent to their communities.[48] The Stop TB Partnership "United to End TB — Every Word Counts: Suggested Language and Usage for Tuberculosis Communications" provides guidance in identifying stigmatizing terms and offering substitutes.[49] The key terms for which substitutes are provided in the guidance are presented in Table 3. The text of each source of law should be searched to determine if these or other stigmatizing terms are used, or if their non-stigmatizing substitutes or equivalents are used instead. Searching the text of a source of law involves reading it carefully and using digital search functions like CTRL-F on a computer keyboard for searchable files (Word documents and most PDFs).

**Table 3. Stigmatizing and non-stigmatizing TB terms from Stop TB Partnership "United to End TB - Every Word Counts: Suggested Language and Usage for Tuberculosis Communications"**

| Stigmatizing Term | Non-Stigmatizing Term |
|---|---|
| People/person suffering from or infected by TB | People/person with TB |
| Treatment defaulter | Person lost to follow-up |
| Treatment compliance or noncompliance | Treatment adherence or non-adherence |
| TB control | TB prevention and care |
| TB suspect | Person to be evaluated for TB |

Stigma, however, is not always blatant or explicit. Sources of law can contribute to structural stigma without using explicitly stigmatizing language. The placement of two ideas in close proximity in a paragraph may be enough to have a stigmatizing effect. In the case of TB stigma, laws can be embedded with assumptions about the untrustworthiness, irresponsibility, or selfishness of people with TB. These may not be explicit in the text, but may be revealed by discourse analysis. Some of the ideas that should be coded when analyzing a legal text include phrases that:

- Introduce new language and terms to connote otherness.
- Medicalize or pathologize difference.
- Dehumanize people with TB or refer to them as objects (e.g., only referring to TB cases).
- Create stereotypes (e.g., dangerous, unpredictable, untrustworthy, noncompliant, or secretive).
- Link people with TB to other disparaged groups or identities.
- Infantilize people with TB, or define them as victims, lacking autonomy and agency.
- Blame people with TB.
- Over-emphasize the danger of TB to normalize exclusion or render people with TB unworthy of consideration, investment, or meaningful engagement.

In addition to searching for specific terms or phrases, the text of each source of law should be analyzed using questions based on the human rights assessment standards. The objective of developing and applying these questions is to determine whether the meaning or likely application of the text is stigmatizing, discriminatory, or fails to protect against discrimination, or, on the contrary, whether it *protects against* discrimination and *promotes* the human rights of people with TB.

The human rights assessment standards presented in Table 1 should be referenced to formulate effective questions to analyze the text. For example, the human rights assessment standard for the right to privacy establishes the right of people with TB to keep their health status private and confidential, except from those to whom they pose a real risk of transmission, and then only for the duration of the risk. Figure 1 provides examples of questions based on this

standard. Additional examples of the questions to be used to analyze text are provided below for each source of law.

**Figure 3. Questions to Assess Sources of Law based on Human Rights Assessment Standards**

| Human Rights Assessment Standard |
| :---: |
| **Right to Privacy** |

↓

| Application to TB in Legal Regime |
| :---: |
| Law and policy must establish the right of people with TB to keep their health status and other health-related information private and confidential, except from those to whom they pose a real risk of transmission and only for the duration of the risk. |

↓

| Questions for Assessment | | |
| :---: | :---: | :---: |
| Does policy establish and provide clear guidelines for health workers to respect rights to privacy and confidentiality of health information and status? | Does legalization establish rights to privacy and confidentiality of health information and status, including for TB? | Does case law recognize employees' right to privacy in health information and status, including for TB, vis-à-vis employers? |

In the event that there are too many legal texts to read in full, a sampling plan may be used to ensure the chosen documents are representative. Techniques for probability sampling of legal texts are beyond the scope of this chapter, but instructions on how to do sampling are available in Chapter 5 of Riffe, Daniel, Stephen Lacy, and in Frederick G. Fico. 2005. *Analyzing Media Content: Using Quantitative Content Analysis in Research*. 2nd ed. Mahwah, New Jersey: Lawrence Erlbaum Associates.

## Sources of Law and Assessment Questions

A country's legal regime consists of constitutions, legislation, executive policies and regulations, and case law. Each source must be examined to measure structural stigma against people with TB. The figures below provide a visual representation of the measurement tool and its application for each source, with examples of assessment questions in areas of special focus. The areas of special focus in each figure come from the list provided above, with consideration for the areas most often addressed by each source of law. The assessment questions are based on the human rights assessment standards, taking into consideration concerns about key populations. For each source of law, they aim to identify

positive provisions or actions, stigmatizing or discriminatory provisions or actions, and gaps in legal protections. Assessment questions may be used in analysis and for interviewing government officials and other stakeholders. While a "yes" or "no" answer to an assessment question is an indication of the presence of positive or stigmatizing provisions in a law, further inquiry should be made to determine whether processes are ongoing to modify, amend, or repeal the provision in question.

## Constitutions

National constitutions are the supreme law of the land. They are the highest source of law and rights in most countries. All legislation, policies, and regulations must conform to the constitution and are guided by its content. In countries with federal systems, sub-national governments, such as provinces and states, may also have constitutions.

Although constitutions are not likely to contain specific references to TB, they are the first source of law to be examined because they are the highest source of national law and they enshrine and protect the rights of all people, including people with TB. In order to examine a constitution, we must obtain and analyze the text in line with the guidance provided above, interview judges and lawyers with constitutional expertise, and, if possible, those who drafted the constitution, and consult secondary sources, such as scholarly and other writings on the meaning of the constitution.

Assessment questions developed in line with human rights assessment standards should be used when analyzing the text of the constitution and interviewing constitutional experts. Secondary sources, including legal scholarship on relevant constitutional issues, may be accessed using Google Search and online databases to provide a general context or more specific information about constitutional provisions and their meaning and practical application.

**Figure 4. Constitutions Assessment Questions**

**Health Care**

Are the rights to life, health and privacy explicitly recognized?

Does the right to health include the right to good quality health goods, facilities and services?

Does the right to be free from discrimination prohibit discrimination based on health status?

**Employment**

Is employment discrimination based on health status prohibited?

Is the right to a safe and healthy workplace explicitly recognized?

Is the state required to provide employment assistance to disadvantaged groups?

## Constitutions

**Education**

Is the right to education explicitly recognized, including free, compulsory primary and secondary education?

Is discrimination in education explicitly prohibited in both public and private institutions?

**Prisons**

Is the right to be free from torture and cruel, inhuman or degrading treatment or punishment explicitly recognized?

Is the right to liberty and security of person explicitly recognized?
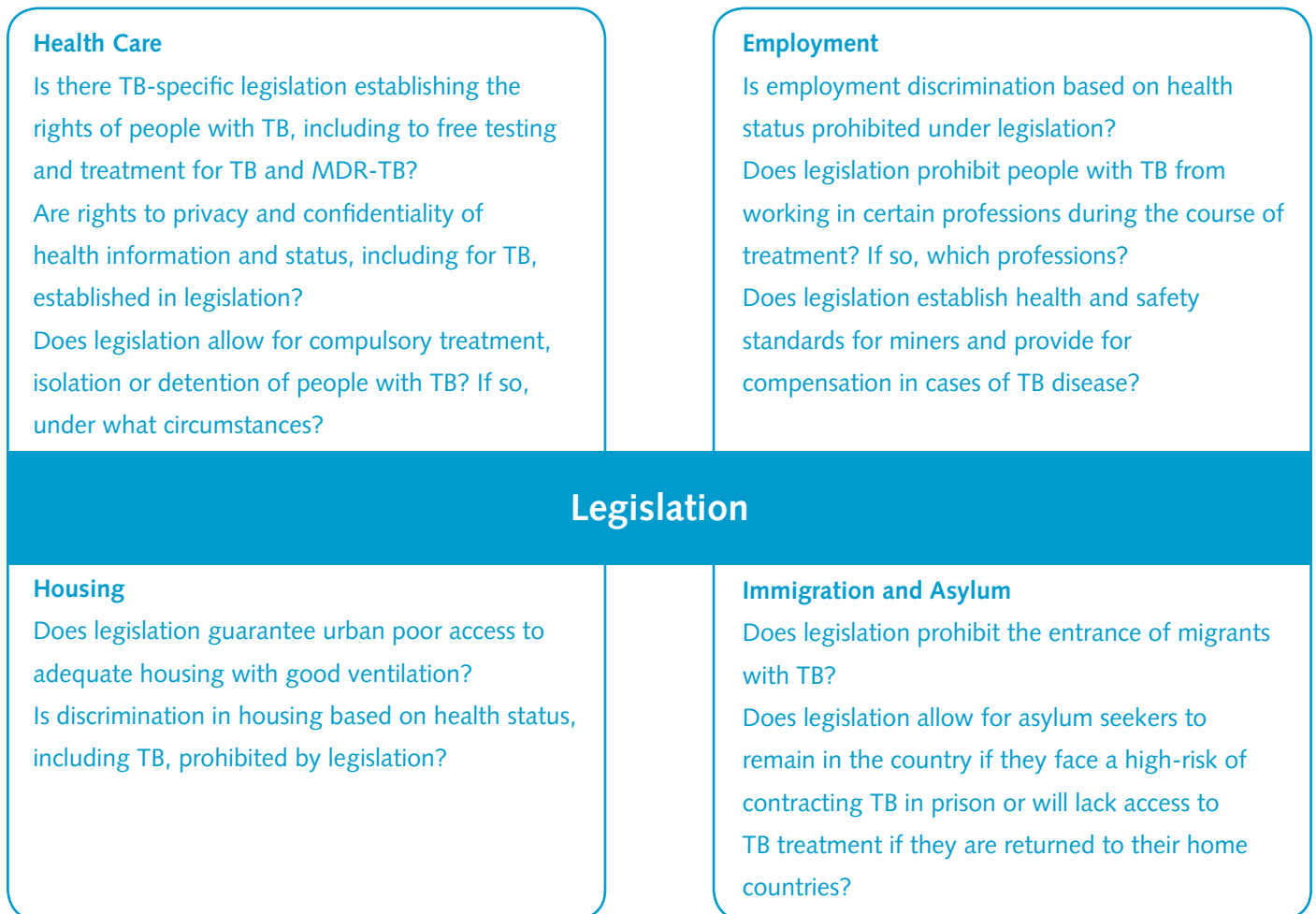
# Legislation

Legislation includes laws, acts, and statutes written and enacted by legislatures of national and sub-national governments. Legislation has the "force of law," as it can establish rights and remedial mechanisms and is enforceable in court. Once enacted, legislation cannot be repealed without another act of the legislature. Legislation is the second highest source of law in a country and is therefore the second source to be examined in assessing the legal regime. In order to do so, we must obtain and analyze the legislation text according to the guidelines above, interview legislators or their staff who drafted and enacted the legislation, consult individuals and agencies tasked with implementing the legislation, and speak with stakeholders whose activities are regulated by the legislation. Questions developed according to human rights assessment standards, as outlined above and in Figure 5, should be used in text analysis of the legislation and while interviewing legislators and other relevant stakeholders.

# Criminal law and criminal sanctions

Criminal law is a special kind of legislation because it authorizes the state to imprison people, depriving them of their liberty. Criminal law is also unique because it tends to stigmatize the behaviors it prohibits and, by extension, the people who engage in them. The UN Special Rapporteur on the Right to Health (2008-14), Mr. Anand Grover, has explained that "criminalization generates and perpetuates stigma" and stigma, in turn, is a "major impediment to the implementation of

successful interventions" in the area of HIV/AIDS.[50] In light of this, special attention should be paid to the use of criminal law and criminal sanctions, including imprisonment, in the prevention, treatment, and care of TB. Criminal laws and other health-related legislation should be obtained and analyzed to determine if people with infectious diseases, including TB, can be imprisoned for stopping their treatment, failing to take appropriate preventive measures, or unintentionally transmitting disease to another person.

**Figure 5. Legislation Assessment Questions**

**Health Care**

Is there TB-specific legislation establishing the rights of people with TB, including to free testing and treatment for TB and MDR-TB?

Are rights to privacy and confidentiality of health information and status, including for TB, established in legislation?

Does legislation allow for compulsory treatment, isolation or detention of people with TB? If so, under what circumstances?

**Employment**

Is employment discrimination based on health status prohibited under legislation?

Does legislation prohibit people with TB from working in certain professions during the course of treatment? If so, which professions?

Does legislation establish health and safety standards for miners and provide for compensation in cases of TB disease?

## Legislation

**Housing**

Does legislation guarantee urban poor access to adequate housing with good ventilation?

Is discrimination in housing based on health status, including TB, prohibited by legislation?

**Immigration and Asylum**

Does legislation prohibit the entrance of migrants with TB?

Does legislation allow for asylum seekers to remain in the country if they face a high-risk of contracting TB in prison or will lack access to TB treatment if they are returned to their home countries?

# Policies and regulations

Policies and regulations are written and promulgated by executive agencies, such as ministries of health, drug regulatory authorities, and other administrative bodies. They contain detailed rules and directives that control a wide spectrum of activities. In many countries, instructions and details related to the implementation of legislation are found in regulations. Policies and administrative regulations are the third source of law to be examined. In order to do so, we must obtain and analyze the text of the policies and regulations in line with the guidance provided above, interview members of agencies or their staff responsible for writing, promulgating, and implementing the regulations, interview stakeholders whose activities are regulated, and speak with the intended beneficiaries of particular policies. Assessment questions developed

in line with human rights assessment standards should be used in analyzing regulation text and interviewing agency officials and other relevant stakeholders. For analyzing stigma in the text of institutional policies, see Chapter 11.

**Figure 6. Policies and Regulations Assessment Questions**

**Health Care**

Does policy establish and provide clear guidelines for health workers to respect rights to privacy and confidentiality of health information and status?

Does policy provide malnourished people with TB nutritional supplements during treatment?

Does policy require people with TB access treatment services in their home town or may they access treatment were they currently reside?

**Prisons**

Does policy require and ensure hygienic, ventilated prison conditions?

Does policy provide for adequate and timely TB and MDR-TB testing and treatment services in prisons and detention centers?

Does policy require solitary isolation prisoners with TB?

### Policies and Regulations

**Public Benefits**

Do disability benefits provide compensation for TB survivors with physical disabilities?

Does workers' compensation provide public and private health care workers who acquired TB in the workplace wage replacement and medical benefits?

**Housing**

Does policy establish adequate standards for housing of migrant workers, including sufficient space and ventilation?

Does policy provide assistance to people with TB in accessing affordable housing?

## Case law

Case law comprises judicial opinions from courts of law that apply and interpret the constitution, legislation, common law, policies, and regulation. Judges apply the law, but also clarify its meaning through opinions. Most importantly, opinions from appellate courts, such as supreme courts, constitutional courts, and high courts, contribute to the interpretation and development of rights established in constitutions and legislation. In order to examine case law, we must obtain and analyze the text of relevant case law, interview judges or their staff responsible for deciding relevant cases, consult lawyers familiar with the areas of special focus, interview parties, including plaintiffs and defendants, to relevant cases, and consult secondary sources, such as scholarly and other writings on the meaning and impact of relevant court decisions. Assessment questions developed in line with human rights assessment standards should be used in analyzing case law text and while interviewing judges, lawyers, and other relevant stakeholders.

**Figure 7. Case Law Assessment Questions**

**Health Care**

Have courts interpreted rights to life or health to include right to access life-saving medicines?

Have courts acknowledged risks faced by health care workers and provided compensation for TB contracted at their workplace?

Have courts allowed detention of people with TB lost to follow-up in prisons or detention centers?

**Employment**

Have courts interpreted prohibited grounds of discrimination to include health status or disease?

Have courts upheld dismissals of employees based solely on their TB status?

Have courts denied claims for compensation for wrongful dismissal based solely on TB status?

**Case Law**

**Prisons**

Have courts imprisoned injecting drug users for personal use?

Have courts held lack of access to TB services or conditions contributing to contracting TB in prisons constitute inhuman or degrading treatment?

Have courts upheld involuntary isolation of prisoners solely on basis of their TB status?

**Immigration and Asylum**

Have courts granted asylum to people based on high risk of contracting TB or lack of access to TB services in home country?

Have courts allowed removal or deportation of people facing high risk of contracting TB in prison or lack of access to TB services in their home country?

## Measuring Compliance with the Legal Regime: What is the Reality on the Ground?

A legal regime assessment is incomplete without determining the level of on-the-ground compliance and implementation of constitutions, legislation, policies and regulations, and case law. These sources of law are each implemented and complied with in different ways. Constitutional rights can be implemented through legislation and policy. Policies and regulations are often needed to implement the objectives and specific components of legislation. Courts apply, interpret, and ensure compliance with constitutions, legislation, and policies and regulations. Finally, legislatures, executive agencies, and private actors must comply with court orders to implement case law.

### Implementation through Law

The first step in measuring compliance is to determine if the source of law has been implemented through legislative, executive, or private action. Contact with relevant institutional actors can help to identify various kinds of implementation. This contact, however, is separate and distinct from understanding the attitudes of these actors, which is discussed below.

For constitutions, this means determining if legislation to implement the constitution has been enacted, and if courts routinely enforce individuals' constitutional rights. This can be done by obtaining and analyzing relevant legislation, as discussed above, to determine if constitutional rights to life, health, privacy, and to be free from torture are explicitly referenced in legislation related to TB. Case law can be obtained and analyzed to determine if courts have interpreted constitutional rights in favor of people with TB, for example, by recognizing and upholding their rights against government and private defendants.

For legislation, we must determine if executive policies or regulations have been promulgated to clarify and direct implementation of the law. This can be done by contacting the relevant agency, such as the Ministry of Health, National TB Program, or Department of Labor, directly or through an online portal to determine what regulations have been put in place.

For policies and regulations, the activities of relevant executive agencies must be examined to gauge the extent to which they have raised awareness about, implemented and enforced their directives. The private actors and regulated industries must also be consulted and interviewed, including employers, health providers, and housing developers, to determine if their activities are in line with the regulations.

For case law, we must establish if court orders are obeyed and implemented by the various government and private parties involved in the cases. This can be done by contacting the parties involved, such as plaintiffs with TB and government and private defendants, to inquire whether court orders have been obeyed through, for instance, disbursements of money to plaintiffs for damages or changes to the law, policy, or practices of government and private defendants.

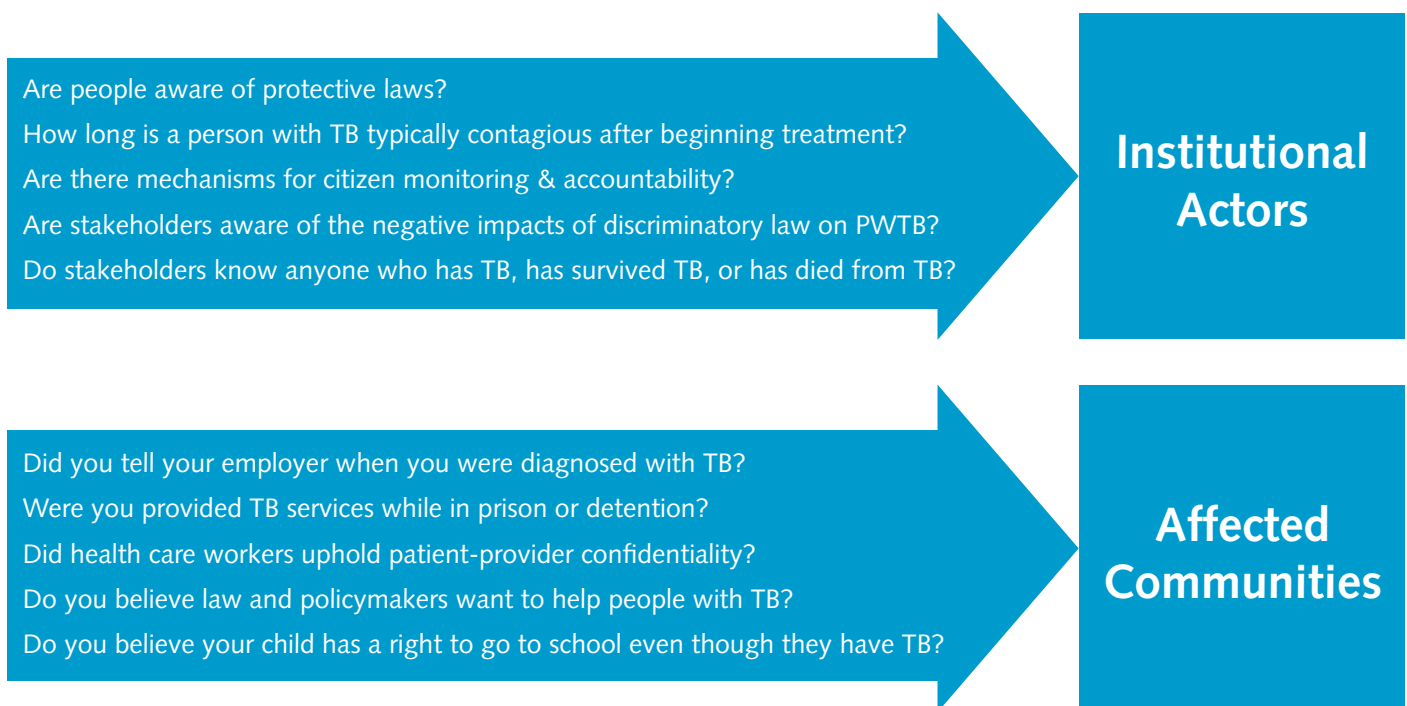## Attitudes of Institutional Actors and Experience of Affected Communities

*"Attitudinal studies of actors within institutions may be indicative of a climate within the institution that tolerates, is complicit in, or even fosters stigmatizing attitudes and practices, even though the attitudes and practices are exercised at the individual level."*[51]

In order to understand the impact of the legal system at the ground level, we must understand the attitudes of the institutional actors that design, enact, implement, and enforce the sources of law. Stigmatizing attitudes reduce support for supportive TB public policies.[1] This includes legislators, policymakers, regulators, health care workers, and judges. Interviews with institutional actors should be conducted using questions developed to reveal their knowledge of TB, attitudes about and experience interacting with people with TB, and familiarity

with challenges faced by people with TB. For detailed guidance on how to measure attitudes and behavior of institutional actors, see Chapters 5 and 8.

It is also critical to understand how affected communities experience the constitutions, laws, policies, and regulations that impact their lives. This includes people with TB, TB survivors, their families, and members of key populations. Interviews with affected communities should be conducted using questions developed to reveal how they are impacted by law and policy and how they are treated by government and private actors, such as employers, educators, prison officials, and public and private health care providers. Chapter 7 explains more on measuring stigmas among PWTB.

**Figure 8. Attitudes of Institutional Actors and Experience of Affected Communities Assessment Questions**

Are people aware of protective laws?

How long is a person with TB typically contagious after beginning treatment?

Are there mechanisms for citizen monitoring & accountability?

Are stakeholders aware of the negative impacts of discriminatory law on PWTB?

Do stakeholders know anyone who has TB, has survived TB, or has died from TB?

**Institutional Actors**

Did you tell your employer when you were diagnosed with TB?

Were you provided TB services while in prison or detention?

Did health care workers uphold patient-provider confidentiality?

Do you believe law and policymakers want to help people with TB?

Do you believe your child has a right to go to school even though they have TB?

**Affected Communities**

## Empirical Indicators

Empirical indicators provide concrete evidence about the levels of compliance with and implementation of sources of law. These include indicators that record law-related phenomenon, such as the number of cases involving claims directly related to TB in which plaintiffs with TB or TB survivors prevail, and health systems indicators, such as the number of prisoners receiving TB and MDR-TB services in a country.

Empirical indicators should be developed to collect data on the implementation of sources of law. For example, data related to case law involving people with TB can be collected through case law databases to empirically assess how people with TB are treated by courts. Rates of dismissals and refusal to hire people with TB in particular industries or geographic areas can be collected through

consultation with employees and employers and relevant government agencies. This can clarify how people with TB are treated by employers. Rates, locations, and methods of involuntary isolation of people with TB can be collected through referencing published government data and consulting prison administrators, government health care providers, and relevant government agencies. This can help gauge whether people with TB's right to liberty and security of person is respected according to the human rights assessment standards.

**Figure 8. Attitudes of Institutional Actors and Experience of Affected Communities Assessment Questions**

| | |
|---|---|
| Number of Cases and Outcomes | Number of claims brought to court by people with TB under the constitution and relevant legislation.<br>Percentage of cases in which people with TB prevail.<br>Percentage of judicial orders in favor of people with TB implemented compared to average rates. |
| Rates of Dismissals and Refusals to Hire | Rates of dismissal of people with TB compared to average rates in particular industries or geographic areas.<br>Rates of refusals to hire people with TB compared to average rates in particular industries or geographic areas. |
| Rate, Locations and Methods of Involuntary Isolation | Rates of involuntary isolation of people with TB and MDR-TB.<br>Record of locations where involuntary isolation occurs.<br>Record of methods used to involuntarily isolate people with TB and MDR-TB, including settings, duration and services provided. |

## Conclusion

Measuring structural stigma against people with TB through the assessment of legal regimes is a multifaceted task. It involves using human rights assessment standards to examine the primary sources of law (constitutions, legislation, policies and regulations, and case law) in special areas of focus, with concern for key populations at high-risk for the disease. Next, in order to understand the impact of the legal regime on the ground, we must measure levels of compliance and implementation. This involves gauging the level of implementation through law, measuring the attitudes of institutional actors and experience of affected communities, and

developing and applying empirical indicators in areas of special focus. At its core, this process aims to assess the level of respect for the dignity of people with TB in national legal regimes to identify and measure structural stigma.

## Acknowledgements

## Appendix

### Sources of Human Rights Law

Human rights are established at the international level in the Universal Declaration on Human Rights (UDHR) and legally binding international treaties.[52] These include, among others, the International Covenant on Civil and Political Rights (ICCPR),[53] the International Covenant on Economic, Social and Cultural Rights (ICESCR),[54] the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD),[55] the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT),[56] the Convention on Elimination of All Forms of Discrimination Against Women (CEDAW),[57] the Convention on the Rights of the Child (CRC),[58] the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (ICMW),[59] and the Convention on the Rights of Persons with Disabilities (CRPD).[60] Each treaty has a body of experts that monitors state compliance, provides authoritative interpretations of the rights in the treaty, and, in some instances, hears complaints of violations from individuals. The Office of the UN High Commissioner for Human Rights Status of Ratification Interactive Dashboard (available at http://indicators.ohchr.org/) can be used to determine whether a particular country has signed, ratified, and acceded to a treaty and is therefore legally bound by its provisions.

At the regional level, the African Charter on Human and Peoples Rights (ACHPR),[61] the American Declaration on the Rights and Duties of Man (ADRDM),[62] the American Convention on Human Rights (ACHR),[63] and the European Convention on Human Rights (ECHR)[64] all contain human rights that are interpreted and developed in regional commissions and courts, including most prominently the European Court of Human Rights. Information about which countries have signed, ratified, and acceded to these treaties is also available online at the African Commission on Human and People's Rights,[65] the Organization of American States,[66] and the Council of Europe's websites.[67]

Human rights are also enshrined in national constitutions around the world. These rights take the form of constitutional rights, enforceable in national courts, but their content and scope is similar to the human rights in international and regional instruments.[68]

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# Chapter 7

# Measuring TB stigma among people with TB using scales

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## Abstract

This chapter explores how to measure perceived or enacted TB stigma in people with TB (PWTB). It aims to give an overview of validated scales and to describe how to analyze and interpret the TB stigma scale. It starts with a comprehensive guide on how to define the study population and sample TB patients, which selection methods to use, and how to determine the sample size required, including adjustment for clusters. All basic formulas required are given. The focus then shifts to how to measure the impact of stigma. We explore how to include people with TB lost to follow-up and how and why to include patients during the diagnostic process. We also explore the TB stigma treatment trajectory, and how stigma may change throughout this process. The method for measuring TB stigma to assess if it is a treatment barrier is outlined. Next, we discuss measuring TB stigma in drug resistant TB (DR-TB) patients and the issues surrounding disease disclosure.

## Objectives

1. To familiarize readers with the literature on stigma among TB patients.
2. To convey the methodological challenges of capturing the full gamut of TB stigma manifestations
3. To teach the core principles for rigorous and reliable measurement of TB stigma in this group.

## Target Audience

Individuals or organizations who want to gauge stigma among PWTB, including TB survivors, advocacy organizations, national TB program staff, researchers, HCWs, CBO and NGO staff, volunteers, and outreach workers. This chapter is not for those interested in self-stigma (See Chapter 10).

# Introduction

Stigma was first defined by Goffman (1963) as "an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society."[1] This has been further defined in the health care context as "a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem."[2] TB patients can be subjected to stigma in four ways. This chapter focuses upon three of the four types of stigma: anticipated stigma, perceived stigma and enacted stigma. The fourth type, self-stigma or internalized stigma, is covered in Chapter 10.

Anticipated stigma is when a person changes their normal behaviors and activities of daily living for fear of stigma, judgment, and exclusion from their community due to their identity.[3] Perceived TB stigma most commonly refers to the *awareness* of stigmatization.[3] Enacted stigma is also known as experienced stigma. It can be demonstrated through discrimination and behaviors of others that harm people with TB. Enacted stigma can range from overt to very subtle – microaggression.[4,5]

## Table 1. Types of Stigma

| Anticipated stigma | Enacted stigma | Self-stigma |
|---|---|---|
| She is to be avoided because she has got TB. | It is your fault you have TB. | I feel guilty and useless for having TB. |

The type(s) of TB stigma you chose to measure among PWTB depends on what you plan to do with the information.

The measurement of stigma in PWTB is important for identifying human rights violations, understanding the scope and severity of stigma affecting people's lives, and in assessing the efficacy of efforts to eliminate stigma.

Many studies have identified a significant burden of stigma in PWTB.[6–13] Enacted stigma can lead to chronic disadvantage via loss of employment, which in turn is a risk factor for TB mortality.[14] Stigma hinders treatment adherence, which leads to poor treatment outcomes and may contribute to the development of drug resistence.[7,12]

This chapter provides practical ways to measure TB stigma in PWTB. These are scattered throughout the chapter, and consider the different areas of stigma that

can be measured. To make the practical steps of measurement clearer, you can search for the steps as follows:

1. Study Design:
   a. Study population and sampling frame
   b. Set sample size and adjust for clustering
   c. Choose a scale.
2. Pilot study with cognitive interviews (if the scale has not been used in that context)
3. Conduct the study with the (new) scale
4. Analyze data and interpret the results.

## How to sample PWTB

The results of any TB stigma measurement will only be as good as the sample that is used.

It is important to get a representative sample of PWTB. To ensure that your sample truthfully represents your patient population, you must:

- Have a well-defined population;
- Use the best method for selecting your sample;
- Use the correct sample size; and
- Adjust for clustering.

## Defining your population

A clearly defined population includes person, place, and time, based on each setting and which population is being evaluated. Measuring TB stigma among patients is best done by posing questions to PWTB, and only if that is impossible (e.g., for infants), query proxies.

It is vital to define the type of PWTB to be measured and to decide whether you are interested in specific types of PWTB, such as those receiving treatment, those not receiving treatment, MDR-TB, HIV/TB, latent TB infection (LTBI) or extra-pulmonary TB. Include the full range of clients relevant to the PWTB population (e.g., different socio-economic conditions, migrants, daily wage laborers, the homeless, urban slum dwellers, criminalized populations, and custodial settings) so the sample is representative.

## Inclusion of clients lost to follow-up in TB

TB stigma and similar exclusionary attitudes (racism, xenophobia, homophobia, etc.) represent a hurdle to treatment completion in some contexts.[12,15,16]

Therefore, study samples should always include non-adherent and clients lost to follow-up, as these populations may be more affected by stigma.[17–20] Clients can be lost to follow-up either in pre-treatment or during treatment. You may wish to over-sample this group to capture their experiences well. See Chapter 15 for methods of measuring the impact of stigma on adherence.

## Inclusion of clients that are still going through or have not yet started the diagnostic process

To reduce bias, include as many different health care facilities, providers, treatment supporters, and patients with different types of TB as possible when drawing a TB client sample.

The study sample should be selected from those with the diagnosis, so that people who are never treated are included. The use of lab registers as a sampling frame is preferable to a TB treatment register so that all people diagnosed with TB are included in the study, and not only those who receive treatment.

This will also ensure that people all along the 'patient pathway' are captured, and stigma can be compared by treatment phase. Embedding a study of stigma into a national TB prevalence survey is another option of measuring TB stigma among PWTB without a diagnosis. This approach helps to identify if stigma was a factor in their delayed health-seeking behavior.

## Inclusion of clients in the private sector

Often people with the highest levels of anticipated TB stigma are those who use health services in the private sector. Private sector services are less likely to participate in name-based TB disease notification and are often more attuned to clients' requirements for audio and visual privacy, confidentiality, and discretion. Be sure to include PWTB who access private sector services to avoid underestimation of TB stigma.

## Where to study stigma

The place refers to the study setting, for example a health care center, district/province, or the country in which the study was undertaken. Studying stigma within a context where the respondent is disempowered or affected by stigmatization may not offer full freedom to be candid. If you must study PWTB stigma within a health care setting, social desirability bias should be assessed using the Marlow-Crowne Scale, which is discussed in more detail in Chapters 4 and 5.[21]

## When to study stigma

TB stigma can be measured from the moment TB has been diagnosed, and throughout the TB treatment time line and beyond. TB stigma accumulates and (may) abate over time. Responses from a single person may differ over

time. Time refers to the stage of treatment the TB patients were when they participated in the study. The point at which you measure stigma during the person's treatment odyssey will determine how much internalized and enacted stigma a person reports, because the longer someone has been labeled as a "TB patient," the more chance he/she has had to be exposed to stigmatization.

Moreover, the physical and emotional states of PWTB and meanings of TB can vary over the course of treatment. As visible symptoms and signs of TB decline, a person may more easily "pass as normal", and their experience of stigmatization may lessen. (Figure 1) This dynamism makes it challenging to know how to interpret studies with cross-sectional designs.

It is critical to include a definitive time frame to ensure that the timing of internalized, perceived, or experienced stigma is clear (Table 2) Also, it is important to capture where each respondent is in their diagnostic/treatment process (e.g., not on treatment yet, two weeks on treatment, or three months on treatment) to allow for analysis of time-related variation in responses.

**Table 2. Types of TB Stigma Expressed with or without a Determined Time Period**

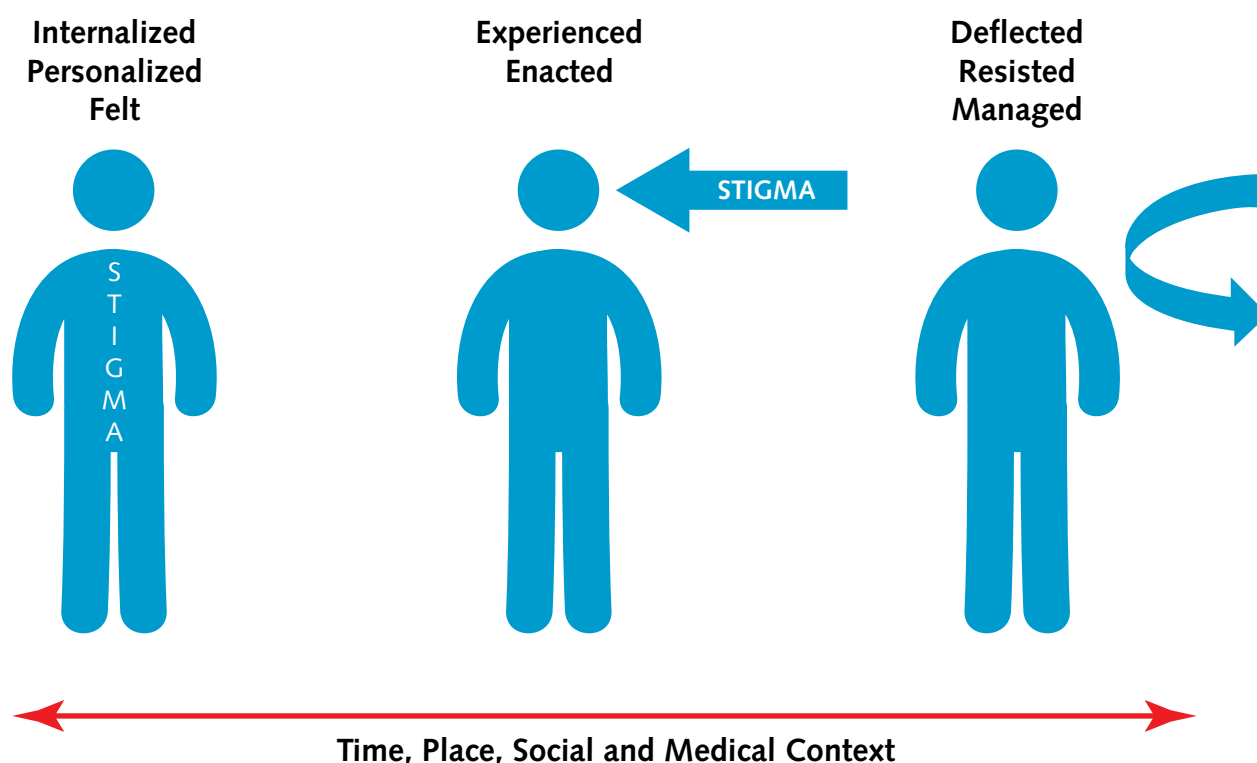| Type of stigma | Undetermined Time Period | Determined Time Period |
|---|---|---|
| **Internalized** | "I feel ashamed to have TB." | "In the last two weeks I have felt ashamed to have TB." |
| **Perceived** | "Others would think less of you." | "In the last two weeks others have thought less of you." |
| **Enacted** | "Others refuse to visit." | "In the last two weeks others have refused to visit." |

Advantages of measuring just after diagnosis and during the intensive phase PWTB may feel more vulnerable to stigmatization just after diagnosis and in the intensive phase of TB treatment because of social distancing to prevent transmission and use of infection control methods, such as masking, that may lead to deductive disclosure.

TB stigma is thought to be acute due to physical isolation, infection control measures, and drug reactions. Often TB stigma studies have included people who have taken TB therapy for less than one month.[22,23] Measuring stigma during the intensive phase ensures that there is less recall bias if you are specifically interested in measuring stigmatization during the early stages of TB treatment.

## Advantages of measuring in the continuation phase

In the continuation phase, PWTB are no longer infectious and physical separation and masking are no longer indicated. Stigmatizing behaviors, such as unnecessary social distancing, that are reported in the continuation phase are more directly attributable to TB stigma. PWTB are experiencing fewer treatment side effects, improved general physical and mental health, and with additional understanding of TB, the potential for confounding is lower.[24] People may be better positioned to reflect on their experience after the acute medical crisis is stabilized.

### Figure 1. How TB Stigma may be Encountered



**Internalized Personalized Felt**

**Experienced Enacted**

STIGMA

**Deflected Resisted Managed**

**Time, Place, Social and Medical Context**

## Advantages of measuring after TB treatment is completed

Surveying people treated for TB about stigma *after their treatment* ends permits the detection of any stigma sequelae after successful treatment. This gives an unambiguous TB stigma signal unclouded by social distancing for the purposes of infection control. To assess TB stigma at the end of treatment, you need to recruit drug-susceptible TB patients who have received five to six months of treatment. If your study population is MDR-TB patients, this would be 9-12 months (with the shorter regimen) or 23-24 months of treatment (with standard-length regimens).

Long term sequelae of TB stigma are understudied. The disability studies field has a range of validated tools for capturing the social impacts of stigmatized

conditions. The Participation Scale (Van Brakel)[25] is an 18-item instrument available in seven languages that has shown good internal consistency, with a Cronbach's alpha of 0.92, intra-tester stability 0.83, and inter-tester reliability 0.80.

This means that the scale is measuring what it is intended to measure. A study by Rajeswari (2005) evaluated the health and well-being of people treated for TB within two months of being diagnosed and between the fourth and sixth months of treatment. They created a questionnaire based on a previous study of the socioeconomic impact on people treated for TB, and a modified version of the SF36 questionnaire, which explores patients' perspectives of their illness, recovery, well-being, and quality of life.[26] At the end of treatment, 47% of patients still had symptoms, which interfered with them visiting friends.[26] At treatment completion, 54% of men and 52% of women reported feeling happy most of the time.

## Advantages of measuring stigma at multiple time points (Cohort Approaches)

Given the temporal sensitivity of stigma measurement, measure stigma at least twice. The size and strength of a PWTB' social network is often dynamic over the course of treatment.[27] This can be due to self-imposed isolation and/or stigmatization. Social capital is highly protective and leads to better TB treatment outcomes.[28] One way to capture the fraying/decaying of family and friendship ties is to ask at diagnosis and again at treatment completion how many close friends one has at different points in time.

**Figure 2. Example of Social Network Size Variation over the Course of TB Treatment**



| Social network size at diagnosis | Social network at two months | Social network at six months | Social network size at 18 months |
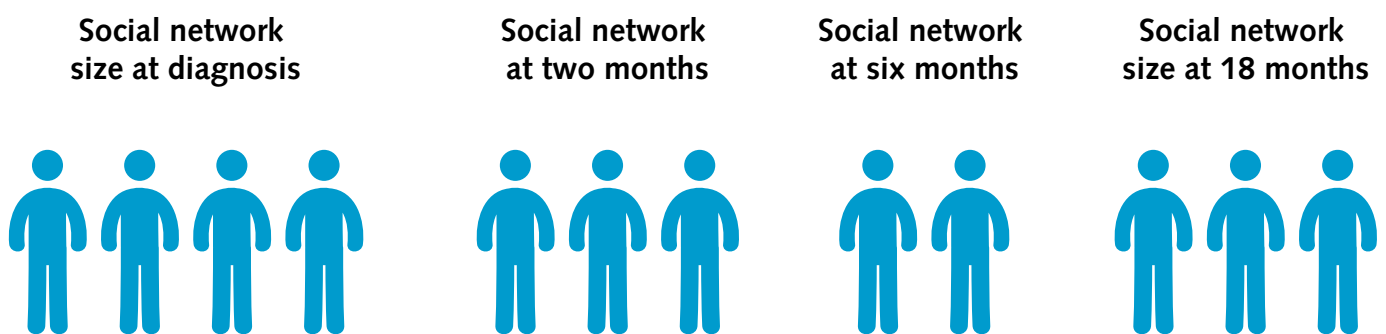
# Sampling Methods

Next, PWTB must be selected into your survey. In theory, the best method is simple random sampling, as this guarantees that any variance between the sample and population are due to chance and not selection bias. This requires a list of everyone with TB, which is rarely available.

Systematic random sampling of those diagnosed with TB in health facilities is a more feasible sampling method if precautions are taken to ensure randomness. To use systematic random sampling, divide the number of PWTB on your sampling frame (e.g., total patients on all lab registers and treatment registers, de-duplicated) by the number of people needed for the study, and then include every nth person for your study sample.

For example, if the state has 3,000 people diagnosed, and you need 500 people for the study, 3,000/500=6, therefore n = 6, and every sixth person in the lab register would be included in the study.

Stratified random sampling is important if you want to compare two populations, such as the stigma among persons treated for MDR-TB compared to the stigma among those treated for DS-TB. In this case, you can choose to select the same number of clients from each group (disproportionate stratified random sampling) or different numbers based on the proportion of each group to the overall population (proportional stratified random sampling).

# Sample Size

The sample size is the number of people from which you will gather information. The sample is a representation of the study population, and does not need to be the whole study population. You need to identify the minimum number of people to include, ensuring that you have enough to fully represent the population or allow for meaningful comparisons between populations, while not wasting resources. However, once you have found the minimum number of people required to get a good representation, increasing this number will not significantly increase the accuracy of the results.

Calculation of the sample size and adjustment for clustering (in case of clustered sampling frames, see Chapter 5) are perhaps the most challenging aspects of measuring TB in clients for non-researchers. It may be useful to seek help from those with expertise.

To find the crude sample size (i.e., sample size for a random sample) required, there are multiple online tools available. These can be found by searching for a "sample size calculator." To find it manually, you can use this formula:

$$n \geq \frac{(N)(p)(1-p)}{(N-1)(D)+(p)(1-p)}$$

$$D = \frac{(\text{Confidence Interval})^2}{Z^2}$$

n = Crude sample size

N = Population size (the total number of PWTB from which the sample will be selected)

p = Prior assumptions about TB stigma level. For example, if you have a good reason to believe that 90% of people will answer yes to a question, then P= 0.9 If you are unsure of how the study population will answer the questions, you can use P= 0.5

Z = Z score represents the area under the curve for the desired confidence level

| Confidence Level | Z Value |
|------------------|---------|
| 90% | 1.65 |
| 95% | 1.96 |
| 99% | 2.58 |

Using the example of a PWTB population size of 3,000 and a desired 95% confidence level with a confidence interval of ±5%, the crude sample size would be calculated as follows:

$$D = \frac{(0.5)^2}{(1.960)^2}$$

$$D = 0.00065$$

$$n \geq \frac{(3,000)(0.5)(0.5)}{(2,999)(0.00065)+(0.5)(0.5)}$$

$$n \geq 341$$

## Example of a crude sample size calculation, on maximum sample size requirement

The sample size calculation is used to ensure that the people who you interview are an accurate representation of your study population, as it is not feasible to interview everyone with TB. It is best to use a conservative approach to the sample size calculation if you are unsure of the TB stigma assumptions in your area. This means that you should calculate the largest possible sample size required. This assumes that half of the population (50%, or p= 0.5) experiences stigma. In general, most studies use a 95% confidence interval, therefore D will equal 0.00065. If we use the unknown prior assumption value of p= 0.5 (and thus (p) (1-p) = 0.5*0.5= 0.25), then the calculation will be:

$$n \geq \frac{(N)\ (0.25)}{(N-1)\ (0.00065) + (0.25)}$$

You only need to know the N value, which is the study population (number of TB clients in your area) to complete the calculation. This can sometimes be found on the Ministry of Health database, the NTP website, the WHO website, or the hospital or clinics registry. Once entered into the formula (ensure you place the population number in the capital N and not lower case n), that is the minimum number of people you need to survey to make your results a true representation of your study population.

Another consideration for sample size (i.e., total persons with TB surveyed) is that the sample is also adequate for a factor analysis. Factor analysis is used to measure the internal consistency of a scale; that is, that your scale is measuring what you want it to measure. In order to conduct an adequate factor analysis, the minimum sample size needs be 5-10 times the number of items in the scale.[29] For example, if the scale contains 18 items, the minimum sample size should be 7 x 18 = 126.

In the examples above, we focus on sampling clearly defined, easily recruitable populations for quantitative research. Chapter 3 has guidance on sampling TB clients for qualitative research. Chapter 9 has guidance on sampling persons affected by TB within hard-to-reach populations.

## Adjusting sample sizes for clustering of stigma

Recruiting PWTB from health facilities is convenient. As PWTB are grouped or clustered through the facilities where they are diagnosed and/or treated, this is called cluster sampling. Each facility represents a cluster of clients. Cluster

sampling is often used to simplify logistics and reduce study costs. However, the convenience of facility-based recruitment also comes with some risk of bias. Stigmatizing attitudes and behaviors are typically clustered.[30–32]

The discriminatory attitudes or behaviors of a single care provider or single treatment supporter can impact all of the TB clients under his/her care. A particular health facility may enact discriminatory policies that harm everyone at that site. Take efforts to reduce the ability of extreme cases to influence study estimates.

**Figure 3. How Stigma Exposures are Clustered by Care Giver and Facility**
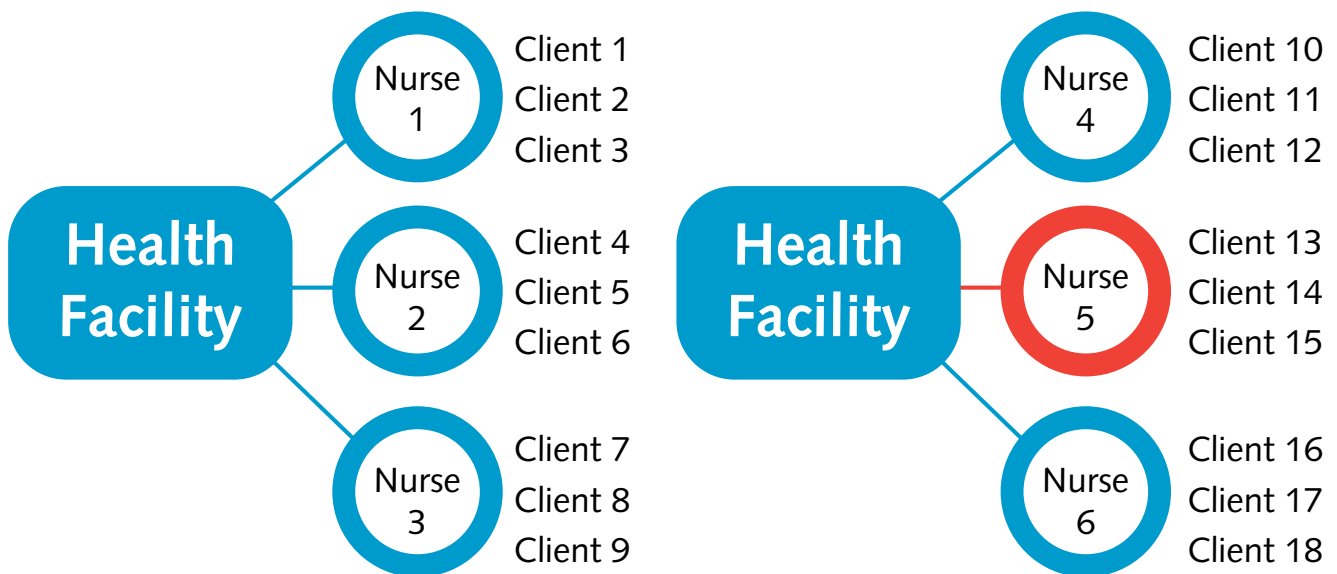


The disadvantage of cluster sampling is that there is population clustering around one facility, as they share the same geographical context and potentially the same TB treatment supporter. Therefore, several corrective steps need to be taken.

## How to minimize bias due to clustering

There are two ways to reduce bias associated with clustering: minimizing, and adjusting and documenting:

1. Make the clusters as small as possible. First, include as many different health care facilities, providers, and treatment supporters as possible when drawing a TB client sample. This will reduce the potential for ascertainment bias.
2. Increase the number of clusters to reduce the potential for sameness among the sample.

While often necessary, cluster sampling creates uncertainty about the results (e.g., loss of precision). To maintain precision, the sample size needs to be increased. The extent of increase can be determined by analyzing the intra-cluster correlation coefficient (ICC) and adjusting the effective sample size

accordingly. To calculate the ICC, you first need to identify the between cluster variance (the amount by which the stigma score of each cluster differs) and the within cluster correlation (how much the stigma score of the individuals within the cluster differ). These numbers can then be added to the following formula to identify the ICC, which is also denoted by the Greek letter $\rho$[33]:

$$\text{ICC or } \rho \quad \frac{\text{(Between cluster variability)}}{\text{(within cluster variability + between cluster variability)}}$$

This will give a value ranged from 0-1, where 0 means that there is no correlation within a cluster and 1 meaning that there is a strong correlation within the cluster. As the ICC number increases, the sample size also needs to increase as the number needed to identify a difference or change is increased. It is best to conduct a pilot study first to identify the ICC, and then the sample size can be adjusted accordingly.

To adjust the sample size for clustering, you need to first identify the Design Effect (DE). To do this, you need to know the $\rho$ value (from the pilot study) and n (the average cluster size):

$$\text{DEFF} = 1 + (n - 1)\, \rho$$

This can then be used to identify the effective sample size needed (ESS) with the following formula:

$$\text{ESS} = ((m * k)) * \text{DEFF}$$

m=the number of subjects in each cluster
k=number of clusters

For example: A study measuring stigma in people with TB recruits patients from five TB clinics (clusters). Each cluster has recruited 30 patients. There was a strong correlation within each cluster, as the PWTB are faced with the same exposure to stigmatization by interacting with the same set of health care policies and providers. The ICC is 0.05.

$$\text{DEFF} = \frac{(30 * 5)}{1 + 0.05\,(30 - 1)} = \frac{(150)}{(30.45)} = 4.9$$

Therefore, the number of PWTB required in this study increases from 150 to 739 (4.9*150.)

Sometimes clustering is unavoidable, such as when facilities have only one or two DOTs providers. In this case, you should be sure to gather information on the specific cluster (stigmatizing exposures) a TB patient belongs to. Always document the code (not name) of the main healthcare worker and the treatment supporter that a TB patient sees.

## Special considerations for measuring DR-TB stigma

Persons with DR-TB may be uniquely exposed to and disadvantaged by stigma, and their experiences of stigma often differ markedly from patients with drug susceptible TB.[34–38] There are four reasons for this difference.

1. DR-TB treatment takes longer than DS-TB treatment, and therefore the exposure to stigma may be longer as the identity "TB patient" is less transient.
2. DR-TB treatment is typically more toxic, with more side effects. People with DR-TB are more likely to experience neuropsychiatric or perception altering side effects as a consequence of their comprehensive treatment regimens and catastrophic costs due to the length of their treatment, both of which can heighten their vulnerability to stigma.[39] Hearing loss, psychological side effects, and impoverishment can reinforce the social construction of DR-TB patients deviant, unpredictable, and dangerous.[36]
3. DR-TB is often assumed to be caused by misbehavior. Unlike in cases of drug-susceptible TB, in the case of DR-TB, there may be treatment adherence behaviors that may contribute to the development of acquired DR-TB. This may tempt health workers to blame individuals for their disease.[39] DR-TB clients may be at higher risk of self-stigma if they harbor self-blame or guilt related to drug resistance caused by non-adherence.
4. DR-TB has more potential to create fear. One of the main facets of all stigma constructs is the social construction of people with TB as being dangerous to the wider community. Perceptions of TB curability is associated with lower levels of TB stigma.[40,41] When a person has DR-TB, doubts about curability may fuel the notion that DR-TB patients represent a mortal risk to others. Therefore, MDR-TB may have a greater 'mark' than drug-susceptible TB.[39]

These differences make it vital to stratify your stigma analyses by type of TB. There are currently no validated stigma scales available specifically for DR-TB stigma. There are currently two DR-TB stigma scales being validated, which should be available by late 2018. The Cataldo Lung Cancer scale has been adapted to DR-TB (See appendix.)

# Choosing an appropriate TB stigma scale

There are multiple choices when choosing a stigma scale. Table 3 provides an overview of the scales available, as well as studies that have re-used an existing validated study. If a scale has already been used in the country in which you wish to measure stigma, there is no need to conduct the pilot study with cognitive interviews. When choosing a study, it is important to validate it in your setting and that it be reliable. Cronbach alpha is a measure of reliability, as it assesses the internal consistence of the scale. A score greater than > 0.7 is deemed acceptable. Validity can be assessed based on how they developed the scale, whether in depth interviews were conducted, if a literature search was conducted, and if the scale was compared to a pre-existing like-scale.

**Table 3. An Overview of Validated TB Stigma Scales for PWTB**

| First Author | Country | Content Validity | Construct Validity | Reliability | No. of items | Sub-scales (if identified) |
|---|---|---|---|---|---|---|
| Coreil (2010a) | United States | Somma TB stigma scale Local interviews | Item correlation (not reported) | $\alpha$=0.87 | 25 | |
| Coreil (2012) | United States | Somma TB stigma scale Local interviews | | $\alpha$=0.93 (HCW); $\alpha$=0.83 (LTBI) | 20 | |
| Meulemans (2002) | Pakistan | None reported | SEM; correlation with family support (r=-0.15) | $\alpha$=0.64 | 2 | Prejudice/ discrimination |
| Macq (2006) | Nicaragua | Literature review Stakeholders Ritsher mental illness scale Expert review | Rosenberg self-esteem (not reported) | $\alpha$=0.70 | 10 | 4 sub-scales: Alienation, Stereotypes, Discrimination, Social withdrawal |
| Somma (2008) | Bangladesh, India, Malawi, Colombia | Literature | | $\alpha$ for each country was 0.65 to 0.85 | 18 | gendered questions on marriage, sex refusal |
| Van Rie (2008)[42–44] | Thailand | Literature Interviews Focus groups Expert review | EFA followed by CFA in larger sample Correlation with O'Brien social support (r=-0.14 and -0.25) Correlation with HIV stigma (range 0.39 to 0.63 | $\alpha$ for subscales was 0.83 to 0.90 test/re-test correlation (r=0.46 and 0.64) | 24 | 2 sub-scales: Patient perspectives towards TB; Community perspectives towards TB |

| | | | | | | |
|---|---|---|---|---|---|---|
| Woith & Larson (2008) | Russia | Fife and Wright HIV stigma scale | | α for subscales was 0.50 to 0.84 | 24 | 4 Sub-scales: Social rejection, Financial insecurity, Internalized shame, Social isolation |
| Abdulelah (2015) | Iraq | FACIT-G and FAHI | EFA | α=0.81 Test/re-test correlation (r=0.70) | 11 | Emotional well-being/stigma (contains non-stigma items) |
| Westaway (1994) | South Africa | Jenkins and Mata | EFA | None reported | 3 | 1 sub-scale is Perceived Social Stigma (stereotypes) |
| Moya 2014[45] | Mexico | Van Rie | EFA | α=0.88 | 12 | Disclosure items did not load |
| Crispin et al.2016, 2017[46,47] | Brazil | Van Rie | EFA | α=0.71 | 12 | Infection control item and HIV item did not load |
| Bond (2017)[48] | Zambia, South Africa | Literature review Qualitative studies Discussions with ICRAAS | Not reported | Not reported | 12 | |
| Hayes-Larson (2017)[49] | Lesotho | Van Rie community perspectives of TB scale | EFA | α=0.9 (from Van Rie) | 11 | |
| | | Not reported | EFA | Not reported | 3 | |

ICRASS = International Consortium for Research and Action Against Health-related Stigma

EFA = Explanatory Factor Analysis

CFA = Confirmatory Factor Analysis

## Self-stigma scales

An example of a validated scale for measuring self-stigma among people with TB is the Van Rie scale.[42] It is one of a small number of scales that has been evaluated for content validity, construct validity, and reliability in multiple settings using rigorous methods.[45,47,49,50] Content validity evaluates whether the items in the scale comprehensively cover the domains.[29] To ensure that the content of the scale was culturally and linguistically appropriate, Van Rie (2008) conducted in-depth interviews and focus groups with people affected by TB, their family members, health care workers, and community members. The scale uses items phrased in the third person to ask questions in an indirect manner. Less direct phrasing was found to be more appropriate where it was originally designed (Thailand). Third person

also can be effective for use in newly diagnosed individuals, who may not have much personal experience with the disease.[50]

Construct validity is used to measure a new scale to a pre-existing 'gold standard' scale or validated scale.[29] Strong correlations were found when the new scale was compared to the O'Brien social support scale.[22] To assess the reliability of the Van Rie stigma scale, the questionnaire was conducted twice within a 30-day period on 15 study participants, the scores were similar, which indicates good reliability and reproducibility. The results are limited due to the small sample size.[22,29] The Van Rie scale consists of 12 questions assessing the patient's perspectives towards TB.[22] A strength of this scale is its re-validity in different populations, including the United States and Mexico.[17,50]

## Enacted stigma scales

Enacted or experienced stigma is the mistreatment of an individual known to have TB.[29] Enacted stigma can have serious internal and external harmful effects on the person with TB. People with TB, especially MDR-TB, can suffer from a variety of mental health issues due to stigma.[39,51] Some types of enacted TB stigma constitute discrimination. There is no consensus on the definitions and boundaries between the two concepts.[52,53] Human rights lawyers tend to see most mistreatment of PWTB as discriminatory whereas social and behavioral scientists tend to view behaviors as stigmatizing. In practice, measure the extent of the problem and attempt to stop it. Chapter 5 details the measurement of discriminatory behavior.

**Figure 4. Overlap between stigma and discrimination**
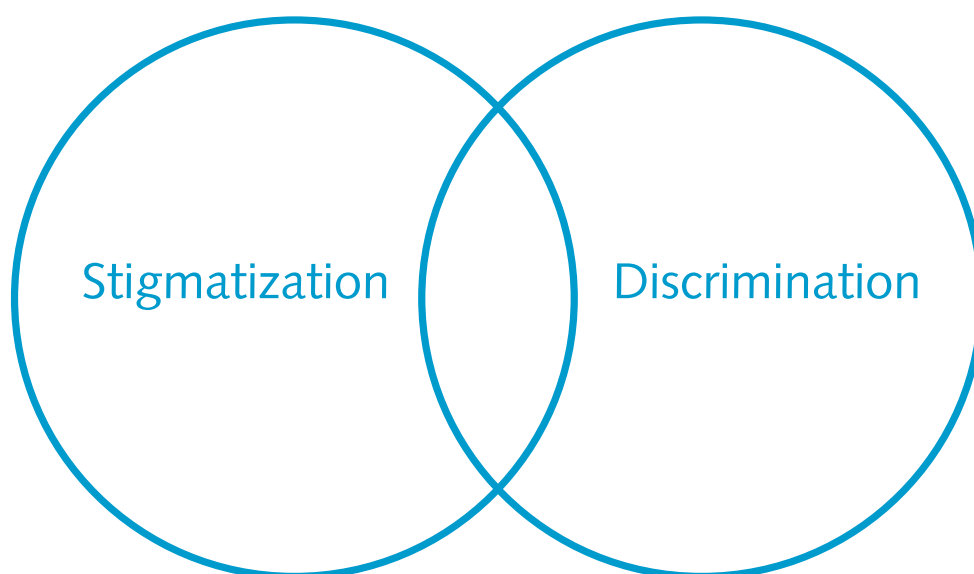


The EMIC (Explanatory Model Interview Catalogue) interview used by Somma et al. (2008) contains 18 indicators of stigma, seven of which are related to experienced stigma (see Table 3).[54] This scale can also distinguish the areas of

experienced stigma (see Table 1). A family member, a friend, or a member of the community can direct enacted stigma towards the person with TB. It can also be directed at a family member or friend of the person with TB by a community member, which is known as courtesy or secondary stigma (See Figure 5. For more information on courtesy stigma, refer to Chapter 8.) The EMIC has two of the three criteria for scale validation. It used literature and local interviews to make it context-specific, and was reliable with fair-to-good levels of internal consistency. The Cronbach alpha ranged from 0.65-0.85 (depending on study site). The scale was not compared to other like scales, resulting in an unverified criterion validity.[55] One criticism of the EMIC scale is that a number of its items are gender-blind. In other words, they are insensitive to gendered power relations within relationships that influence getting married, refusing sex, or providing support. For this reason it may underestimate TB stigma among men, and should be used primarily for samples of women.

**Table 4. Explanatory Model Interview Catalogue (EMIC) Interview – 18- items**

| | |
|---|---|
| 1 | Desire to keep others from knowing |
| 2 | Disclosure to confidant |
| 3 | Think less of yourself |
| 4 | Shamed or embarrassed |
| 5 | Others would think less of you |
| 6 | Adverse effect on others |
| 7 | Others have avoided you*# |
| 8 | Others refuse to visit *# |
| 9 | Others think less of the patient's family*^ |
| 10 | Problems for your children*^ |
| 11 | Problem getting married despite cure*# |
| 12 | Support from spouse expected |
| 13 | Partner refuses sex due to TB *# |
| 14 | Other problem in marriage (after cure) |
| 15 | Problem for relative to marry*^ |
| 16 | Asked to stay away from work, groups *# |
| 17 | Decided to stay away from work, groups |
| 18 | Presumed other health problems |

Notes: *Enacted stigma; #Primary stigma (person with TB is stigmatized); ^Courtesy stigma (PWTB family members are stigmatized).

There are also very useful generic tools for measuring enacted stigma described in Chapter 14, including:
• Everyday discrimination scale; and
• Experiences of discrimination (EOD) index.

Generic measures are useful if you need to compare two stigmatizing conditions.
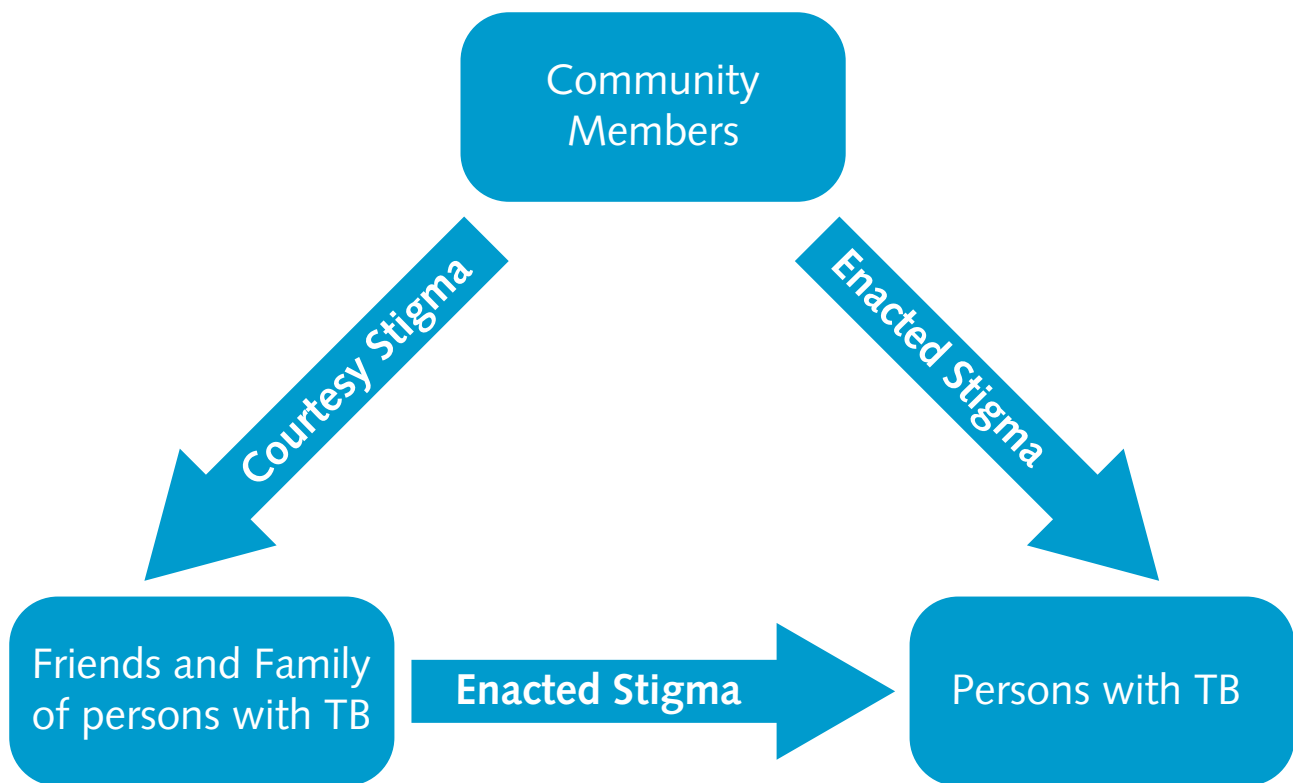
## Measuring TB disease disclosure: is it a proxy for stigma?

A desire to conceal a stigmatized disease is not a direct measure of stigma, but is often a *consequence* of stigma.[32,45,56] In the case of TB, where rapid diagnosis and effective treatment leave no sequelae, there is no reason to promote disclosure.

"Disclosure concerns are highly related to stigma in general, and more specifically have been theorized to constitute the basis of felt and internalized stigma; thus, receiving support after disclosure plays a key role in the reduction of stigma. Another approach suggests that felt stigma is likely to internalize if there is a lack of social support, implying that a higher level of social support reduces social isolation, which in turn decreases disclosure concerns."[57] Disclosure can be challenging to interpret as both affirmative and negative responses could indicate stigma. In Somma et al.(2008), the disclosure item was dropped in two of the four study sites as it lowered the internal consistency.[54] Disclosure items should be minimized or avoided in TB stigma scales.

## Subtle forms of TB Stigma: Microaggressions

A common form of enacted stigma is microaggression. Microaggression is a more subtle form of stigma, and involves prejudice, demeaning communication,

and discreet discrimination to certain individuals based on their marginalized social groups.[5] There are three sub groups in measuring microaggression: microassault, such as name calling and avoiding the individual, microinsult, being rude and insensitive towards the individual, and microinvalidation, which is the exclusion of individuals and nullification of their feelings, thoughts, and reality.[5] Gonzalez argues that microaggression has arisen due to the increase in social censure of crass mistreatment, political correctness, and norming of behaviors that restrict the acceptability of more overt forms of enacted stigma.

There have been several scales developed to measure microaggression in several groups of marginalized people, such as the Racial and Ethnic Microaggression scale (REMS), the LGBT People of Color Microaggression scale (LGBT-PCMS), and the Mental Illness Microaggressions Scale-Perpetrator (MIMS-P).[5] There is no validated discrimination scale available for use in TB stigma; however, the themes are highly pertinent, and the items could be adapted for the future development of TB stigma scales. They can ensure that the more subtle forms of enacted stigma are captured. Comprehensive TB stigma scales should query a broad range of issues related to TB clients' rights, as these are particularly actionable.[58]

## Domains in the patient rights charter include:[59]

1. **Care:** There should be equitable access, without discrimination, to TB education, prevention, and care according to established standards. This includes the needs of PWTB with MDR-TB and HIV co-infection.
2. **Dignity:** TB services should be offered in a respectful environment, without stigma, and with moral support from the community.
3. **Information:** Information should be provided on all aspects of TB, including prognosis, costs, and side effects. Experiences should be shared with peers.
4. **Choice:** Patients have a right to a second opinion, access to medical records, and the right to accept or refuse medical interventions or to take part in research.
5. **Confidence:** There should be personal dignity, privacy, and confidentiality about the medical condition.
6. **Justice:** Patients have the right to complain, appeal, and to be heard promptly and fairly.
7. **Organization:** Patients have the right to participate as stakeholders in policies and programs and establish TB patient platforms.
8. **Security:** There should be job security and rehabilitation, nutrition security, or food supplements, if needed.

The reproductive health field has validated scales for respectful care that can be adapted for TB (Appendix 2), and the Cataldo scale (Appendix 1) has domains specific to respect.

## Harms of enacted stigma

The effect of stigma on people with TB can be severe and may outlast the impact of the illness itself. Enacted stigma can be small, compounding factors, such as microaggression, or it can be overt drastic social exclusion. Some people with TB also experience divorce, being fired from their workplace, or banishment to another village.[7] A comprehensive measure of enacted stigma (i.e., discrimination) should cover infringement of patient's rights (See Chapter 6 for more on Human Rights).

## Accounting for multiple forms of exclusion and sources of stigma

When studying TB stigma among patients, it is important to also measure the extent and severity of other forms and root causes of exclusion and discrimination, as it is possible to confuse mistreatment due to TB stigma with mistreatment reflecting racism, xenophobia, homophobia, sexism, or other hostile attitudes. Ways to approach syndemic or intersecting stigmas are covered in Chapter 14.

## Piloting the scale and cognitive interviews

Once you have completed your study design and chosen a previously validated scale to use, you need to test it to ensure that it is appropriate for the context. It is also important to include other scales, where appropriate, such as a social desirability scale and questions referring to other potential stigmas to account for confounders (see below). The pilot study can be conducted on a smaller number of participants (5-20), and the participants can be selected by convenience sampling, not random sampling. This method is easier than random sampling, as you can visit one or two TB clinics and ask PWTB to participate as they enter or leave the facility.

Cognitive interviews are used to assess the study participants understanding of the scale and questionnaire. It includes question such as "what did this question mean to you?" or "what does (refer to certain question) mean to you?" You can then use these results to alter the scale and questionnaire if needed.

## Conduct the interview/data collection

Once you have revised the TB scale, you can conduct your interviews.
How to measure TB stigma among people with TB: Who asks matters
The best people to conduct the interviews, if self-surveys are not being used, are researchers and TB survivors. With training, many community advocates can also be interviewers. As explained in Chapters 1 and 12, engaging TB survivors

in research roles has many advantages. Former TB patients and their families have indispensable insider knowledge, and their engagement often enhances the quality, acceptability, and social validity of the work. As with all researchers, TB survivors need research training to perform effectively. Being a TB survivor does not automatically imply that one does not harbor stigmatizing beliefs, so all data collectors need basic stigma training.[66]

It is best to avoid healthcare workers as interviewers or proxies. The use of the local health care workers or local community health volunteers might introduce bias.[20] Examples from the study in Kenya show different prioritization of stigma by PWTB versus health workers (Table 5). TB patients ranked TB stigma as a greater challenge than healthcare workers in the same setting.

**Table 5. Ranking Challenges, TB Patients versus Providers [adapted from Onyango-Ouma W., 2005]**

| TB Patients | Provider/Stakeholders |
|---|---|
| 1. Delay/inefficient services | 1. Shortage of staff |
| 2. Negative provider attitudes | 2. Delay |
| 3. Provider lateness/unavailability | 3. Seminars that take providers away for a long time |
| 4. Long treatment duration | 4. Open waiting space |
| 5. Strict drug collection times | 5. Lack of privacy |
| 6. Suspicion that one has HIV | 6. Isolation |
| 7. Many injections | 7. Feeling unvalued/stigma |
| 8. Lack of privacy | 8. Lack of full-time services at chest clinic |
| 9. Congestion | 9. Duration of treatment |
| 10. Discrimination | 10. Proximity of TB clinic to voluntary counseling and testing (VCT) |
| 11. Open waiting area | |
| 12. Bad food | |
| 13. Being asked for a transfer letter | |
| 14. Weekly drug doses | |
| 15. Shortage of providers | |

# Analyze the data and interpret the results

Most scales use the Likert system, where 0 is assigned to the negative stigma response and 5 is assigned to the affirmative stigma response. Pay attention to any positively phrased questions to ensure you recode them correctly (e.g. if someone responds "strongly agree" to the statement "TB patients are just like me," that would need to be reverse coded as a 0). The scores are then added and compared across multiple variables, such as gender, location, age, treatment duration, health care provider, etc.

## Beyond TB stigma prevalence

In order to effectively address stigma, one needs to know more about it than its prevalence. Mixed-method studies are typically required to develop interventions. See Chapters 3, 10, and 17 for how to identify the mechanics of stigmatization.

## Combining TB stigma questions with other surveys of people treated for TB

Depending on the time and resources available, TB stigma can be measured in many different, valid ways. Measuring stigma can be made part of an array of routine TB projects, including catastrophic cost surveys,[60,61] quality of care measurements, situation analyses, prevalence surveys,[62–64] knowledge attitudes and practices (KAP) surveys, and national program reviews.

It is often assumed that TB stigma plays a primary role in the treatment experience. It is frequently assumed to be one of the most important challenges for patients. However, in some settings, stigma is less important to patients than treatment affordability, waiting time, and drug availability. A 2013 TB patient survey suggested that TB stigma ranked among the lowest priorities for Nigerian PWTB when contextualized among all of the challenges they faced.[65] It is useful to be able to situate the severity of TB stigma in the wider context of patients' perceptions of quality of care.

Since 2009, the TB community has been measuring stigma, as part of a patient-centered approach, using the QUOTE-TB tool.[38,65] The QUOTE-TB tool is an innovative approach involving locally grounded and validated measurement. The methodology originated in the European patients' rights community. QUOTE-TB can be assessed here:

http://pdf.usaid.gov/pdf_docs/Pnadp455.pdf

## Conclusion

Studying the prevalence and severity of stigma from the perspective of PWTB and survivors is vitally important.[37] It is crucial to engage TB survivors in the study process and to plan the research so it has a clear population and to mitigate the effects of biases. The three main biases are selection bias, social desirability bias, and ascertainment bias. The use of random sampling in the correct population will reduce the effect of selection bias. To reduce the possible impact of ascertainment bias, you will need to increase the sample size in cases of clustered sampling. This can be further reduced by the inclusion of patients who have been lost to follow-up or who have not yet commenced TB treatment.

# Acknowledgements

# Appendix 1
## Cataldo et al. (2011) – Cataldo Lung Cancer Stigma scale - Self-perceived lung cancer stigma (adjusted to DR-TB)[67]

| Response Categories | Strongly Disagree | Disagree | Agree | Strongly Agree |
|---|---|---|---|---|
| **Stigma and Shame** | | | | |
| I feel guilty because I have DR-TB. | | | | |
| I work hard to keep my DR-TB a secret. | | | | |
| Having DR-TB makes me feel like I'm a bad person. | | | | |
| I'm very careful whom I tell I have DR-TB. | | | | |
| I feel I'm not as good as others because I have DR-TB. | | | | |
| I worry people who know I have DR-TB will tell others. | | | | |
| Having DR-TB makes me feel unclear. | | | | |
| In many areas of my life, no one knows I have DR-TB. | | | | |
| I feel set apart, isolated from the rest of the world. | | | | |
| I told people close to me to keep my DR-TB a secret. | | | | |
| Telling someone I have DR-TB is risky. | | | | |
| People's attitudes make me feel worse about myself. | | | | |
| As a rule, telling others has been a mistake. | | | | |
| My DR-TB diagnosis was delayed because I put off going to the doctor. | | | | |
| I regret having told some people that I have DR-TB. | | | | |
| Having DR-TB in my body is disgusting me. | | | | |
| Some told me DR-TB is what I deserved. | | | | |
| My DR-TB diagnosis was delayed because my healthcare provider did not take my" (smoker's) cough" seriously. | | | | |
| Smokers could be refused treatment for DR-TB. | | | | |
| **Social Isolation** | | | | |
| I have lost my friends by telling them I have DR-TB. | | | | |
| I stopped socializing with some because of their reactions. | | | | |
| People have physically backed away from me. | | | | |
| People I care about stopped calling after learning that I have DR-TB. | | | | |
| People seem afraid of me because I have DR-TB. | | | | |
| People who know tend to ignore my good points. | | | | |
| People avoid touching me if they know I have DR-TB. | | | | |
| Some people don't want me around their children. | | | | |
| People avoid me because they associate DR-TB with death. | | | | |
| Some people have grown more distant. | | | | |
| Knowing, they look for flaws in your character. | | | | |

| | | | | |
|---|---|---|---|---|
| I was hurt by how people reacted to learning I have DR-TB. | | | | |
| I worry about people discriminating against me. | | | | |
| **Discrimination** | | | | |
| People with DR-TB are treated like outcasts. | | | | |
| Most people believe a person with DR-TB is dirty. | | | | |
| Most people think a person with DR-TB is disgusting. | | | | |
| Most are uncomfortable around someone with DR-TB. | | | | |
| I worry that people may judge me when they learn I have DR-TB. | | | | |
| People with DR-TB lose jobs when employers learn about the disease. | | | | |
| **DR-TB related to adherence (dependent on the context)** | | | | |
| DR-TB is viewed as a self-inflicted disease. | | | | |
| Others assume that a patient's DR-TB was caused by non-adherence, even if he or she never missed treatment. | | | | |
| Others assume that a patient's DR-TB was caused by smoking, even if he or she had stopped smoking years ago. | | | | |
| Some people act as though it is my fault that I have DR-TB. | | | | |
| Healthcare providers don't take coughs seriously. | | | | |

Source: Cataldo, J. K., Slaughter, R., Jahan, T. M., Pongquan, V. L., & Hwang, W. J. (2011, January). Measuring stigma in people with lung cancer: pPychometric testing of the cataldo lung cancer stigma scale. In Oncology nursing forum (Vol. 38, No. 1, p. E46). NIH Public Access.

# Appendix 2: Illustrative Exit interview items for measuring respectful care adapted from Sheferaw et al.[68]

Below are some examples of items used in exit interviews:

## Friendly care:

I felt that health workers cared for me with a kind approach.

The healthcare workers treated me in a friendly manner.

The healthcare workers talked positively about my recovery.

The healthcare worker showed his/her concern and empathy.

## Abuse-free care:

The health provider threatened me with negative consequence if I did not obey.

The healthcare workers shouted at me because I haven't done what I was told to do.

I was assured that information about my health status would be protected.

## Discrimination-free care:

Some of the healthcare workers did not treat me well because of some personal attributes.

Some healthcare workers insulted me or my companions due to my personal attributes.

I was treated the same as any other client.

Once I was no longer infectious, I was not segregated from others.

## Respectful care:

I was kept waiting for a long time before receiving services.

Service provision was delayed due to internal problems in the health facilities.

All healthcare workers treated me with respect as an individual.

The healthcare workers spoke to me in a language that I could understand.

The healthcare provider called me by my name.

The healthcare care workers discussed with me how best to engage my close contacts while preserving my privacy.

## Empowering care:

I was encouraged to choose my treatment supporter.

I was given enough control over my own treatment decisions.

I was given enough information to understand TB disease.

I received information and tools to help me to protect my family and friends.

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# Chapter 8

# Measuring secondary stigmas among TB-affected workers and families

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## Abstract

This chapter focuses on strategies for measuring secondary TB stigma among those who may not have TB themselves, but are associated with the disease through their work or relationships. This chapter aims to provide insight into secondary stigmas in TB-affected families and members of the TB-associated workforce by introducing courtesy and dirty work stigma. We discuss common drivers and domains of *courtesy* and *dirty work* stigma. We outline the advantages and disadvantages of available validated secondary stigma scales. Healthcare workers and family care givers who care for people with tuberculosis are scarce and serve as a vital resource for the elimination of TB. Understanding the community and workplace stigmatization affecting this group will help in designing effective programs and policies that support their life saving work.

## Objectives

1. To introduce two secondary TB stigmas: dirty work and courtesy stigma.
2. To familiarize readers with drivers, experiences, and consequences of secondary stigmas.
3. To describe the relative merits of available scales, and the need for innovative new scales.

## Target Audience

This chapter is for people who plan to measure TB-stigma in families or workers affected by TB. This chapter was written for national TB program staff, labor unions, environmental and occupational health organizations, NGOs, CBOs, partners, and advocates. The content is also appropriate for social workers, palliative care workers, and organizations working on family welfare as this chapter teaches readers how to measure secondary TB stigma that extends to families and care givers affected by TB.

## Introduction to Secondary Stigmas

The problems caused by TB stigma extend beyond the denigration of people with TB. Although the bulk of stigma research has focused on TB patients, research has shown that stigma does not only devalue a person or a group with a disparaged trait (e.g., TB) but can likewise harm family members, friends, volunteer caregivers,[1] HCWs, TB activists, and miners who are associated with said trait.[2,3]

The aim of this chapter is to provide an overview of existing ways of measuring secondary stigma, and ultimately to reduce secondary stigma.

## Introduction to Dirty Work Stigma

Dirty work stigma is a form of occupational secondary stigma. Dirty work is defined as a sociological term for occupations that are stigmatized. According to Hughes (1951), "Work is said to be dirty if society perceives it to be physically, socially or morally tainted."[4] In other words, occupations that are widely perceived by society as disgusting, degrading, dangerous, or immoral are referred to as dirty work'(see Figure 1)[5] In contrast to courtesy stigma, where stigma is attached to family members and those related to people with TB (PWTB), dirty work stigma entails devaluation due to a disparaged occupation. Health care workers specialized in infectious diseases, including TB, may face dirty work stigma.

Dirty work stigma is correlated with low job satisfaction and depression.[6] Health care workers who specialize in drug and alcohol dependency, sexually transmitted disease, mental illness, or those who treat marginalized populations also face similar stigma.[2,6–9]

## Why dirty work stigma is important to measure

Dedicating oneself to the fight against TB is noble, but it is not necessarily perceived as a prestigious specialization for many HCWs. In Europe, specializing in treating infectious diseases (and in particular TB) is low in the hierarchy of medical specialty prestige.[10–13]

TB HCWs can experience stigmatization and discrimination due to being in close contact with TB patients.[14,15] HCWs who offer TB services may be discredited or devalued in workplace hierarchies by other HCWs.[16] Those who feel discredited by their jobs may begin to feel that they are performing dirty work instead of saving lives.[17] Those who believe their TB work will evoke disdain from peers or family may be less able to champion the needs of TB patients when they are disparaged. Stigmatized health workers may lack empathy, concern, and respect

for their TB patients.[18] HCWs discredited for their work can experience declines in self-efficacy, self-worth, and self-care.[6,9,15,19–22] Dirty work stigma discourages healthcare providers from attending onsite TB screenings or from disclosing their TB disease should they become ill.[15,23,24]

## Drivers of dirty work stigma

The drivers of dirty work stigma include structural factors (e.g., government policies, lack of protection of confidentiality),[25] low levels of institutional support (e.g., lack of investment in safe working conditions for those in TB-affected industries, lack of training and clarification among the health care force),[26] and exaggerated (irrational) fear of infection,[27] which may be a function of insufficient knowledge of the cause, transmission-mode, and curability of TB and DR-TB disease.[28] In some settings, dirty work stigma is compounded by links to stigmatized groups and identities (e.g., homelessness, drug dependency).[27]

## Manifestations of dirty work stigma

The manifestations of dirty work stigma for HCWs may include:
• Decreased, inconsistent, or no social support from family.[7]
• Denial of professional development opportunities.
• Social rejection, prejudice and discrimination by peers.
• Feeling of being treated poorly by peers.[7]
• Gossip/fear of gossip.[6]
• Insulting, blaming, and shaming.
• Labeling (e.g., labeling as infectious themselves).[14]
• Physical and social avoidance and exclusion by co-workers.

## Scales to measure dirty work stigma

In the following section we introduce validated scales to measure secondary stigma in TB and related fields. There are a few scales available to measure components of dirty work stigma. Although there is only one validated three-item TB secondary stigma scale, other scales can be adapted and used to measure additional dimensions of dirty work stigma in the context of TB. Choosing a scale or merging items from different scales into one scale is dependent on the study objectives (Table 1).
There is no validated TB stigma scale for TB dirty work stigma that includes drug-resistant TB (DR-TB), but experts believe that dirty work stigma associated with care services provided to DR-TB patients may be qualitatively and quantitatively different in terms of the domains and severity.[29]

To help chose the scale that will meet your needs, it is helpful to review the stigma domains each covers and how the items are designed. First is the scale

detailed in "External and Internal TB stigma among HCWs" by Wouters et al., 2016.[30]

In 2016, Wouters et al. validated a tool to measure different levels of TB and HIV stigma among the healthcare workforce in South Africa.[30] The entire questionnaire for the pilot study included 87 questions that were directly related to stigma, as well as socio-demographic questions (e.g., age, sex, occupation, and education), HIV-TB related knowledge questions (e.g., symptoms, way of transmission) and questions on confidentiality in the workplace (e.g., "Do you think confidentiality is maintained in your occupational health unit?")

Wouters et al developed and validated two TB secondary stigma scales:
1. Others' External Stigma toward TB (EOS): How respondents perceive stigmatizing behavior and attitudes of health providers towards TB-associated HCWs (EOS) – five items
2. Respondent's external stigma toward TB (RES): How respondents behave and think about TB-associated HCWs – three items (See Chapter 5).

It is more common to ask participants about other health providers stigmatizing than to ask about their own discriminatory behaviors.[31] This is to avert social desirability bias. Five items in Wouters Others' External Stigma toward TB (EOS) measure perceived stigma toward healthcare workers. The domains that are covered in EOS focus on blame and avoidance norms:

Others' external stigma toward TB (EOS):[14]
1. HCWs who are suspected of having TB are stigmatized in this hospital.
2. HCWs in this hospital avoid contact with coworkers who they think may have TB.
3. Some HCWs in this hospital would not want to eat or drink with a coworker who they think has TB.
4. Some HCWs in this hospital are stigmatized when others find out that they have gone for TB screening.
5. I have noticed that some other HCWs in this hospital feel uncomfortable working near coworkers with TB.

Another scale is the Mental Health Professionals Secondary Stigma Scale/ MHPSSS by Jesse, 2015.[9]

This stigma scale was originally developed and validated to measure secondary stigma among mental health professionals. The psychometric properties of this measure were developed based on Goffman, 1963.[9] The items were adjusted to the TB-context for this guidance. Further, it assesses the consequences that are related to HCW's worries about their own health and reputation. This version substitutes the word TB for HIV. It has yet to be validated, and is included for illustrative purposes.

Response categories: five-point Likert scale ranging from strongly disagree, disagree, neutral, agree, to strongly agree. Items 1 to 11 address reactions HCWs get to their occupation.

## Domain: Negative Affect

1. People sometimes seem disgusted when they find out that I work with TB-patients.
2. People often become uneasy when they learn that I work for TB-patients.
3. Sometimes even my family and friends seem disgusted by the kind of patients that I work with.
4. People sometimes talk to me about how they find the type of clients that I work with to be disgusting.

## Domain: Peril

5. At times, family and friends tell me that I am in danger because of the type of patients that I work with.
6. People tell me that TB-patients can be dangerous.
7. People think that the type of patients that I care for can never really change.
8. People have strong (positive or negative) reactions when they lean about that I work with TB-patients.

## Domain: Labeling

9. At times, I feel stigmatized by others because of the type of patients I work with.
10. People will always associate me with the type of patients I work with now.
11. At times, people hold me responsible for the poor choices made by my patients.

Items 11 to 19 aim to address the consequences for their choice of occupation.

## Domain: Fear of patients

12. I worry that I could get infected by my TB-patients.
13. At times, I am fearful of the type of patients that I work with.
14. I would rather work with different types of patients.

## Domain: Concealability

15. I usually don't talk about what I do for a living to people that I have just met.
16. I feel reluctant to mention that I care for TB-patients when asked about my job.
17. I try not to talk about what I do for a living unless I am asked directly.
18. I like to talk to people about the work that I do.
19. I feel that it is important to talk with my family and friends about the types of problems my patients face.

Another means of measuring stigma was detailed in HIV/AIDS-related stigma as perpetrated and experienced by nurses by Uys et al., 2009.[32]

This study was the first to measure stigma experienced by nurses for HIV/AIDS care in five African countries.[32] The study resulted in a nine-item instrument, ($\alpha$=0.90). Two factors encompassed whether nurses who were caring for HIV patients experienced stigmatization in their social milieu or by colleagues. The response categories are a five point Likert scale, ranging from never, once or twice, several times, to most of the time. The items were adjusted to TB for the purposes of this guidance.

### Domain: Gossiping
1. People said HCW who provide TB care also have TB.
2. People said HCW would only work with TB patients if they had TB themselves.
3. Someone said that HCW who care for TB patients spread the disease.
4. People made negative remarks about HCWs involved with TB care.

### Domain: Fear of infection
5. The spouse of a HCW who cares for TB patients feared that the HCW would bring the mycobacteria home from work and give it to him/her.
6. People said that HCW get infected by taking care of people with TB.

### Domain: Labeling
7. People said HCWs who work in home care have TB.
8. Someone called a HCW names because she takes care of TB patients.
9. A HCW was stigmatized because of the TB services she provides.

It could be interesting to add questions that are related to loss of social support due to a HCW working with TB patients. Likewise, you could raise questions about the impact of decreased or loss of social support.

## Table 1. Secondary Stigma Scales for HCWs

| First Author | Country | Population | Content Validity | Construct Validity | Reliability | Items | Domains |
|---|---|---|---|---|---|---|---|
| Wouters (2016)[14] | South Africa | HCWs | Literature Coreil/ Van Rie scales Expert review | EFA, CFA, SEM Correlation with HIV stigma (r=0.23 to 0.98) Correlation with TB knowledge (?) Correlation with confidentiality (r=-0.22 and -0.23) | A for subscales was 0.65 to 0.87 | 3 | Colleagues' external TB stigma, respondent's external TB stigma, respondent's internal TB stigma |
| Coreil (2012)[33] | United States | HCWs | EMIC | Local interviews | $\alpha$ =0.93 (HCW); | 20 | |
| Jesse (2015)[9] | United States | Mental health professionals | Literature | PCA | $\alpha$ =0.88 | 21 | Concealability, course, disruptiveness, negative affect, peril |
| Uys et al. (2009)[32] | South Africa Swaziland, Lesotho, Tanzania, Malawi | HIV/AIDS stigma instrument - nurses (HASI_N) | FGD | EFA | $\alpha$=0.901, $\alpha$=0.69 | 9, 5 | Labeling, gossip, fear of infection, peer stigmatization of nurses |

FGD, focus group discussion, EFA exploratory factor analysis, PCA principal component analysis

## Stigma of other TB-Affected Occupations: Mining

Workers in TB-associated industries, such as deep pit gold or platinum mining, can also be harmed by TB stigma.[34]

Miners' vulnerability to TB can result in being perceived and treated by family as vectors of infection, even when they have no health problems or have a non-infectious illnesses, such as silicosis.[34] They may have their rights violated by over-zealous or involuntary TB screening efforts. Miners are frequently the target of TB campaigns, although mining associations have noted that often ill-

conceived interventions compound the TB stigma they face (Vama Jele personal communication).[35]

*"When I was working at the mine, when I got ill, at home they were suspecting that maybe I don't have TB, maybe other illness, maybe HIV, so people called me names."*[34]

Teurling's study of stigma among employees at South African gold mines showed that miners were strongly aware of the stigma surrounding their occupation as contaminating.[36] The social production of TB stigma in South African mines is hard to disentangle from the history of colonialism, migration, apartheid, and the political economy of health and wealth in the region.[34,37,38] In the case of migrant silica miners (whose work is widely known to place them at risk for TB), TB stigma can lead to social distancing and distrust upon return to their home communities, and as a result miners may be reluctant to seek care for symptoms in order to avoid reinforcing stereotypes.[4,34,39]

There are no validated stigma scales specifically for miners, but Hayes-Larson et al. have tested an expanded Van Rie scale among a group of TB patients in Lesotho (many of whom were miners).[40] Hayes Larson added items querying internalized stigma and personal social exclusion, which were particularly resonant among the men.[40] Any tool developed for miners should include items pertinent to fear of discrimination in the job market, fear of catastrophic costs, and economic insecurity.[34,41–43]

## Confounders

When measuring the impact of secondary stigma, it is important to be able to distinguish TB stigma from other potential sources of workplace stress that can be confused with stigmatization. Helping professions and repetitive physical work can have high levels of burnout.[9,14] The Maslach burnout inventory (MBI) scale measures the work-related distress that can be a confounder of dirty work stigmas.[44] Maslach (1993) developed a scale that describes three dimensions to assess burnout: emotional exhaustion, depersonalization, and personal accomplishment.[44] The first dimension is characterized by feeling emotionally drained and exhausted by one's work and relationship with patients.

Another potential confounder of secondary stigma is poor working conditions to the perceived organizational support scale.[9] The eight-item scale was developed to measure the perceived level of organizational support and job conditions.[45] The items of this scale were formulated in a very general manner. It would be beneficial to adjust them to the healthcare setting, in particular to the TB-context.

## Sampling

Based on your research question you need to decide who is essential and should be included in your study. Examples are:

- HCWs who are caring for DS-TB patients.
- HCWs who are caring for DR-TB patients.
- HCWs who are caring for DS-TB and DR-TB patients.
- The whole medical workforce of a setting.
- Other health professionals who are working with DS/DR-TB patients.

## Challenges

**Key takeaways:**
- When planning a study on measuring secondary stigma, consider previously validated questionnaires.
- Phrase questions appropriately for the target audience and study objectives.

## Courtesy Stigma in Families affected by TB

Goffman (1963) defined courtesy stigma and associative stigma as stigma acquired as a result of being related to a person with a stigma. Courtesy stigma is the loss of social standing experienced by those who interact with stigmatized people (see Figure 1) It entails overt disapproval due to the association of being in contact, caring, or working for a stigmatized individual or group. It is also referred to as carry over stigma.

**Figure 1. Family Members and Social Network**



Family & Social network —— People with TB
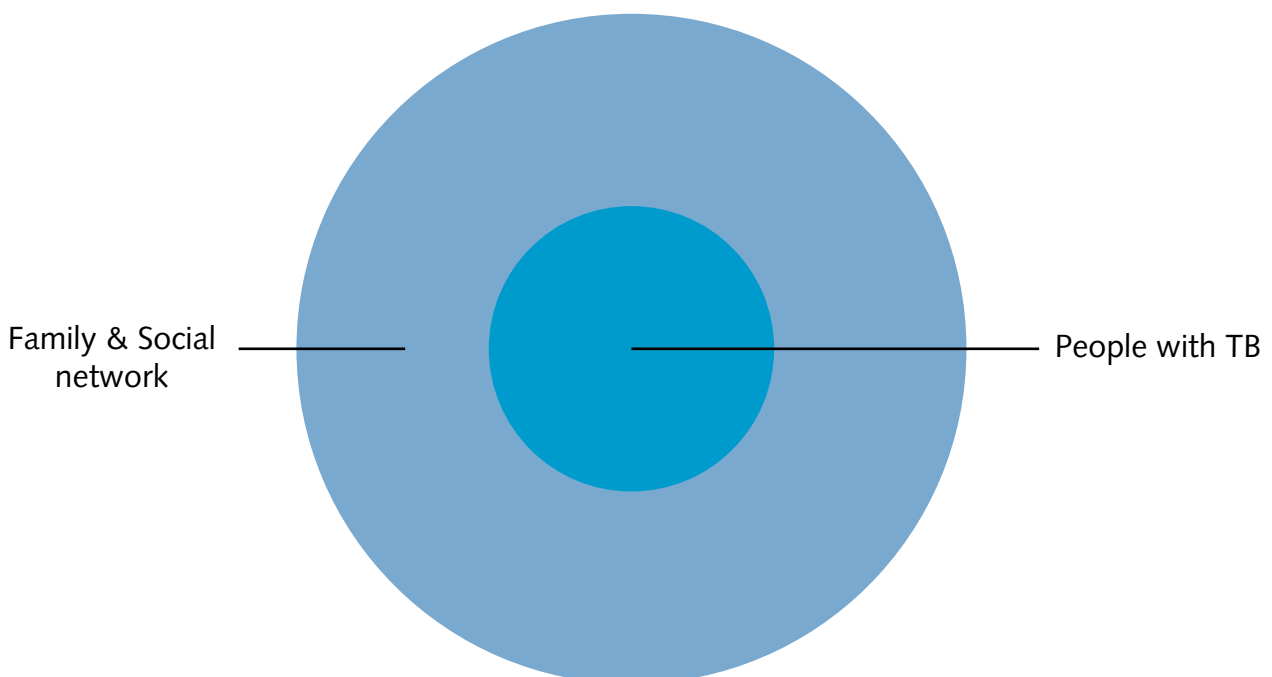
## Why courtesy stigma is important to measure

People that feel ashamed or discredited by their association with a stigmatized individual often hide their relationships or encourage the affected individual to hide their TB-status. Family members who fear the courtesy stigma of TB have been known to discriminate against relatives with TB, including limiting their access to care, denying them household resources, and in extreme cases, disowning them.[46] Family members of a TB-infected person can experience loss of social status as a consequence of negative inferences made about the extended family.[1,25,47–51] In settings were TB is believed to be hereditary, a diseased relative can impose a persistent social taint on the whole family, which persists even if the loved one dies of TB.[46,49]

The level and repercussion of courtesy stigma can vary widely by context.[25] Damage to family reputation can impact employment, education, and marriage prospects.[25,47,52] In communities where social capital functions as a safety net, loss of social status can imperil family survival.[25,51] Courtesy stigma may manifest as a reluctance to expedite care for ill family members, due to fear of disease disclosure to the broader community.[1,33,46]

*"Thinking that neighbors might hate [him] I had not told them about his disease... We went to the village after his diagnosis, but I didn't say that he is suffering from such disease because it was village and once they know they start back-biting and may hate us."*[49]

In addition to weakening the social standing of allies, courtesy stigma damages the support networks and quality of services given to those who have a stigmatized condition.[1] The quality of social support has a big influence on treatment outcomes.

Family social support is a powerful source of resilience and can be undermined by courtesy stigma.[1,53] Studies suggest that courtesy stigma can be mitigated and is influenced by knowledge of cause, curability, and mode of transmission.[28,54] A lack of constructive engagement of families in the TB treatment process may foster stigma in families, particularly when members are inadequately informed.[34]

The evidence of the extent to which the social network of a person with TB experiences courtesy stigma comes largely from ethnographic studies. It is important to create an enabling environment where individuals with TB and their families can seek treatment free of discrimination and prejudice.[55] The shrinking of a patient's social network during treatment can have negative consequences for recovery.[48,56] Atre found that female TB patients in India were less confident of family support than their male peers (2011).[57] The household dynamics in TB-affected families appear to vary widely.

# Drivers of courtesy stigma in families

Touso found that families of lower socioeconomic status experienced more secondary stigma.[58] They also found low TB knowledge to be correlated with stigma in families. The relationship between TB knowledge and TB stigma in the general public or patients is highly variable.[51,59–61] However, it makes sense that scientific uncertainties about duration of infectiousness among patients on treatment and the efficacy of home-based infection control measures could contribute to stigma.[62,63] Fear of infection is a major driver of stigma in families affected by TB.[51,64–67]

Whereas Coreil found that secondary TB stigma in Florida was tied to national identity and concerns about xenophobia among Haitians.[25]

## Scales for measuring TB Stigma in Families

Courtesy TB stigma remains under-researched. Valid and reliable instruments are needed for an efficient mapping of courtesy stigma. Most of the measurement scales for courtesy stigma in families were developed in Haiti, Brazil, and Mexico.

**Table 2. Scales available to measure secondary stigma in families**

| First Author | Country | Content Validity | Construct Validity | Reliability | Items | Domains |
|---|---|---|---|---|---|---|
| Coreil (2010b)[25] | U.S. and Haiti | EMIC stigma scale Local interviews | EFA | α=0.80 for both | 21 (US) 20 (H) | U.S. (four sub-scales): internal shame, external problems, disclosure, Haiti (five sub-scales): internal shame, external problems, disclosure, family reputation, other illness communicability |
| Bond (2017)[68] | South Africa and Zambia | Ethnographic work | n/a | n/a | 4 | Blame, transmission knowledge |
| Arcêncio (2014)[1] | Brazil | Literature review, FGD | CFA EFA | α =0.79 | 9 | Shame, treatment carry over, disclosure carry over |
| Arcêncio (2014)[1] | Brazil | Literature review, FGD | CFA EFA | α =0.79 | 7 | Self-efficacy of social support, interactions with HCW |
| Touso (2014)[58] | Brazil | Arcêncio (2014)[1] | Arcêncio (2014)[1] | Arcêncio (2014)[1] | 10 | Danger of infection, shame, treatment carryover, disclosure carry over |

Coreil et al scale was derived from the EMIC scale (Chapter 7) and uses a locally relevant vignette. It includes two items on secondary stigma: loss of respect for the family, and problems for children.[25] The EMIC scales focus on specific gendered consequences (marriageability), and therefore may not perform equally well across all settings or all social groups. The Arcêncio scale measures anticipated stigma, and is well-validated, perhaps because most items focus on disease concealment.

## Arcêncio scale (+ Touso addition)

1. My family member asks me to keep the TB a secret.
2. I feel ashamed because my family member has TB.
3. I hide the fact that my family member has TB from the community.
4. My family member hides his/her diagnosis from the community.
5. I avoid talking about TB in the presence of other family members or neighbors.
6. I'm afraid that someone will see me at the health care clinic where my relative is being treated.
7. I substitute another word for TB in my conversations with my family member.
8. I substitute another word for TB in the conversations with my friends.
9. I've noticed changes in my family member since the TB diagnosis.
10. (I am worried about becoming infected).

Touso's added fear of infection (#10) to the Arcêncio scale to expand the stigma construct.[58] Given the importance of danger/peril of transmission, a scale of courtesy stigma should include several items on fear of infection.

Arcêncio also developed a scale to measure family members' attitudes toward engagement in TB treatment.[1] This is a measure of the family members' perceived self-efficacy in providing support as well as the effectiveness of the health system in empowering support systems. This scale is:

1. I was guided by the health care team regarding the TB medication.
2. The health care team includes me in the care.
3. My family member trusts me and my advice.
4. We talk about TB.
5. I have been examined at the clinic where my relative is receiving anti-TB treatment.
6. I follow the medication intake of my family member.
7. I am prepared to follow the medication regimen.

Use of the validated Arcênio scales (with the addition of fear of infection items) is recommended because the scales are validated, brief, self-weighting, and capture subtle forms of stigma. Combination with the Coreil (2010) and Bond

(2017) items specific to family (problem with children, gossip, and respect for the family) are also likely to be very pertinent in high-burden settings.

## Conclusion

Secondary stigma among HCW should be measured and reduced to ensure a voluntary TB workforce.[15,29,30,69] Secondary stigma among TB caregivers is counterproductive to global TB elimination efforts, since it deprives them of the right to contribute to TB treatment and prevention, dissuades talented people from joining the fight against TB, and negatively impacts health care delivery, TB treatment adherence, and recovery. Perceptions and experiences of secondary stigmas can be detrimental to the well-being of those who lose status via care giving. More research is urgently needed to develop and validate measures to assess courtesy and dirty work stigma. Instruments to measure courtesy and dirty work stigma need to be refined to better understand the drivers and consequences of secondary stigma. Existing scales can be applied and expanded into a range of settings, or can provide a basis for local adaptation. Understanding the community and workplace stigmatization affecting caregivers will help to design effective programs and policies to support their work.

## Acknowledgements

# Appendix 1 : The Maslach Burnout Inventory (MBI)[44]

The following statements deal with how you may or may not feel about your work as a TB health provider. Response categories: seven-point Likert scale ranging from one (very mild) to seven (very strong).

**Emotional exhaustion/regret of professional choice (Consequences)**
1. I feel emotionally drained from my work.
2. I feel used up at the end of the workday.
3. I feel fatigue when I get up in the morning and have to face another day on the job.
4. Working with people all day is really a strain for me.
5. I feel burned out from my work.
6. I feel frustrated by my job.
7. I feel I'm working too hard on my job.
8. Working with people directly puts too much stress on me.
9. I feel like I'm at the end of my rope.

**Depersonalization (Consequences)**
1. I feel I treat some patients as if they were impersonal 'objects'.
2. I've become more callous toward people since I took this job.
3. I worry that this job is hardening me emotionally.
4. I don't really care what happens to some patients.
5. I feel patients blame me for some of their problems.

**Personal accomplishment (Consequences)**
1. I can easily understand my how my patients feel about things.
2. I deal very effectively with the problems of my recipients patients.
3. I feel I'm positively influencing other people's lives through my work.
4. I feel very energetic.
5. I can easily create a relaxed atmosphere with my patients.
6. I feel exhilarated after working closely with my recipients.
7. I have accomplished many worthwhile things in this job.
8. In my work, I deal with emotional problems very calmly.

# Appendix 2: Perceived organizational support scale by Eisenberger (1997)[45]

Response categories: seven-point Likert scale ranging from one (strongly disagree) to seven (strongly agree) (Drivers). When thinking about my place of employment, I feel:
1. My organization cares about my opinion.
2. My organization really cares about my well-being.
3. My organization strongly considers my goals and values.
4. Help is available from my organization when I have a problem.
5. My organization would forgive an honest mistake on my part.
6. If given the opportunity, my organization would take advantage of me.

7. My organization shows very little concern for me.
8. My organization is willing to help me if I need a special favor.

## Appendix 3: Arcêncio scale[1]

1. My family member asks me to keep the TB a secret.
2. I feel ashamed because my family member has TB.
3. I hide the fact that my family member has TB from the community.
4. My family member hides his/her diagnosis from the community.
5. I avoid talking about TB in the presence of other family members or neighbors.
6. I'm afraid that someone will see me at the health care clinic where my relative is being treated.
7. I substitute another word for TB in my conversations with my family member.
8. I substitute another word for TB in the conversations with my friends.
9. I've noticed changes in my family member since the TB diagnosis.

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# Chapter 9

# Sampling methods for measuring TB stigma in hard-to-reach populations without sampling frames

*Lisa G. Johnston*

## Abstract

Levels of TB stigma vary among different groups. Social exclusions can be compounded and may create measurement challenges. Measuring TB stigma among people who use drugs and/or alcohol, migrants, and those with a history of incarceration requires expertise and sophisticated methodology. Using a probability-based sampling method to measure TB stigma among hard-to-reach populations will yield more representative and actionable estimates.

This chapter presents two probability-based sampling methods, time location and respondent-driven sampling, for hard-to-reach populations (those with no sampling frame). Time location sampling involves mapping the times and places where the population congregates, and then randomly selecting and sampling mapped times and places. Respondent-driven sampling samples the network of the population and uses a chain referral peer-to-peer recruitment methodology. This chapter will also present the specific benefits and challenges of each methodology, and detail calculating a sample size.

## Objectives

In this chapter, you will learn:
1. The difference and importance of a probability versus a non-probability based sampling method.
2. The steps in conducting a survey using time location sampling, and information about additional resources.
3. The steps in conducting a survey using respondent driven sampling, and information about additional resources.
4. Parameters for deciding whether to use time location sampling or respondent driven sampling for a particular population.
5. To calculate a sample size for studies using time location or respondent driving sampling.

## Target Audience

This chapter is for social scientists, epidemiologists, researchers, and program planners who require TB stigma estimates in hard-to-reach populations. Due to the complexity of the sampling and analytic procedures, we recommend that these studies be undertaken in conjunction with a strong research partner.

## Introduction

Accurately measuring TB stigma among populations that are hard to reach is essential for building comprehensive intervention programs. These groups are often socially excluded and stigmatized.

By definition, it is challenging to conduct probability-based sampling on hard-to-reach populations, as these populations may lack the sampling frames (i.e., a list of all persons you want to sample) needed to accurately determine the probability that each person has an equal chance of being selected into a sample.[1,2] In addition, these populations, which comprise people who use drugs, people dependent on alcohol, the homeless, ex-offenders, ex-miners, the mentally ill, and undocumented migrants, are often marginalized, may practice illegal behaviors, have unstable living situations and irregular working hours, do not trust authorities, and are subject to high levels of stigma and discrimination.[3]

It is widely understood that TB stigma can be enmeshed and conflated with other kinds of social exclusions and marginalities. When measuring TB stigma in marginalized groups, it is important to measure other stigmas that can combine with TB stigma to have synergistic and reciprocal negative impacts on health-seeking or adherence behavior. (See Chapter 14)

Actionable TB stigma estimates rely on sampling methods that are probability based, meaning that each member of the population has a known probability of being selected. Probability-based sampling is any sampling method that uses simple random sampling, systematic random sampling, stratified random sampling, and cluster or area random sampling. Probability sampling of a hard-to-reach population allows researchers, program managers, and policymakers to make decisions with TB stigma estimates that better represent the population sampled.

## Convenience is not enough

Non-probability sampling, which includes purposeful and convenience sampling, samples populations with no known probability of selection, resulting in outputs that are biased and provide information that only represent the sample and not the population sampled. Although non-probability sampling methods are often less expensive and easier to implement than probability-based sampling

methods, they tend to give biased results that tend to be invalid.

## Doing it right

It is worth the extra cost and effort to have TB stigma estimates that represent the sampled population. Probability-based methods more closely resemble the truth.

Currently, two methods, time location sampling (TLS) and respondent-driven sampling (RDS), have been developed to approximate probability for sampling hard-to-reach populations without sampling frames. These methods have been used to measure behavior and disease burden in numerous hard-to-reach populations throughout the world for well over a decade.[4,5,3,6,7] This chapter will describe the pre-survey research, implementation, and data analysis needed to conduct a TB stigma survey using TLS or RDS.

**Figure 1. Process of conducting a TB stigma survey**



Pre-survey formative research → Implementation → Data-analysis

It will also guide how to decide which method to use and the challenges and comparative advantages of each method. Finally, this chapter will discuss sample size calculation considerations, and provide information about the estimated costs and staffing needs.

## Overview: time location sampling (TLS)

TLS, venue-day-time sampling or time-space sampling, is adapted from targeted and cluster sampling techniques.[8–11] This method relies on mapping and listing venues where the population congregates and is therefore accessible.[8,12] Briefly, TLS entails identifying and listing the days and times when the population congregates at specific venues in a sampling area (e.g., a city).

Deciding which venues to sample is important. Venues should not be locations that could over-represent people. For instance, if an important study outcome is discrimination at health care centers, you might want to avoid health care venues that are known to overly discriminate against the target population. In addition, you also want to avoid venues where your population would not be. That is, do not try to capture persons who use drugs at a drug treatment center. Table 1 lists some examples of appropriate and inappropriate venues for specific populations.

Less appropriate venues are those where people may be non-representative of the group with regard to stigmatization. Places which oblige disclosure of stigmatized identities can be assumed to attract those who are more resilient to stigmatization.

**Table 1. Examples of more appropriate and less appropriate venues for specific hard-to-reach**

| Hard-to-Reach Population | More Appropriate Venues | Less appropriate Venues |
|---|---|---|
| Undocumented migrants | Day labor pick-up points, migrant neighborhoods, bars, restaurants and other venues where migrants socialize, migrant health clinics. | Immigration offices or ex-patriot associations. |
| People who inject drugs | Shooting galleries or other areas where people inject drugs, areas where people buy drugs, emergency rooms, and needle exchange programs. | Drug treatment centers, outpatient departments, opioid substitution clinics. |
| People dependent on alcohol | Bars or shabeens (taverns). | Alcohol treatment centers. |
| The homeless | Soup kitchens, homeless shelters, streets, transitional housing. | Jobs programs. |
| Former-offenders | Day labor pick up points and places where former offenders socialize. | Parole offices. |
| Former-miners | Transport hubs, Mining communities. | Mining employment offices. |
| Men who have sex with men | Nightclubs, cruising sites or places where sex partners can be found, city blocks, parks, bath houses and other areas where men who have sex with men work, socialize and live, gay pride parades. | LGBT community centers or government-run HIV clinics. |

The number of group members at each location provides a sampling weight that can be used a priori, to draw a self-weighting sample, or post priori, in analysis. The specific steps to completing a sampling frame of mapped time and location units, randomly selecting and then visiting time and location units, and systematically collecting information from consenting members of the population are described below.

Two questions to ask yourself before considering the use of TLS are:

1. Can the population be found at accessible venues?
2. Can these venues be accurately mapped?

# Mapping the venues-sampling frame construction

A complete mapping of venues is essential to conducting TLS and is the foundation of two sampling frames.[11,13,14] The first sampling frame is a list of venues where the population can be found (public or private location attended by the target population), and the second sampling frame is a list of venue-specific sampling periods (usually four hours periods). Accurately identifying all possible venues will involve meeting with a diverse selection of the population, local research entities and community-based organizations, community leaders, venue owners, managers, workers, and patrons. Venues can be low frequency, such as a meeting or party that occurs once a month, or high frequency, such as a high traffic street that is used 17:00 to midnight Monday through Friday.

# Enumeration

**Venues, days and times are known as 'VDTs'.**

Two enumeration methods are used to set up the inclusion of a venue and the associated days and times in the complete list of venues.[13,14] In order to discern venue-specific sampling periods, standardized enumerations of the population during possible high attendance day-time periods are conducted. Venues, days, and times are known as VDTs, and the time periods are usually four hours, but they can be other consistent periods of time.

**Type 1 Enumeration** is performed at all venues and assures that the population of interest actually attends the venue at the days and time slots are high attendance. To do this enumeration, staff members go to the venue to observe activity and count patron attendance. Non-duplicate counts of patrons, often using a counter clicker, can be conducted for 30 minutes and then multiplied by eight to estimate the total number of patrons that might attend during a four-hour sampling event. Those VDT periods that produce sufficient numbers will be thoroughly evaluated with Type 2 enumerations. This should be recorded onto a form that lists the venue name and location, the time frame and day of the week during which the enumeration was conducted, and the type of venue.

Factors that could impede venue attendance should be recorded (holiday, security, natural hazards, etc.) Type 1 enumeration does not require interaction with the population.

**Type 2 Enumeration** is conducted at venues that have sufficient population numbers but where it is unclear if enough of the patrons are population members. The purpose of a Type 2 enumeration is to determine the number of eligible persons who attend a venue at a particular day and time period.

Keys components of Type 2 enumeration are:

1. Include venues that had sufficient numbers of population members;
2. Count patrons (can use a clicker to record the counts);
3. Approach patrons to establish that they are part of the population of interest and are potentially eligible for the study; and
4. A general sense of where and what kind of enumeration area is best for the venue (e.g., if the venue is a street, identify which part of the street is the best place for the enumeration).

Type 2 enumeration does require interaction with the population. Only those VDTs where more than 75% of the population of interest is present should be included in the final 'complete list of venues'.

Both Type 1 and Type 2 enumerations are the basis for building the overall 'complete list of venues.' Information about each venue is entered into a database that includes venue identification number, venue type, name and location, and the year, day, and time (Table 2).

**Table 2. Example of a Universe of VDTs**

| ID | Venue Information | | | Venue Day Time Information | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Name | Type | Location | M | T | W | TH | F | S |
| BR001 | Mama's lodge | Brothel | T Street | | | | | 20:00-00:00 | 20:00-00:00 |
| BR002 | No name | Brothel | X Lane | | | | 19:00-2300 | 19:00-23:00 | 19:00-23:00 |
| S001 | No name | Street | V Street | | 17:00-21:00 | | 17:00-2100 | 17:00-21:00 | |
| B001 | Sam's place | Bar | Y Shopping | 16:00-20:00 | | | 16:00-20:00 | | |
| D001 | Xtreme | Disco | Center Corner, X and Y Streets | | | | | 22:00-02:00 | |

Once the VDTs are listed, develop a calendar to schedule sampling events based on the number of VDTs available to sample on each day, staffing needs, and infrequent or one-time events, such as a meeting that is held once a month. The sampling calendar will be organized by hours, days, and weeks during a one month period or until the sample size is reached.

## Selecting VDTs to sample

Once all of the VDTs are selected and listed in the calendar, randomly select the

required number of venues (sometimes referred to as n by researchers.) The number of VDTs will be randomly selected based on the sample size for the study.

If 150 patrons must be interviewed for a certain study, and you know that selecting five VDTs will give you a hypothetical sample size (based on the enumeration described above) of 150, then run a random selection of five VDTs.

**Figure 2. Example of 5 Randomly Selected VDTs**
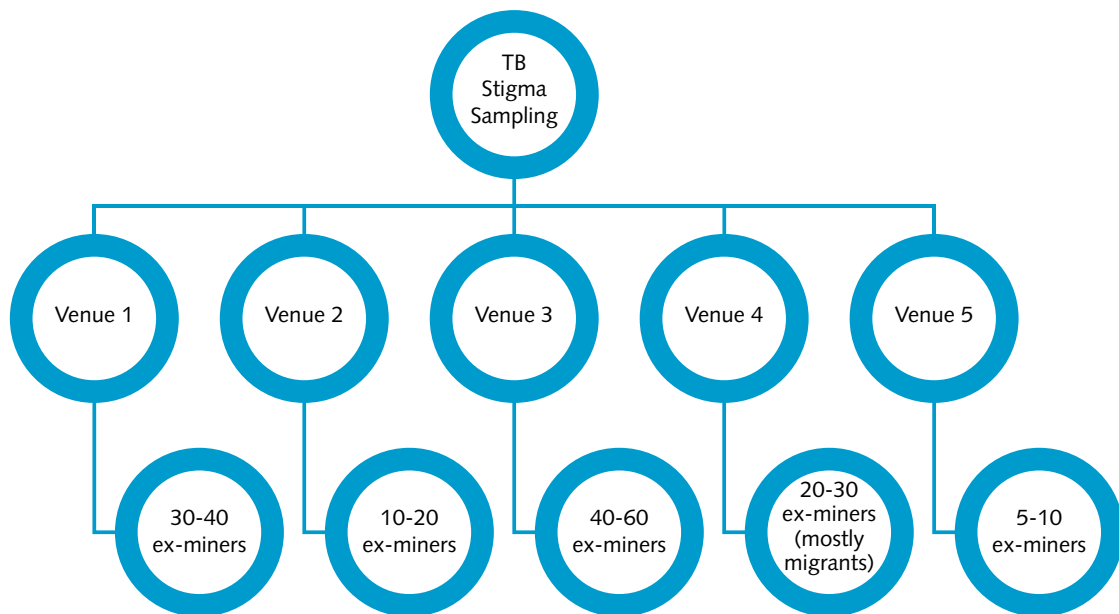


You can use an online program such as Stat Trek (http://stattrek.com/statistics/random-number-generator.aspx) to randomly select venues. Once the random list of VDTs is determined, they can be arranged in order of smallest number of VDTs to largest.[13] For instance, since ID D001 in Figure 2 has the smallest number of VDTs (n=1) compared to the others venues, it would be first on the list. Schedule the venue with the smallest number VDTs first, as these should be the easiest to sample.

When venues have more than one date and time, randomly select one of the dates and times, and then schedule the randomly chosen dates and times on the first available day of the week.[13] Continue until all sampling events are scheduled.

VDTs should be selected without replacement, meaning that the same site cannot be sampled twice.

## Sampling at VDTs

Data collection may take place at the venue, if space permits, in a mobile site near the location, such as a van, or by making appointments for potential participants to come to a designated study site.

Sampling usually takes place during four hour time frames. Sampling boundaries should be established at each selected venue by creating an imaginary line, such as on a street corner or in a park, or based on the area, like the interior of a bar.[13] When a selected venue is visited by staff for sampling, enumeration Type 2 is used to count the population members that cross the imaginary line or that enter a boundary area during the sampling period and event (usually four hours).

Type 2 enumeration is important for counting population members and intercepting and determining if population members are eligible for the study. During the sampling event, if someone is eligible for the study, they may complete a consent process and proceed with the interview. This process continues until the x hour sampling event is finished (e.g., for D001 in Figure 2, this would be at 2 a.m.). Record when someone refuses to participate.

All participation is voluntary and refusals are normal and expected. Permission should be obtained from venue owners or managers before sampling. Incentives are usually offered to those who enroll and complete a survey.[13,14]

## TLS Staffing

The sampling staff for TLS usually consists of a team leader and interviewers. The role of the team leader is to enumerate, oversee interviews, and manage staff safety. The interviewers approach potential interviewees and assesses them for eligibility. If eligible, the interviewers enroll them into the study by conducting consent and completing the interview.

## Analysis of TLS Data

Differences in venue size and attendance patterns require that weights be applied to TB stigma estimates collected through TLS. Commonly used weights are produced using the enumeration count (Type 3) of each event as the basis for the weight.[13]

The weighting is based on enumeration counts of each sampling event which can be used as probability weights (p weights). This adjustment should produce estimates that reflect the ratio of the number of persons enrolled to the number of eligible persons at each recruitment event. If the same ratio is seen across all recruitment events, then the sample is self-weighted and no adjustment is needed. To do this, simply take the total number of potential subjects enumerated at each event over the total number of subjects enumerated for all events (for instance, if 102 people were enumerated (eligible) for event X and the total number enumerated for all events was 6300, that would be 102/6300 = 0. 0162). In addition, take the total number of interviews completed at each event over the total number of completed interviews for all events (for instance, if 7 people were interviewed at event X and the total number of interviews

for all events was 435, that would be 7/435 = 0.0161). To calculate the p weight for each event simply divide the enumeration weight over the sample weight: 0.0162/0.0161 = 1.006. This p weight can be applied to each interview completed during that event.

An additional weight of frequency of attendance is also recommended to account for some people having a higher probability of being in the sample because they frequent a venue more often than others.[15] This is a weight that is generated based on a survey question about the number of times each respondent has attended that venue in a given week and is the proportion of frequency by each person in each event over the sum of frequencies.

## Limitations of TLS

When the full sample size is finally reached and analyzed, it should be representative of the population that attends the venues. Keep in mind that these are more visible members of hard-to-reach populations and that there may be differences with those who do not attend venues. The actual data collection from population members may be fast (no longer than one month), but the complete mapping of venues and enumeration can be time-consuming, depending on the size of the geographic area being sampled.
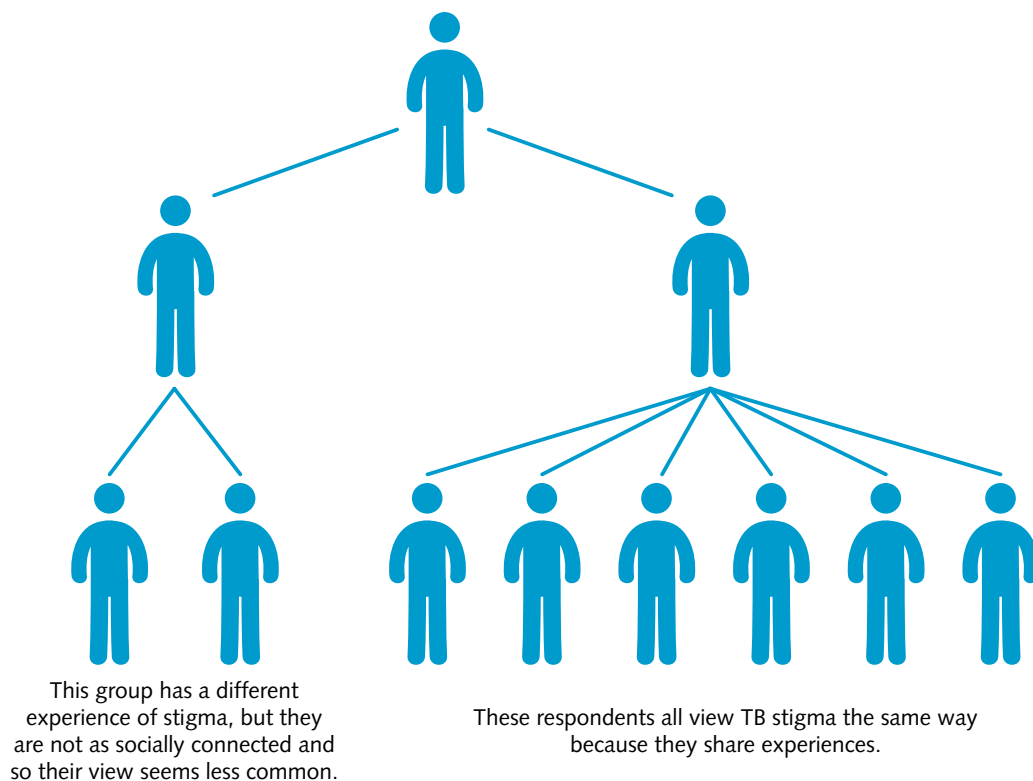
Because population members may be asked to participate as they are walking down the street, at home, at a meeting, or while they are socializing with friends at a bar or dance club, refusal rates may be high.[11,15,16] To improve acceptability:

1. Ensure visual and auditory privacy;
2. Keep your questionnaire short; and
3. Offer incentives during the interview.

## Overview: Respondent-driven Sampling

Respondent-driven sampling (RDS) was introduced in 1997 as a novel method to recruit and provide generalizable estimates of socially networked hard-to-reach populations.[17] RDS is considered both a sampling and an analysis method, and every survey requires both in order to be termed RDS.[18] RDS is adapted from chain referral sampling methods, which rely on referrals from initial survey participants, referred to as a seed in RDS, to recruit additional survey participants. Chain referral sampling alone produces biased samples because the recruited respondents most likely have characteristics similar to that initial respondent.[19]

**Figure 3. Problems with Chain Referral Sampling**



This group has a different experience of stigma, but they are not as socially connected and so their view seems less common.

These respondents all view TB stigma the same way because they share experiences.

This results in a final sample that is over-representative of the characteristics of respondents with more social connections and under-representative of the characteristics of those respondents with fewer social connections.

RDS uses several theory-driven statistical adjustments to sampling and analysis to mitigate the biases of convenience chain referral sampling.[3,20,21] RDS relies on people to recruit their peers through coupons with unique code numbers.[17,22] The recruitment process includes small incentives for survey participation and peer recruitment. Incentives, and peer norming from recruits, (i.e., *"I know you and you know me and I want to enroll in the survey since you have already enrolled and you are asking me to enroll"*), encourage people to enroll in the survey and to influence their peers to enroll as well.[23]

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Two questions to ask yourself before considering the use of RDS are:

1. Do members of the population recognize each other as a member of that population?
2. Can a handful of these population members be identified to participate in a survey?

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## Pre-survey Assessment

Formative qualitative research is needed to inform the design of any study in hard-to-reach populations. Chapter 3 provides guidance on how to conduct formative work. A pre-survey assessment will contribute to RDS planning by describing the target populations' social network properties (i.e., how populations are socially networked and the types of activities they do together),

identifying useful seeds, measuring the acceptability of RDS recruitment, and informing RDS survey logistics.[3,21,24]

The most important evaluation is whether the population is socially networked to the extent that they can recognize and recruit each other as part of that population. Ideally, social network sizes should be large enough (≥ three) to sustain recruitment and develop the long recruitment chains needed for RDS analysis. In addition, population members should be able to recruit at least three of their peers into a survey. If they do not know or would be unable to do this, then RDS will probably not work.

It is also important to understand how strong connections are between peers within social networks (i.e., are their peers just acquaintances that they see once a month, co-workers that they only see while at work, are they casual friends that they meet for coffee or close friends that they spend time with each day?) Having both weak and strong ties can assist in RDS recruitment, whereas just having strong ties may indicate that recruitment is not sufficiently spread throughout the entire network.

A pre-survey assessment should help ensure that networks comprise multiple types of relationships (e.g., friendships, acquaintances, co-workers, room-mates, sex partners, etc.) and activities. Table 3 lists the questions that should be included during the pre-survey assessment.

## Table 3. Questions to Measure Networks during Pre-Survey Assessments for RDS[21]

| Social Networks | Questions |
|---|---|
| Do population members form a social network? | Do you know or spend time with other population members? Are population members easily recognizable to one another? How are they recognizable? What types of activities or behaviors bring them together? |
| Do the target population members have large social network sizes? (This question is tied to the survey eligibility criteria.) | In a survey of males who currently inject drugs, ≥18 years, living in city A, ask: How many males do you know who also know you, currently inject drugs, are ≥18 years and live in city A? How many of them have you seen in the past month? |
| Do the target population members form diverse social network ties? | Please tell me about how your population members, friends and acquaintances interact with each other (What activities do they do together?) |
| What is the structure of the social network? Are there cliques and if so, can you find bridges to include them? | If you suspect that population members form distinct geographic social networks, ask: Do you know population members who socialize/work in or are from other parts of the city? If you suspect that population members form distinct social network types, ask: Do you know population members who are different than you (e.g., older vs. younger miners; street vs. home-based persons who inject drugs, etc.)? |

A pre-survey assessment, often the first contact by researchers with the community, can demonstrate that the survey staff are willing to listen and to make survey changes based on feedback. Most importantly, a pre-survey assessment can help inform whether RDS is an appropriate method for a particular population and socio-cultural context.

## Data Collection

Recruitment begins with a small, diverse and influential group of people referred to as "seeds" or eligible respondents pre-selected by the researchers.[17]

**Figure 4. Preselected respondents (Seeds) who will recruit respondents with unique coupons**
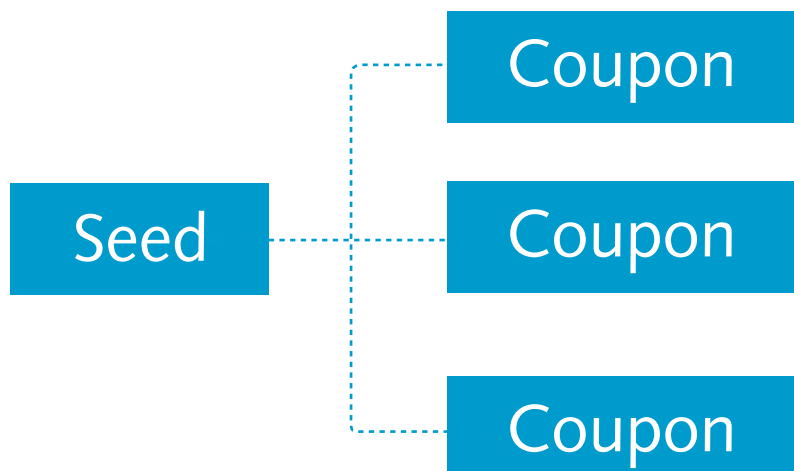


Each seed receives a set number, usually no more than three, of coupons to recruit their peers. These peers present the coupons, usually at a fixed site or web address, to survey staff to enroll in the survey.[21] Eligible recruits who finish the survey process are also given a set number of coupons (no more than three) to recruit their peers. The recruited peers of seeds who enroll in the survey become wave one respondents, and the recruits of wave one respondents become wave two respondents (Figure 5).[21]

This recruitment process continues through successive waves until the calculated sample size is reached. The waves produced by effective seeds make up recruitment chains of varying lengths (Figure 5). The goal is to acquire long recruitment chains made up of multiple waves, an indication that the final sample is not biased by the non-randomly selected seeds. In Figure 5, there are five recruitment chains, with the longest recruitment chain reaching 14 waves. The seeds are the larger nodes with arrows pointing away from them. The grey nodes are females and the blue nodes are males.
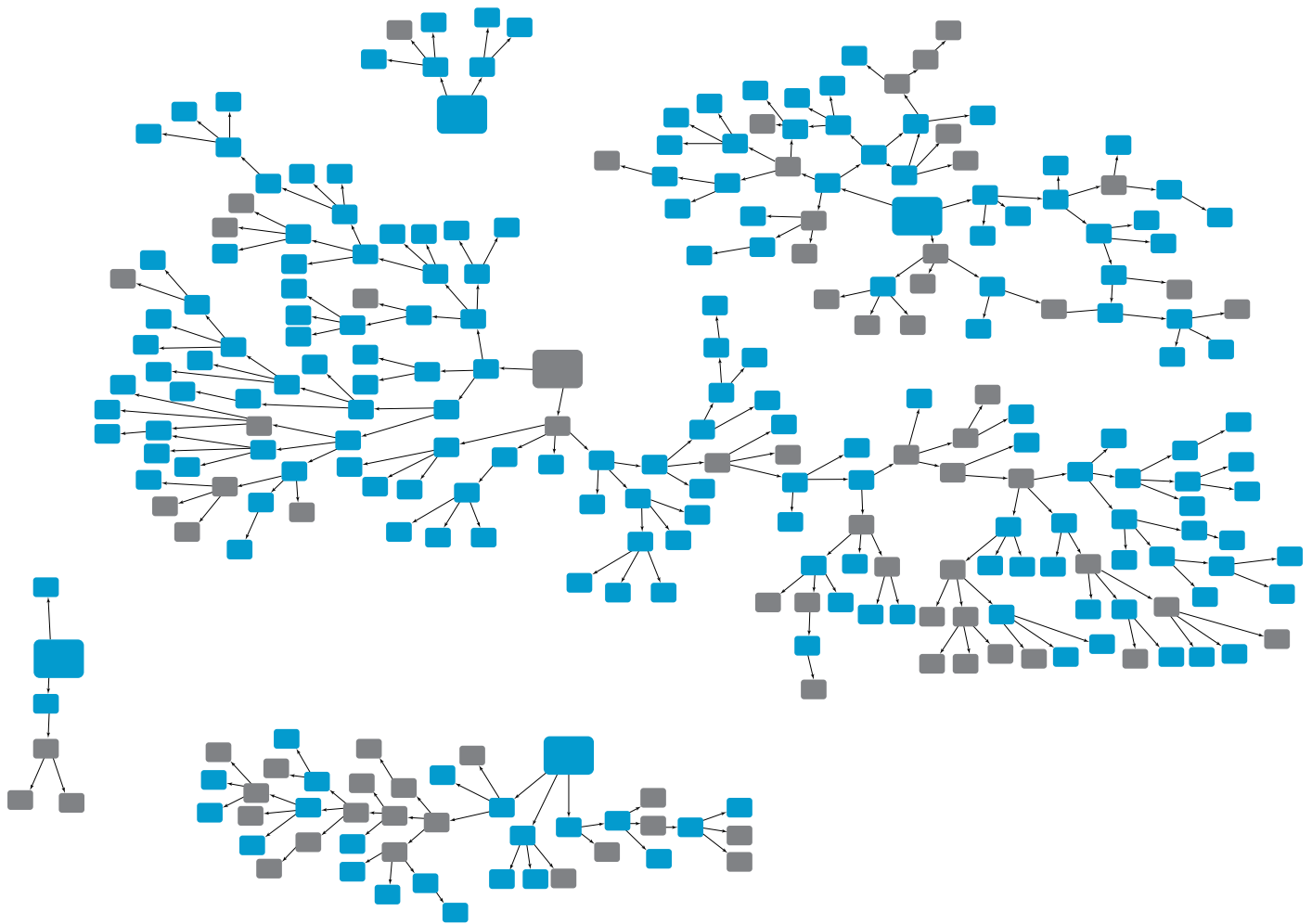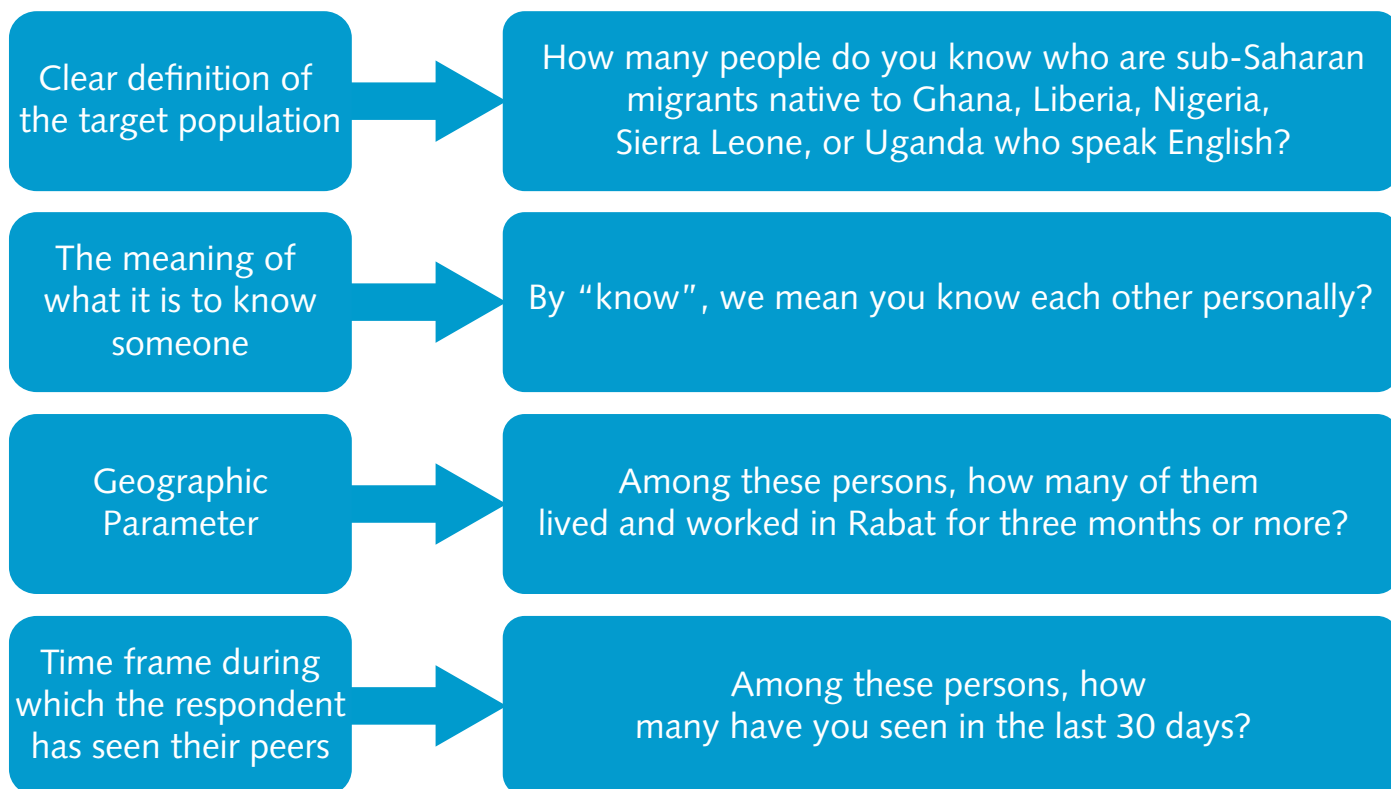
## Essential data to collect during data collection

During data collection, it is vital to gather information on who recruited whom and each participant's social network size for analysis purposes.[20,26] Recruitment information is monitored through unique numbers on recruitment coupons, and should be carefully recorded as each participant enrolls. Each respondent's social network size is measured through questions about the number of people each participant knows who fulfills the eligibility criteria and whom they have seen during a set time period, usually one week to one month. These are usually a cascade of questions resulting in a final, non-zero, number representing a participant's network size (Figure 6).

**Figure 6. Description of the Social Network Size Question Topics and an Example of the Questions among Sub-Saharan Migrants in Rabat, Morocco[25]**

| | |
|---|---|
| Clear definition of the target population | How many people do you know who are sub-Saharan migrants native to Ghana, Liberia, Nigeria, Sierra Leone, or Uganda who speak English? |
| The meaning of what it is to know someone | By "know", we mean you know each other personally? |
| Geographic Parameter | Among these persons, how many of them lived and worked in Rabat for three months or more? |
| Time frame during which the respondent has seen their peers | Among these persons, how many have you seen in the last 30 days? |

## RDS Coupons

Coupons must contain a unique RDS identification code to link recruiters with recruits.[21] Coupons should be carefully developed, easy to read, and have a pleasant appearance so that study participants realize that the coupons have value. Coupons should include unique RDS identification codes, interview site location, mobile phone number to make appointments, days and hours of enrollment, and expiration dates. Below is an example of a coupon used for a survey of undocumented women from Central America who are living in Houston.[3,27]

**Figure 7. Example of a Coupon used in an RDS Survey of Migrants**

0702

**INVITATION COUPON TO PARTICIPATE**

**Project Linkages**

The University of Texas School of Public Health

Health Survey of Central American Women in Houston

___/___/___
Disbursement date

___/___/___
Expiration date

You must present this coupon to participate in the survey!

Compensation for your time ($35)

We take appointments and walk-ins Monday-Friday; by appointment only on Saturdays

**Interview Sites**

"Cornwall Square" Apartments
123 Noname St.
Apartment # 100A
Hours:
Please call for a special appointment

"Preston Point" Apartments
Corner of Nowhere and Somewhere
Apartment # 100A
Hours:
Monday & Wednesday: 9:30 - 15:30
Tuesday & Thursday: 9:30 - 16:30

**Questions? Or to make an appointment please call 713-XXX-XXXX or 713-XXX-XXXX**

# Coupon numbering

There are many different ways to track who recruited who during RDS data collection, including a random or serial numbering system or a systematic numbering system. The key to either system is to correctly manage who recruited whom. For the purposes of analyzing RDS data, either numbering system described below is acceptable.

## Random or serial numbering

Random or serial numbers are merely numbers that identify each participant. For instance, some surveys use a four-digit number. The first number can represent the city or the population being studied. For instance, 1 means the study is being conducted in Bangkok, Thailand. The remaining three digits can be numbers that start from 001 up to the sample size, for instance, 450. These numbers could also be alphabet characters. For instance, at the beginning of the identification, you could have F for female sex worker and 1 for Bangkok. See Table 4 for a sample coupon monitoring system.

**Table 4. Example of a coupon ledger using random or serial numbers**

| Date | Participant | Coupon 1 | Coupon 2 | Coupon 3 | Notes |
|---|---|---|---|---|---|
| June 1, 2017 | F1001 | F1007 | F1008 | F1009 | |
| June 1, 2017 | F1008 | F1111 | F1112 | F1113 | |
| June 2, 2017 | F1111 | F1213 | F1214 | F1215 | |
| June 2, 2017 | F1214 | -- | -- | -- | Ineligible |
| June 3, 2017 | F1009 | F1223 | F1224 | F1225 | |

In the example above, the participant coupon numbers are in column 2 and the coupons given to each participant are in the columns 3, 4, and 5. You will see that in the sixth column under notes, that one person (coupon number F1214) who tried to enroll was found to be ineligible, so this person was not given recruitment coupons. There are benefits and challenges with this coupon numbering system.

A benefit is that the coupon numbers can be preprinted as barcodes on labels and easily affixed to coupons and in the coupon ledger. The numbers are only a few digits and easy to record. A challenge to this method is that if any mistakes occur, it is hard to know who is linked to whom. Any errors in the numbering system may result in data analysis problems. If collecting data with monitors, this method is practical.

# Systematic Coupon Numbering

Some researchers, especially those who rely on paper management, may prefer to use a systematic numbering method that identifies seeds and the completion of each seed's waves. Depending on the number of seeds, this coupon numbering system will start with a unique number provided to the seed. For instance, in a study with ten seeds, the first two-digits on each coupon will be 1 through 10.

For example, Seed 1 has the number 1, and then Seed 2 has 2, etc.

| | |
|---|---|
| Seed 2 | 2 |
| Seed 3 | 3 |
| ... to Seed 10 | 10 |

Since most RDS studies allow for the recruitment of three peers, the numbers following the seed numbers are 1, 2, or 3 as shown in Table 4. For instance, if seed number 5 is interviewed and given three recruitment coupons, then the recruits for seed number 5 would receive the following coupon identification numbers: 51, 52 and 53. If a recruit with coupon 53 is interviewed, then he or she will receive coupons with the identification numbers of 531, 532 or 533. This process occurs according to the number of waves produced by each seed. So coupon 533 represents the second wave produced by seed 5. You can also put letter of the alphabet at the beginning to denote the population or the city being sampled.

## Table 5. Example of a Coupon Ledger using Random or Serial Numbers

| Date | Participant | Coupon 1 | Coupon 2 | Coupon 3 | Notes |
|---|---|---|---|---|---|
| June 1, 2017 | 1 | 11 | 12 | 13 | |
| June 1, 2017 | 12 | 121 | 122 | 123 | |
| June 2, 2017 | 123 | 1231 | 1232 | 1233 | |
| June 2, 2017 | 121 | -- | -- | -- | Ineligible |
| June 3, 2017 | 13 | 131 | 132 | 133 | |
| June 3, 2017 | 1233 | 12331 | 12332 | 12333 | |
| June 4, 2017 | 12333 | 123331 | 123332 | 123333 | |

In the example above, the participant coupon numbers are in column 2 and the coupons given to each participant are in the columns 3, 4, and 5. You will see that in the sixth column under notes one person (coupon number 121) who tried to enroll was ineligible, so this person was not given recruitment coupons.

This method makes it easier to manage the progress of the seeds. For instance, you can track which seeds are efficient recruiters, which seeds did not recruit anyone and the number of waves completed by each seed. In the last row, you can see that the participant enrolled on June 4, 2017, with coupon number

12333. This person was recruited by 1233 and was given three recruitment coupons (123331, 123332, and 123333.) The number of waves for the participant enrolling on June 4, 2017, is 4. That is, the first digit is the seed (number 1) and the remaining digits tell us the number of waves (2333). Figure 8 depicts the growth of the waves in a chain, starting with seed 3.

**Figure 8. Example of the Systematic Numbering System Increasing by Wave**

| 3 | 32 | 321 | 3211 | 32112 | 321123 |
|---|---|---|---|---|---|
| Seed | Wave 1 | Wave 2 | Wave 3 | Wave 4 | Wave 5 |
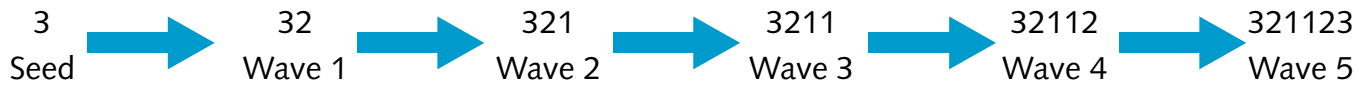
The three recruitment coupons given to this person will produce participants for seed 1 and have 5 waves. So during data collection, it is easy to see which seeds are recruiting and how many waves there are. Knowing which chains are producing (by looking at the seed number) is important for knowing if a new seed needs to be added (in case one seed has not recruited anyone). Knowing the number of waves is important for decisions about coupon reduction (if recruitment is fast and/or chains are too short or there are too few waves) and ending the survey so that no valid coupons remain in the community once the survey is finished. These numbers also make it easy to visually see who recruited whom. One of the challenges to using this number is that they can get very long, so extra care is needed during monitoring. For instance, coupon number 411111222222111, initiated from seed 4 and makes up 14, waves is not unusual in an RDS survey.

## RDS Staffing

The data collection staff in RDS usually consists of a site manager to manage the flow of participants, a screener who oversees someone arriving at the interview site with a valid coupon (the screener may also explain the study to the participant, conduct the consent process, and ask questions about social networks). There also may be someone to explain how to use the computerized system, and a coupon manager who explains the recruitment process and gives out properly numbered coupons.[21] The coupon manager may also pay out the incentive, since they are the last person a participant usually sees.

## Web based RDS

Given the large percentages of people using the internet and who have cellular phones, the increasing cost involved in conducting these types of surveys, researchers are modifying RDS for use in a web or mobile phone-based format.[28–31] This involves the strict control of coupons being passed through online networks. Once someone receives a coupon, they can respond to questions online. Incentives (i.e., a gift card or phone card) can be sent online

once a survey is completed. This methodology requires fewer staff and does not involve the cost of a fixed site.

## RDS Data Analysis

Once TB stigma estimates are collected with RDS methods, they must be analyzed to reduce biases by applying computational weights. RDS uses a weighting system whereby those with larger network sizes are given less weight and those with smaller social network sizes are given more weight.[20,26,32] The unit of analysis in RDS is a network structure rather than an individual, and the analysis generalizes to the networks of the sampled population.[26,33] This influences the kind of estimators we use, the way we understand the variance around the estimates, and how we interpret the findings.

Because the weighting techniques are complicated, there are free software packages available for adjusting TB stigma estimates collected with RDS. There are currently two widely used open source software programs: the RDS Analysis Tool (RDSAT) (www.respondentdrivensampling.org) and RDS Analyst (www. hpmrg.org). The latter program is based in R Project for Statistical Computing (a free software programming language) and has graphical user interfaces with drop down boxes to make analysis easier. It includes all the current estimators (available up to 2013) and allows direct downloading of all file types (SPSS, STATA, SAS, R, Excel, txt, etc.). In addition, it allows you to build graphics and plots to use in diagnoses if the population is made of subgroups that are distinct to individual chains or "bottlenecks", whether the estimates are still biased by the non-randomly selected seeds, convergence, or other biases (i.e. you want to avoid bottlenecks and you want convergence) in the data. It can also display results.[18]

Key variables should be assessed for convergence to know whether or not the recruitment chains are long enough to have minimized the bias from the selected seeds. For instance, in Figure 9, the vertical axis shows the adjusted estimate in RDS Analyst for four age groups, and the horizontal axis shows the number of subjects (n=250) enrolled in the survey. The solid lines indicate variation, beginning from the seeds, as the participants enroll in the survey. When the solid lines rest upon the dotted lines that represent the final weighted estimate for each of the categories, convergence has been reached.

Figure 9. Plot showing Convergence for Age Groups
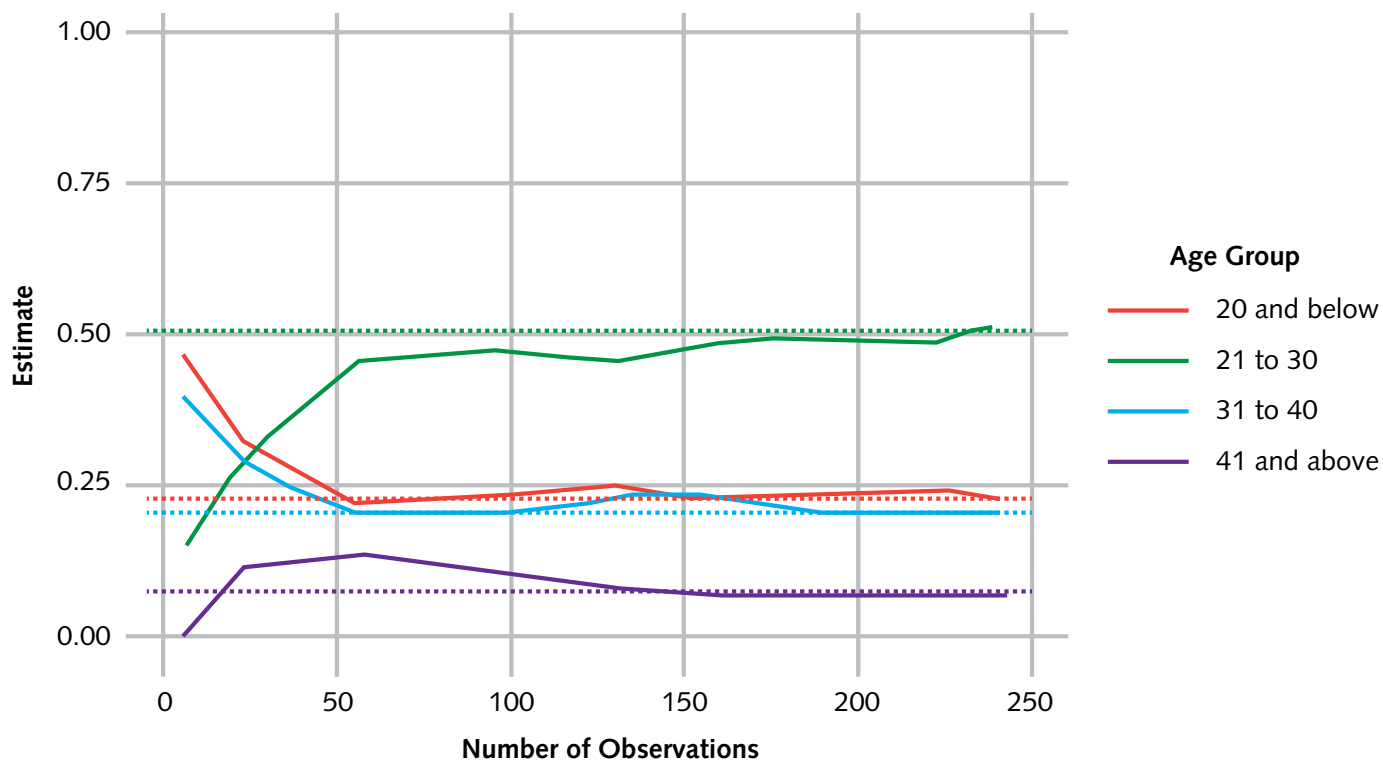


## Choosing between TLS and RDS

If the majority of the population you want to study are found at visible venues, then TLS may be the best sampling option. If the population is socially networked and can be motivated to recruit, then RDS may be the best sampling option. RDS may include more hidden persons and/or subgroups that are not well connected to the larger network. Neither method may provide representative TB stigma estimates on all parts of the population sampled.

As an example, RDS surveys of males and females who inject drugs often struggle to enroll females. This may be because the networks of males and females who inject drugs are substantially different. In an RDS survey conducted in Myanmar, males who inject drugs were found to be more connected to other males who inject drugs and to some females who inject drugs, but females who inject drugs were not connected to any other females who inject drugs. When the samples were finally gathered, there were so few females in the sample that the estimates ended up representing the network of males who inject drugs only.

## Costs of the surveys

The overall costs of conducting these surveys will vary based on sample size, country, population, number of staff members, costs for a fixed site (RDS), and numerous other factors. There are few cost comparisons conducted between TLS and RDS. One survey conducted among people who inject drugs in Vietnam found the costs to be slightly lower for RDS (Table 6).[34]

## Table 6. Field Implementation and Logistics Expenditures in USD for RDS and TLS Among People who Inject Drugs, Hai Phong, Vietnam, 2011-2012

| | RDS (n = 415) | | TLS (n = 432) | |
|---|---|---|---|---|
| | ($) Total | ($) Cost/ participant | ($) Total | ($) Cost/ participant |
| Recruitment* | 1,000 | 2.4 | 4,800 | 11 |
| Incentives | 2,050 | 5 | 2,100 | 5 |
| Staffing and other costs^ | 9,200 | 22 | 10,300 | 24 |
| **Total** | **12,250** | **29.4** | **17,200** | **40** |

*For RDS, this includes payment for referrals. For TLS, this includes cost of peer-educators, mapping staff, and coupon distribution.

^For both RDS and TLS, this includes survey team management and data collection staff, including interviewers, lab technicians, and data entry specialists. All surveys were conducted in existing health clinics, for which there were no charges.

## Planning and data collection time

Both methods require the submittal and approval of a protocol, which can take between one to six months. Planning times will vary between survey methodologies. Remember that TLS will require more up-front time, as it is necessary to map venues and create and select VDTs. In many surveys, with all else being equal, RDS data collection may take more time than TLS.

In the example above of RDS and TLS among people who inject drugs, the RDS survey took six weeks, and the TLS survey took 10 weeks, including mapping. In another example of RDS and TLS among men who have sex with men in Guatemala, a sample size of 507 was reached in 11 weeks using RDS, while for TLS a sample size of 609 was obtained in 7.5 weeks.[35] Both surveys included a formative research phase, which for RDS includes assessing networks and survey logistics[24], and for TLS it includes mapping and enumeration. RDS formative research took four weeks, while for TLS it took 8 weeks.[35] In a 2008 review of 123 RDS surveys (published and unpublished) conducted worldwide, the median number of weeks it took for data collection was eight, with a range of 2 to 52 weeks.[4] In a 2016 review of 222 publications reporting on RDS surveys conducted worldwide, the median number of weeks for data collection was 12, with a range of 2 to 124 weeks.[36]

## Sample size calculations

Any standard sample size calculation formula can be used to sample populations using TLS or RDS, however a minimum design effect of two is needed for RDS.[37,38] The sample size needed to conduct a survey can be based on the number of participants needed to accurately measure a stigma indicator in a population. For the formula detailed below, the expected proportion is needed. For instance, past surveys of migrants may have found that 20% of migrants

have experienced discrimination at a healthcare facility. This would be the expected proportion. However, when nothing is known about the population, an expected proportion of .50 is most often used to calculate the sample size.[11] Below is an example of a general formula to calculate a sample size (n) in order to measure a stigma indicator:

$$n = D * \frac{Z_{1-\alpha^2} \; P(1-P)}{SE^2}$$

| | | |
|---|---|---|
| n | = | Sample size required |
| D | = | Design effect |
| $Z_{1-\alpha^2}$ | = | The z score for power (.95 is often used) |
| P | = | Expected proportion |
| SE | = | Precision or standard error (usually set at .01) |

Using the formula above and assuming a design effect of 2, a 95% confidence interval and an expected proportion of .5 (50%), the sample size will need to be 769. The following website allows you to plug in the parameters and calculates the sample size using the above formula:

http://epitools.ausvet.com.au/content.php?page=1Proportion

http://www.sample-size.net/sample-size-conf-interval-proportion/

If a design effect is not included in the calculator, then double the calculation.

## Conclusion

This chapter presented two probability-based sampling methods, time location and respondent-driven sampling, for measuring TB stigma in hard-to-reach populations (those with no sampling frame). Conducting a survey using TLS or RDS can be challenging and requires that numerous assumptions be met. The extra efforts are necessary to ensure that the breadth and extent of stigmatization of vulnerable groups are fully captured so that actions can be taken to address it.

## Resources for conducting TLS or RDS surveys

In order to ensure the proper implementation and analysis of TLS and RDS, it is best to use the following resource guides, all of which provide step-by-step information for conducting these surveys.

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## References for Respondent-driven sampling

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Tyldum G, Johnston L. Applying Respondent Driven Sampling to Migrant Populations: Lessons from the Field. Palgrave Macmillan; 2014. 146 p.

## Important websites

For information on downloading RDS analyst software and analyzing RDS data:
www.hpmrg.org

For information on downloading RDSA software and resources:
www.respondentdrivensampling.org

## Acknowledgements

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# Chapter 10

# Measuring self-stigma, well-being, resilience and self-agency among people with TB

*Nadine Ferris France, Stephen H-F Macdonald, Ronan R. Conroy, Deirdre Ni Cheallaigh, and Elaine Byrne*

## Abstract

The chapter covers key features of self-stigma and methods to measure it. We first present several challenges in defining self-stigma, notably the need to consider its complex nature. We then highlight common drivers and domains of self-stigma, and their relevance to people being treated for TB or having survived it. We then focus on the assessment of TB self-stigma, reviewing evidence from TB studies and other conditions for which self-stigma is a challenge, such as mental health and HIV. We describe methods to assess not only how much, but also why self-stigma is being experienced. We recommend a new measure, the Ryff Scales of Psychological Wellbeing, to help shift the scope of measurement away from purely assessing negative personal experiences toward a more holistic and supportive approach.

## Objectives

1. Provide an overview of self-stigma and the ways in which it affects people living with TB.
2. Review the common drivers and major domains of TB self-stigma.
3. Present methods of assessing TB self-stigma and why it is important not to focus solely on the negative experiences of PWTB.
4. Provide guidance on understanding and measuring coping and support strategies against TB self-stigma.

## Target Audience

The intended audience includes researchers, national TB program managers healthcare workers, NGO and CBO staff and volunteers, outreach workers, and

survivors of TB. Readers are likely working with people who are in treatment for TB who may be experiencing self-stigma. This chapter may also be useful to those involved in developing interventions to address self-stigma. Other users may benefit from applying the recommended measurement tools to improve their understanding of how self-stigma may affect their programs.

## Introduction

One of the major challenges in measuring self-stigma is the approach and the terminology used. The term "self-stigma" or "internal stigma" can encompass a number of different manifestations such as shame, guilt, and withdrawal.[1-3] However, these are individual manifestations of self-stigma and do not necessarily describe the concept in full.

While measurement of self-stigma is a useful exercise, it is important to note that self-stigma is multifaceted. Valuable insights can therefore be lost if self-stigma is treated as one simple measure. For example, guilt and social withdrawal are both domains of self-stigma.[2,4,5] However, a person with high levels of guilt but low levels of social withdrawal is different from a person with low levels of guilt but high levels of social withdrawal. It is important that self-stigma, and its drivers and its manifestations are viewed as complex, interacting factors, rather than as isolated items on a scale.

There are two ways of assessing self-stigma. In epidemiological studies, it can be useful to get an overall measure of self-stigma for each individual. However, when we are implementing programs to bring about change in an individual, self-stigma must be measured in such a way that a person's individual experience is shown. This approach can be used to set goals for change and to monitor progress and achievements. The same scale may be used for epidemiological research and case formulation; however, the goals are different.

In addition, when a case-formulation instrument is needed, there is a lack of tools for measuring stigma and self-stigma outside a high-income country context. As such, existing tools may not suit the cultural and social contexts of other regions. There is also a lack of research on the interface between stigma scales and the experience of self-stigma in other cultures.

## Overview of self-stigma

## Defining self-stigma

Stigma occurs at various, interrelated levels, as described in previous chapters. Enacted stigma (discrimination) refers to actions or omissions because of stigma (e.g., microaggressions). They can lead to an individual anticipating or perceiving

him or herself as stigmatized. External stigmas can manifest themselves as prejudices and negative stereotypes. They can lead to targeted individuals being perceived negatively, harmed, or socially ostracized.[1] On the other hand, self-stigma or internal stigma* exists within the individuals with HIV, TB, hepatitis, diabetes, mental health or addiction issues.[6] It can occur or exist independently of experiences and perceptions of social stigma, and in anticipation of negative social reactions. For example, an individual who develops a stigmatized condition such as TB may also hold the same negative and prejudicial beliefs held by wider society. This can result in harmful effects, such as shame, guilt, self-blame, feelings of worthlessness, and disempowerment.[1,2,7–9] A useful definition, which accurately reflects the complexity of HIV self-stigma, has been proposed by Justice Edwin Cameron. His definition is highly transferable to TB: "Self-stigma is self-disabling inner feelings of contamination, shame, self-rejection, and self-loathing experienced by people with HIV, and those who fear they have HIV, even when there is no objective reason to fear rejection or discrimination, and even when there is good objective reason to believe that they will receive external support, protection, treatment, and acceptance."[10] Self-stigma has a detrimental impact on the lives of people affected by diseases like addiction, HIV, and TB. For example, it can lead to depression, social withdrawal, and fear. Self-stigma can reduce access to health services, and negatively influences treatment compliance, mental health status, and general wellbeing.[11–14] The phenomena of external stigmas and self-stigma are highly complex and inter-related.[15,16]

Self-stigma has added potential for harm in the context of people coping with TB, other infectious diseases, or other chronic conditions. This is because they require consistent engagement with health services and social support to maintain good health and wellbeing. Self-stigma is growing as an area of concern and has been documented across a broad range of domains, including mental illness, HIV, diabetes, leprosy, weight disorders, and tobacco use.[2,5,17–21,2,5] Research in the fields of HIV, TB, and epilepsy has found that people affected by these conditions stigmatize themselves much more than other people actually stigmatize them.[22,23]

Self-stigma can lead to social withdrawal, disengagement from health services, reduced treatment compliance, and more. While the impact of TB on physical health can be plainly seen, its immediate effects on other areas of a person's life and well-being should also be considered when formulating strategies for coping and resilience.[2,24–27] This chapter, therefore, focuses not only on methods and strategies for measurement of self-stigma, it also suggests methods to better understand and characterize self-stigma so that tailored plans to limit its negative effects can be developed.

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\* Self-stigma or internal stigma is often called "internalized stigma" in the literature, which we feel does not fully explain the complexity of the issue. "Internalized" suggests that stigma is something that only exists outside and is then internalized. This misses the important point that stigma can already exist inside a person because he or she is part of the same society as those who stigmatize.

# Common drivers of self-stigma

The challenge in identifying the drivers of self-stigma is that the outcome is driven by several interacting factors. First, there are social factors, such as cultural background and context, access to services, and sources of information. There are also self-factors, including the individual's own belief system, life experiences, and coping mechanisms. Third, the contextual factors, such as the conditions of the individual's life, their power relationships with others, and their living conditions. These factors are illustrated in Figure 1, which is a conceptual framework of the drivers of self-stigma in relation to HIV. This framework was published in 2015 in Ferris France et al. as a distillation of concepts from Morrison.[2,8] Although it originally focused on HIV, the framework can be applied to other conditions where self-stigma is a concern, such as TB. We should also note that stigma can exist in a person's immediate surroundings, despite not being obvious in the population as a whole. For example, stigma and discrimination in the overall population may be low, however, an individual may be stigmatized by healthcare workers or family members. The factors in this framework may therefore operate at both the population and the individual levels.
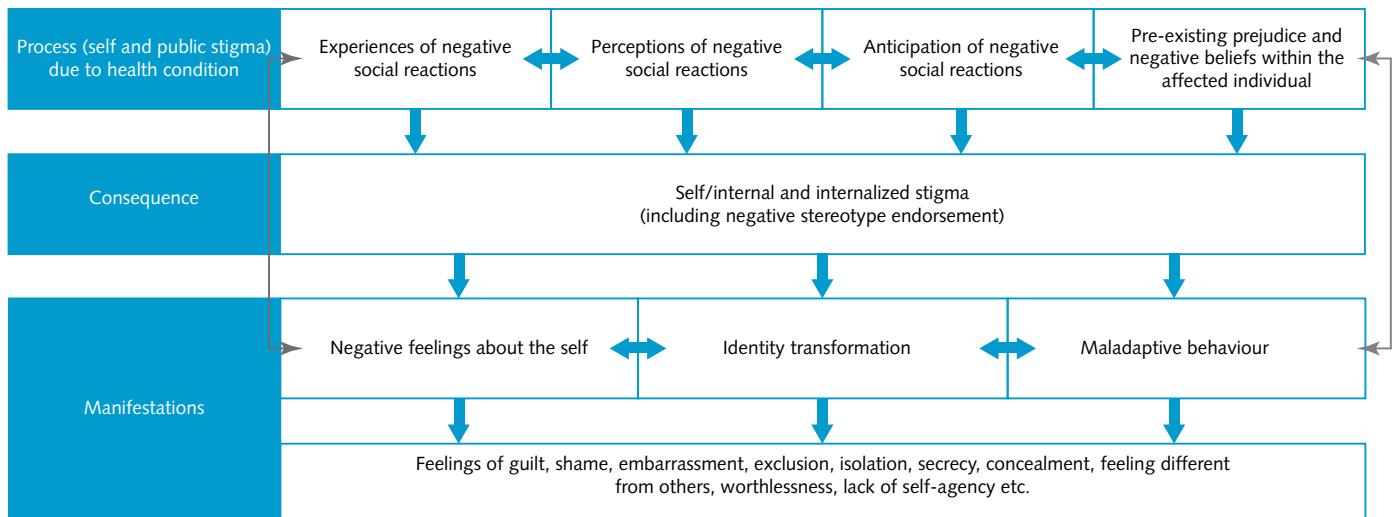
## Figure 1. Conceptual Framework
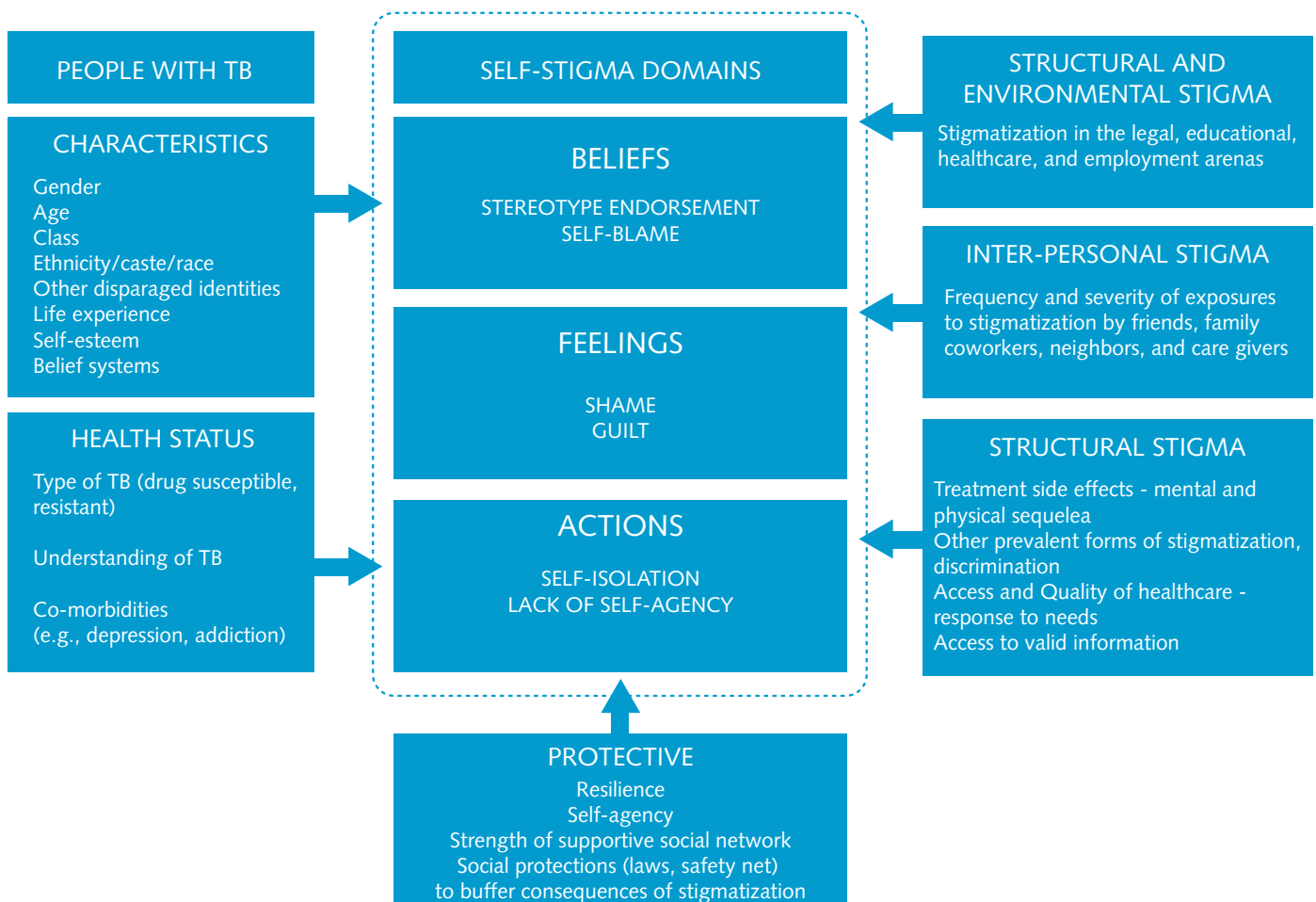
# Common domains of self-stigma

The framework in Figure 2 has been adapted from Stevelink et al.'s 2014 paper reviewing internalized stigma instruments[4] (originally adapted from Livingston and Boyd[28]). The framework was developed from evidence published on many different illnesses and conditions, including HIV, TB, mental illness, cancer, etc. It outlines the processes and conditions that drive self-stigma and its consequences. The common domains of self-stigma are not solely applicable to any one condition; they are likely to be observed to some degree irrespective of the disease context. Building on Stevelink et al.'s work, we have added concepts that recognize self-stigma as existing in the individual, often independently from social stigma and in anticipation of negative social reactions.

**Figure 2. Framework of the processes, consequences, and manifestations of self (internal) stigma (adapted from Stevelink et al. 2012).**
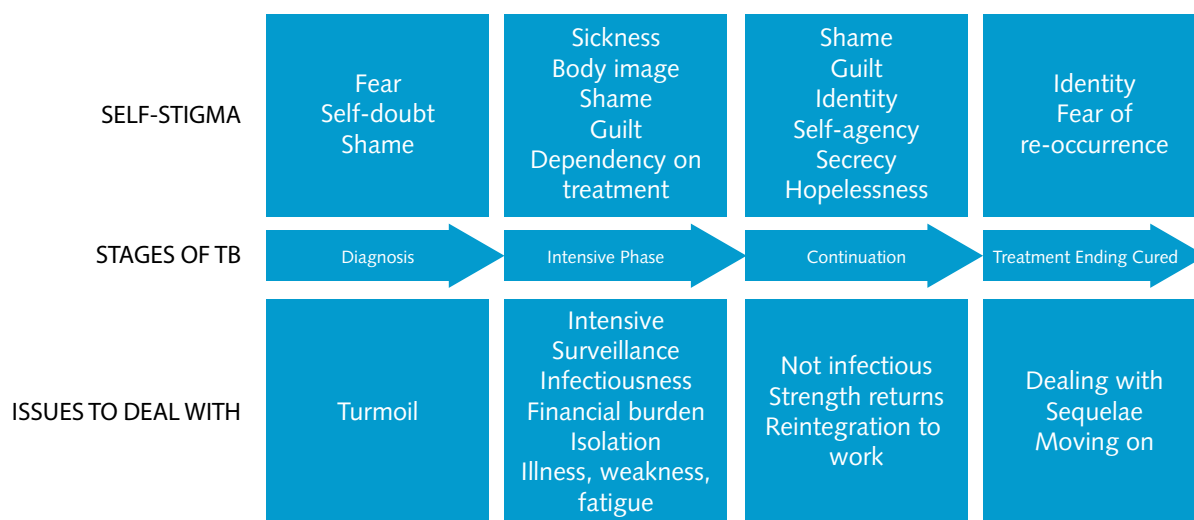


| Process (self and public stigma) due to health condition | Experiences of negative social reactions | Perceptions of negative social reactions | Anticipation of negative social reactions | Pre-existing prejudice and negative beliefs within the affected individual |
| --- | --- | --- | --- | --- |
| Consequence | Self/internal and internalized stigma (including negative stereotype endorsement) | | | |
| Manifestations | Negative feelings about the self | Identity transformation | Maladaptive behaviour | |
| | Feelings of guilt, shame, embarrassment, exclusion, isolation, secrecy, concealment, feeling different from others, worthlessness, lack of self-agency etc. | | | |

# Self-stigma and TB

Addressing self-stigma among people treated for TB is part of the evolving landscape of TB care, where an increased focus on social and behavioral factors acts as a necessary complement to specific health system improvements, such as access to medications, health facilities, and the provision of services.[29] The outward behavioral manifestations of TB self-stigma may vary, depending on illness severity. For example, people without outwardly visible symptoms may avoid accessing services that are known to be frequented by other people with the same condition, or may take medications only when others cannot see them, if they take medications at all.[30] Conversely, TB self-stigma may have parallels with self-stigma experienced in conditions such as leprosy, which have more obvious physical signs. If a patient with TB experiences chronic coughing or wears a mask to prevent its spread, this may identify the patient as a target for stigmatization, potentially worsening the dimensions of self-stigma, such as fear or poor self-image. The potential for compounding stigma's effect due to multiple stigmatized identities or conditions must also be recognized (See Chapter 4).[31]

## Figure 3. TB and self-stigma across the person's treatment itinerary

| SELF-STIGMA | Fear<br>Self-doubt<br>Shame | Sickness<br>Body image<br>Shame<br>Guilt<br>Dependency on<br>treatment | Shame<br>Guilt<br>Identity<br>Self-agency<br>Secrecy<br>Hopelessness | Identity<br>Fear of<br>re-occurrence |
|---|---|---|---|---|
| STAGES OF TB | Diagnosis → | Intensive Phase → | Continuation → | Treatment Ending Cured → |
| ISSUES TO DEAL WITH | Turmoil | Intensive<br>Surveillance<br>Infectiousness<br>Financial burden<br>Isolation<br>Illness, weakness,<br>fatigue | Not infectious<br>Strength returns<br>Reintegration to<br>work | Dealing with<br>Sequelae<br>Moving on |

## Methods for assessing TB self-stigma

## Overview

Quantitative measures can clearly show the *'how much'* of TB self-stigma, that is, the net burden. However, it is also critical to investigate the *what* and the *why*, meaning, the characterization of self-stigma at the level of an individual. Attention should also be paid to the processes that create and maintain stigma. This ensures that prevention and management strategies can be formulated to mitigate self-stigma's harmful effects. To assess self-stigma, mixed methods can be used to build an understanding of the quantitative data, which may otherwise lack meaning and context. (See the *TB Stigma Measurement Companion Curriculum* for more detailed information). Most research to date measuring stigma has been quantitative psychometric studies. (See Chapter 7 for a discussion of the methodological issues for such studies, such as sample size and statistical analysis.) What is largely missing is phenomenological research to help understand the experience of self-stigma and its associated meaning and beliefs, at both the level of an individual and their culture.

## Figure 4. Measurement of domains of TB self-stigma

| BELIEFS | FEELINGS | ACTIONS |
|---|---|---|
| STEREOTYPE ENDORSEMENT: believing negative stereotypes about myself | SHAME: Feeling ashamed of who I am or who I am not | SOCIAL WITHDRAWAL: letting my support system unravel by turning inwards |
| SELF-BLAME: believing I am personally responsible/ to blame for my TB | GUILT: feeling guilty for what I have done or not done | LACK OF SELF-AGENCY: shrinking my ambitions, plans, hope |
| LACK OF SELF-AGENCY: believing that I cannot change or improve my situation | PERCEPTION OF WHAT OTHERS THINK: feeling afraid of judgement, what others think, do, not do, anticipated stigma | NEGATIVE COPING: limiting self-care |

## RESILIENCE

## Sample quantitative measure: Van Rie Tuberculosis-Related Stigma Scale

An example of a well-validated scale to assess TB stigma and self-stigma is the one created by Van Rie et al. in 2008.[32] The Van Rie Tuberculosis-Related Stigma Scale examines stigma across key domains, such as: fear surrounding transmission and disease; values and attitudes relating to shame, blame, and judgment; and disclosure. The scale was positively evaluated in Stevelink et al.'s 2012 psychometric assessment of internalized stigma instruments.[4] For more information on the Van Rie scale, see Chapter 7. For guidance on the use of quantitative measures to assess TB self-stigma, please refer to section B, "Measurement," in the companion curriculum. For general notes on methodology, see Section E, "Methodological Considerations for Self-Stigma Measurements."

## Qualitative measures to assess TB self-stigma

Self-stigma has been investigated in a wide range of qualitative studies across different fields. The application of qualitative methods, such as key informant interviews and focus group discussions, has yielded in-depth information on the types and conditions of self-stigma that are experienced. However, research on the core self-stigmatizing *beliefs* of people living with a specific disease is still missing. No "best" instrument exists because many of the underlying drivers of self-stigma are fundamental in human social interactions. Self-stigma impacts on common and often predictable aspects of life, such as personal interactions, education, social participation, and access to health care. Van Brakel et al. acknowledged this fact in their 2006 review on the measurement of health-related stigmas,[33] noting that: "… the similarity in the consequences of stigma in many different cultural settings and public health fields suggests that it would be possible to develop a generic set of stigma assessment instruments."[33] The challenge lies in configuring a qualitative instrument to produce the best data to fit the research question at hand. The Companion Curriculum contains examples of qualitative tools that can be used without modification, or as a framework for developing instruments that work in a specific context. See section C, "Assessment and Understanding," in the Companion Curriculum for practical guidance on using qualitative measures to analyze self-stigma. Please also see Section E, "Methodological Considerations for Self-Stigma Measurements," for general notes on methodology.

## Adapting other scales to measure TB self-stigma

Practitioners may also wish to look at other self-stigma scales to find scale items that may be useful to adapt for application in their specific work. We can recommend several scales: the Internalized AIDS Stigma Scale (IASS[34] developed

by Kalichman et al. in 2009, and the early work of Holzemer et al. in 2007).[35] Both provide useful frameworks to understand and assess self-stigma, which would have to be adapted to the TB context. The Self Stigma Scale by Kato et al designed for diabetes is also well validated and predictive of self-care.[19,36,37] There are also scales that can be used to measure dimensions of well-being affected by the presence of self-stigma, such as depression, engagement in life, and quality of life. Examples include the Center for Epidemiologic Studies Depression Scale, (CES-D)[38] and the Quality of Life Scale, (HAT-QoL)[39] to measure mood and perceived stress. The People Living with HIV Stigma Index[40] contains quantitative and qualitative measures; it is considered by some to have unique social validity because it is implemented by and for PLHIV. Other scales assessing internal stigma can be found in the 2012 Systematic Review by Stevelink et al.[4]

## Innovation and expanding measurement of self-stigma intervention outcomes: The Ryff Scales of Psychological Wellbeing

When measuring self-stigma in interventions and programs, one significant drawback is that many of the existing measures capture only negative personal experiences. They do not capture a person's aspirations for change or the vision of the life that they would like to lead. Our analysis of qualitative data from intervention groups in Zimbabwe pointed to the real need to assess aspirations and goals. This led us to adopt the Ryff Scales of Psychological Wellbeing[41,42] approach.

In our earlier work,[2] we observed that the core beliefs and drivers of self-stigma influenced many areas of participants' lives. The core beliefs and drivers were much broader than can easily be described by scales that examine self-stigma's *manifestations*, such as guilt, shame, or social withdrawal. We also identified the need for a framework to guide the analysis of qualitative data, to help with the characterization of self-stigma, and thus the development of future interventions. The Ryff Scales are adaptable for both purposes, and have been applied in a wide variety of settings.[41–43]

The Ryff Scales were designed to look at psychological wellbeing in a holistic manner. They examine six dimensions: purpose in life; environmental mastery; positive relationships; personal growth; autonomy; and self-acceptance. The scales can help measure how well a person has mastered these areas of his/her life, with a high degree of reliability and validity.[43–45] Many of the common manifestations of self-stigma, such as shame, isolation, and worthlessness, map strongly to the Ryff dimensions. This makes the Ryff Scales a useful positive measure to use, together with existing negative self-stigma scales.
The Ryff Scales are useful for both quantitative and qualitative methodologies. For example, during our work on self-stigma among PLHIV in Zimbabwe,[46]

we included the Ryff Scales in a quantitative questionnaire pre- and post-intervention. This allowed us to compare wellbeing between baseline and follow-up time points. At the same time, we conducted focus group discussions and interviews with respondents, using the Ryff Scales as a framework for analysis. This yielded insights into the drivers and coping mechanisms of individuals experiencing self-stigma, and how these mapped to the six dimensions of psychological wellbeing. See Section D, "Merging Qualitative and Quantitative – One Tool," in the companion curriculum for guidance on how to apply the Ryff Scales in a practical setting. See Section E, "Methodological Considerations for Self-Stigma Measurements," for general notes on methodology.

## Measuring resilience

The personal impact of having TB varies widely. Understanding resilience may be a useful lens through which to know the differential impact of stigma upon TB patients. Resilience is the process of adjusting to, and managing and deflecting stress or trauma. There are many domains of resilience that can be measured, including: personal competence; coping ability; tolerance; strengthening effects of stress; acceptance of change; secure relationships; control; and spiritual influences. Other authors have identified key resiliency attitudes, including: insights, independence, creativity, humor, initiative, relationships, and values orientation. While there is no gold standard tool, Windle et al.'s review of the quality of resiliency scales advocates for the use of three scales, based on their psychometric properties:[47]

1.  The Resilience Scale for Adults (RSA) has 37 items[48] and has been validated. It is available in English and Spanish.
2.  The Brief Resilience Scale has five self-weighting items on a Likert scale.[49]
3.  The Connor-Davidson Resilience Scale (CD-RISC) has 25 items. It is available at: http://www.connordavidson-resiliencescale.com/

**Table 3: The Brief Resilience Scale**

|  | Please respond to each item by marking one box per row | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|---|---|---|---|---|---|
| BRS 1 | I tend to bounce back quickly after hard times | 1 | 2 | 3 | 4 | 5 |
| BRS 2 | I have a hard time making it through stressful events | 5 | 4 | 3 | 2 | 1 |
| BRS 3 | It does not take me long to recover from a stressful event | 1 | 2 | 3 | 4 | 5 |
| BRS 4 | It is hard for me to snap back when something bad happens | 5 | 4 | 3 | 2 | 1 |
| BRS 5 | I usually come through difficult times with little trouble | 1 | 2 | 3 | 4 | 5 |
| BRS 6 | I tend to take a long time to get over set-backs in my life | 5 | 4 | 3 | 2 | 1 |

Approved translations of the CD-RISC currently exist in the multiple languages. The choice of resilience scale depends on whether you plan to intervene to improve resilience. If you plan to measure resilience as part of a baseline, then it is wise to use a more comprehensive tool to help inform your interventions.

## Measuring TB treatment self-efficacy

Self-stigma is thought to be a determent to self-care. A closely related concept is self-efficacy.

A scale to measure coping self-efficacy for TB treatment was developed and validated by Mason et al. in Vietnam.[50] The scale was derived from ethnographic research and draws from social cognitive theory. It measures four domains:

- Self-efficacy for communication with the doctor (5 items)
- Self-efficacy for support seeking (4 items)
- Self-efficacy for disclosure of diagnosis (7 items)
- Self-efficacy for medication adherence (10 items)

Patients rate their level of confidence for the series of questions on a temperature scale, from zero to ten, with zero being the lowest and ten representing maximum confidence.

## Conclusion

There are few well-validated measures to assess self-stigma among people treated for TB. However, those that do exist, such as the Van Rie Tuberculosis-Related Stigma Scales, are being used in an increasing range of settings. Many of self-stigma's outward manifestations are fundamentally human in nature, and may transcend culture and language. This means that quantitative measures may be adapted to different contexts and patient groups. It also means that tools that have already been well-tested in measuring self-stigma for conditions such as HIV or mental illness also have the potential to be adapted. Several factors help with successful measurement. They include the careful choice of instruments, combining quantitative and qualitative approaches, appropriate selection of individual items, rigorous piloting, and use of information derived from the pilot. Qualitative approaches are needed to examine and understand the underlying beliefs and drivers of TB patients and to further identify coping strategies. The Ryff Scales provide an opportunity to bring together the quantitative and qualitative methods. This may help to enhance the ways in which we approach the management of self-stigma, and shift the focus toward the promotion of patient well-being, rather than simply aiming for the simple absence of negative symptoms. Finally, there is also the need to develop new interventions to address TB self-stigma.

# Acknowledgements

# Appendix 1: Self-stigma domains and illustrative items

## IDEAS: COGNITIVE DOMAINS OF SELF-STIGMA
## Stereotype Endorsement

**Stereotype Endorsement**

I think that I am less careful than others because I developed TB disease.

I am not clean because I developed TB disease.

My body is inferior to others because I developed TB disease.

I cannot measure up to ordinary people because I developed TB disease.

TB disease is a sign of weakness.

TB disease is something that happens to careless people.

It is quite natural to be rejected because of TB disease.

**Self-Blame**

If I had taken better care of myself, I would not have developed TB disease.

If I had taken my TB treatment as instructed, I wouldn't have developed drug-resistant TB.

If I had taken my ART and IPT as instructed, I would not have developed TB disease.

If I had not smoked, I would not have got TB.

If I had not been drinking or drugging I would not have got TB.

If I had not been detained, I would not have got TB.

If I had worn my respirator at work, I would not have got TB.

If I had not spent time in certain places, I would not have got TB

If I had avoided certain people, I would not have TB.

**Seeing the light at the end of the tunnel**

Things will go back to normal once TB treatment is done.

I have plans for my life after TB treatment is over.

I will feel relief once my strength returns.

When I get over TB disease, there is a lot ahead of me.

## FEELINGS: AFFECTIVE DOMAINS OF SELF STIGMA

**Shame**

I cannot feel confident about who I am because of myself with TB.

I have negative feelings about myself with TB.

I am unhappy because I developed TB disease .

I hate my body because TB disease made me physically weak.

I get embarrassed because of having TB.

I feel angry because I developed TB disease.

I feel uncomfortable that my TB infection progressed to disease.

I am ashamed of having TB.

**Guilt**

I cannot forgive myself for exposing my loved ones to TB.

I feel upset that TB disease makes it hard for me to care for my family.

Caring for me is a financial burden on my family that is hard for me to accept.

**Perceived Self-Efficacy**

I give up on myself because I developed TB disease.

There is nothing I can do to get rid of TB.

I cannot change my situation now that I have TB.

I feel helpless because I developed TB disease.

I am discouraged because I developed TB disease.

I need assistance from others because I developed TB disease.

Even if my TB is cured, the treatment side-effects may be permanent.

Completing my TB treatment makes little difference, because it could come back.

**Anticipated Stigma**

Others would mistreat me if they find out that I developed TB disease.

TB will create obstacles for me in the future.

I worry that my family will be discredited by my having TB disease.

I will be denied work because I developed TB disease.

# ACTIONS: BEHAVIORAL DOMAINS OF SELF-STIGMA

**Self-isolation, social withdrawal**

I avoid interacting with others because I developed TB disease.

I keep my distance from others because I developed TB disease.

I hide myself to protect other people's health.

I dare not make new friends because they might find out that I developed TB disease.

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# Chapter 11

# Measuring Discursive and Rhetorical Stigma

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## Abstract

This chapter provides an introduction to critical discourse analysis to detect TB stigma in language and text. The chapter introduces several frameworks useful to identify discursive TB stigma, and provides guidance for developing research questions and collecting and analyzing data.

## Objectives

1. To introduce basic concepts of discourse and textual analysis and its importance for healthcare policy-making.
2. To sensitize readers to how TB stigma can be hidden in rhetorical framing and use of language.
3. To provide examples of earlier studies of discursive (TB) stigma.
4. To teach methods to trace/unveil a discourse in TB text.
5. To provide practical suggestions for how to identify, analyze, and interpret discourse for TB stigma.

## Target audience

This chapter meets the needs of activists, national TB program staff, implementing agencies, non-governmental organizations, donors, partners, and advocates who seek to scrutinize written materials, speeches, policies or visual communication to detect stigmatization. The techniques described are readily accessible for those with a background in social sciences, humanities, or communication sciences. No detailed knowledge of statistics or legal concepts is necessary.

## Introduction

There are different approaches to the analysis of textual data, such as interviews or policy documents, in order to understand how stigma is produced and its effects, including content, discourse, discursive, and textual analyses. These approaches are rooted in different philosophical traditions, ranging from more positivist approaches (content analysis), post-positivist (certain forms of discourse and discursive analysis), and constructivist and critical discourse analysis. The reader is referred to Flick[1] for more information. This chapter explores critical discourse analysis of TB texts to identify how language and discourses construct stigma.

## Discourses and stigma

Stigma entails a normative judgment based on specific values. It is present in text and how we speak about other people or an illness. Practices might be reflected in these words, and words influence the practices and how patients and illnesses are handled. As shown in Chapter 1, the process of building enduring and harmful stigmas often starts with subtle terminology and framing.

Figure 1 summarizes the key concepts of measuring discursive stigma. All stigmas are built upon a common backbone. With practice, it becomes easy to pick out these building blocks of stigmatization in dialogue and text.

**Figure 1. Discursive Steps toward Stigmatization**
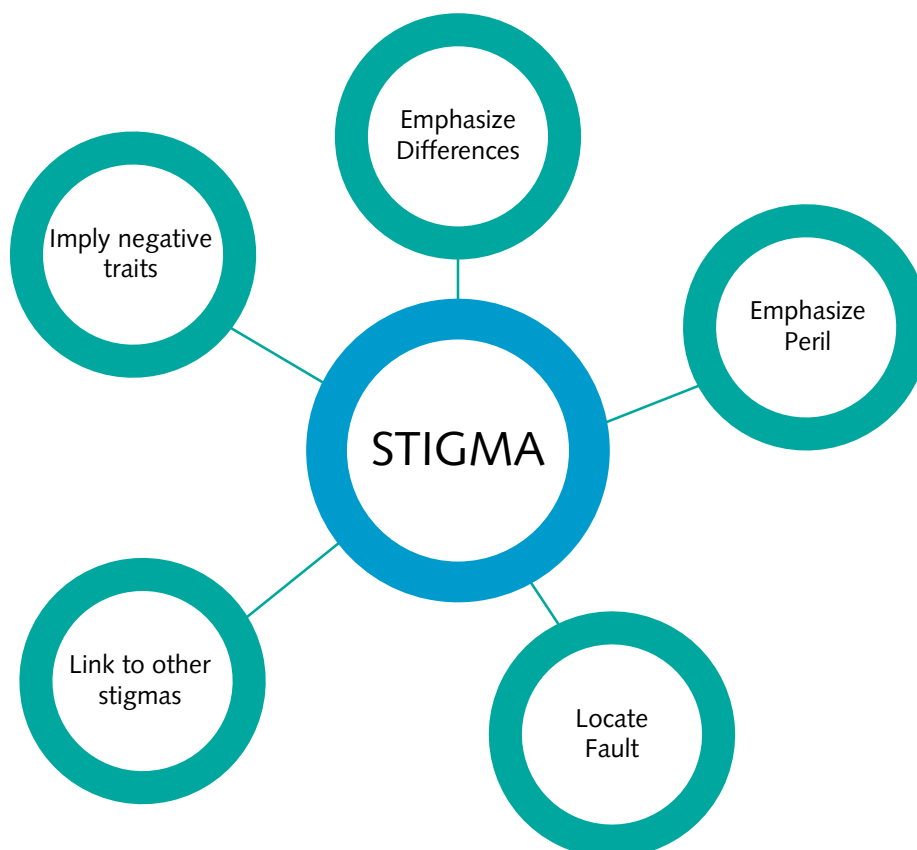
Many approaches to the study of text dispute that language is a neutral medium that reflects reality.[2] Rather, the language we use actively constructs, shapes and (re)produces practices, identities, roles, and experiences.

**Box 1: Defining Discourse**

A discourse is a set of ideas or patterns of thinking that can be identified within text, messages, dialogues, conversations, and art.[3] A discourse includes producing, disseminating, and receiving the text[4] A discourse brings meaning into social relations. It characterizes relations between people who communicate with each other. It entails specific communication events (newspapers, articles, or reports) and links with other discourses.[2]

Discourses define obligations and distribute responsibilities.[5] A text is not meaningful by itself, but only through the interconnection with other texts, the different discourses it draws upon, and the social context of its production, dissemination, and consumption.

Using a certain discourse has consequences. It can "..reinforce, reproduce, or support a given discourse and at the same time deny, disqualify or silence that which does not fit with that discourse." (p.119)[6]

Discourses may be explicit or obvious, or hidden within a text.

## Discourses that dwell on differences

To stigmatize, one first needs to create categories. This requires marking differences and over-emphasizing the differences between groups. The invention and over-use of clinical classifications and labels can contribute to stigmatization, even if the labels themselves seem neutral. Advocates have recently called for ending the use of stigmatizing and discriminatory language in TB research and practice (see Box 2 for examples).[7] Many of the labels used to describe TB patients are disempowering, assign blame or punishment, and contain moral judgments (such as 'treatment defaulter' instead of 'loss to follow-up', 'TB suspect' instead of 'person to be evaluated for TB', 'non-compliance' instead of 'non-adherence'). This terminology also serves to mask other actors' responsibilities for providing care, and the structural reasons for why patients might not be able to access or adhere to treatment (such as health system failure, drug stock-outs, lengthy and toxic treatment regimen, the cost of treatment and poverty, etc.).[7,8]

For example, the term TB care (rather than control) suggests a more egalitarian and collaborative approach, which supports the adoption of alternative ways to support PWTB, such as peer support and buddying systems. Some of these labels have been changed in official WHO guidance documents.

**Moving to non-stigmatizing terminology in TB**

Treatment default - loss to follow-up
Tuberculosis suspect - Person to be evaluated for presumptive tuberculosis
Tuberculosis control - Tuberculosis prevention and care
Compliance - Adherence
Research subjects - Research participants

Additional suggestions can be found in the Stop TB Partnership's Tuberculosis Terminology Guide: http://www.stoptb.org/webadmin/cms/docs/Every%20Word%20Counts%20TB%20 Language%20Guide.pdf

# Discourses that link TB to negative traits, stereotypes, and labels

The way we talk about people suffering from and coping with a disease is not neutral (Box 3). Susan Sontag, in her book on *Illness as Metaphor*, uses TB and cancer to show how the language used to describe patients and diseases can associate conditions with certain character traits. For example, when militaristic metaphors are used, patients are often encouraged to "fight against" their illness. Winning or losing a battle is not only a matter of strength but also of character and will. The war metaphor suggests that recovery therefore, is largely a matter of willpower, and holds people individually responsible for getting better. Those who appear to passively accept their illness, rather than fight it, are rendered culpable and shamed, leading to victim blaming. The metaphor could, therefore, have stigmatizing effects.[9]

Box 3: The Implications of Naming People Affected by an Illness Differently

'TB **Patients**' refers to people that have an illness. This term is associated with services of the welfare state. Patients are entitled to visit health care services. Traditionally, the role of the patient is considered to be passive: they undergo treatment.

**Consumptive** implies a person who is gradually being depleted, who is dissipating, and becoming less of her/himself.

**Person living with TB (PLTB)** suggests a person who is coping with a situation, and the emphasis is placed on the humanity of the individual and their vitality.

Depending on how we name people with a disease, different roles and options are implicitly assigned to them.[9]

## Discourses that emphasize peril and danger to generate fear

TB is transmitted through the air via droplets produced by coughing and singing. However, this 'fact' can be described in many different ways. It is also 'a fact' that approximately 90% of those infected never develop the disease. Which facts are highlighted influences how afraid we become.

The political uses of language are well known. Several frameworks can be employed to analyze discourses on TB.

Politicians and policymakers tend to depict the problems they would like to address in a way that will convince others that the situation needs change. According to Stone[11], several **symbolic devices** are crucial in representing problems in policy text. **Metaphors** frame issues in a certain way and often imply things not explicitly stated (such as the war metaphor discussed above). **Storylines** are important symbolic devices. Policy texts quite often make use of a story of decline by depicting a situation as becoming worse and predicting that it will end in a disaster if we do not intervene immediately. Such a narrative makes the reader fearful, and thus more receptive to the proposed action to avoid the disaster.

Numbers are also symbolic devices that can be used to substantiate storylines. Although numbers are considered objective, the choice to mention certain numbers and not others can change the message dramatically[11] and the way they are categorized and represented may marginalize some patients (Box 4). An example is if the storylines depict a population as high prevalence and a transmission threat to others due to their assumed inherent characteristics or practices.

Several scholars indicate that the way TB treatment and patient categories are defined marginalize some patients from treatment and have stigmatizing effects. For instance, the DOTS strategy focuses on patients who are infectious and counts those in treatment as category 1. Patients who are non-infectious to others receive less attention, and their diagnosis and treatment is of lower priority (such as sputum negative or extra-pulmonary TB).[12] Patients need to have a residential address to be eligible for treatment.[13] The biomedical categories of newly diagnosed, retreatment, relapse, and failure cases do not always match the treatment and pharmaceutical history of patients in Nepal. For instance, the definition of a new smear-positive patient, presenting for the first time to the health center and having received less than a month of treatment, meant that those patients who had received more than a month treatment in the private sector were not allowed into the national TB program. They were not in the newly diagnosed, retreatment, or relapse categories. By generating non-eligible TB patients and turning them away, the TB program might be creating MDR-TB if patients are forced to continue unregulated or interrupted treatment in the private sector. Those patients that are not allowed into the program are not being counted as having MDR-TB. They will ultimately not show up in national databases.[14]

## Discourses that link TB to other disparaged behaviors or identities

Bacchi[15] argues that not only do politicians represent a problem in a certain way, they also shape and create problems by defining a phenomena or situation as a problem in the first place. For instance, if TB is defined as a problem of a particular group, it becomes a disease of others and a non-native threat. This is inaccurate and counterproductive because immigrants who are then unsure of their immigration status and legal rights to health care are less likely to access health care.

Similarly, Gusfield[16] shows that solutions depend on how public problems are defined. According to him, public problems have moral and cognitive dimensions. The cognitive side consists of beliefs about the facts and events which compromise the problem (these can be theories, empirical beliefs about poverty, mental disorder, alcoholism, or MDR-TB, etc.) The moral side allows the situation to be viewed as painful, immoral, or unjust, and it allows moral judgments and makes alteration desirable. Not all groups have the same ability and power to define and shape public problems such as TB control or MDR-TB.[17] Those who own the problem (e.g. the government or WHO) publicly define the problem. Owners have credibility, can capture public attention, possess authority, and can make claims. Public problems are characterized by conflicts over such ownership.

In order to analyze discursive TB stigma in policy and politics, the researcher needs to:

1. Identify the particular storyline that is used; and
2. Analyze the different symbolic devices used and identify how problems are defined.

Overall, these metaphors, ideologies, definitions, and discourses have implications for the explanations chosen and the solutions sought (Box 5).

**Box 5. The 'Risk Of Contagion' Discourse in UK TB Policy through the Construction of Risk Categories**

Craig analyses the public health policy on TB in the UK, and reveals how TB is constructed within a public health discourse of 'risk of contagion'. She shows how different categories of risk for TB are constructed through discourses of immigration, creating insiders and outsiders and producing racialized risk categories. The implications of this risk discourse are that the different risk categories provide justification for enhanced surveillance of those who cannot manage their risks. The risk of TB is thereby attached to particular social categories (e.g. the 'foreign-born'), and not to the structural inequalities that place people at risk and help maintain such racialized positions. The consequence of such a stigmatizing discourse is that the response to TB is mainly focused on local risk management, and those individuals who are seen as unable to manage their risk.[18]

## How to analyze TB stigma using discourse analysis

Discourse analysts examine how individuals and problems are constructed in text and language and the implications for assigning responsibilities and solutions. A discourse analysis of TB stigma would, for instance, examine explanations of the problem of TB, who is being blamed for it, how solutions are justified and legitimized, and what the underlying value claims are in these explanations, justifications, and legitimizations.[2]

When conducting critical discourse analysis, the researcher is interested in understanding the relations between a discourse and its social and historical context. Examples include the relationship between discourse and state power and how state power is manifest in discourses (legislation, policies, and communication). A critical discourse analysis adds a normative element, as the analysis also focuses on how a discourse departs or overlaps with certain value standpoints.[2] Discourse analysis includes a set of methods or tools and a lens for framing the problem.[4]

# Identifying a research question to analyze discursive stigma

There are different frameworks to analyze discursive TB stigma. These will lead to slightly different research questions. In order to determine how discourses are stigmatizing, the following questions are helpful (Box 6).

**Box 6. Possible Research Questions to Identify Discursive Stigma**

- How are TB and TB patients constructed? What are the implications for assigning responsibilities and solutions?[2,4,19]
- What are the explanations for the causes of TB (or MDR-TB, diagnostic delay, screening, treatment adherence, quality control, etc.)? Who is being blamed for it, how are solutions justified and legitimized, and what are the underlying value claims in these explanations, justifications, and legitimizations?[2,16]
- How are policy problems (such as TB, MDR-TB, diagnostic delay, screening, treatment adherence, quality control, etc.) represented and shaped through symbolic devices (metaphors, story lines) and numbers?[11]
- How are policy problem represented and constructed? How has this discourse come about?[15]

## Collecting, selecting and identifying texts

TB control efforts entail many different words and texts that can contain stigmatizing notions and thus are useful for an analysis of discursive stigma. These include not only those words spoken between patients and caretakers, but also between healthcare workers, program officers, policymakers, written text in TB policy documents, guidelines, education material, leaflets, posters, records, registers, treatment cards, package inserts of diagnostics and drugs, articles in the media, and government reports.

## Primary and secondary data sources

The data for a discourse analysis can be from secondary sources collected from existing text, such as documents, publications, databases, and records. They can also draw on primary data sources, such as interview transcripts, observation notes, or conversation recordings. An analysis of policy and media discourses would generally rely on secondary data sources, such as newspaper articles, policy guidelines, and meeting notes. In addition, it could be accompanied by interview material to further explore the underlying reasons for the use of certain language. An analysis of conversation pattern between providers and patients, for instance, would rely primarily on recordings and observations (primary data sources), but could also be accompanied by medical reports, referral slips, and letters (secondary sources).

The advantages of primary data sources are that the analyst is involved with the collection and can steer data collection and adapt it to research needs (by choosing participants and sites, framing questions in interviews differently, etc.) However, collecting primary data sources is not always feasible. Some of the databases that might be helpful in identifying secondary data sources include PubMed, Social Science Citation Index, Communication Source, Arts and Humanities Citation Index, ProQuest, and Web of Science. National newspaper and hospital archives, government archives, and global media databases (Factiva, LexisNexis, PressReader) may also be useful.

## Sample size

In order to limit the secondary data sources to be studied, it helps to choose the most important and widely distributed texts or those that compare settings/ topics or limit the analysis to a certain time period.[4] Consult Chapter 6 on sampling techniques for texts and Chapter 2 for collecting primary data sources.

**Box 7. Examples Data Collection Techniques**

Reitmanova and Gustaffson aimed to uncover press constructions of the presumed or imagined health risk to Canadians posed by immigrants exposed to TB or other infections. The authors sampled newspaper articles in ten major Canadian newspapers (from those cities with high rates of TB or immigrants) over a ten year period through keyword search in Factiva, LexisNexis, and newscan.com. They chose only English-speaking newspapers (a bias), and those with the widest circulation and reach. This resulted in 273 pieces of text for analysis. They identified racializing and medicalizing discourses stigmatizing the immigrant body as a health threat.[20]

Andrade and colleagues analyzed the discourses of nurses around the challenges of adherence to MDR-TB treatment. They interviewed 13 nurses working with TB patients in Brazil. The interviews revealed the prejudices in nurses' speech that is linked to TB which is marked by stigma, segregation, and exclusion.[21]

## Making data manageable

Audio files are converted into written form once data collection is complete. The text is coded, or organized into chunks that are tagged with keywords. Usually, one would code for research question, different discursive elements (symbolic devices, use of numbers, problem definitions), and discourses emerging from the data.

The coding can be done by hand or by using a qualitative data analysis software package such as (Atlas.ti, Nvivo, or MAXQDA). See Chapter 17 on qualitative analysis methods for more information on coding and software.

# Data analysis

Below are a set of stages and prompts that can guide a critical analysis of discursive TB stigma. These were adapted and collated from different authors and frameworks using discourse analysis or critical policy analysis.[2, 11, 16, 19, 22-26] The analysis identifies the constructs of individuals and problems and the rhetorical devices used and examines assigned solutions and the implications of these discourses.

**0.      Pre-analysis:**

- Free association: what is the first thing that comes to mind when reading the text?
- Itemize objects and subjects that appear: identify these nouns in the text, list them, and write a short description of each. These can now be considered the objects of your study and they represent discourses.
- Itemize the subjects: who are the people that appear in your text? List them. The author and the audience are two subjects that are always present, even if not mentioned explicitly. This list will help you to answer some of the following questions.

**1.      What constructs of TB, a TB patient, a TB health worker, work with TB patients, and work with TB are being produced, and by whom?**

- How is the individual defined? (e.g., patient, citizen, client, threat, someone coming from outside the area or country, etc.) How are people in the text represented or characterized? (e.g., deserving or undeserving of sympathy, not to be trusted, unreliable.)
- Consider the assumptions that the author makes (in case of secondary source materials only) about the individuals and how the definition of the individual would change if these assumptions were different.
- If accompanying visual material is used: what does the image represent? Who is the producer? In what context is the image used? How does it interact with other pieces of the text? What symbols, cultural references, or signs are depicted? Why was this image chosen? How is the image given meaning? What is made visible or invisible by the image?
- How is the problem defined? (e.g., the disease, the work, the control efforts, etc.)
- What are different theories about the causes for the problem? What are explanations of the problem? What are underlying assumptions? Is there an assumption of blame?
- Who can speak, and who is given voice in the text?
- Who cannot speak?
- Who is being referred to?
- Who is the intended audience?

- What is silenced? (that is, not mentioned or left out of the account.)
- What message(s) are intended by the author (explicit and implicit)?
- Could this event have been reported in a different way? Identify all words with a negative meaning and substitute them with a positive meaning.
- Who is the owner of a discourse/problem definition? Who has credibility, can capture public attention, possess authority in the field, can make claims, and is being reported by others looking for definitions and solutions?
- Where and when were these discourses developed?
- Who would benefit or be threatened from alternative discourses?

## 2.    What rhetorical devices are being used (to construct TB stigma?)

- How are problems presented? What are the rhetorical instruments? What story lines, metaphors, and numbers are used to convince others?
- What underlying norms are included?
- What are the historic roots of these norms/ideologies? What is the socio-cultural and political context of these norms/ideologies?
- To what extent are these rhetorical instruments stigmatizing? Is there medicalizing, creating difference as untrustworthy or dangerous, locating responsibility for difference, evoking peril and threat to those considered normal, blaming?
- How far are stigmatizing attitudes and approaches identified in discourses (in reports, categories, or text) influenced by history and historical discourses, or by a country's or institution's past?
- To what extent and in what ways do research, science, and knowledge in the TB community (evidence based medicine, evaluation of interventions, monitoring requirements) influence the identified discourses?

## 3.    What are the action outcomes of these descriptions?

- What solutions are assigned?
- How are solutions justified and legitimized? What are the underlying value claims in these explanation, justifications, and legitimizations?
- How are these actions stigmatizing, if applicable? Is mistreatment justified, is there exclusion and discrimination?

## 4.    What are the implications?

- How do these actions challenge, sustain, or foster stigma in relation to TB?
- How does an identified discourse make visible/invisible actor positions?
- What can and cannot be said?
- Who can speak and who must listen?
- What is the individual expected to know in response to the discourse?
- What is the individual expected to do in response to the discourse?
- Whose social constructions are valid and which are unimportant?

Results of such an analysis can involve identifying several potentially competing discourses or mutually reinforcing discourses. It may demonstrate how discourses construct, maintain, and reproduce stigma, and also reveal that individuals may be unaware that their discourses have stigmatizing effects (Box 8). Such a critical analysis helps to understand how a certain discourse legitimizes particular ways of seeing and understanding TB, and how this becomes accepted as normal practice. It also explains how individuals and alternative discourses are able to challenge the existing discourse.[22] It can also reveal how discourses are linked with the ways in which epidemiological knowledge about TB is produced, such as through a particular categorization of ethnicity or migration-related status in medical records.[25]

## Box 8. Example of Data Analysis Steps

Ranjbar and colleagues conducted a discourse analysis of text passages from 63 interview transcripts of HIV caregivers who discuss their work with HIV-positive individuals. They chose text passages and analyzed them for the different versions of reality that caregivers constructed, and what actions followed. They identified the caregivers' descriptions and constructions of HIV/AIDS, their clients, themselves, and of their work. They examined the rhetorical devices that they used in their constructions, and then they looked at what actions resulted from these constructs and if these actions fostered or challenged stigma. Thanks to this analysis, the authors were able to show that the healthcare workers own discourses of how they followed rules and minimized their own risk of HIV infection inadvertently contributed to broader discourses of HIV as controllable and manageable. These discourses are stigmatizing and blame HIV-positive individuals for their own illness. This also shows that individuals are not always aware when their discourses have stigmatizing effects.[23]

Below are two examples of the analysis of the discourses reported. These are discourses that one can identify when using some of the questions listed above. Ogden examined the discourse of power and control in the language of public health and its effect on interventions such as DOTS. Craig highlighted discourses in the popular press, policy, and practice, and demonstrated how stigma is reinforced or reproduced through different texts and practices.

## Box 9. Two Example Discourses on TB

| | Discourse 1: Discourse of control | Discourse 2: Risk of contagion from a new pandemic in the UK[18] |
|---|---|---|
| How is the individual defined? | Poor patient, infectious, uneducated, passive recipient of care. | People born outside the UK constructed as sources of contagion and polluters in the popular press who bring a disease into the country. The groups are identified as coming from different ethnic minority backgrounds who engage in practices (such as spitting) that are implicated in the spread of disease. Communities are stigmatized. Other groups that may be stigmatized through risk discourses include drug users, homeless people, and prisoners. |
| How is the problem defined? | Non-adherence to TB treatment | The public health problem of the new pandemic, risk of contagion. |
| What are the rhetorical instruments? What storylines, metaphors, and numbers are used to convince others? | Metaphor of control, TB patients cannot be trusted, need to be controlled. | Masks old causes (poverty, poor housing/sanitation) by presenting new attributes (MDR & HIV). Metaphor of pollution, insider/outsider. Categorizing people with TB as coming from outside and posing a risk to the country. |
| What are the underlying norms? | Control is better than trust. | Individuals are held responsible for their plight and a neo-liberal discourse of 'no rights without responsibilities' underpins social policy, further implicating the individuals as being responsible for their own health and illness. |
| What solutions are assigned? | Supervision of treatment intake. | Micro risk management, surveillance, infection control and screening at ports, sanatoria, detaining, and removing the 'polluters'. |

| | | |
|---|---|---|
| How do these actions impact stigma? | Victim/patient blaming. | Risk of TB is attached to social categories, such as 'foreign born', which reproduces categories of racialized risk. |
| What cannot be said? What is silenced? | Patients might not be able to adhere because of structural reasons, inaccessibility of health centers. | Structural inequality and processes that place people at risk and maintain racialized positions are ignored. |
| What must the individual do? | Access health center | Manage their own risk. |
| What must the individual know? | When to access health center for screening, adherence to treatment, and monitoring. | How to manage their own risk. |

## Overcoming challenges to discourse analysis

One of the major challenges in analyzing discourses is that people are so used to certain discourses that we take them for granted and are not able to distance ourselves from them. One way to overcome this is to replace words with synonyms or replace negative words with positive ones. In what way does the outcome, connotation, or meaning of the message change? This exercise will make you aware of how words matter and how they might represent a certain discourse of control or risk of infection. Another way to overcome this challenge is to include those affected by TB into the research team. Lastly, thinking through alternative problem definitions, representations, or metaphors and their implications may aid in analyzing discourse. If a problem is defined in economic terms, what consequences would definitions in social and political terms have?

Discourse analysis is a three-dimensional analysis of text, context, and discourse, and how they interrelate. Texts belong to discourses on which they draw, that they might constitute, and which are influenced by social reality.[4] Researchers studying discourses need to go beyond pointing out the relationship between text and context, but instead analyze the role of discourse, which requires an understanding of how structured sets of text and their production, dissemination, and reception constitute the social practices.[4] Such an analysis is challenging but necessary to show how language matters, especially in the context of stigmatization.

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# Chapter 12

# Community Advocacy in TB Stigma Research

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## Abstract

The focus of this chapter is community advocacy in TB and the role community advocates play in measuring, reducing, and eliminating TB stigma.

TB community advocacy momentum is building. Advocacy has become a mechanism to increase investment in scientific research, access to new drugs and diagnostics, particularly for the vulnerable and underserved, and to enhance the realization of human rights in the context of TB policy and programming. Stigma is one of the many factors hindering TB control. Measuring and responding to it is now a priority for the global TB community. As efforts to find, treat, and care for people with TB intensify, TB community advocates must join forces and engage in advocacy that contests policy and programmatic norms and shifts societal perceptions of TB. This chapter echoes the critical need to measure stigma in order to reduce and eliminate it. This chapter also emphasizes the role community advocates must play in leveraging measurement results for advocacy and throughout the entire measurement process and thereafter.

The topics covered in this chapter include:

1. The role of advocacy in reaching the global TB elimination targets.
2. The TB advocacy community.
3. Engaging TB community advocates in stigma measurement processes:
    a. Before the research begins;
    b. During the research process; and
    c. After the research is concluded.
4. Top tips for community advocates and recommended advocacy priorities to modify practices that stigmatize people with TB.

## Objectives

1. To emphasize the importance of community advocacy in reaching the global TB elimination targets.
2. To highlight the value of community advocates in research, and the connection between the two.
3. To explore who TB community advocates are.
4. To engage TB advocates throughout the research processes.
5. To outline top tips for community advocates and provide recommendations on advocacy priorities to modify practices that stigmatize people with TB.
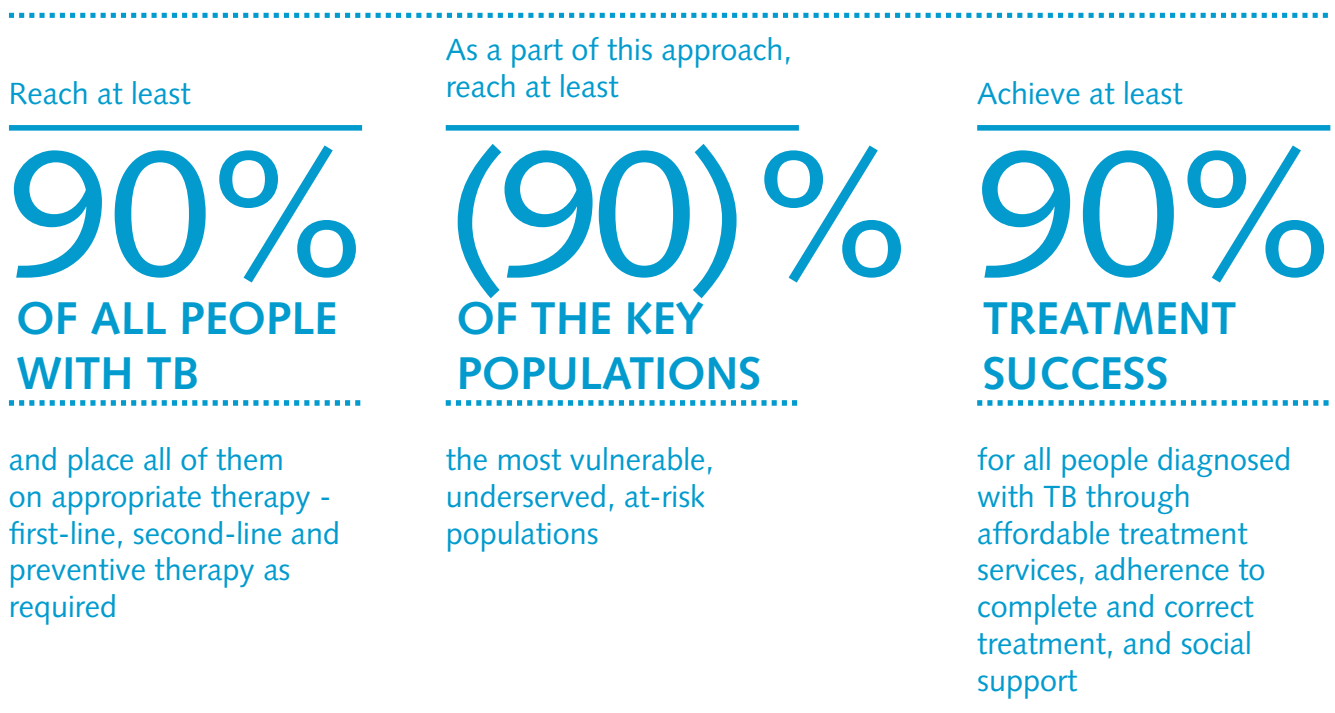
## Target audience

This chapter is for people affected by TB, community and civil society advocates, researchers, and policymakers.

## The Role of Advocacy in reaching the global TB elimination targets

Stigma towards people with or vulnerable to TB drives discriminatory behaviors in the workplace, health facilities, schools, and communities. In many countries, discriminatory laws and policies reinforce this environment of social exclusion and marginalization. When society discriminates against people with TB, this discourages people from accessing health-care services, getting a diagnosis, and enrolling and adhering to treatment. This in turn hampers efforts to reach the people centered at the 90-(90)-90 Global Plan targets to end TB.

**Figure 1. The Targets of the Global Plan to End TB**

Reach at least

# 90%
## OF ALL PEOPLE WITH TB

and place all of them on appropriate therapy - first-line, second-line and preventive therapy as required

As a part of this approach, reach at least

# (90)%
## OF THE KEY POPULATIONS

the most vulnerable, underserved, at-risk populations

Achieve at least

# 90%
## TREATMENT SUCCESS

for all people diagnosed with TB through affordable treatment services, adherence to complete and correct treatment, and social support

# Global Plan to End TB 2016-2020

To reach the End TB milestones, the Global Plan advocates for safe environments that are free from stigma and discrimination and supports community centered, human rights-based, and gender-sensitive advocacy efforts to eradicate stigma.

Health advocacy started gaining momentum in the early 1980s in reaction to public health's over-emphasis on curative medicine, which was pigeonholing policy development.[1] The *Ottawa Charter on Health Promotion*[2] identified advocacy as a strategy for health promotion in 1986,[3] and the World Health Organization defined health advocacy in a *Health Promotion Glossary* in 1998, recognizing the role advocacy plays in policy engagement as well as the need to foster collaboration and innovation across disciplines. Today health advocacy is often described as one of the foremost strategies for the achievement of health promotion aims, which embrace democratic participation, community development, and empowerment.[4] Health advocacy has two main goals: the protection of vulnerable people (representational advocacy), and the empowerment of people who require support by enabling them to express their needs and make decisions (facilitation advocacy).[5] In the field of international development, there is an increasing emphasis on evidence-based policy making,[6] evidence as a means to bolster advocacy[7] and the need for collaboration to enhance research.

Community advocates play a critical role in research, and their increased engagement stems from community and advocate demands for self-determination and meaningful participation in interventions.[8] Communities are also uniquely placed to document and analyze the intersectionality between stigma and poverty, stigma and social exclusion, stigma and gender, and HIV and TB, which is required to understand the subtleties of TB communities and effective TB responses.

One model for community advocates engagement in research is community-based participatory research (CBPR). It is grounded in principles of collaborative and equitable community engagement in research and shared ownership of research issues, processes, and products. It is based on two principles, perspective and politic. The variety of perspectives inherent in CBPR infuse diversity into research design, and many advocates leverage their political influence by owning research findings, incorporating them into policy, and using their authority and networks to realize change.[10] According to the Institute of Medicine, CBPR increases community understanding of the issues and enhances researchers' ability to understand community priorities, the importance of addressing community priorities, and the need for culturally sensitive advocacy, communications, and research approaches.[11]

## Why researchers are increasingly turning to Community-based Participatory Research

- There is a growing recognition that traditional research approaches have failed to solve complex health disparities.
- Community members are increasingly demanding that research address their locally identified and defined needs.
- Significant community involvement can lead to scientifically sound research.
- Research findings can be applied directly to develop interventions specific for communities.
- This approach to research has the potential to build greater trust and respect between researchers and communities.

When this approach is not pursued, a number of negative outcomes can occur. Communities can become disengaged and disempowered. The breakdown in relationships can mean that research may be incomplete or inaccurate, not have options for follow-up, or lose key partners.

In the case of TB, marginalized and vulnerable communities must be engaged and empowered if we are to treat all people with TB.[12] A guiding principle in TB research, particularly that focused on the experiences of those living with TB, should be ensuring that communities and people affected by TB are included as equal partners during research and that capacity is built to ensure this engagement is effective.

One reported barrier to the uptake of research findings is the lack of contact and collaboration between researchers, policymakers, and community advocates,[13] as well as the capacity (financial and skills) of community organizations to promote research uptake and influence policy.[14] Researchers collect data and advance science by reporting and summarizing their findings. They are usually less familiar, however, with engaging policy makers and communities in the research process, which drives advocacy efforts. Successful advocacy that effects change requires close partnerships and communication and interaction across various disciplines. Research that informs advocacy can push infrastructural (e.g., community infrastructure), public policy (e.g., changes to laws) and societal change (e.g., attitudes to the construct), as conveyed in Figure 2.
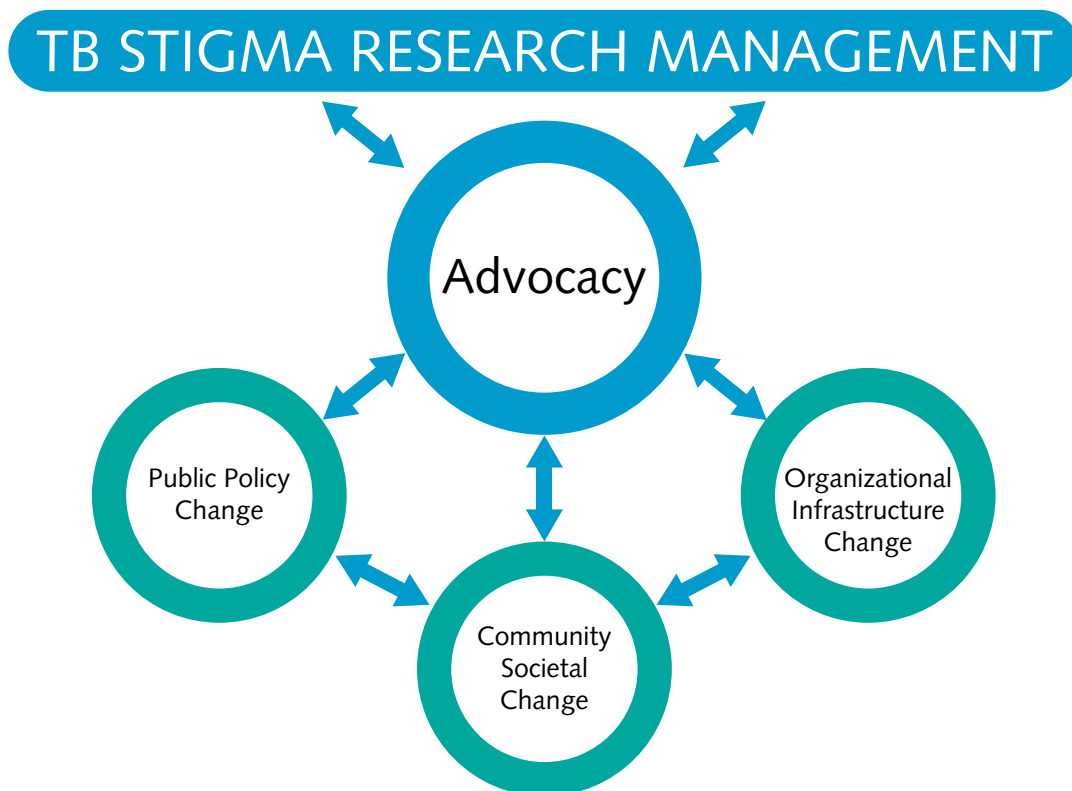
## Examples of Community Advocates in HIV and TB Research

**Community Advisory Boards - HIV**

An example of CBPR can be seen in the context of HIV/AIDS research when the U.S. National Institutes of Health (NIH) first mandated the use of Community Advisory Boards (CABs) in clinical trials in 1987.[15] This was in response to AIDS activism of that time. CABs can be used as a liaison between the community and researchers, informing the community about the research, including their rights to consent, strengthening the consent process, ensuring subjects are protected during the process, disseminating results, and advocacy.[16] Today CAB involvement is a requirement for all National Institute of Allergy and Infectious Diseases (NIAID) sponsored programs.[17]

While research can help community-driven advocacy, community-driven advocacy can help research. The potential value of the skills and reach of community advocacy networks have persuaded many researchers to partner and collaborate with civil society.[18] Evidence-based advocacy integrates the otherwise independent but overlapping work of communities, researchers, clinicians, public health officials, and policymakers to apply scientific principles to widespread health promotion efforts.[19]

## People Living with HIV Stigma Index

One extraordinary initiative that merges research, health promotion, and advocacy is the People Living with HIV Stigma Index. People living with HIV and HIV Policy and program managers understand that to achieve universal access to treatment, prevention, and services, you must address stigma and discrimination. The HIV Stigma Index is a tool that measures and detects changing trends in the stigma and discrimination experienced by people living with HIV. Over 100,000 people living with HIV have been trained and engaged with this tool, which helps the community own the process and enhances their capacity to engage in research. The HIV Stigma Index is the world's largest social research project implemented by people living with HIV. According to GNP+ (Global Network of People Living with HIV), the process was as important as the output, as it operationalized the Greater Involvement of People Living with HIV and AIDS (GIPA) principle, while building an evidence base to inform advocacy.

## Community Advisory Boards & Community Research Advisory Group – TB

The Global TB Community Advisory Board (TB CAB) and the Community Research Advisory Group (CRAG) to the U.S. Centers for Disease Control and Prevention's Tuberculosis Trials Consortium are two groups of research-literate community activists who advise on community needs and scientific priorities for the TB response. Working closely with Treatment Action Group (TAG), both groups advise institutions conducting TB clinical trials. TB CAB advises institutions conducting clinical trials on new TB drugs, treatment regimens, diagnostics, and vaccines, and provides input on study design, early access, regulatory approval, post-marketing, and implementation strategies.

## Who are the TB advocates?

In the past, TB advocacy efforts contrasted starkly with those for HIV/AIDS. While communities of people living with HIV joined forces, the TB response remained passive. This reaction can be explained by the top-down bio-medical approach to TB, the lack of commitment to engage with communities, and the absence of funding for community support groups and community advocacy platforms. Today, however, the TB advocacy community is expanding, as more advocates engage strategically and collectively within complex social, scientific, and political environments.[20] Stigma must now become a focus of these TB community advocacy and peer support structures. Given the very nature of stigma, people affected by TB can become disconnected from their social support networks, their family members, and partners. Community networks already address the social exclusion stigma has inflicted on their peers. Stigma advocacy is a critical next step.

There are different community and civil society advocacy platforms at the global, regional, and national levels who must be engaged in all aspects of the TB response. These include:

**Global advocates**
- Treatment Action Group.
- The Global TB Caucus.
- RESULTS.
- Global Coalition of TB Activists.

**Regional advocates**
1. Europe and Central Asia
   - TB People.
   - TB Europe Coalition (TBEC).
2. Africa
   - African Coalition on TB (ACT).
3. Asia and the Pacific
   - Activists Coalition on Tuberculosis Asia Pacific (ACT Asia-Pacific).
4. Latin America and the Caribbean
   - Americas TB Coalition.
   - Red de Personas Afectadas por Tuberculosis en Latino América y El Caribe (REDTBLAC).
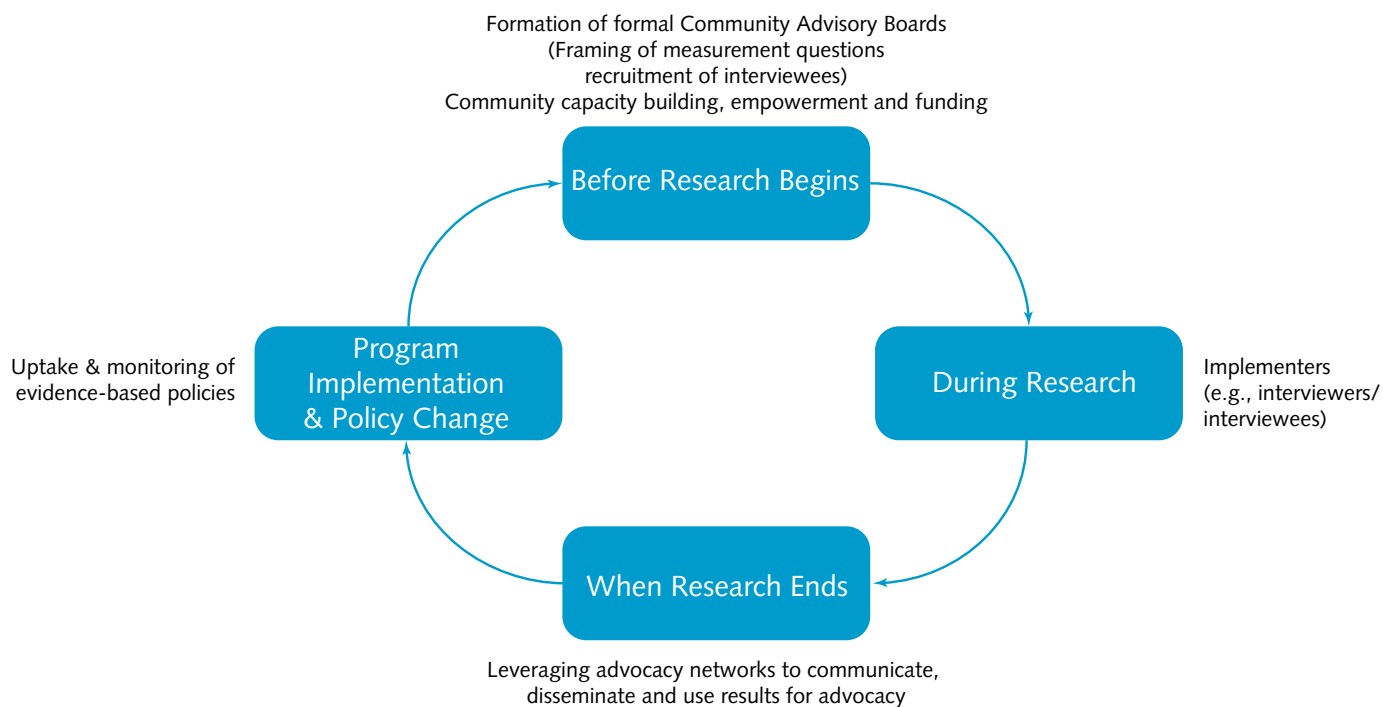
# National Community Advocates

At a national level, there are a plethora of organizations engaged in TB advocacy that connect TB experiences to the broader political, social, scientific, and advocacy realms. Throughout 2016-2017, Stop TB Partnership supported these networks to engage in collective, informed, and community-driven advocacy at the national, regional, and global levels. These include:

- Tajikistan: STOP TB Partnership Tajikistan.
- India: Touched by TB.
- Cameroon: National TB Community Coalition Cameroon.
- Democratic Republic of Congo: Stop TB RDC.
- Cambodia: National Network of People Living With or Experiencing TB.
- Ghana: Ghana Unites Against TB.
- Georgia: TB Georgian Coalition.
- Tanzania: Tanzania TB Community Forum.
- Ethiopia: Ethiopian national TB Community Coalition.
- Sierra Leone: Civil Society Movement Against Tuberculosis in Sierra Leone (CISNAT-SL).

## Engaging TB community advocates in the stigma measurement process

Like other research processes, measuring stigma should not be imposed on communities, but rather it should embrace a participatory approach that calls for grassroots engagement.[21] Figure 3 depicts the role community advocates can play throughout the research cycle.

**Figure 3. Community engagement in TB stigma measurement. Adapted from A. DeLuca, et al.[22]**

Formation of formal Community Advisory Boards
(Framing of measurement questions
recruitment of interviewees)
Community capacity building, empowerment and funding

**Before Research Begins**

**During Research** — Implementers (e.g., interviewers/ interviewees)

**When Research Ends**

Leveraging advocacy networks to communicate, disseminate and use results for advocacy

**Program Implementation & Policy Change** — Uptake & monitoring of evidence-based policies

## Before research begins

Communities must first mobilize before research begins (De Luca et al.) Community engagement can be in the form of a community advisory board, which can manifest the social value of TB stigma research for communities and can help communities accept the research as a partnership.[23] The community advisory board can also help formulate research questions. A key sub-population to engage in stigma measurement are those who were lost to follow-up. A better understanding of the link between lost to follow-up during treatment, timing, and their assessment of stigma factor could be key to designing timely intervention strategies.[24]

When soliciting community engagement in research, researchers will have to be mindful of label avoidance, and how community members may opt out if they perceive that their participation is to be accompanied by a label. In the context of mental health and service provision, many people choose not to access health services for fear of the "mental patient" label, and the potential discrimination

associated with this label. Researchers and community members should work together to address ways to avoid labeling in the context of TB stigma measurement.

For example, the mental health community is changing the terminology to be more sensitive to those with the condition; e.g., dementia is now called Alzheimer's disease, and manic-depressive illness is now called bipolar disorder. TB suspect is an example of terminology related to TB that could be more sensitive and empowering for those with the disease. In order to be empowering and inclusive, there must be thoughtful discussion between community members and researchers regarding how research is framed and presented to communities as well as the process and language used to recruit community members.

## Ethical research

Other ethical considerations that should be taken into account are informed consent and confidentiality, as well as cultural and linguistic sensitivities. Like all studies that involve human subjects, the TB stigma measurement process will have to observe standards pertaining to ethical issues and data protection. Those implementing the research should make sure that it conforms to that country's ethical and data protection requirements. Each interviewee must be asked to consent to the collection and processing of their personal data after being fully informed about the nature of the TB stigma measurement research, who is involved, how the data will be managed and kept, and what the data will be used for.

Similarly, every effort must be made to ensure that the data collected from the community is kept confidential. Any breaches of confidentiality could lead to supplementary stigmatization, loss of employment, or more serious legal consequences for individuals who identify with a criminalized community, including people who use drugs. Measures to avoid this must be developed in collaboration with community members. This should be part of a broader community engagement strategy in support of research. A barrier to community engagement is lack of funding.

Other ethical considerations that should be explored include the cultural, social, and linguistic sensitivities of communities. Engagement should be appropriate to the groups being engaged. The appropriateness of imagery or terminology may vary across cultures, genders, and languages.

## When research ends

Community advocates can play a critical role in leveraging the results of stigma measurement research. The community can push for change at the public policy, community, and organizational/infrastructural levels. Research results can be the solid foundation for influential and effective advocacy. This is particularly significant in the case of operational research focusing on community-based models of prevention, treatment, care, and support. Communities have a vested interest in these approaches, and are therefore an important ally in driving change.

Affected communities can also play an important role in monitoring and shadow reporting. This potential increases as the potential to access and engage new technologies increases. Communities can connect with the National TB Program, advising them of issues with implementing new policies, laws, or systems in an appropriate manner that is people-centered, gender sensitive, and based on human rights. Communities can therefore gather evidence and educate. They can also connect with other stakeholders, or the Country Coordinating Mechanism for eligible Global Fund Countries, to report implementation challenges. This form of shadow reporting, especially in partnership with the National TB Program, can actively result in stronger TB programs.
Finally, the community can work with other actors to effectively address research findings and policy changes. When education, monitoring, and reporting prove ineffective, communities can connect with the media, court system, and independent human rights commissions to access legal aid.

## Using the courts for advocacy

The court system can provide an avenue for advocacy. KELIN is an organization in Kenya established to protect and promote health-related human rights. This organization filed a petition against a TB patient being sentenced to prison. On March 24, 2016 (World TB Day) the High Court declared that the practice of incarcerating TB patients is illegal and unconstitutional.[25] Another example is Lawyers Collective, an organization in India that successfully fought to get one woman access to the medication Bedaquiline.[26] A legal route also sets a precedent for subsequent court cases.

## Legislative and regulatory advocacy

Regulatory and legislative advocacy are often used by organizations seeking to have their voices heard. Although the specific procedures vary depending on the legal jurisdiction, the strategies are common across countries. Led by its members, the Global TB Caucus is a unique international network of political representatives who work together at the local, regional, and global levels to advocate for TB prevention and control.

Members of the Caucus in particular commit to:

- Working across geographical and political divides in a non-partisan and inclusive fashion;
- Engaging with civil society and all other stakeholders involved in the fight against the TB epidemic; and
- Confronting the stigma and social isolation associated with the disease.

In the Philippines one of the most comprehensive global laws on Tuberculosis that has been signed into law was sponsored by the Asia Pacific TB Caucus Co-Chair, Congresswomen Dr Helen Tan MP. It seeks to increase state investments for the prevention, treatment, and control of TB. The Philippines and Japan are among a few countries in the world that have existing legislation against TB.

## Advocating through the media

The media is one of the most common mediums leveraged for health advocacy. It is challenging for advocates to generate enough interest for the media to address their issues over an extended period of time. New media platforms, including social media, offers opportunities for affected communities to capture and maintain the mainstream media's attention. Public health communication and advocacy campaigns are credited with raising awareness and encouraging people to access treatment and care. Communication and engagement strategies that engage different media industries and audiences are critical to bringing about meaningful change.

Mass media interventions have proven effective in changing individual behavior, reducing stigma and raising awareness.[27,28,29] The media has the potential to generate knowledge about TB, promoting awareness of TB services, and reduce stigma.[30] *Unmask Stigma* is an international TB stigma awareness and education campaign motivated by the personal experiences of health care workers and patients with TB.

The challenge for the media and advocates is to not reinforce biased beliefs and stigmatizing attitudes. According to research conducted by the European Commission and the London School of Economics and Political Science, the media has contributed to the negative attitudes towards people with mental health problems in the European Union by sensationalist and inaccurate portrayals of mental health.[31] *Unmask Stigma* mitigated this potential problem by designing and promoting the campaign under the leadership of those who were directly impacted by TB and TB stigma.

# Tips for community advocates

1. **Understand your epidemic.** Be knowledgeable, informed, and prepared.
2. **Understand your environment.** Develop an in-depth understanding of the political and social context you wish to influence.
3. **Understand the strengths and weaknesses of your position.** Scrutinize the issue from all perspectives, including opposing views.
4. **Define your desired outcome.** Define what you want to achieve (inform and educate, build awareness, or change laws, policies, or behaviors.)
5. **Identify key people and partnerships.** Understand who the strategic partners that you need to influence are.
6. **Develop a strategy.** Plan how you are going to achieve your desired outcome.
7. **Be certain of the facts.** Inaccurate or misinterpreted information will diminish the advocacy efforts and the issue itself.
8. **Be constructive.** Build partnerships and allies and propose solutions rather than problems.
9. **Be regular and consistent.** Be present in order to be effective.

## Table 1. Recommendations for advocacy priorities to modify practices that stigmatize people with TB[32]

| TB Policy or Practice | Strategies to Mitigate Stigma |
|---|---|
| TB screening and testing | • Inform and counsel patients about TB and/or differential diagnoses pre- and post-screening<br>• Protect patient confidentiality (e.g., share test results in private)<br>• Advise patients of their right to access treatment |
| TB notification | • Protect confidentiality of TB test results and patient anonymity (e.g., use unique patient IDs, or draw on local HIV reporting methods)<br>• Institute safeguards to ensure that TB test status does not affect a person's employment status, immigration status, or qualification for other government benefits or services (e.g., implement firewall policies between public health services and other state functions, such as immigration and border control) |
| Contact tracing | • Integrate TB-related health literacy and counseling into contact investigations (e.g., family counseling and support patients in disclosing their illness)<br>• Protect patient confidentiality (e.g., avoid naming or labeling the index patient wherever possible)<br>• Provide preventive therapy where warranted (i.e., ensure that a TB diagnosis is followed by the option to initiate therapy under free and informed consent) |
| Control infection risk | • Inform and counsel patients about TB transmission risks and how to reduce these<br>• Normalize face mask use and emphasize its capacity to protect patients<br>• Identify safe peer and social support networks to mitigate social isolation |

| | |
|---|---|
| TB Treatment | • Inform and counsel patients about TB treatment, including duration, potential side effects, expected initiation benefits, availability of free treatment, and the importance of adherence<br>• Promote equitable access to newer, safer, shorter, treatment regimens<br>• Engage patients in decisions regarding auxiliary therapy, where possible (e.g., management of side effects, mental health, and nutritional supplementation)<br>• Refer patients to services and resources to facilitate adequate support for adherence, including referral to champion patients and TB survivors<br>• Advise patients of their right to access treatment as opposed to just their mandate to initiate and adhere to therapy<br>• Establish systems that respect patient decisions to access TB services from their preferred provider and maintain continuity of care (e.g., public–private health partnerships, integration of TB and HIV services) |
| TB treatment monitoring | • Build TB treatment literacy to support self-administration<br>• Implement adherence promotion strategies that are feasible and acceptable to patients (e.g., phone reminders, smart pill boxes, and peer networks)<br>• Promote mechanisms to protect patients' employment and enable access to social security during TB treatment<br>• Facilitate safe reintegration of patients into social and work settings to foster social well-being and financial independence (e.g., by sensitizing employers and families to TB)<br>• Assess palliative care needs and resources for patients who may be incurable, and their caregivers |
| TB research activities | • Involve research participants and other community members and stakeholders in the research development and dissemination process (e.g., following the recommendations of the Good Participatory Practices for TB Drug Trials)<br>• Create a community advisory group to inform the research process and ensure that research practices and procedures do not inadvertently result in stigmatization of patients with TB |
| TB consciousness and awareness raising activities | • Raise global consciousness by connecting TB-affected communities through media and other forms of public representation (e.g., via stories and images of healthy TB survivors rather than those that reinforce negative stereotypes against groups most affected by TB)<br>• Disrupt the current narrative underlying practices that may be stigmatizing (e.g., reframe TB screening contact tracing practices as empowering so that an index patient gains control of his/her illness and uses this knowledge to protect others)<br>• Use TB science to affirm rather than neglect the rights of patients with TB (e.g., emphasize when a patient becomes non-infectious just as vigorously as his/her infectious state was emphasized)<br>• Sensitize employers to support employees with TB and promote employment of TB survivors<br>• Build spaces for consciousness raising by bringing together people affected by TB to share their experiences and identify common challenges to change practices that stigmatize or impede patient-centered care (e.g., through peer networks and advocacy forums)<br>• Routinely invite TB survivors to speak at TB conferences and meetings to acknowledge their suffering and to give them a voice in the mainstream TB community |

Other effective principles and interventions for stigma-related advocacy priorities are informed by the Global Plan to End TB and adapted from *Confronting discrimination – Overcoming HIV-related stigma and discrimination in health care settings and beyond*.[33]

At the community level, priorities include empowering individuals and communities to address and respond to discrimination, leveraging community healthcare workers who can mitigate discrimination and stigma, and leveraging community-based organizations who can document rights violations. One example of this is Stop TB Partnership's *OneImpact*, a digital platform that enhances community empowerment and social accountability.

In the healthcare setting, priorities include training and supporting health workers to overcome personal and institutional discriminatory attitudes and actions, and strengthening accountability for discrimination-free health care. The fundamental ethical principles at the heart of clinical care are those of non-maleficence (do no harm), beneficence (do good), and trust. Other priorities include enforcing the right to health, which includes judicial accountability, and providing people-centered services, rather than those that put diseases at the center of health systems. Examples of this include:

- Adapting service opening hours to suit service users;
- Integrating HIV and sexual and reproductive health services to avoid the disclosure of confidential information;
- Addressing discrimination and building trust between stakeholders; and
- Consultation with beneficiaries to ensure that their needs are understood and actually met, and to improve their overall engagement with health services.

At the policy level, priorities include eliminating discriminatory laws and policies, introducing protective legislation, strengthening the legal and policy frameworks to address discrimination, and ensuring that all actors take responsibility for the elimination of discrimination.

## Conclusion

Stigma must be eliminated in order to reach the people centered at the 90-(90)-90 targets. It must first be measured, however, before it can be addressed. The TB community advocacy movement is expanding, and community advocates have a critical role in measuring and eliminating stigma. Community advocates need to be involved in the research processes and implementation from beginning to end. Drawing from the contexts of TB and HIV, protective laws and policies must replace those that discriminate. Health-care workers must provide people-centered care and be aware of personal rights. Individuals and governments must be held accountable by empowered communities who can monitor health services, help address grievances related to stigma and discrimination, and improve health services. When governments, health service

providers, and communities put these measures into place, the global commitment to end stigma and TB can be realized.

## Acknowledgements

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# Chapter 13

# Costing Stigmatization: Justice enhanced cost-effectiveness methods

*Alice Zwerling*

## Abstract

This chapter lays out the methodological foundations for incorporating social justice into a cost-effectiveness analysis. Many core strategies in TB have unintended consequences that are not yet quantified in policy debates. For example, contact investigation can result in legally sanctioned violation of patient privacy – disclosing disease status to social networks.[1] Even direct observation of treatment (DOT), has a stigmatizing dimension due to its underlying assumption on untrustworthiness. Methods for discerning these trade-offs are explained in this chapter in easy to follow step-by-step approaches.

## Objectives

1. To understand the fundamentals of economic evaluation and its application to understanding impacts of TB stigma.
2. To introduce the concept of a novel methodology: Justice-enhanced cost-effectiveness analysis, designed to incorporate social justice concerns, such as stigma, into traditional cost-effectiveness analyses.

## Target audience

The chapter is for National TB program staff, implementing agencies, non-governmental organizations, donors, policymakers, activists and technical partners. Health economists in university settings, organizations with research staff, and teams with economics backgrounds can also gain from applying the principles described in this chapter.

# Introduction to economic evaluation and its role in TB control

In the words of Drummond et al., "economic evaluation is the comparative analysis of alternative courses of action in terms of both their costs and their consequences."[1] It provides a systematic and transparent framework for assessing and comparing costs – both explicit and implicit - and efficiency. Economic evaluation can provide evidence to support officials making difficult choices around what and how to fund key interventions and programs. It can provide the framework to systematically approach key decisions, increasing the explicitness and accountability in decision-making.

For example, when the novel diagnostic TB test GeneXpert (Xpert) was introduced, several economic evaluations were conducted to assess the additional yield from Xpert (additional cases diagnosed, unnecessary treatment avoided, reduction in time to treatment initiation) and the costs of the Xpert system compared with the standard of care at the time, sputum smear microscopy (SSM). Economic studies showed the additional sensitivity and specificity of Xpert could be highly cost-effective compared with SSM in certain settings.[2-4] In the absence of evidence, decision-makers often rely on educated guesses or gut-feelings, or they simply continue supporting the status-quo. Economic evaluations help ensure limited resources are used to achieve the most health benefit for the least cost, leading to more efficient programs, less waste, and larger health gains.[5]

If resources, such as drugs, healthcare workforce, time, and money were at infinite supply, there would not be a need for economic evaluation. However, NTPs, NGOs, and large funding agencies all operate with finite and scarce resources. Decision-makers in the TB community want and need to use scarce resources efficiently to ensure that the most health benefit is attained for the smallest cost. Costs and cost-effectiveness are therefore important considerations when implementing and scaling-up TB programs. Economic evaluation is a key tool to ensuring this, and it provides a framework to support critical choices.

## Introduction to economic evaluation

Economic evaluation has become a critical element in the decision-making process of resource allocation. Many organizations, governments, and funding agencies now require it as part of the decision-making process, along with traditional clinical trial and epidemiological data. Economic evaluation is used to compare alternative programs or may assess the consequences of introducing a novel program or expanding an existing approach.[1,6-8] Economic evaluations are concerned not just with how effective a program or test is (e.g., how many additional cases diagnosed with Xpert versus SSM), but also with program cost (Figure 1).

There are several types of economic evaluation. Cost-minimization analysis compared programs or interventions with the same outcome or assumed equal effectiveness (same number of persons diagnosed in standard of care approach and novel intervention) and seeks to compare only the costs, with the aim to identify the least costly approach. Cost-effectiveness analysis (CEA) compares both health and cost outcomes, with health units measured in natural units, such as the number of persons with TB diagnosed or cured, or number of deaths averted. Cost-utility analysis (CUA) is a form of cost-effectiveness analysis where health outcomes are measured as health benefits, commonly referred to in health economic literature as health utilities[9]: disability-adjusted life years (DALYs)[10,11] or quality-adjusted life years (QALYs)[12] as opposed to natural units. The outcomes in a CUA would be $ per DALY averted or $ per QALY gained.

**Figure 1. Economic Evaluation Always Involves a Comparative Analysis of Alternative Courses of Action**
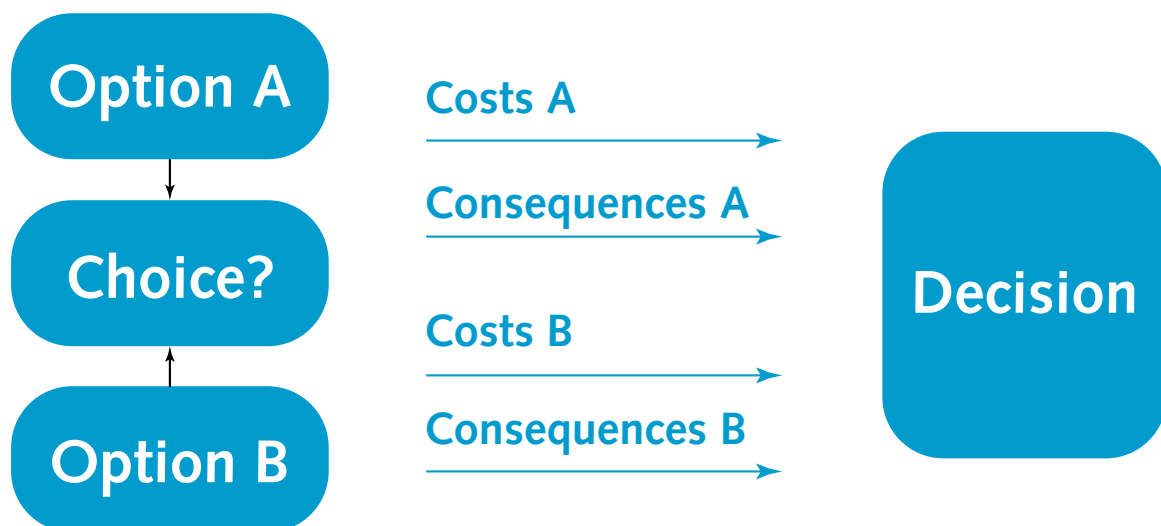


The incremental cost-effectiveness Ratio or ICER is a common primary outcome for most CEAs. It represents the incremental cost of a particular intervention or approach compared with another intervention (typically the standard of care) divided by the incremental effectiveness of that approach.

$$\text{ICER} = \frac{\text{(Cost of Approach A – Cost of Approach B)}}{\text{(Effectiveness of Approach A – Effectiveness of Approach B)}}$$

Taking the example of a CEA assessing Xpert versus SSM, the ICER could be $/additional case diagnosed. In this case, it would represent the incremental cost of diagnosing one additional case of TB using Xpert compared with SSM. If the ICER is $200/additional TB case diagnosed, we conclude it would cost an additional $200 to diagnose each additional TB case using Xpert compared with

SSM. When calculating an ICER, there will always be a comparison between two approaches, often a novel intervention under question and the current standard of care.
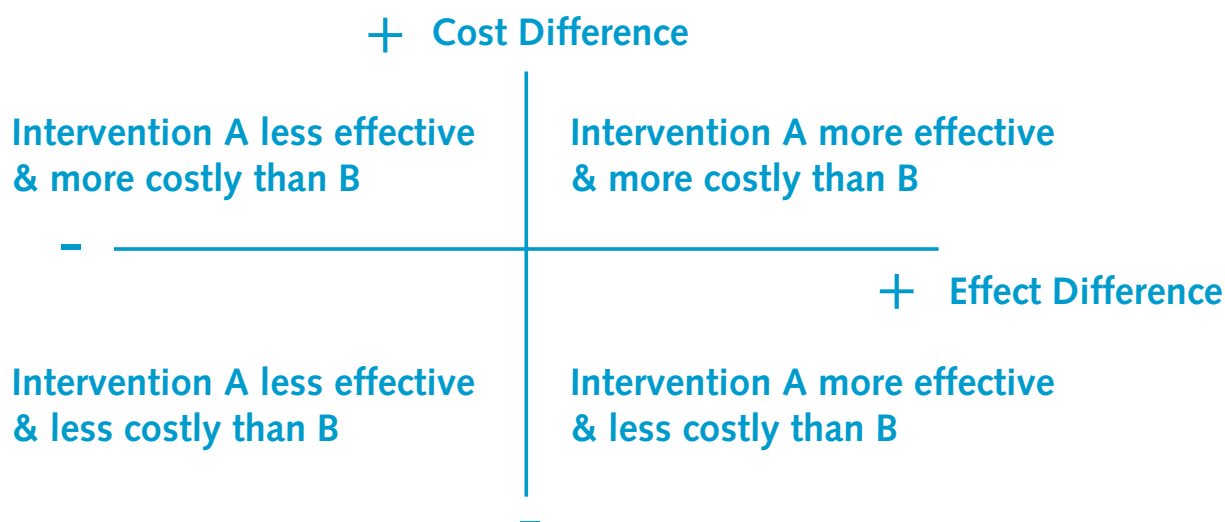
Many analyses employ ICER thresholds to interpret whether a particular ICER value should be considered cost-effective or not. WHO recommends that an ICER value smaller than the gross domestic profit (GDP) per capita for a given country be considered highly cost-effective, and an ICER less than three-fold the GDP per capita be considered cost-effective. However, these thresholds can be very controversial when used to make resource allocation decisions in the absence of other important considerations, as they do not account for equity or social justice concerns. Finally, it is critical to note that cost-effective does not equal affordable. Many interventions which are found to be cost-effective are still costly programs to implement, and affordability of scale-up and implementation of novel interventions requires careful consideration beyond simple cost-effectiveness estimates.

## The Cost-effectiveness plane

The cost-effectiveness plane (Figure 2) is a graphical expression of ICER and provides a useful way to think about cost-effectiveness outcomes.[13] Along the horizontal axis is the difference in effectiveness between two approaches (e.g., the difference in effectiveness between Xpert cases diagnosed and SSM cases diagnosed). Along the vertical axis is the difference in cost between the two approaches (difference in cost between Xpert and SSM). If the ICER lies in the upper left quadrant, the novel approach or Xpert in our example is less effective (diagnoses fewer TB patients) and is also more costly. In this scenario, we would reject the novel test in favor of the more effective and cheaper standard of care or SSM.

If the ICER lies in the lower left quadrant, the novel approach is less effective but also less costly. If the ICER lies in the lower right quadrant, the novel approach is more effective and less costly than the standard of care. This is the ideal situation (albeit rare), where a novel approach is both more effective and cheaper. Finally, if the ICER lies in the upper right hand, the novel approach is more effective and more costly. In such a case, which is common with new interventions, further resource allocation decisions will require consideration of available resources, health priorities and other demands, and affordability.

**＋ Cost Difference**

| | |
|---|---|
| **Intervention A less effective & more costly than B** | **Intervention A more effective & more costly than B** |

**＋ Effect Difference**

| | |
|---|---|
| **Intervention A less effective & less costly than B** | **Intervention A more effective & less costly than B** |

## Economic evaluation: study design

Designing a cost-effectiveness study follows many of the same principles as any research study, but instead of trying to prove that a hypothesis is true or false, its purpose is to aid in decision-making concerning a specific problem (i.e., should we invest in intervention A or B.) Table 1 outlines the key elements in designing a cost-effectiveness analysis. We will discuss each step in more detail, and additional resources on economic evaluation study design can be found at the end of this chapter.

**Table 1. Key Steps in Designing a Cost-Effectiveness Analysis**

| |
|---|
| 1. Define the research problem<br> • What decision needs to be made? |
| 2. What interventions will be compared?<br> • What is the standard of care or the base case scenario?<br> • What is the alternative scenario that you want to evaluate? |
| 3. Define the target population<br> • To what population should the results be generalizable? |
| 4. Choose the costing perspective to model<br> • Who will be making the decision (health care system or societal perspective)? |
| 5. Choose the time frame and analytic horizon under study |
| 6. Decide on outcome measures for effectiveness data.<br> • Cases diagnosed, cases averted, DALYs/QALYs? |
| 7. Define what costs are to be included |
| 8. Define what functions and level of the health system to model. How detailed will the decision analysis or other model approach be? |

Defining the research question is a critical element, as this will guide the rest of the methodological design. You must know what question you are trying to answer or what decision you are trying to make before setting out a cost-effectiveness study. Ensure your question is specific, with a clearly defined population, intervention/program of interest, comparison, and primary outcome. For example, in the case of the cost-effectiveness of Xpert compared to smear, a specific question should include the population and setting (e.g. persons with symptoms of active TB in Malawi).

Choosing the alternatives to be compared is an important element of selecting the study question and objectives. Choice of comparison can be critical. Comparison with one approach can make your intervention look highly cost-effective while another comparison could have it showing poorly. Some cost-effectiveness analyses have looked at comparing SSM alone versus Xpert in addition to SSM, while others compare Xpert as a replacement for SSM. A novel intervention is often compared with the standard of care or status quo. This is a helpful comparison for policymakers and budget holders to know what a new approach would cost relative to what they are currently paying. Standard of care may be SSM or, in other settings, it may include LED microscopy.

Cost-effectiveness analyses are not always generalizable, as they are highly dependent on the setting, population, and context modeled.[14-16] Results from a CEA looking at Xpert in HIV + persons may not be generalizable to a setting with low HIV prevalence, as diagnostic accuracy varies across these groups. When choosing the target population, take great care to ensure the results will be generalizable to your population(s) of interest.

## Costing perspective

The costing perspective deals with the viewpoint used to assess the research question and affects which costs and outcomes will be included in the analysis. Typically, economic evaluations employ either a health system or societal perspective.[1,17] The health system perspective, sometimes referred to as the decision-maker perspective, is concerned only with costs and outcomes relevant to the health system or decision-maker. In the case of government funded TB programs, only costs incurred by the health system would be included in the analysis. In the societal perspective approach, a wider range of costs and outcomes may be included, such as costs borne by the TB patient and their families, and costs borne by society in terms of lost time and wages through employment.

## Timeframe & analytic horizon under study

The time frame in an economic evaluation refers to the duration or time when the intervention is in effect, while the analytic horizon is the duration over which

outcomes and costs are observable or measured (Figure 3).[1,7] In some instances they may be the same duration. However, in TB we are often concerned with outcomes (death, treatment cure, etc.) that occur after the intervention period or time frame, therefore the analytic horizon is frequently much longer than the time frame. The analytic horizon must include all main costs and health benefits during this period. It should be chosen to allow for seasonal variation (if these are thought to be likely) and must include the intervention implementation and running time.

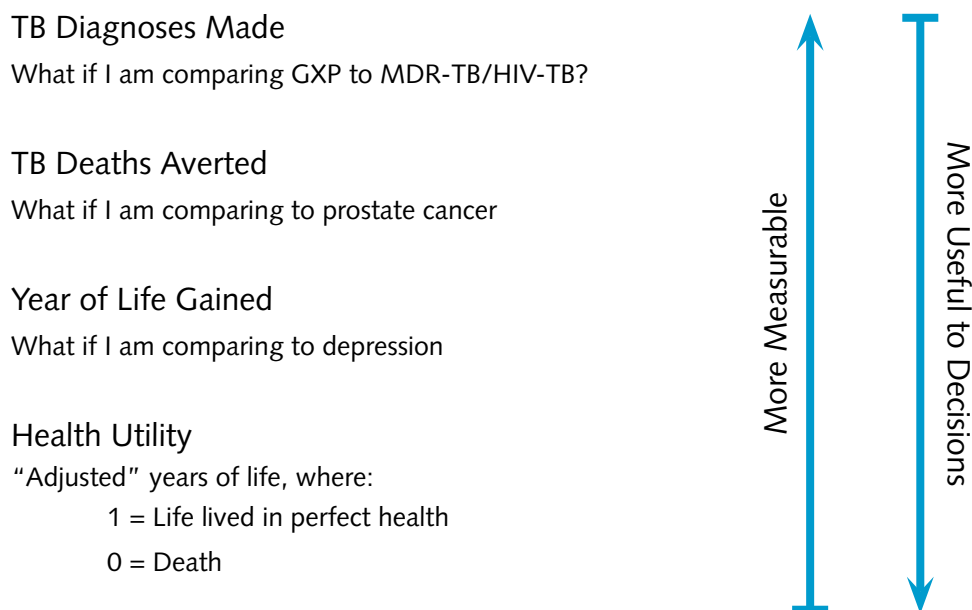**Figure 3. Schematic of Time Frame and the Analytic Horizon**
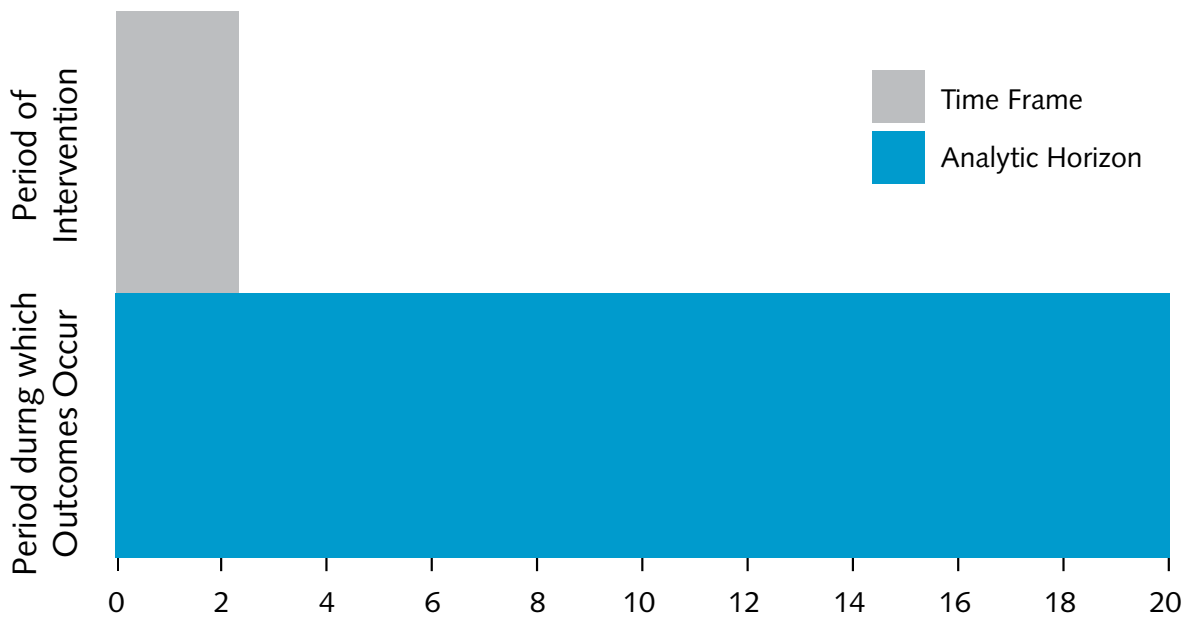


## Choosing outcome measures for effectiveness data

The effectiveness outcome measure should be chosen to have relevance to patients, providers, and decision-makers. They should reflect the question under study. The TB patient diagnosed may be a natural outcome in an Xpert analysis, but would be unhelpful if the intervention looked at novel MDR-TB treatment regimen, for example. Natural units or intermediate outcomes generally are more specific to your research problem (i.e., cases or death averted, cases diagnosed, increased physical activity, or reduction in symptoms). But these units can be difficult to compare across different disease areas. How can one compare one additional TB case diagnosed versus one case of malaria treated?

Final outcomes typically consider full expected lifespan, and can be compared across different diseases. They include the health utilities we discussed earlier (disability-adjusted life years (DALYs) - measure of years in perfect health lost, quality-adjusted life years (QALYs) - measure of years lived in perfect health gained). In our Xpert example, using health utilities as an effectiveness outcome measure, we can compare an ICER of $100/DALY averted (from Xpert CEA) with an ICER for prostate cancer screening of $300/DALY averted.

**Figure 4. Options for Effectiveness**

TB Diagnoses Made
What if I am comparing GXP to MDR-TB/HIV-TB?

TB Deaths Averted
What if I am comparing to prostate cancer

Year of Life Gained
What if I am comparing to depression

Health Utility
"Adjusted" years of life, where:
       1 = Life lived in perfect health
       0 = Death

*More Measurable*

*More Useful to Decisions*

# Deciding what costs should be included?

Costing is a vast topic, and there are many good resources for methods on measuring and valuing cost inputs for economic evaluations.[1,18-20] First, relevant activities for costing must be identified. For example, in costing a novel test such as Xpert, we might identify activities to be costed to include symptom screening for TB, referral for sputum, sputum collection, performing the smear, performing the Xpert test, feedback of test results, initiating treatment, etc. All activities directly involved with the provision of the novel program and its comparator (standard of care, SSM in this example) should be included and costed. Once relevant activities have been identified, unit costs will need to be calculated for each activity. Unit costs typically consist of overhead and capital costs, salaries, consumables and drugs, and equipment.

# The key costs to include:

- Overhead costs including utilities.
- Buildings and furniture.
- Salary costs, including training and supervisory costs.
- Equipment.
- Maintenance.
- Transport.
- Administrative costs, including internet, phone, stationary, postage, etc.
- Consumables.
- Diagnostics.
- Drug costs and ancillary drug costs.
- Program specific/novel intervention related costs (implementation costs may also be included if relevant to the study question).

For economists, costs are not simply how much we pay for something (market price), but they are thought of in terms of opportunity costs as well. Opportunity costs refer to the value that could have been gained from the next best alternative when one course of action is chosen. For example, a nurse who decides to volunteer her time to do TB screening may have a financial or explicit cost of $0. However, if she does voluntary TB screening, society loses the ability to employ her skills in the emergency room of a public hospital, for example. The value of the donated time (or the implicit cost of working at a public hospital) should therefore be accounted for in a CEA analysis. More details on other costing approaches and methodologies can be found in the resources listed at the end of this chapter.
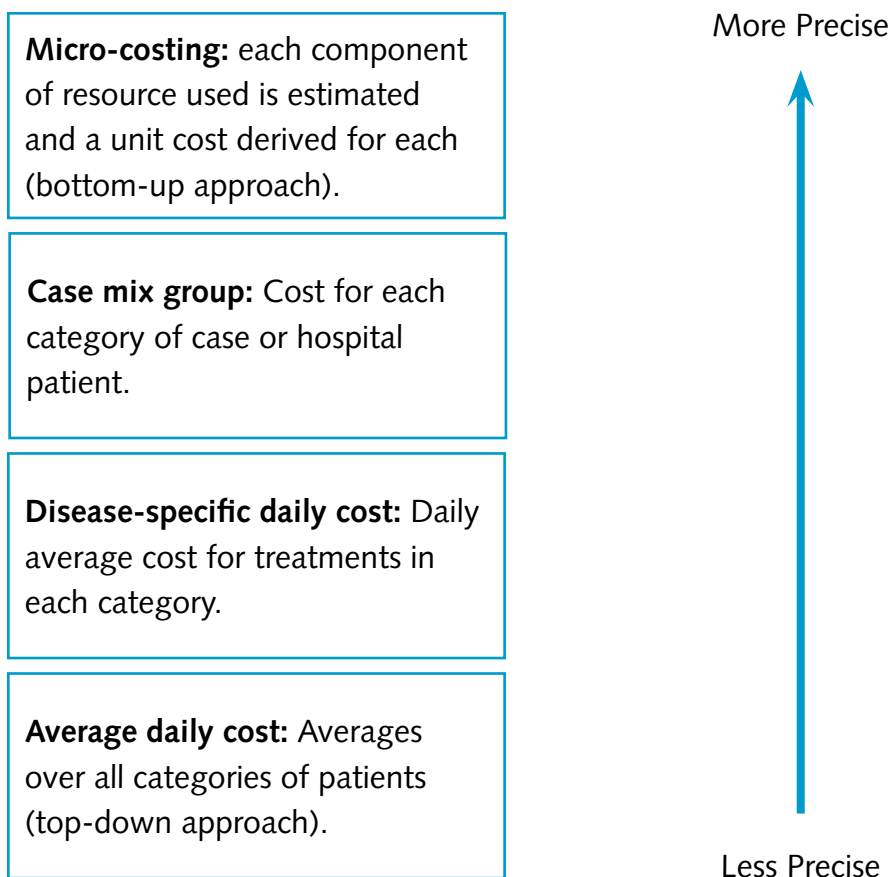
Unit cost estimation can be done using two different approaches: bottom-up and top-down estimation. In the bottom up approach, one identifies all resources used for each service and assigns a cost value to each resource. All resources used in a particular service or activity are then summed for that activity to build a total unit cost. This is often referred to as an 'ingredients' approach. For example, a unit cost for an Xpert may include overhead, consumables, including the cartridge, equipment, and labor costs. Bottom-up costing can be advantageous as it provides transparency, granularity, and versatility, but it tends to underestimate the true costs.

Top-down costing involves using total expenditures for an activity or service and dividing the total cost by the number of units of activity. In the Xpert example, one can use the total program budget/number of patients tested to calculate a unit cost per person tested. Advantages of the top-down approach include its reliance on more easily available costing data. It is a simpler approach and typically requires fewer resources in terms of money and time compared with the bottom-up approach. However, it tends to overestimate true costs and cannot identify key drivers of cost. When adequate manpower and resources are available, performing both bottom-up and top-down costing for unit costs is strongly advised. Unit costs from the two approaches can then be averaged to define summary unit costs.

## How precise should cost estimates be?

Empirical costing is a resource-intensive process that takes time and effort. There may be limitations to the costing effort due to constraints on data availability or time. Some judgment calls are needed to decide how accurate or precise cost estimates should be within a given study. The degree of precision required will depend on the likely quantitative importance of each cost category in the evaluation.

**Figure 5. Precision in Costing**

**Micro-costing:** each component of resource used is estimated and a unit cost derived for each (bottom-up approach).

**Case mix group:** Cost for each category of case or hospital patient.

**Disease-specific daily cost:** Daily average cost for treatments in each category.

**Average daily cost:** Averages over all categories of patients (top-down approach).

More Precise

Less Precise

## How can measured stigma be incorporated into traditional cost-effectiveness analyses

Some elements of measured stigma may be incorporated directly into either the cost or effectiveness measure in a traditional cost-effectiveness analysis. For example, stigma may result in financial costs when an individual with a TB diagnosis loses their job. As explained above, costing and cost-effectiveness analyses can take a health system or societal perspective. The societal perspective takes a broader approach and may include both direct and indirect costs to the patient, including costs associated with lost wages, travel costs, costs for additional medication not supplied by the health system, or additional child care or support for family members.

While not all impacts and effects of stigmatization may be included in the costing component, some, such as lost wages, can be. Unfortunately, these costs are rarely incorporated in traditional CEA, as societal perspective is rarely employed in TB CEA due to the additional time and resources required. Traditional approaches capture only one small part (the financial aspect) of the stigma impact on a TB patient, neglecting other important social impacts.

While not typical in most cost-effectiveness analyses, some elements of stigma could conceivably be included in the effectiveness component. For example,

the health utility, specifically the quality-adjusted life year (QALY), is intended to capture both the morbidity and mortality experienced by a patient given a particular health state. Accounting for time spent not in full health, this can include adverse events from treatment, or mental health effects from having been diagnosed. Elements of stigma impacting an individual's mental health and well-being could conceivably be included in this measure. However, this is rarely done, as it requires an involved and potentially lengthy undertaking to assign appropriate QALY weights to a variety of health states (including stigmas impacts) in a setting-specific manner.

## What does traditional cost-effectiveness analysis leave out in relation to stigma?

Traditional cost-effectiveness analyses have some important limitations which consumers should be aware of. From a policy perspective, it is important to consider that cost-effectiveness analyses assess average costs and effects, and do not necessarily account for the differences in costs and consequences of interventions among different patient or population groups. The identities of these groups (poor, migrants, vulnerable populations, geographically hard to reach populations, etc.) and the a priori distribution of costs and health status across these groups may have an important role in assessing social desirability or equity of certain interventions or programs under study. Therefore, the equitable distribution of costs and health effects across different groups should be an important factor in the decision-making process.

At the same time, more novel TB drugs and diagnostics are being introduced, and more are in development. Cost-effectiveness analyses continue to play an important role in the uptake and implementation of these new interventions and technologies. However, in many cases, the cost of new interventions can be prohibitively expensive while only conferring a small improvement in health benefit for the general population. As a result, such interventions would likely not be cost-effective in a traditional CEA.

For example, novel MDR-TB treatment regimens may reduce stigma impacts for patients with drug resistant-TB, but they come at a high cost and may not necessarily improve treatment outcomes when compared with standard therapy. In such instances, traditional cost-effectiveness analyses may find such novel regimens to be not cost-effective. In the absence of an explicit discussion of stigma, a CEA may lead to a policy decision that not only does not reduce stigma and other social injustices, but may in fact, promote interventions that increase stigma. In the case of novel MDR-TB drugs, which are very expensive and may offer only a small increase in effectiveness, a CEA in certain resource-constrained countries may deem these to not be cost-effective. Therefore, such countries may choose to continue using existing MDR-TB regimens, despite the potential for novel regimens to reduce stigma.[21]

The vast majority of current cost-effectiveness analyses addressing decisions around implementation and scale-up of novel TB treatment regimens do not specifically address and include issues around stigma (beyond stigma-associated costs as outlined above). As more stigma measurement tools are now being designed and validated, there is an opportunity to adapt our traditional cost-effectiveness approach to incorporate these elements and promote a more socially just decision-making process in which stigma is explicitly considered.

There are several methodological approaches now used in health economics developed with the aim of incorporating elements outside of traditional cost-effectiveness analysis. These include direct integration through quantitative equity weighting (extended CEA or ECEA)[22], mathematical programming to assess equity-related opportunity costs, and multi-criteria decision analysis (MCDA)[23,24], in which small groups of stakeholders are asked to weigh equity in comparison with efficiency and other priority-setting concerns.[25] While these approaches may offer some ability to incorporate equity elements beyond those typically accounted for in CEA, none were developed specifically to incorporate social justice concerns, such as stigma.

## An innovative methodology to explicitly consider stigma in CEA: Justice Enhanced CEA

Justice-enhanced CEA or JE-CEA is a novel conceptual methodology developed to explicitly consider elements of social justice (such as stigma) alongside traditional CEA. JE-CEA is a systematic, data-informed approach to enable decision-makers to explicitly consider the expected impacts on social justice elements, including stigma, alongside a traditional CEA. It involves three steps: the systematic collection of data about the stigma people experienced, the empirical findings from step 1 to inform social justice assessments (this can also be limited solely to measured stigma), and incorporation of stigma assessments into a decision analytic framework, including traditional CEA assessments. Please note that JE-CEA is a novel methodology under development.[26]
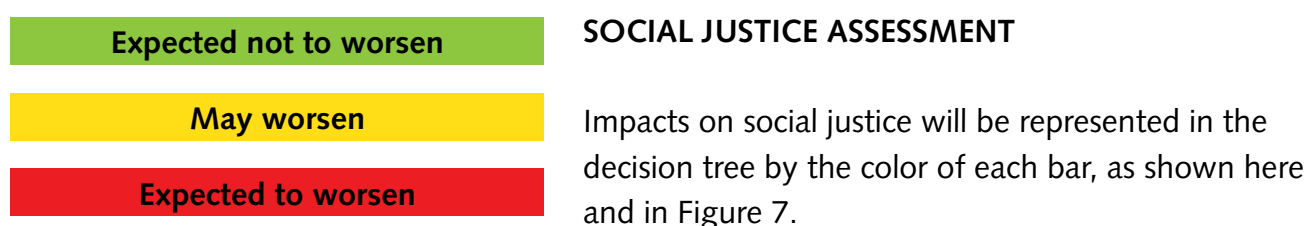
**Box 1. Current Limitations in Traditional CEA and Examples of Ways Justice-Enhanced CEA May Bolster Traditional CEA**

| Current gaps in traditional CEA | Advantages of JE-CEA approach |
|---|---|
| • No formal assessment of social justice.<br>• May promote policy choices that are cost-effective, but contribute to further clustering of disadvantage.<br>• Cannot provide information to highlight areas of negative social impacts for standard or novel interventions.<br>• Does not systematically include certain major considerations of social justice relevant to decisions that economic evaluation informs. | • Introduce language of social justice into CEA.<br>• Encourage the inclusion of formal assessments of social justice impacts in future decision and policy-making.<br>• Provide key information surrounding social justice necessary for advocacy (price negotiations of novel drugs for resource limited settings).<br>• Highlight need for data collection activities to inform future formal social justice assessments.<br>• Present considerations of social justice simultaneous with those of cost-effectiveness. |

For any given policy question to which CEA is applicable, the 'enhancement' added by JE-CEA adds a social justice assessment that enables decision-makers explicitly to consider expected impacts on the clustering of disadvantage. For example, using three impact levels, the social justice assessment for a given scenario under analysis could be either 'Expected not to worsen…', 'May worsen…', or 'Expected to worsen…" the clustering of disadvantage', as color-coded in Figure 6. We use the language of 'worsening' here because, as noted above, a just decision process for questions of health policy should avoid exacerbating the clustering of disadvantage in affected populations.[27]

In the context of scaling-up novel MDR-TB regimens, our assumption is that successful disease treatment is the main vehicle to alleviate disease-imposed disadvantage. In addition, JE-CEA is distinctively concerned with helping policymakers to avoid making people worse off. JE-CEA is designed to support the comparison of therapeutic regimens in terms of their exacerbation of disadvantage across core dimensions of well-being – agency, association, and respect – while undergoing the therapeutic regimen. Our intended scope of application for "the clustering of disadvantage" is within the personal life experiences of the affected populations.[26]

**Figure 6. Impact on Social Justice to be Overlaid over a Traditional CEA Decision Tree**

| Expected not to worsen |
| May worsen |
| Expected to worsen |

**SOCIAL JUSTICE ASSESSMENT**

Impacts on social justice will be represented in the decision tree by the color of each bar, as shown here and in Figure 7.

These assessments would be compiled by using empirical findings to track the occurrence, magnitude, and breadth of cross-cutting impacts on the three core dimensions of well-being (agency, association, and respect) identified in the social justice framework developed by Bailey et al.[28] For instance, empirical findings indicate that patients who are cured after MDR-TB treatment tend to suffer marital strife as a result of their prolonged hospitalization or public ridicule coming from the MDR-TB hospital. An MDR-TB cure requiring hospitalization might be associated with adverse impacts of moderate magnitude across association (social isolation) and respect (stigma).[26] Such levels of a social justice impact could be assessed for each major type of outcome under the treatment regimens to be compared.

In Figure 7 we show a hypothetical assessment with possible outcomes of cure, toxicity, and failure. Each outcome could have a probability and an expected impact on social justice informed by empirical data for both standard and novel MDR-TB regimens.

Social justice assessments can be presented in parallel to a decision tree, as is commonly used for CEA (Figure 7). Each social justice assessment will have two dimensions, including a proportion of the patient population exposed to each outcome (length of the bar shown in Figure 6), and a level of impact on the clustering of disadvantage under that outcome (color of the bar). An overall social justice or stigma assessment can be compiled by laying the bars for each regimen in question alongside each other (see the bottom of Figure 7) and presenting summary bars for each alternative. In the hypothetical example of Figure 7, the summary bars indicate that, relative to the standard regimen, the novel regimen is favored on both dimensions of the social justice assessment (the proportion exposed and level of impact).[26]

In this simplified decision analysis tree, we present how social justice assessments may be overlaid with the decision analysis framework corresponding to particular branches in the model. In a decision analysis model, a hypothetical cohort of patients enter at the left of the tree and progress through the branching structure towards the right. A probability at each branching node predicts what proportion of the patient cohort continues down each branch. The bar colors represent the average expected impact on social justice experienced across each branch pathway, while the length of the bars corresponds to the proportion of the cohort experiencing that particular social justice impact. For the overall social justice assessment, assessments are concatenated across each intervention arm.

# Data to inform JE-CEA: MDR-TB patients' lived experiences

To perform JE-CEA comparing MDR-TB treatment regimens in a given setting, empirical estimates of the impact on core dimensions of well-being are required. A qualitative evaluation is needed to determine if, how, and to what extent each regimen might worsen the clustering of disadvantage experienced by patients. For example, a meta-analysis of prior qualitative research on TB patients' experience indicates that patient-centered barriers to TB treatment adherence include a lack of community, family, or household support.[29] In-depth interviews with MDR-TB patients and their healthcare providers can be used to explore social isolation as well as other ways in which MDR-TB treatment may compromise agency, respect, and association for patients. Interviews can be used to compile formal social justice assessments, which are then incorporated into the JE-CEA decision analysis. Future work could build on qualitative findings to refine decision analysis by developing tools to better quantify the factors most likely to exacerbate disadvantage.[26]

**Figure 7. Hypothetical, Simplified Example of the Proposed Methodology Incorporating Social Justice**
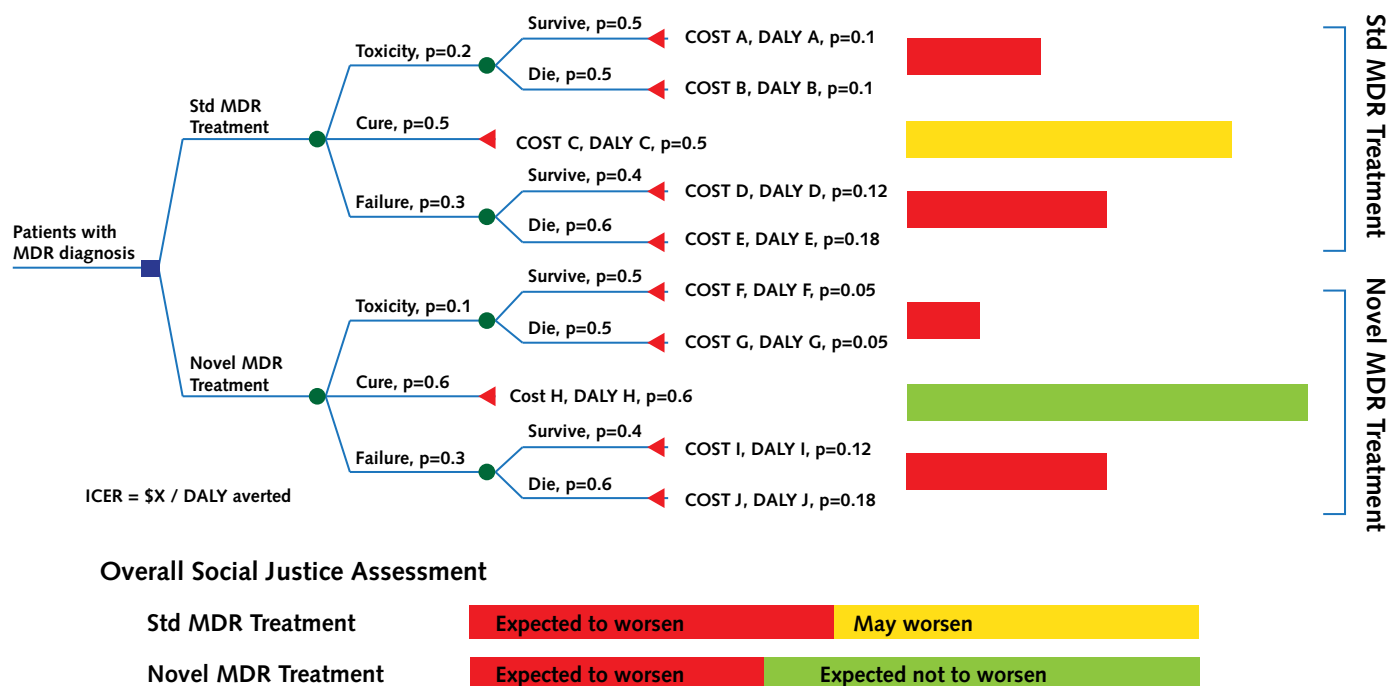


(p: probability; DALY: disability-adjusted life years; MDR: multi-drug resistant tuberculosis; ICER: incremental cost-effectiveness ratio)

# Synthesis

Decision-makers should be empowered to assess both value for money and impact on disadvantage, and explicitly stating any trade-offs between them. When they are concordant, the case for making a certain decision is bolstered. When they are discordant, decision-makers should evaluate the discrepancy. In

cases like the example discussed above, in which the hospitalization required by standard MDR-TB treatment is associated with stigma and social isolation, which could be averted by a novel (but high-cost) regimen requiring no hospitalization, the CEA component of JE-CEA (the ICER) might favor the standard regimen. The justice-enhanced component (social justice assessment) favors the novel regimen. JE-CEA would present decision-makers not only with this discrepancy, but also with the relevant impacts on each side. In this case, JE-CEA might provide the additional justification needed for policymakers to implement costly regimens in order to improve the plight of MDR-TB patients, and ultimately for civil society to press for price reductions of novel MDR-TB regimens.[26]

## Strengths and limitations of the JE-CEA approach

JE-CEA could fill important gaps in the current approach to economic evaluation (Box 1). These include introducing social justice language into economic evaluation, encouraging awareness and inclusion of social justice impacts when making health-related decisions, highlighting the need for data collection and analysis to demonstrate how treatment regimens can exacerbate social disadvantage, and encouraging decision-makers to incorporate formal social justice assessments in key policy and resource allocation decisions. Additional resources and expertise would be required to compile formal social justice assessments across different settings. It remains unclear how far such assessments may be generalizable (though the same could be said about the economic considerations of CEA). It is important to note that social justice may not be the only element lacking in CEA, and evaluations should also include assessments of fairness, equity, or age preference. The methodology proposed here is a first attempt to include elements like social justice in a formal assessment of CEA. While transmission is a critical issue for MDR-TB control, JE-CEA relies on a decision analysis model and does not explicitly account for transmission.

JE-CEA methodology is currently under conceptual development. Its full elucidation must be borne out through empirical research and discussions with clinicians and policymakers. Further work will refine this concept by including empirical estimates/observations of the perceptions of social justice impacts, as well as quantitative efforts to appropriately balance cost-effectiveness and social justice considerations. The adoption of JE-CEA will require the engagement and education of key stakeholders as well as thoughtful dissemination across various settings. Being able to see social justice assessments alongside traditional CEA outputs leaves policymakers with difficult decisions, particularly in cases of discordance. Like traditional CEA, however, JE-CEA is not designed to replace the decision-making process but to provide a more complete picture that can be used to organize and inform deliberations. Importantly, we do not suggest that JE-CEA is the only way to incorporate social justice assessments into economic evaluation; rather, the development of JE-CEA may stimulate improved

approaches that could further promote the inclusion of formal social justice assessments into traditional CEA, policy development, and decision-making processes.

## Conclusion

Current prevailing methods for economic evaluation do not fully address social justice considerations. As a result, assessments may overlook important potential benefits in reducing clusters of disadvantage and thereby alleviating the patient burden. Here we propose justice-enhanced CEA as an alternative approach. Formal assessments of social justice can and should be undertaken in conjunction with CEA to provide more complete information to decision-makers. Otherwise, initially costly interventions (such as the rollout of novel regimens for MDR-TB) may never be scaled-up, and clinicians will not have access to certain (more expensive) treatments. Clustering of disadvantage may be worsened among already badly-off populations, and sufficient pressure is never applied for the economics of those interventions to change. Incorporating social justice assessments into CEA can lead to more ethically responsible decision-making, ultimately creating a healthier and more just society.[26]

## Acknowledgements

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# Chapter 14

# Measuring TB Stigma as part of a Syndemic

*Ellen M.H. Mitchell, Amrita Daftary, Gill Craig, Lisa Redwood*

## Abstract

Mistreatment of people with TB is rooted in prejudice.[1] Oppression can be layered, cumulative, and hard to disentangle. A syndemic stigma is when two or more stigmatized identities are fused in the public consciousness. It is it challenging to tease out the negative impact of TB stigma for the purposes of policy and intervention. This chapter teaches readers to measure different types of intersecting stigma and prejudice using validated scales. We offer practical guidance to address the challenges posed by syndemic stigma. A compilation of scales for measuring other biases is provided. We present TB/HIV stigma scales for when the two stigmas are interwoven.

## Objectives

1. To grasp the methodological challenges inherent in syndemic stigmas and the risks associated with a overly narrow approach to measurement of TB stigma.
2. To appreciate the advantages of an intersectional approach to measurement of TB stigma.
3. To appreciate the various scales available for measuring other types of stigma.
4. To understand the methodological implications of an intersectional approach.

## Target Audience

This chapter is intended for those who are comfortable measuring TB stigma, and who want to ensure that any claims of causality are not confounded. The intended audience includes social scientists, clinicians. It is essential reading for M&E officers, TB program staff, CBO staff, activists, and those without a firm foundation in the social sciences. This chapter builds upon Chapters 2, 3, and 9.

# Introduction

The concept of syndemic stigma was recently developed by medical anthropologists to describe disparaged characteristics, qualities, and behaviors that co-occur, such as being poor and having TB or using drugs and developing TB.[2]

A syndemic is a set of intertwined and mutually enhancing epidemics involving disease interactions at the biological level that develop and are sustained in a population because of harmful social conditions and injurious social connections.[3] The syndemics model of health focuses on the biosocial complex, which consists of interacting, co-present, or sequential diseases and the social and environmental factors that promote and enhance the negative effects of disease interaction.[4]

Syndemic stigmas have been referred to as compounded, layered, or intersectional stigmas in the literature.[5,6] These terms imply that stigma is enabled by structural inequalities, which leave some groups more vulnerable than others.[2] A syndemic stigma is occurs when underlying inequities cluster, which may compound social exclusion.[7,8] Racism, xenophobia, classism, and other prejudices can potentiate TB stigma.[9,10]

The burden of multiple disparaged characteristics and behaviors, such as being poor, having TB, and being malnourished, is not new, but the language may be unfamiliar.[11]

**Figure 1. Clustering of illnesses, social exclusions, and prejudices can create syndemic stigma**
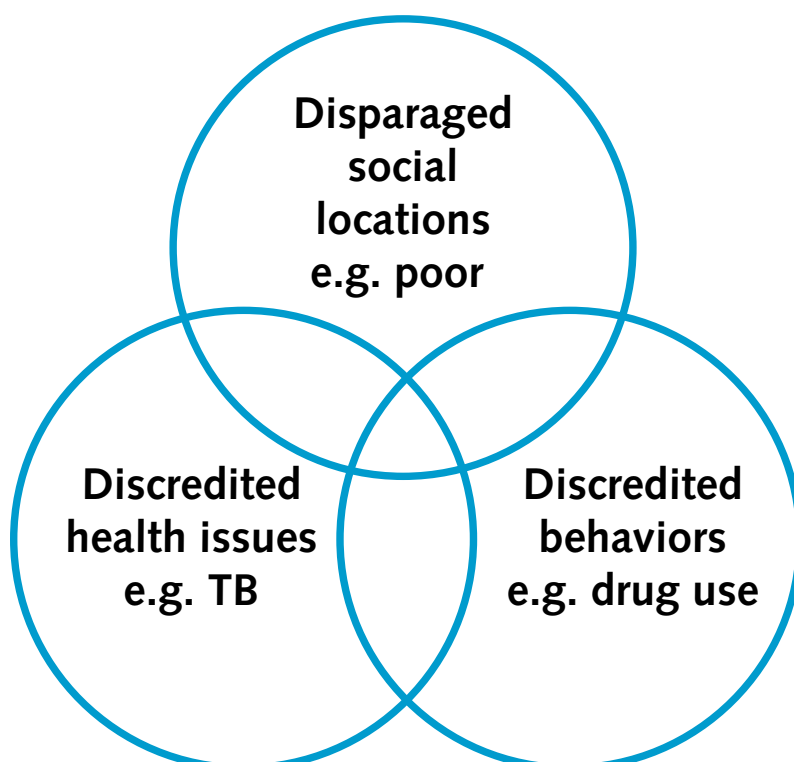
Intersectionality was developed by the African American feminist Kimberlé Crenshaw to understanding the experiences of people facing multiple, simultaneous oppressions or privileges.[12]

Intersectionality is closely linked to the public health idea of syndemics, as both involve looking at all social influences (e.g., race, class, gender) concurrently in order to better understand health and behavior.[13]

Intersectional or syndemic stigmas complicate and enhance our ability to understand the life experiences of people with TB (Figure 1). For example, migrants, prisoners, the homeless, people living with HIV, smokers, and persons dependent on tobacco, alcohol, or drugs already experience varying degrees of social exclusion.

**Figure 2. Stigmas that may impact people with TB**

Intersectionality means that we explore TB stigma with the understanding that its expression is likely to vary by gender, class, race, ethnicity, behavior, identity, and co-morbidity.[12] In measuring TB stigma, other pervasive stigmas must also be accounted for.[14–16] Failure to measure auxiliary (and possibly dominant) forms of exclusion may lead to an over- or under-estimation of the stigma associated with TB. It will also complicate efforts to reduce stigma.

An awareness of syndemic stigma changes the way we design and measure TB stigma in several ways:

1. We accept that a particular person can be subjected to different forms of prejudice and self-stigma simultaneously. The existence of other stigmas must be captured.
2. We recognize that TB stigma can have a differential impact on particular people because TB stigma is often mediated by other stigmas. The magnitude, direction, and impact of other stigmas must be clarified.
3. We must ensure that we are measuring TB stigma, and the confounding potential of other stigmas must be mitigated.

This chapter guides readers in measuring different types of intersecting stigma and prejudice using validated scales. This guidance will evolve as research continues and best practices are further articulated.[17]

## TB Syndemic Stigmas

Readers of this book are already familiar a disease syndemic. We recognize TB-HIV, TB-diabetes, TB-smoking, TB-silicosis, and TB-depression as interlinked and destructive syndemics that must be addressed with multi-disciplinary collaboration.[18–23]

**Figure 3. The Compounding Effect of Multiple Oppressions**
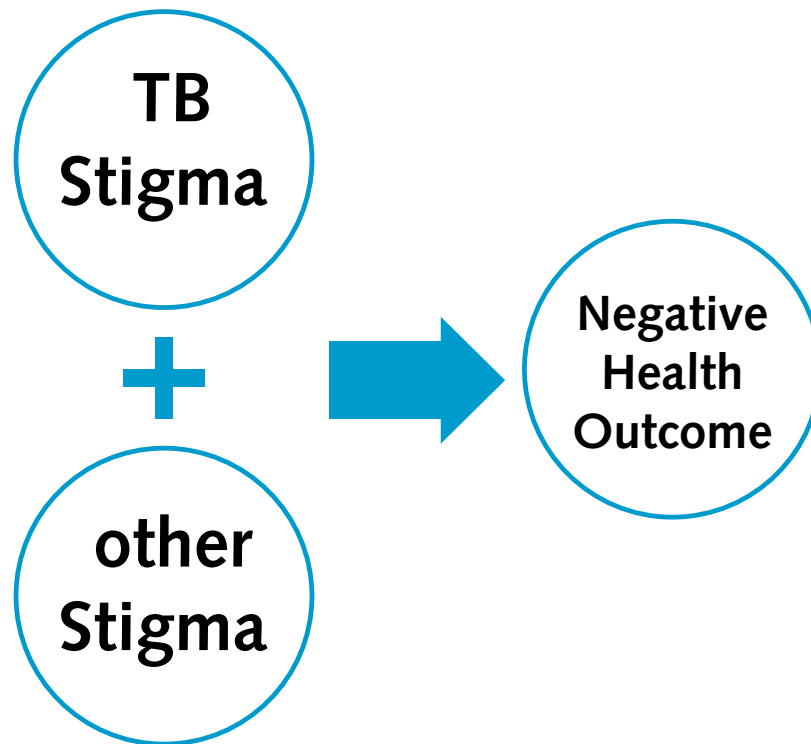


Stigmas can be additive, and compound the impact of TB stigma. In most settings, TB is disproportionately concentrated among people and communities who are already social excluded.[24] Marginalized groups with elevated TB risk include the poor, those who are malnourished, homeless, drug dependent, people with HIV, sex workers, and migrant populations.[24–26]

In some Asian countries, TB is linked to smoking, and the stigma of smoking and lung cancer may marginalize people at risk for TB.[27] In sub-Saharan Africa and Central Asia, people with TB may experience stigma due to the presumed association between TB and HIV, which is associated with sexual transgression, promiscuity, amorality, and death.[16,28] In Europe and North America, TB is often rhetorically linked to poverty, ethnicity, and race, including immigrants and those living in indigenous communities.[29] TB is more common among people deprived of liberty and homeless persons.[31] Shaming and blaming of TB patients can be related to smoking, drinking, or other discreditable behaviors.

It may be challenging for members of disparaged groups to discern exactly why they are being stereotyped, shamed, blamed, or discriminated against given their high background level of social exclusion and discrimination.[30]

The ethnographic literature suggests that TB stigma is not always the predominant form of discrimination for many affected by TB.[31] Other stigmas may mitigate or exacerbate the effect of TB stigma.[32,33] For example, anticipated cancer or smoking stigmas may deter smokers from seeking care for a painful chronic cough, or anticipated HIV stigma may inhibit some people from seeking TB treatment.

**Figure 4. Challenges of Attribution for People with TB Experiencing Discrimination**

**Multiple Stigmas**

**Experienced Stigmatization**

# Cause

# Effect

Just as some attributes may compound TB stigma, socially desirable attributes (e.g., being wealthy or educated) may deflect and buffer stigmatization.

## The Temporizing Effect of More Pernicious Stigmas

In some situations, stigmas can be so negative that they dwarf the impact of TB stigma. Individuals with heavily stigmatized co-morbidities (e.g., drug dependence or severe mental health issues) may prefer to self-identify as having TB rather than disclosure of the more discrediting condition. This behavior is called covering.[16]

In some circumstances, TB can be the more discrediting of two stigmatized identities.[34] With widespread access to antiretroviral therapies and poor access to second-line TB medicines, some find it less stigmatizing to be treated for HIV than to be treated for DR-TB.[35] Label avoidance, or the tendency to resist publicly acknowledging a stigmatized identity, can impede stigma measurement.[36] People may under-report concealable stigmatized identities (CSI) or cover with another label. To minimize label avoidance, surveys need to be carefully phrased and should be posed by trustworthy data collectors.[37]

**Figure 5. Covering an DR-TB diagnosis with an HIV diagnosis**



DR-TB
STIGMA

HIV
STIGMA

**Preferred self-presentation
as an ART client**
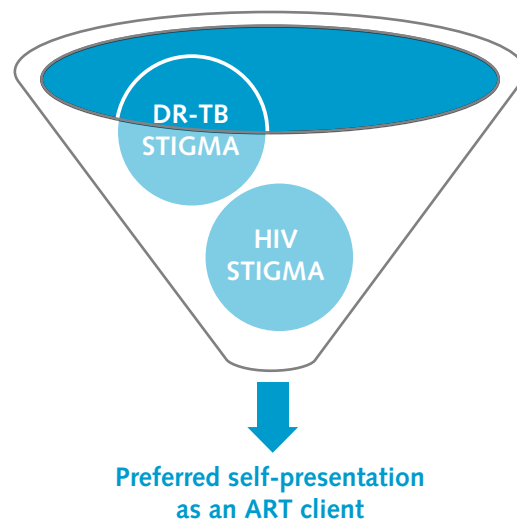
## Gender Lens

Applying a gender lens is important when measuring TB stigma. Previous TB stigma scales have been gender blind, meaning that they failed to recognize that the autonomy and power of women/girls and men/boys varies in specific social, cultural, economic, and political contexts.[38] The assumption that stigma questions are valid for all genders may have produced spurious results. Sexism as a mediating factor in TB stigma is gaining attention.

Recent studies of anticipated and internalized stigma among men in Malawi, Zambia, Tanzania, Lesotho, and South Africa have drawn attention to the powerful role of stigma in care seeking.[39–44] Two studies found that women are more adherent to TB treatment when they perceive high levels of stigma, while men, on average, were less adherent.[45,46] While little is known about TB stigma among transgender populations, lack of trust and low cultural competence has encumbered TB outbreak investigations.[47–49]

Do not mistake TB stigma for other exclusions and prejudices that may be equally or more detrimental.

## Other Stigmas as Latent Confounders: The Case of TB Stigma and Gender

In order to develop tools that accurately capture different stigmas, one must know which forms of prejudice coexist with TB stigma in a given setting. When we develop TB stigma measurement scales, we have to ensure that they have content validity. Other stigmas can be a latent confounding factor if we are not selective when choosing items for a scale.

The EMIC scale, a widely used TB stigma measurement tool, has sexual negotiation and marriageability questions that are profoundly gendered.[42,50] One item queries whether a TB patient has been refused sex. This is supposed to measure TB stigma, but it is likely confounded by gendered heteronormative power relations in sexual situations. Using the EMIC scale in India, Bangladesh, and elsewhere has led many stakeholders to conclude that women experience higher rates of TB stigma, in part because they are more likely to be refused sex than men are. When these gendered items are not included in stigma scales, the difference in rates of TB stigma between men and women are no longer found.[51]

**Figure 6. Sexism as a latent confounder in an explanatory model of treatment adherence**
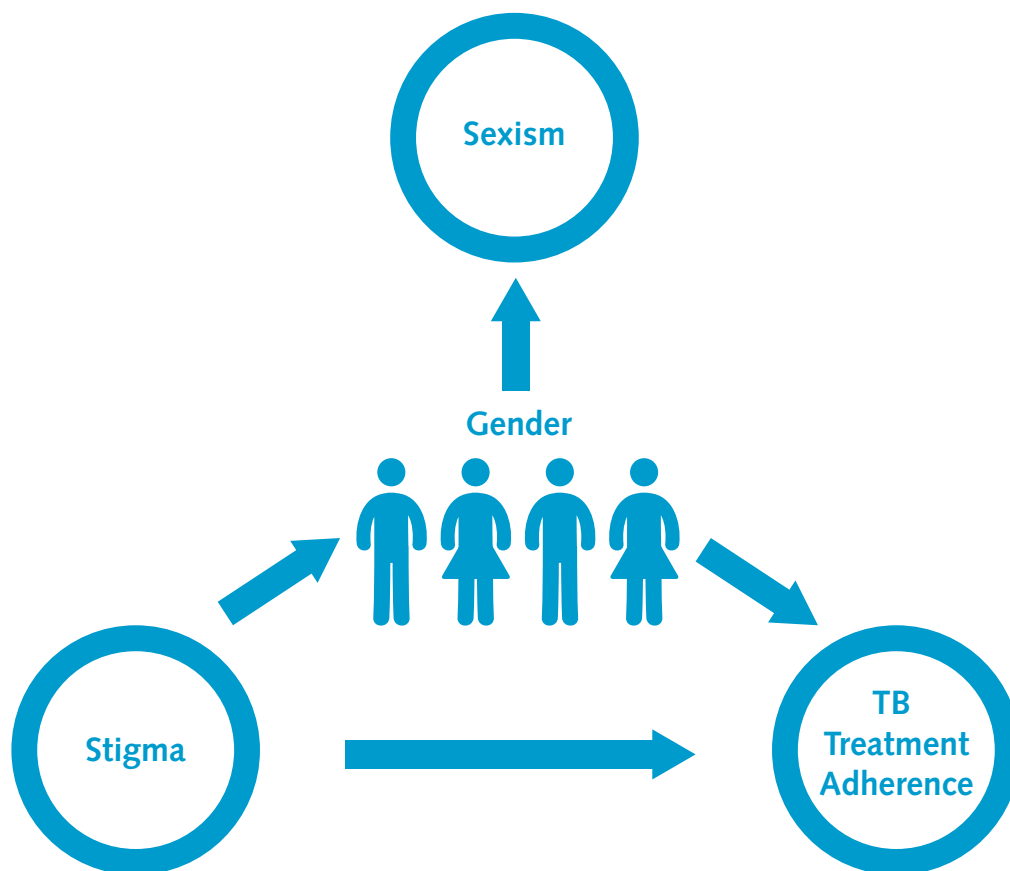


The sampling and bias detection methods described in Chapters 3 and 9 are tools to assess the possible confounders of TB stigma measures in marginalized groups. Chapter 16 has statistical tools for detecting whether a stigma scale is measuring two or more different constructs.

## Practical Approaches for Measuring Syndemic Stigma

The following are tips for overcoming the methodological challenges associated with measuring TB stigma in the context of other prejudiced attitudes and behaviors:

- Assess local drivers and intersecting stigmas through complementary qualitative research (Chapter 3).
- Measure all relevant stigmas with validated scales.
- Increase study sample sizes to account for the added statistical power necessary to permit multivariate analyses.
- Use sampling techniques appropriate for marginalized groups (Chapter 9).
- Assess covariance and confounding when analyzing impacts of stigma.

Validated scales for many stigmas can be used in conjunction with a TB stigma scale. A partial list of stigmas and prejudices that may coexist in the presence of TB stigma includes:

1. HIV.
2. Alcohol and substance use and dependency.
3. Poverty.
4. Homelessness.
5. Occupation.
6. Involvement with the criminal justice system.
7. Xenophobia/immigration status.
8. Racism.
9. Sexism/misogyny.
10. Illiteracy or lack of education.
11. Mental illness.
12. Smoking.
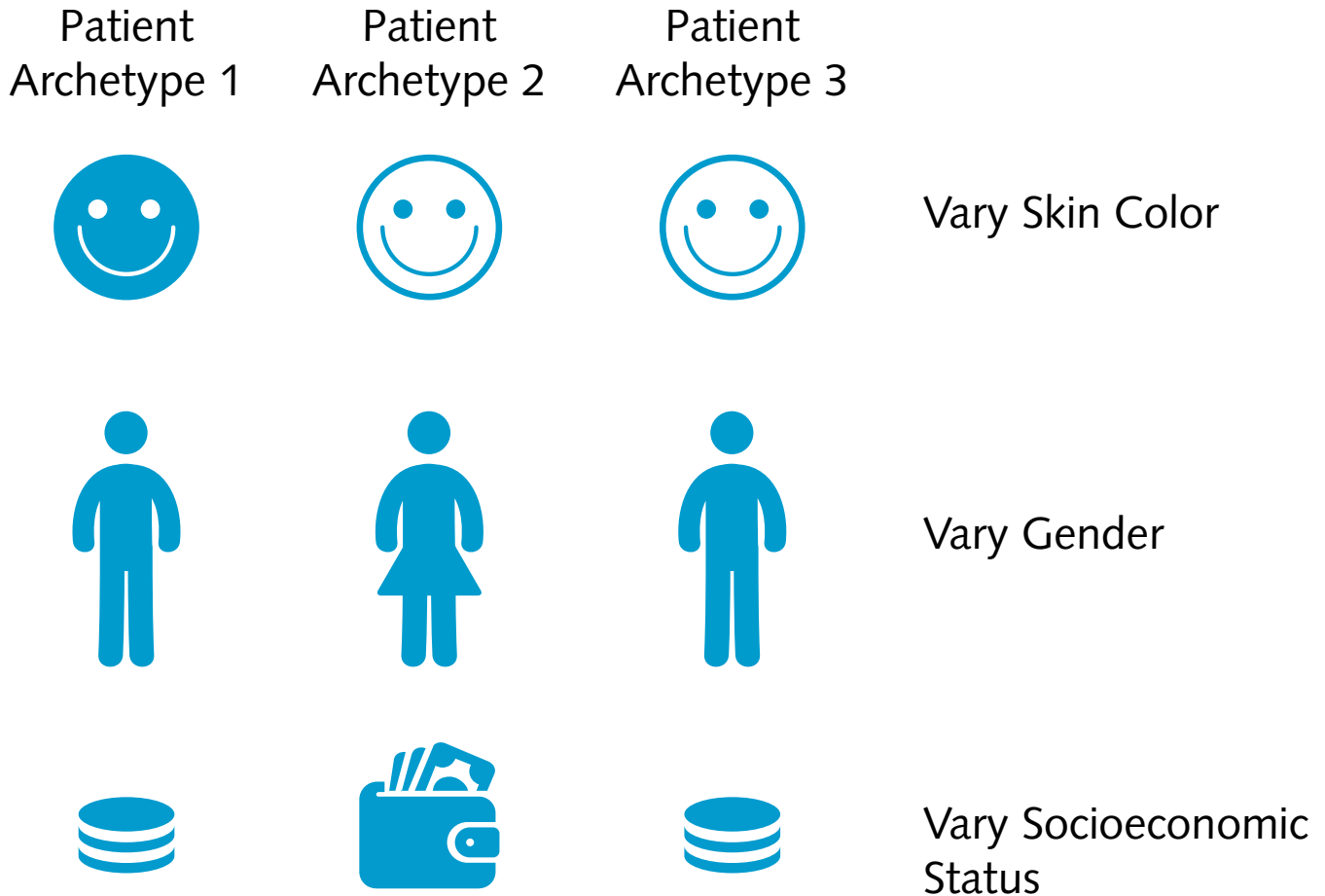13. Lung cancer.
14. Hearing loss.

Qualitative studies assessing the role of multiple stigmas affecting people with TB, and the social dimensions of TB stigma, are introduced in Chapter 3.

## Using Vignettes to Measure Intersectional Stigmas

Vignettes can be used to tease out multiple types of prejudice, which the respondent may not be conscious of, when measuring sintersecting stigmas by survey or interview.[52–55] Vignettes that vary the characteristics of a person in a narrative can reveal biasis.[52,56,57] By pairing different stigmatized conditions, one can see whether compounding different stigmas lessens the effects of the

individual stigmas, is the sum of the individual effects, or more than doubles the individual effects of the separate stigmas. Vignettes allow for the presentation of realistic patient populations and clarify their multiple stigmatized identities.

**Figure 7. Varied characteristics of vignette subjects**

| Patient Archetype 1 | Patient Archetype 2 | Patient Archetype 3 | |
| --- | --- | --- | --- |
| | | | Vary Skin Color |
| | | | Vary Gender |
| | | | Vary Socioeconomic Status |

You can also use names in the narrative, which implies a particular ethnic background.

The Social Distance Scale by Kelly and colleagues is widely used for vignette-based measurement.[58–60] The following are the yes/no survey items after the vignette:

1. If you met '[insert name]', would you be willing to strike up a conversation with him?
2. Would you attend a party where 'A' was present?
3. Would you attend a party where 'A' was preparing food?
4. Would you be willing to work in the same office with 'A'?
5. If you were a friend of 'A's, would you be willing to continue friendship at this time?
6. If you were 'A's' landlord and his lease was up in two months, would you renew his lease?
7. Would you allow your children to visit 'A' in his home?

# Resources for Validated Scales to Measure Stigma

It is beyond the scope of this TB Stigma Measurement Guidance to describe all forms of prejudice, stigma, and discrimination that co-occur with TB and require measurement. However, here is a list of validated scales that should be considered in a survey instrument.

| Stigma | Scales |
| --- | --- |
| Stigma of HIV status | HIV Stigma scale (Berger)[61]<br>Community Perspectives Towards HIV/AIDS (Van Rie)[62] |
| Stigma of HIV for Healthcare Workers | Wouters HIV Stigma Scale[63]<br>Uys Stigma Scale (see Chapter 8)[64] |
| Stigma of alcohol Dependency | Alcohol Use Disorders Identification Test (AUDIT)[65,66] |
| Stigma of Substance Use and Dependency | Substance Abuse Self-Stigma Scale[67]<br>Stigma of Substance Abuse Scale[68] |
| Stigma of Poverty or Homelessness | Attitude Toward Poverty Scale[69] |
| Stigma of Involvement with the Criminal Justice System | Self-Stigma of Individuals with Criminal Records Scale (SSICR)[70] |
| Xenophobia and Racism | Racial and Ethnic Microaggression Scale (REMS)[71] |
| Sexism, Misogyny, Homophobia, and Transphobia | LGBT People of Color Microaggression Scale (LGBT-PCMS)[72]<br>Sex work stigma[73]<br>Sexual stigma[74] |
| Stigma of Mental Illness | Hopkins Symptom Checklist (HSCL-25)<br>Mental Illness Microaggressions Scale-Perpetrator (MIMS-P)[75]<br>The Ryff Scales of Psychological Well-Being[76,77]<br>Patient Health Questionnaire - Nine Item (PHQ9) |
| Stigma of Traumatic Events | Harvard Trauma Questionnaire (HTQ)[78] |
| Stigma of Chronic Illness | Chronic Illness Anticipated Stigma Scale (CIASS)[79] |
| Stigma of Smoking and Lung Cancer | Internalized Stigma of Smoking Inventory (ISSI)[80]<br>Cataldo Lung Cancer Stigma Scale[81] |
| Stigma of Diabetes | Diabetes Self-Stigma Scale (SSS)[82,83] |
| Generic Discrimination | Experiences of Discrimination (EOD) Index[84] |
| Stigma of Hearing Loss | Hearing Attitudes in Rehabilitation Questionnaire (HARQ)[85]<br>The Attitudes Toward Loss of Hearing Questionnaire (ALHQ; Cienkowski & Pimentel, 2001) The Hearing Handicap Inventory for the Elderly (HHIE) |

## Special Scales for the TB/HIV Syndemic

Separating co-occurring TB and HIV stigma can be challenging.[88] A variant colloquially referred to as the 'new/thin TB' has emerged, which refers to people with TB/HIV coinfection.[88,89] When TB and HIV disease symptoms are conflated, the meaning of the individual diagnoses changes.[88,90] In these situations, measuring both TB and HIV stigma using separate scales may not fully capture the local construct.



When two diseases are indivisible, use the validated TB/HIV stigma scales.

In South Africa, Wouters et al. developed a scale with three statements: 'TB is a sign that someone has HIV,' 'Someone with TB has probably also got HIV,' 'TB symptoms make HIV more noticeable. Each was rated on a four-point Likert scale indicating strong agreement, agreement, disagreement, or strong disagreement.

They also tested how interlinked the stigmas are, as defined by the respondent (the Compound Stigma by the Respondent (CS-R)). The item 'Someone who has TB should feel equally guilty about it as someone who has HIV' was used and rated on a four-point Likert scale.

Finally, Wouters et al. tested how interlinked HIV and TB stigmatization was perceived to be by colleagues (Perceived Compound Stigma by Colleagues (CS-C)). They used two items on a four point Likert scale: 'People are afraid of

working together with someone who has TB because they think that the person also has HIV' and 'People with TB tend to be treated badly because they may have HIV.' These items had good reliability and can be used in settings with a high TB and HIV prevalence rate.

## Survey Questionnaire Length

The survey questionnaire may be long if many scales are included. To minimize respondent burden, use the shortest valid scales available. The instrument can be sub-divided and administered over several sessions, if necessary. As with any study, balance feasibility and comprehensiveness.

## Statistical Challenges of Intersectional Stigma Measurement

Latent Profile Analysis (LPA), latent class analysis, and moderational analysis are statistical approaches to dealing with the challenges of intersectionality. This person-centered statistical approach assumes that stigmas are associated with one another. These skills are beyond the scope of this guidance, as they require a sophisticated grasp of statistical methods. DeVellis's Scale Development: Theory and Applications offers insights on these complexities.[91]

If you believe that TB stigma in your setting is moderated by other stigmas, but you want to detect the TB stigma signal, then you will need a larger sample size. If necessary, consult a statistician. Chapter 9 has guidance on sampling considerations for measuring TB stigma among stigmatized groups.

## Conclusions

TB typically affects those who are devalued in society. TB stigma does not exist in a vacuum; its proper measurement requires attention to the many other forms of prejudice that affects people with TB. This chapter discusses an intersectional approach to syndemic stigma measurement. Despite the difficulty in differentiating types of stigma, it is possible to detect harmful attitudes and behaviors attributable to TB stigma versus those caused by other biases, fears, and prejudice. Approaching stigmas as syndemic acknowledges interconnectedness, without conflating them. This is a challenge for effective TB stigma measurement and reduction. This topic is an emerging field, and guidance will evolve as research continues.

## Acknowledgements

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# Chapter 15

# Measuring the Impact of TB stigma on Outcomes

*Ellen M.H. Mitchell, Rajita Bhavaraju, and Lisa Redwood*

## Abstract

Preventing suffering in people with TB is a pillar of the END TB strategy.[1,2] Yet, some stakeholders also want to know if TB stigma interferes with treatment completion and recovery, or if it contributes to death, before they will dedicate scarce resources towards addressing it. This implies that researchers should know how to measure the impact of TB stigma on health outcomes, which may be challenging. This chapter describes methods to quantify the consequences of TB stigma on TB treatment adherence and survival.

## Objectives

1. To describe how to determine the impact of TB stigma on adherence behaviors and TB mortality.
2. To convey the importance of developing and operationalizing comprehensive theoretical frameworks.
3. To emphasize the methodological challenges and statistical considerations that must be addressed when studying the impact of stigma on adherence behaviors and outcomes.

## Target Audience

This chapter is for readers with a social and behavioral science and/or epidemiological background who have a basic understanding of epidemiological and statistical concepts, such as sampling frames, sample size, confounding, and regression analysis, as well as forms of qualitative data collection and analysis.

# Introduction

Stigma's impact is widely felt, but poorly quantified. Policymakers, ministries of health, and country coordinating mechanisms want to know the relative importance of stigma among the many challenges facing TB programs.

In Chapter 13, we introduced the justice enhanced cost-effectiveness analysis, which looks at TB stigma as a consequence of certain choices. In this chapter, we look at how TB stigma can cause specific consequences. Here we will define stigma-related outcomes of TB diagnosis and treatment and provide possible standard definitions for measurement. We will also look at study designs, including mixed methods, for measuring stigma in the context of how it may affect TB outcomes.

**How does TB stigma affect TB patients' self-care, adherence to treatment, retention in care, and infection control practices?**

**How does stigma contribute to death and disability?**

A frequent critique of the TB stigma research to date has been its narrow focus on personal experiences of stigma, with little attention on how these experiences contribute to negative health outcomes. We believe that any mistreatment, denial of care or basic needs, and inability to fully enjoy one's human rights is reason enough to measure and intervene on stigma. The fact that stigma hampers health outcomes can only strengthen the resolve of some stakeholders to help measure and reduce stigma.

The impact of stigma on TB treatment self-efficacy and adherence appears to vary widely by context, gender, and type of TB.[3–5] Much of this variance is attributable to the diversity in measurement criteria and use of non-standardized definitions of stigma and adherence.[6] However, it is plausible that different people react to stigmatization in different ways. Studies in Russia, Uganda, and Thailand found that perceived TB stigma increased patient treatment adherence.[7–9] However, large studies in South Africa and Pakistan found stigma a significant barrier to adherence.[10–13] Small studies of fewer than 1,000 TB patients typically detected no effect.[14] Two studies found women were more adherent to TB treatment when they perceive high levels of stigma, while men were less adherent, particularly if they found TB treatment humiliating.[9,15]

It is likely that stigma impacts people's treatment experience in different ways. Studies of TB stigma in Mexico, Malawi, Zambia, Tanzania, Lesotho, and South Africa have drawn attention to differential impact of TB stigma on men and women.[16–22] Two studies found women were more adherent to TB treatment when they perceive high levels of TB stigma, while men were less adherent, particularly if they found direct observation of TB treatment humiliating.[9,15] There is also clear variation of stigma's impacts among sub-populations (e.g., pastoralists and drug users).[23,24]

# Challenges

One of the challenges in determining the impact of stigma on TB care seeking, adherence, and mortality is that these outcomes are attributable to a wide variety of factors and are often multi-causal. Stigma can occur at multiple points in the patient pathway, so its cumulative impact is difficult to quantify.[25,26] There are also many possible confounders when measuring the true impact of TB stigma on an undesirable outcome.[25] Measuring the relative influence of stigma on downstream outcomes almost always requires a large sample and a comprehensive questionnaire, making it a resource-intensive endeavor for both researcher and respondent.[26]

In this chapter, we will discuss possible methods to assess the role of TB stigma on treatment initiation, treatment adherence, and (near) mortality.

## Assessing the role of TB stigma on treatment initiation and adherence

TB treatment initiation and adherence are very complex behaviors that have many factors and mediating influences.[27,28] A comprehensive theoretical framework is necessary to study stigma.

Munro et al. provide a framework based on four categories of factors (structural, personal, health services, and social context.) See Figure 1.[11]

**Figure 1. Model of Factors Associated with TB Treatment Adherence (Munro et al.)**
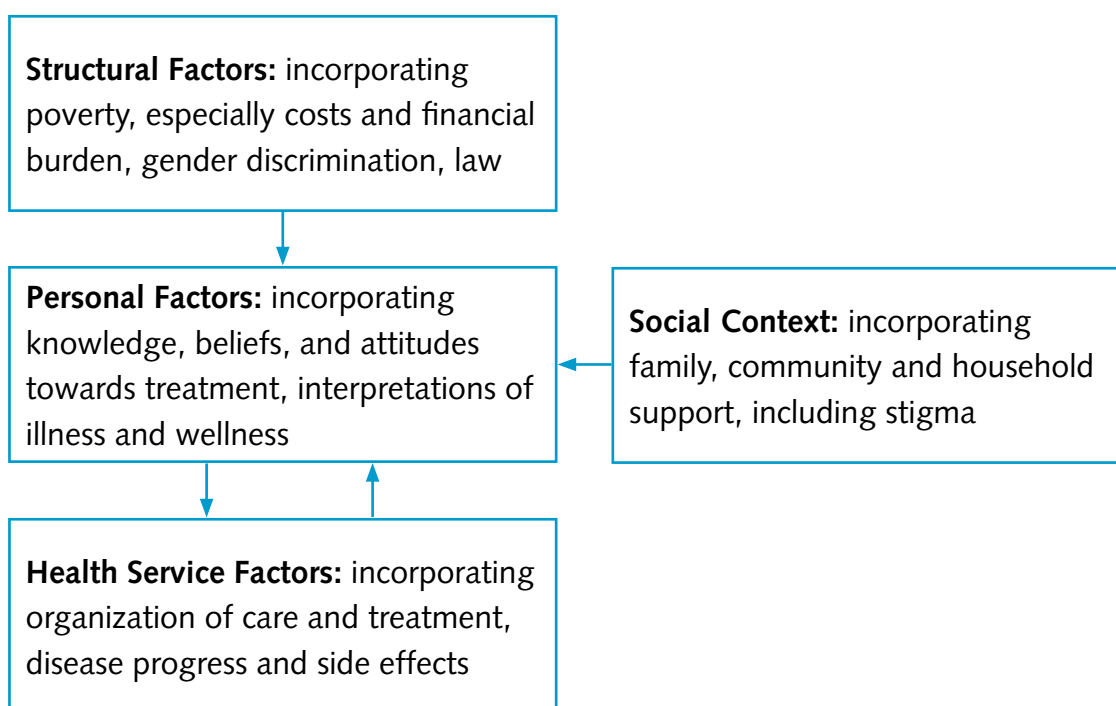


Note:
▼▲ suggest a bi-directional relationship between factors. For example, health service interventions directed at patients are likely to influence patient adherence behavior through the filter of "personal factors." Similarly, patients' interactions with health services are likely to be influence by their knowledge, attitudes, beliefs about treatment as well as their interpretations of illness and wellness.

A systematic review of the qualitative literature by Munro et al. identified eight general categories of influences upon adherence to TB treatment:

1. Organization of treatment and care.
2. Interpretations of illness and wellness.
3. The financial burden of treatment.
4. Knowledge, attitudes, and beliefs about treatment.
5. Law and immigration.
6. Personal characteristics.
7. Treatment side effects.
8. Family, community, and household support.[29]

Adherence to drug-resistant (DR)-TB treatment has similar determinants, but the relative importance (rank) may be significantly different.[30] Stigma is often a more potent determinant of adherence in longer MDR-TB treatment regimens. Additional adherence challenges among DR-TB patients include:

1. Extended periods of isolation in some settings.
2. Extended length of treatment of certain regimens.
3. Toxic side effects of specific drugs that create disincentives for completion.
4. Inaccessibility of health services, such as inconvenient operating hours.[31–33]

A recent review of TB adherence for pediatric patients by Weaver identified a more complex set of factors influencing adherence.[34] TB stigma is only one of a myriad of issues, including caregivers that need to be carefully considered as moderators of adherence and influencers on treatment outcomes, even with good adherence.

## Figure 2. Factors Influencing Pediatric TB Treatment Adherence (Weaver et al.)
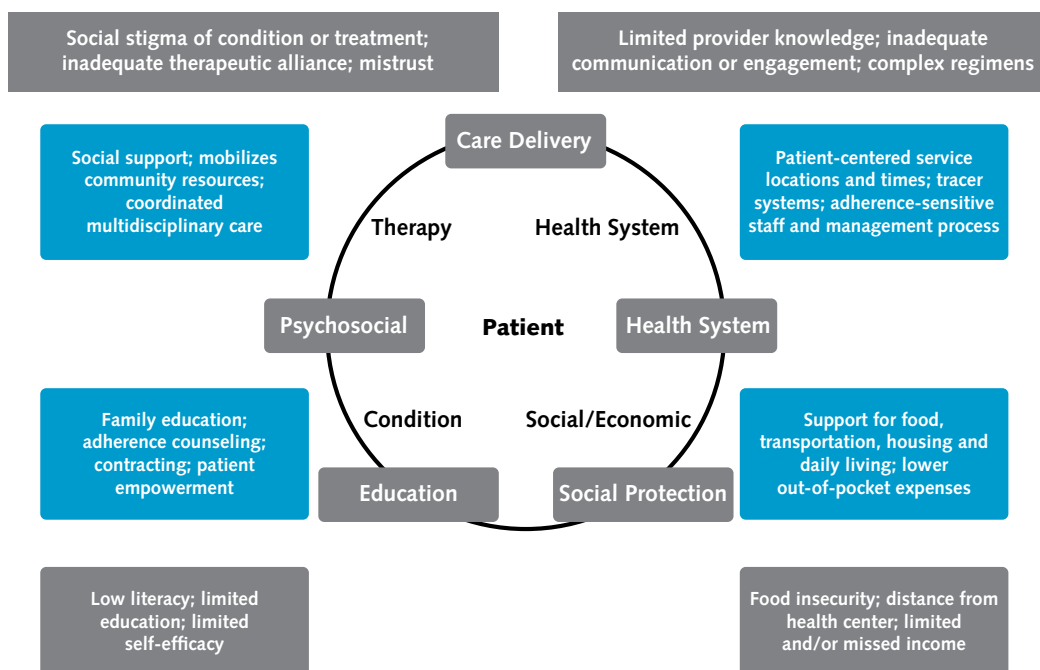


Notes: The central circle which contains the adherence dimensions used by WHO is surrounded by the 5 main categories of relevant interventions. The factors that may promote treatment adherence are shown in blue boxes and factors that may threaten treatment adherence are in gray boxes. Therapeutic alliance refers to relationship-building between providers and patients.

Figure 3 is illustrative of the range of factors that would need to be measured along with stigma in order to determine the relative importance of stigma as a barrier to TB treatment adherence.

## Figure 3. Logic Model for a Study on the Role of Stigma on Treatment Adherence and Mortality

| PEOPLE WITH TB | FREQUENCY AND SEVERITY OF EXPOSURE TO STIGMATIZATION | POTENTIAL CONFOUNDERS | OBSERVABLE PHENOMENA |
|---|---|---|---|
| **CHARACTERISTICS**<br>Gender<br>Age<br>Class<br>Ethnicity/caste/race<br>Self-efficacy<br>Resilience<br>Other disparaged identities<br><br>**HEALTH STATUS**<br>Type of TB (drug susceptible, resistant)<br><br>Severity of TB<br><br>Concealability of TB | HEALTH CARE<br><br>SOCIAL NETWORK<br><br>EMPLOYMENT<br><br>COMMUNITY | 1. Quality of care<br>2. Access to health facility<br>3. Availability of drugs<br>4. Treatment regimen (length, complexity)<br>5. Cost of transport, care<br>6. Opportunity costs of adherence (time, money)<br>7. Treatment literacy/Interpretation of symptom resolution<br>8. Tolerability of side-effects<br>9. Co-morbidities (e.g., depression, addiction, HIV, hepatitis)<br>10. Strength of supportive social network<br>11. Social protections (laws, safety net) to buffer consequences of stigmatization<br>12. Other prevalent forms of stigmatization, discrimination | TREATMENT ADHERENCE<br><br><br>TB MORTALITY OR RECOVERY |

**Important methodological considerations include:**

1. What is the best definition of adherence? The WHO's definition of 'lost to follow-up' (or TB treatment non-adherence) is "a TB patient who did not start treatment or whose treatment was interrupted for two consecutive months or more."[35]
2. How will adherence to TB medication be measured? By a self-reported measure of how many doses were missed? This is a very subjective question if asked directly to the patients (e.g., highly susceptible to recall and social desirability bias).
3. Stigma should be measured using a validated tuberculosis stigma measurement scale that has been adapted to the local context (see Chapters 5, 7, and 10).

**Failure to include those lost to follow-up and those treated in the private sector will lead to underestimates of the importance of TB stigma upon TB treatment outcomes.[9,69,70]**
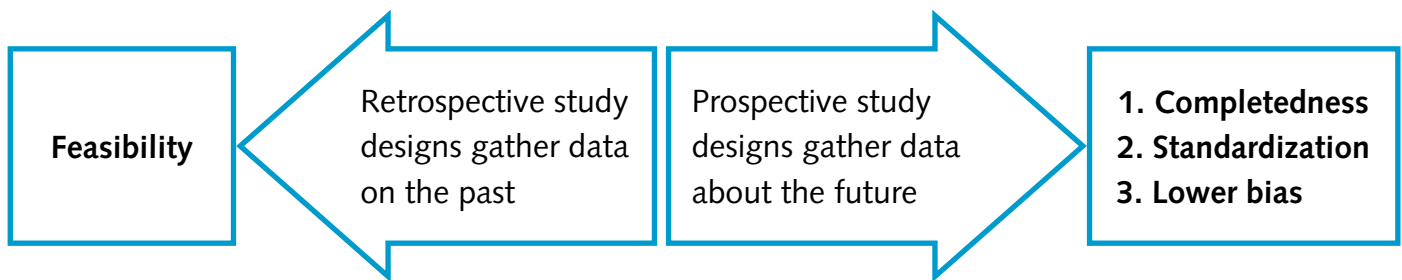
To study the influence of stigma upon retention in care with any precision, one must be willing and able to trace those lost to follow up. This is an energy and resource intensive effort, but failure to reconnect with a representative sample of those lost to follow up introduces bias in the study sample. Plans for such a study should include sufficient time, money, and energy for tracing.

Prospective studies may be less biased than retrospective studies because one can include more address and social contact variables during the enrolment

process, and therefore improve the probability of finding those lost to follow-up in the future. Prospective studies also better allow for capturing key information in a standardized manner. Prospective studies do take longer to conduct. The global target is successful treatment outcomes for at least 85% of the patients.[36] A relatively small proportion of patients being lost to follow-up will jeopardize this goal. A case-control approach is often used when an outcome is relatively rare, such as loss to follow-up.

**Figure 4. The Comparative Advantages of Retrospective and Prospective study designs**

| Feasibility | Retrospective study designs gather data on the past | Prospective study designs gather data about the future | 1. **Completedness**<br>2. **Standardization**<br>3. **Lower bias** |
|---|---|---|---|

## Case control studies

To evaluate the influence of stigma on late diagnosis or loss to follow-up, a case control study design can be used.[28] Case control studies are an efficient design when the outcome (e.g., non-adherence) is relatively rare. The case control study will examine the difference in stigma between the (smaller) number of TB patients lost to follow-up and the (larger) number of TB patients who were retained in care to see differences in stigmatization among TB patients that were lost to follow-up ("cases") and a sample of those that completed treatment ("controls").

To discern the influence of stigma, it is vital to consider relevant confounders. This is done by ensuring that both the case and control groups are balanced or matched with regard to other drivers of adherence. The confounders would include the known influences on TB treatment adherence, such as access to care, co-morbidities (e.g., drug and alcohol dependence), and gender, (Figure 5).[37]

**Figure 5. Matching in a Case-Control Study**
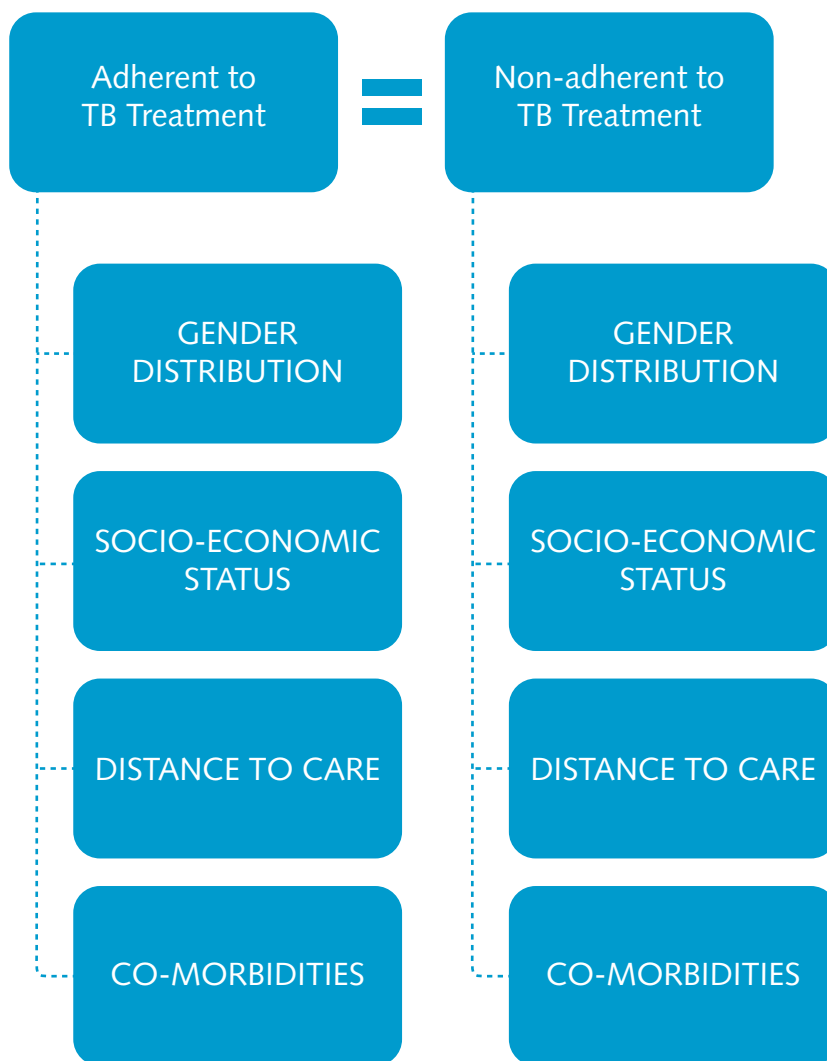


**Planning a study of the impact of TB stigma on treatment initiation and adherence**

1. Establish an operational and meaningful definition of your adherence outcome of interest, e.g. loss to follow-up.
2. Assess and strategize about how (and how soon) those patients lost to follow up can best be found (taking into consideration outmigration, death, etc.)
3. Based on the above, chose your study design (e.g., retrospective, prospective, case control)
4. Theorize all the determinants of loss to follow-up in your settings (literature review, formative interviews with persons lost to follow-up) and build your conceptual framework.
5. Operationalize the framework (i.e., decide how best to measure the determinants of loss to follow-up).
6. Size the study (e.g., determine the sample size) based on your estimate of the relative importance of TB stigma upon loss to follow-up.

# Challenges

One challenge to the measurement of treatment adherence is social desirability bias. Many people with TB are well aware of the norms regarding TB treatment adherence. Therefore, it can be hard to ask about it directly. Moreover, in planning an intervention, it is often necessary to know why and how stigma discourages TB treatment adherence. This favors a qualitative approach. Table 1 offers sample interview questions that were posed to TB patient participants recruited at health centers. These questions we used to identify the drivers and facilitators of TB stigma that contributed to loss to follow up or treatment non-adherence.[11,14] Although researchers were interested to learn about the role of stigma on adherence, questions about stigma, exclusion, discrimination, or fear were not asked outright. An indirect approach prevented over-inflation of the relevance of stigma in patients' illness experiences, and misrepresentation of the components and drivers of TB stigma in the study setting.

**Table 1. Interview Guide for Treatment Adherence among TB Patients**

| Topics | Sample Questions |
|---|---|
| **Ice breaker** | How are you feeling today? |
| **Diagnostic Journey** | How did you feel when you learned you have TB? <br> Have you had TB before? Do you feel differently this time? <br> How did you become a patient at that clinic? How did you choose that clinic? |
| **Perceptions** | What did you think about TB before you became ill? What about now? <br> Why do you think you got TB? |
| **Health Care** | Tell me about your experience at that clinic. How do you spend your time there? <br> Think about the last few times you came to that clinic. What do you think about the care you have received? <br> How did the nurses treat you? What about the doctors? <br> What have they told you about your treatment? <br> If you feel unwell between appointments, what do you do? <br> If you wanted to change something, what would it be? |
| **Social Circumstances** | Tell me a little about yourself and your life. <br> Who do you live with? How did they respond when you became ill? <br> Have any of your family members also been treated because of your illness? If so, how did this make you feel? <br> Does anyone help you with your treatment (or accompany you to the clinic)? <br> How has your life changed since you became ill? <br> How are you managing your expenses? <br> Are you working or were you working before? How has that changed? |

| Coping | How are you dealing with your illness? |
|---|---|
| | How about the demands of treatment? How does that go? |
| | How do you feel – Physically? Emotionally? |
| | What do you do when you feel tired or unwell? Who do you reach out to? (Who do you trust and why?) |
| | What has been the hardest thing for you over the past few months/weeks? |
| | What are your thoughts about the future? |
| | Has anyone discussed with you how TB is spread? How does this make you feel? |
| **Participatory Probes (may be inserted throughout to elicit thick descriptions)** | Can you tell me what happened next? |
| | Can you tell me the reason why? |
| | Can you tell me more about that? |
| | How did this make you feel? |
| | What did you do then? |
| | Can you give me an example? |
| | Think back to the last week…? |
| | How has this changed over the last few months? |
| | *Silence and non-lexical conversational sounds such as "mhm" or "uh-huh" are also helpful probes |

## Assessing the impact of TB stigma on TB mortality

High TB mortality rates are increasingly understood as an indicator of many different problems in the health system and community. Limited awareness of TB in society and restricted accessibility to care and/or quality of health services can hamper survival. Lack of insurance or permanent employment is a risk factor for TB mortality.[38] Evidence suggests that co-morbid TB patients (i.e., those with HIV, hepatitis, diabetes, etc.) are particularly vulnerable when the quality and timing of clinical care services are suboptimal and/or diagnosis is delayed, not just because TB diagnosis may be more challenging in these persons, but due to compounded stigma.[39–41] Exploration and analysis of death among TB patients can lead to a clearer and specific understanding of why deaths have happened and where stigma reduction interventions are likely to make the most difference.

Stigma can contribute to life threatening situations and loss of life directly, but often the contribution is more distal, and harder to capture.[25,26] Most research on predictors of TB mortality have chosen not to measure stigma.[42] It is important to distinguish if stigma contributes to mortality but when and how it does so, because it will require a different set of corrective actions to reduce it. Below are consequences of stigma at different points along the patient pathway.

1. Delays or deciding not to seek care for TB symptoms (see Chapter 4).
2. Delays or failure to refer or diagnose with TB.
3. Delays or failure to provide correct TB drug treatment.
4. Delays or failure to provide appropriate TB treatment supports.

5. Delays or failure to adhere to TB treatment.
6. Delays or failure to provide appropriate care for co-morbidities.
7. Low quality of acute care provided to a severely ill TB patient.

Insights into the person's care-seeking itinerary (and the often-long chain of social, economic, and clinical events) that led to his/her life-threatening hospital admission can help us to decide where to focus improvement efforts. Approaching the problem at the individual level in the context of the patient-centered approach can lead to improvement of the whole health care system.

Sample questions include:

• Are certain types of TB patients avoiding the health care system because they feel unwelcome or have experienced mistreatment?
• Is there a problem with availability, distribution, or accessibility of TB services?
• Are TB patients seeking care early, but not being referred to trained providers?
• Is the care that TB patients receive inadequate or sub-optimal?

The journey that people follow from initial infection to recovery or death has critical intervention points along the way. Any potential delays and challenges along this itinerary, including health seeking delays, poor accessibility of services, difficulties in diagnosis or initiation of treatment, or challenges in coping with the many consequences of illness, can contribute to a negative outcome.

## Challenges in studying stigma and TB mortality

There are several methodological challenges to understanding the relationship between stigma and TB mortality.

1. Stigma's effects on mortality can be difficult to pinpoint as they can occur all along the patient-pathway.[25]
2. There are so many predictors of TB mortality that samples and questionnaires must be comprehensive.
3. Death is an uncommon outcome among people diagnosed with TB. Most TB deaths are from people who are not diagnosed. And many deaths among people diagnosed with TB are not due to TB. Therefore, sample size requirements can be a challenge.
4. Identifying TB deaths is a challenge among people who die without a diagnosis.

## Conceptualizing the impact of stigma

Given that TB mortality can have dozens of contributing causes, it is important to have a good conceptual model (See Figure 4). Stigma can be both a proximal

and a distal influence, felt both directly and indirectly during the disease process.[25,26,43]

## Accounting for confounding impact of other influences on TB mortality

As with adherence studies, parsimonious measures of all the factors are essential to keep the data collection instruments a reasonable size. Qualitative data collection can add value and help elucidate some of these measures.

## Sample size considerations for a mortality study

The necessary sample size of a valid study tends to exceed 300.[44] This is a major feasibility consideration for TB programs seeking timely information for policy and planning. Large samples of people who die from TB is a challenge, even though TB is the leading infectious cause of death in the world. Death is a rare outcome of TB disease among those who are diagnosed and provided effective treatment. The rarity of deaths among those with treated TB disease makes evaluating the role of stigma in TB mortality very challenging for most TB programs.

## Identification of TB deaths

It is challenging to identify people who die from TB without being diagnosed. Most of the established methods of identification, such as verbal autopsy, do not work well for TB because the symptoms are non-specific.[45,46] It is rarely practical to measure the impact of TB stigma on TB mortality by only interviewing families who have experienced a loss. Families with a TB death often dissolve, move, or simply do not wish to participate.[47,48]

## An alternative to study mortality directly: near miss audit
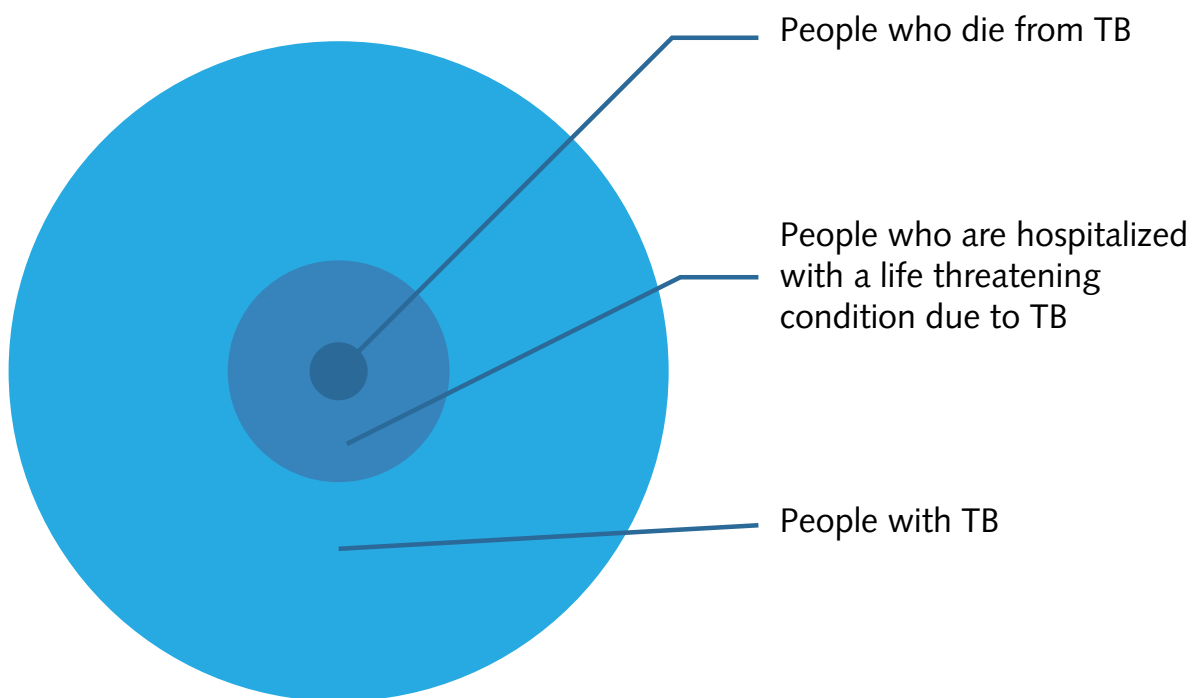
A more feasible proxy for mortality is to conduct a near miss audit, as is done routinely in the fields of maternal mortality, air transport, and workplace safety.[49–53] A near miss is defined, for the purposes of TB stigma assessment, as a person with TB in serious life threatening condition or with a high risk of imminent death.

The study of emergencies often catalyses action by highlighting specific gaps in care. The use of near-miss methods in maternal health has led to concrete improvements and declines in maternal mortality. The use of near miss audits in maternal mortality led to the counter-intuitive conclusion that investing in

improvements in antenatal and primary care would have only marginal impact on maternal mortality.[54,55]

The methods can be used at the facility, district, state, or national levels. The major disadvantage of using near miss is that you will not capture the impact of stigma on those who never seek care.[49] Thus, even with a large sample, you will never be able to generalize to all who were negatively impacted by stigma at the community level, and the study probably will exclude those most inhibited by stigma. There may be delays in interviewing near-miss patients due to extent of illness.

**Figure 6. Relative Size of the Population with Acute TB Complications versus Those Who Die from TB**



- People who die from TB
- People who are hospitalized with a life threatening condition due to TB
- People with TB

## Definitions of a TB near miss

The term "life threatening condition" needs to be strictly defined and agreed upon by all stakeholders. It is important to adopt a specific definition of near miss for adults and children, as severe disease manifests very differently. For example, oxygenation is only of limited utility in judging severity in many pediatric respiratory conditions.

Common measures of imminent mortality that have been used in TB mortality studies include:

- Acute Physiology and Chronic Health Evaluation II (APACHE II).[56–61]
- Sequential Organ Failure Assessment (SOFA) scores.[58,62]

For low resource settings, simpler scales may be more feasible. The Tropical

Intensive Care Score, (TropICS) includes emergency surgery, respiratory rate, systolic blood pressure, Glasgow Coma Scale, and blood urea, and hemoglobin is fairly accurate and requires few tests. There is a 95% confidence interval (CI), AUC 0.767 (0.741-0.792).[61]

To observe the role of stigma in TB-HIV client mortality, one could use urine LAM positivity as the definition of a TB-HIV case at high-risk for mortality.[63,64] Positive urine-lipoarabinomannan (LAM) status was strongly associated with mortality at 90 days (adjusted hazard ratio 4.2; 95% CI 1.50-11.75) in adult PLHIV in South Africa. LAM-positive PLHIV adults had a three-fold risk of death within 12 months (3.58 mortality hazard ratio (95% CI, 1.26-6.73). Urine LAM is a point of care screening tool for TB in acutely ill PLHIV.

## Accounting for multiple stigmas upon TB mortality

As discussed in Chapter 14, TB stigma is unlikely to be the only stigma negatively affecting people at high risk of mortality. In some settings, deaths are more common among TB patients with multiple stigmatized co-morbidities.[65]

## Planning a near miss investigation

The following steps should be taken when conducting a near miss:

1. Establish the purpose of the study and which methodology to use.
2. Decide how to define a near miss in the context of the chosen review.
3. Develop a consensus on the threshold for the near-miss cases to be reviewed.
4. Consider how to identify eligible cases of near miss TB.

In order to analyze TB deaths and improve TB services, look at the antecedents, health seeking behavior, and perceptions of care provided to review the timing and quality of care in health facilities. Exploring the same patient's experience from two different points of view can reveal much more than simply a one-sided record review, especially when records are poorly kept, poorly designed, or entirely absent.

**Figure 7. TB Stigma as a Contributor to Near Misses**

Health Seeking Delay + Referral Delay + Diagnostic Delay + Treatment Delay + Low Quality of Care = Near Miss
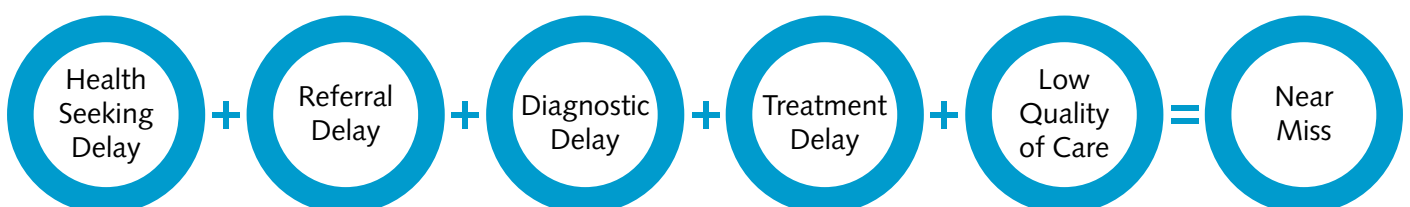
## Method

Successful implementation of the TB near miss audit depends on fostering a climate of confidentiality and trust. Using a non-punitive, non-threatening, inquisitive approach to describe and analyze the factors leading to adverse outcomes is essential.

Both health care and community workers and family members should be assured that the sole purpose of the audit is to learn valuable lessons and to save lives. These reviews seek only to identify barriers to accessing and receiving quality care in the health care system. They must never be used for litigation, management sanctions, or personnel decisions.[66]

The combined findings of the Community-based Near Miss Review (CBNMR) and the Facility-Based Near Miss Audit (FBNMA) should be used by local change agents:[67] This includes people with the power and commitment to improve health care quality and access (e.g., administrators, district leadership, activists). The tools are not intended strictly for use by researchers, but rather by multidisciplinary stakeholder teams committed to reducing mortality and morbidity among TB patients. The change process can be similar to the *WHO Strategic Approach* in that it is a participatory process with stakeholders who have diverse research, policy, clinical, and community skills.[68]

FHI 360 has also published international research ethics training materials in English, Spanish, French, and Portuguese, which can help the team to understand the ethical dimensions of a near-miss audit. A key principle for effective near miss audits is "no name, no blame, no shame."[66]

https://www.fhi360.org/resource/research-ethics-training-curriculum-retc-second-edition

For a word version of the Community-based Near Miss Review (CBNMR) and Facility-Based Near Miss Audit (FBNMA) tools, as well as methodology advice on how to carry out an audit, please refer to the Lessons from Loss manual (See also Appendix 1).

https://www.challengetb.org/publications/tools/hss/Lessons_from_Loss.pdf

## Conclusion

In this chapter we have outlined the key steps in measuring the consequences of stigma so an appropriate response can be mounted. To determine if TB stigma is a major contributor to non-adherence, sequelae, or mortality, a very careful study design and a robust sample size is required. When measuring TB stigma to

determine if it is a barrier to treatment, it is important to include (and control for) all other possible barriers to treatment adherence.

The main advantage of studying TB stigma among near misses rather than among TB patient who have died (via mortality audits or case reviews) is that the complications of TB occur much more frequently than TB deaths, enabling a more appropriate sample size to be generated.

## Acknowledgements

# Appendix 1: Illustrative Instrument for Gathering Data from Families on Factors that Influence Non-Adherence and Mortality

This is for co-habitants or witnesses to the care of the person with TB.

I am…………………and this is…………………. who will help me by taking notes during this interview. We want to have this discussion so that we can learn your ideas and opinions to improve the care of people with TB in the future. By listening to families, we can better understand what it was like for [insert name] and your family. We hope that by talking with you, we can learn how to avoid the challenges that you have faced.

Sometimes it is difficult to be open, especially when you are being asked about how other people do their work or when talking about sad times. However, I hope you can be open and honest with me, because what you have to say can help others. Your information will be combined with the interviews of many other families, and your names will never be used. If you feel uncomfortable, we can take a break and return later. You may end this interview at any point and no one will be angry with you.

Because there will be a lot of information that I will not be able to remember or write down, I would like to tape record this discussion. If you do not feel comfortable with that, it is OK for me to take notes only.

1. Community code:       [__][__]
2. Date of interview:       [__][__]/[__][__]/[__][__]
3. Field worker code:       [__][__]
4. Relationship to the patient of respondent:
   ☐ Spouse
   ☐ Mother/father
   ☐ Brother/sister
   ☐ Son/daughter
   ☐ Other household member
   ☐ Other (specify) _____

## SOCIO-DEMOGRAPHIC DATA

5. Date of Birth of PWTB       [__][__]/[__][__]/[__][__]
6. Gender:       ☐ Female       ☐ Male       ☐ Transgender
7. Age of the PWTB (in years)                                             [__][__]
8. Education level of PWTB:            Include relevant categories       [__][__]
9. Occupation of PWTB: (adapt as required)   Include relevant categories       [__][__]
10. What was PWTB's main tribe/ethnicity?   Include relevant categories       [__][__]
11. What was PWTB's religion (if any)?       Include relevant categories       [__][__]
12. PWTB's marital status            If relevant, include categories       [__][__]

13. What do you think caused the problem that led to [insert name]'s hospitalization?
14. When did this problem start? [__][__]/[__][__]/[__][__]

15. Why do you think the illness started when it did?

16. What do you think the sickness does to people who have it? How does it work?

17. Were there any particular reasons why [insert name] got [insert name of sickness]?

Do not read out the list. Tick any risk factors if mentioned by the respondent:

- ☐ HIV co-infection
- ☐ Diabetes
- ☐ Child under five years
- ☐ Elderly
- ☐ Pregnancy/postpartum
- ☐ Mentally ill
- ☐ Alcohol-addicted
- ☐ Drug-addicted
- ☐ Smoker
- ☐ Malnourished
- ☐ Previously treated for TB

- ☐ Miner
- ☐ Factory worker
- ☐ Resident of an urban slum
- ☐ Former prisoner or prison staff
- ☐ Healthcare worker
- ☐ Soldier
- ☐ Refugee or internally displaced (IDP)

- ☐ Marginalized man who has sex with men
- ☐ Sex worker
- ☐ Transgender
- ☐ Migration
- ☐ Indigenous
- ☐ Homelessness
- ☐ Orphan or vulnerable child
- ☐ Other(specify):_____ _____
- ☐ Not known_____


## SYMPTOMS OF TB (and HIV)

18. From the time [insert name] started feeling ill, what health complaints did he/she have, and when did those start?

(Interviewer: First ask for the symptoms, then probe for the dates. Tick all options mentioned.
DO NOT PROBE for symptoms, only for the dates! If exact date unknown: beginning of month=07, mid-month=15, end of month = 22, if part of the month entirely unknown =99)

| Symptom | Tick all options mentioned | | Date symptom started: dd/mm/yy |
|---|---|---|---|
| 19. = Cough | ☐ | a. | [__][__]/[__][__]/[__][__] |
| 20. = Production of sputum | ☐ | b. | [__][__]/[__][__]/[__][__] |
| 21. = Chest pain | ☐ | c. | [__][__]/[__][__]/[__][__] |
| 22. = Haemoptysis (coughing blood) | ☐ | d. | [__][__]/[__][__]/[__][__] |
| 23. = Fever | ☐ | e. | [__][__]/[__][__]/[__][__] |
| 24. = Night sweats | ☐ | f. | [__][__]/[__][__]/[__][__] |
| 25. = Weight loss | ☐ | g. | [__][__]/[__][__]/[__][__] |
| 26. = Breathlessness | ☐ | h. | [__][__]/[__][__]/[__][__] |
| 27. = Fatigue | ☐ | i. | [__][__]/[__][__]/[__][__] |
| 28. = Loss of appetite | ☐ | j. | [__][__]/[__][__]/[__][__] |
| 29. = Headache | ☐ | k. | [__][__]/[__][__]/[__][__] |
| 30. = Body pains | ☐ | l. | [__][__]/[__][__]/[__][__] |
| 31. = Other, specify ……………………code [__][__] | ☐ | m. | [__][__]/[__][__]/[__][__] |
| 32. = Other, specify ……………………code [__][__] | ☐ | n. | [__][__]/[__][__]/[__][__] |

[Note: If the exact date is not known, probe for an estimate. This information is critical. You can often use community events as a reference for probing, for example, by asking if the person developed symptoms before or after a commonly observed event/occurrence, such as recent elections, harvest time, religious celebrations, rainy season, etc., and how many weeks before or after the event.]

33. In addition to the hospitalization of [insert name] has the sickness caused other problems for your family?

**HEALTH SEEKING BEHAVIOR**

Now, I would like you to name all the persons, clinics or hospitals that [insert name] visited for care about [insert name]'s sickness and the investigations done at each, if any.

*Repeat the questions below until all providers have been mentioned and discussed. Before moving on to other topics, confirm the order of the providers attended. A provider may include any sort of care provider, including: shop, pharmacy, traditional healer, hospital, private clinic, or community health volunteer. Note: if the family member has any medical records available, and agrees that the interviewer can see those records, they can be used to verify the information (e.g., date of clinic visits, investigations done, etc.)*

| Provider | Date of first visit | Test(s) done | Amount spent (excluding transport) | Date sputum and/or chest X-ray performed |
|---|---|---|---|---|
| Categories: 1=hospital/health center/dispensary 2=private clinic, 3=herbalist 4=pharmacy 5=community health volunteer 6=lay person 7=other | If exact date unknown: beginning of month=07, mid-month=15, end of month = 22 part of month completely unknown=99 | Tick all answers that apply; Do NOT record Medical History or Physical Examination | A. Cash: exact amount. Can't remember =99999 Free/no cash =00000  B. In-kind 1=yes 2=no 9=don't know | Very important |
| 34. (full name of provider) _____ 35. Category: [_] | 36. [_][_]/[_][_]/ [_][_] dd/mm/yy | 37. [_]Physical exam 38. [_]Sputum 39. [_]Chest X-ray 40. [_]Blood test 41. [_]Biopsy 42. [_]Referred for test(s) 43. [_]Other: (specify):……….. | 44. [_][_][_][_][_] 45. B. [_]  …………..… 46. Code[_],[_] | 47. [_][_]/[_][_]/ [_][_] dd/mm/yy |
| 48. (full name of provider) _____ 49. Category: [_] | 50. [_][_]/[_][_]/ [_][_] dd/mm/yy | 51. [_]Physical exam 52. [_]Sputum 53. [_]Chest X-ray 54. [_]Blood test 55. [_]Referred for test(s) 56. [_]Other: (specify):……….. | 57. [_][_][_][_][_] 58. B. [_]  …………..… 59. Code[_],[_] | 60. [_][_]/[_][_]/ [_][_] dd/mm/yy |
| 61. (full name of provider) _____ 62. Category: [_] | 63. [_][_]/[_][_]/ [_][_] dd/mm/yy | 64. [_]Physical exam 65. [_]Sputum 66. [_]Chest X-ray 67. [_]Blood test 68. [_]Referred for test(s) 69. [_]Other: (specify):……….. | 70. [_][_][_][_][_] 71. B. [_]  …………..… 72. Code[_],[_] | 73. [_][_]/[_][_]/ [_][_] dd/mm/yy |

We are now going to talk about health facilities [insert name] he/she may have visited and how she/he went to the facility. Please give us the exact figures as much as possible.

A. What are the available transport means from [insert name]'s house to the facilities where [insert name] went for TB test and/or treatment?

B. What is the cost one way?

C. How long did it take him/her?

| A. Transport Means | B. Cost (one way) | C. Duration |
|---|---|---|
| Insert relevant categories [e.g., bus =1, bike= 2] | Currency | 1=≤10 minutes<br>2=10-30 minutes<br>3=31-59 minutes<br>4=1-2 hours<br>5=> 2 hours<br>99=don't know |
| 74. [_] | 75. [_][_][_] | 76. [_][_] |
| 77. [_] | 78. [_][_][_] | 79. [_][_] |
| 80. [_] | 81. [_][_][_] | 82. [_][_] |

83. Is this facility where [insert name] was getting TB treatment the nearest to his/her residence?
1=Yes, 0=No, 9=Don't know   [__]

84. If no, why did [insert name] attend this facility but not the one nearest to him/her?

85. Did [insert name] consider going to the hospital earlier than he/she did?
1=Yes, 0=No, 9=Don't know   [__]

If yes, what were reasons that [insert name] didn't go earlier?

Verbatim: _____
_____
_____
_____

| Do not read the options to the participant. Only probe by asking: "Were there any other reasons?" Tick all mentioned options (1=yes, 2=no, 9=don't know) | |
|---|---|
| 86. Money factor (specify) | [_] |
| 87. No money for transport to facility | [_] |
| 88. No money to pay at the hospital | [_] |
| 89. Illness did not seem serious | [_] |
| 90. He/she did not know what illness s/he had | [_] |
| 91. Self-treatment effective | [_] |
| 92. TB thought to be without cure | [_] |
| 93. Natural/environmental issue- rains, snow, harvest, earthquake | [_] |

| 94. Sought traditional/herbal remedies | [_] |
|---|---|
| 95. Fear of VCT/HIV testing | [_] |
| 96. Fear of hospital overnight admission | [_] |
| 97. Fear of injection | [_] |
| 98. Cause of problem was non-medical (witchcraft, curse, fate) | [_] |
| 99. Distance to health facility | [_] |
| 100. Long waiting in queues | [_] |
| 101. No one to assist in family | [_] |
| 102. Co-morbidity (e.g., drug-use, alcoholism, mental illness, etc.) | [_] |
| 103. Bad experience with health care system ……………………………………… | [_] |
| 104. Family opposition | [_] |
| 105. Child care responsibilities | [_] |
| 106. Fear of loss of employment | [_] |
| 107. Religious prohibition | [_] |
| 108. Civil strife, war, danger, crime | [_] |

109. How many visits to the formal health care system were made before TB was diagnosed? For each provider, what kind of treatment was given?

| Provider (See question 30 and record names in the same order) | Type of treatment |
|---|---|
| 110. | 111. |
| 112. | 113. |
| 114. | 115. |

116. What kind of treatment do you think [insert name] should have received?

117. If TB treatment was provided, did [insert name] take the TB treatment every day?
1=yes, 0=no, 3=don't know        [__]

118. Probe: Why not?

Verbatim: _____

_____

_____

_____

119. Feared side effects                    1=yes, 0=no 7=n/a  [__]
120. Couldn't afford                          1=yes, 0=no 7=n/a  [__]
121. Didn't want to go to clinic for DOT    1=yes, 0=no 7=n/a  [__]

122. What do you think [insert name] hoped would happen after taking this treatment?

## COMMUNITY CARE AND SUPPORT

| | | | |
|---|---|---|---|
| 123. | Did the [insert name] receive any kind of extra support from the TB program or the community to help get better? | 1=yes, 0=no (skip to #134), 9=I don't know | [__] |
| What treatment support did the PWTB receive? | | | |
| 124. | Food support? | 1=yes, 0=no 7=n/a | [__] |
| 125. | Financial support? | 1=yes, 0=no 7=n/a | [__] |
| 126. | Microfinance? | 1=yes, 0=no 7=n/a | [__] |
| 127. | Home-visits by health care provider? | 1=yes, 0=no 7=n/a | [__] |
| 128. | Counseling? | 1=yes, 0=no 7=n/a | [__] |
| 129. | Treatment reminders (SMS)? | 1=yes, 0=no 7=n/a | [__] |
| 130. | Transport reimbursement? | 1=yes, 0=no 7=n/a | [__] |
| 131. | Treatment supporter? | 1=yes, 0=no 7=n/a | [__] |
| 132. | Legal aid | 1=yes, 0=no 7=n/a | [__] |
| 133. | Other (specify) | 1=yes, 0=no 7=n/a | [__] |

## AWARENESS OF TB

134. How can a person prevent getting infected with TB? (Do not read answers out loud.) Tick all options mentioned.

Verbatim: _____

_____

_____

_____

| | | |
|---|---|---|
| 135. | Opening the windows at home | [__] |
| 136. | Covering mouth and nose when coughing or sneezing | [__] |
| 137. | Avoid sharing dishes/utensils | [__] |
| 138. | Purify water | [__] |
| 139. | Washing hands | [__] |
| 140. | Closing windows | [__] |
| 141. | Abstaining from sexual contact | [__] |
| 142. | Pray regularly | [__] |
| 143. | Other (please explain): | [__] |
| 144. | Do all people who get infected with TB eventually develop TB disease? 1=yes, 0=no, 9=don't know | [__] |
| 145. | Why do some develop the disease and some do not develop the disease? Verbatim: _____ _____ | |
| How can a person who is already infected with TB reduce their risk of developing TB disease? (Do not read answers out loud) | | |
| 146. | Prayer | [__] |

| 147. | Avoid alcohol, drugs and/or smoking | [__] |
|------|-------------------------------------|------|
| 148. | Use a bed net | [__] |
| 149. | Eat healthy food | [__] |
| 150. | Avoid infection with HIV | [__] |
| 151. | Take antiretroviral medicines if they have HIV | [__] |
| 152. | Take medicines that prevent development of TB disease (IPT) | [__] |
| 153. | Avoid people who are sick | [__] |
| 154. | Other (specify) | [__] |
| What are the signs and symptoms of TB? (Do not read answers out loud) | | |
| 155. | Rash | [__] |
| 156. | Cough that lasts longer than two weeks | [__] |
| 157. | Coughing up blood | [__] |
| 158. | Severe headache | [__] |
| 159. | Nausea | [__] |
| 160. | Weight loss | [__] |
| 161. | Fever without clear cause that lasts longer than two weeks | [__] |
| 162. | Chest pain | [__] |
| 163. | Shortness of breath | [__] |
| 164. | Night sweats that lasts longer than two weeks | [__] |
| 165. | Ongoing fatigue | [__] |
| 166. | Other (specify) | [__] |
| 167. | With effective medicines, can TB be cured? 1=yes, 0=no, 9=don't know | [__] |
| 168. | What is needed to cure someone of TB? <br><br> Verbatim: _____ <br><br> _____ <br><br> _____ | |
| 169. | How long does it usually take to cure TB? <br> 1=Between 1-5 months <br> 2=Between 6-12 months <br> 3=Between 13-24 months <br> 9=Do not know <br> 7=TB has no cure | [__] |
| 170. | Once a PWTB has taken TB treatment daily for a month, are they still a risk of giving the disease to other people when they cough? | [__] |
| 171. | Do you think you personally could get TB? <br> 1. Yes <br> 0. No <br> 9. Do not know <br> 4. Has (had) TB now | [__] |
| 172. | Where are the places you might go for care if you had symptoms of TB? (Please tick all mentioned, but do not read) | |
| 173. | Go to a public health clinic or hospital | [__] |
| 174. | Go to a pharmacy | [__] |
| 175. | Go to a traditional healer | [__] |
| 176. | Go to a chemical seller | [__] |

| 177. | Go to a private clinic | [__] |
|------|------------------------|------|
| 178. | Go to a pastor or religious leader | [__] |
| 179. | Other | [__] |

If you would not go to the public health clinic, what is the reason? (Please tick all that apply)

| 180. | Not sure where to go | [__] |
|------|----------------------|------|
| 181. | Cost | [__] |
| 182. | Difficulties with transportation/distance to clinic | [__] |
| 183. | Do not trust medical workers (confidentiality) | [__] |
| 184. | Do not like attitude of medical workers | [__] |
| 185. | Cannot leave work (overlapping work hours with medical facility working hours) | [__] |
| 186. | Do not want to find out that something is really wrong | [__] |
| 187. | Other (please explain) | [__] |

Now we would like you to think about the community where you live. I will read some statements aloud, and ask you to judge how much you agree or disagree.

| | Strongly agree | Agree | Disagree | Strongly disagree |
|---|---|---|---|---|
| 188. Some people may not want to eat or drink with friends who have TB | | | | |
| 189. Some people feel uncomfortable about being near a person who has had TB | | | | |
| 190. Some community members will behave differently towards that person for the rest of their life | | | | |
| 191. Some people do not want those with TB playing with their children | | | | |
| 192. Some people keep their distance from people with TB | | | | |
| 193. Some people think that those with TB are disgusting | | | | |
| 194. Some people do not want to talk to others with TB | | | | |
| 195. Some people are afraid of those with TB | | | | |
| 196. Some people try not to touch others with TB | | | | |
| 197. Some people may not want to eat or drink with family members who have TB | | | | |
| 198. Prefer not to have people with TB living in their community | | | | |

199. In your opinion, what should be done to solve the TB problem in this community?

200. Who should be doing these activities? (If not specified)

201. What role can the community play in solving the TB problem? (If not mentioned)

Thank the participant and tell her/him that their contribution has been very valuable. Emphasize that

this information will be kept confidential and will only be used to improve the care of future patients.

Make sure to give extra time to go over some of the misconceptions that were discussed. A TB factsheet could be handed out, but where literacy is an issue, talking with the people further would be more effective.

*Remember that the household members of a TB case who has passed away are probably in need of TB screening themselves.*

*Consider bringing screening tools and equipment to offer free diagnosis and treatment.*

## Appendix 2: Illustrative Instrument for Gathering Data from Facilities on Factors that Influence Non-Adherence and Mortality

Questions are written in normal font, interviewer instructions in Italic, instructions on skip patterns are underlined.

| | | |
|---|---|---|
| 202. | Facility code: | [__][__] |
| 203. | Date of audit: | [__][__]/[__][__]/[__][__] |
| 204. | Field worker code: | [__][__] |

**DEMOGRAPHIC AND BASIC CLINICAL DATA FROM RECORDS OR FROM CLINICAL STAFF WHO TENDED THE PWTB, THE TB CLINICAL RECORDS AND THE TB REGISTER**

| | | |
|---|---|---|
| 205. | PWTB Initials: | [__].[__]. |
| 206. | Date of birth: | [__][__]/[__][__]/[__][__] |
| 207. | Gender: ☐ Female ☐ Male ☐ Trans | |
| 208. | Age of the PWTB (in years): (if infant, use decimal) | [__][__] |

**RISK FACTORS AND VULNERABLE GROUPS**

209. Which (if any) risk factors did this PWTB have in his/her chart? Tick all that apply

☐ HIV co-infection
☐ Diabetes
☐ Child under five years
☐ Elderly
☐ Pregnancy/postpartum
☐ Mentally ill
☐ Alcohol-addicted
☐ Drug-addicted
☐ Smoker
☐ Malnourished
☐ Previously treated for TB

☐ Deep pit miner
☐ Factory worker
☐ Residence in an urban slum
☐ Former prisoner or prison staff
☐ Healthcare worker
☐ Soldier
☐ Refugee or internally displaced (idp)
☐ Contact of a TB case

☐ Marginalized man who has sex with men
☐ Sex worker
☐ Transgender
☐ Migration
☐ Indigenous
☐ Homelessness
☐ Orphan or vulnerable child
☐ Other(specify):_____
_____
☐ Not known_____

**TIMING OF SYMPTOMS OF TB**

210. From the time this PWTB started feeling ill, what health complaints (symptoms) did he/she have, and approximately when did those start?

(Interviewer: First ask for the symptoms, then probe for the dates. Tick all options mentioned. DO NOT PROBE for symptoms, only for the dates. If exact date unknown- fill in: beginning of month=07, mid-month=15, end of month=22, if part of the month entirely unknown=99.)

| Symptom | | Tick all options mentioned | Date symptom started: dd/mm/yy |
|---|---|---|---|
| 211. | = Cough | ☐ | a. [__][__]/[__][__]/[__][__] |
| 212. | = Production of sputum | ☐ | b. [__][__]/[__][__]/[__][__] |
| 213. | = Chest pain | ☐ | c. [__][__]/[__][__]/[__][__] |
| 214. | = Haemoptysis (coughing blood) | ☐ | d. [__][__]/[__][__]/[__][__] |
| 215. | = Fever | ☐ | e. [__][__]/[__][__]/[__][__] |
| 216. | = Night sweats | ☐ | f. [__][__]/[__][__]/[__][__] |
| 217. | = Weight loss | ☐ | g. [__][__]/[__][__]/[__][__] |
| 218. | = Breathlessness | ☐ | h. [__][__]/[__][__]/[__][__] |
| 219. | = Fatigue | ☐ | i. [__][__]/[__][__]/[__][__] |
| 220. | = Loss of appetite | ☐ | j. [__][__]/[__][__]/[__][__] |
| 221. | = Headache | ☐ | k. [__][__]/[__][__]/[__][__] |
| 222. | = Body pains | ☐ | l. [__][__]/[__][__]/[__][__] |
| 223. | = Other, specify ……………….code [__][__] | ☐ | m. [__][__]/[__][__]/[__][__] |
| 224. | = Other, specify ……………….code [__][__] | ☐ | n. [__][__]/[__][__]/[__][__] |

**TB DIAGNOSIS AND MANAGEMENT**

| | |
|---|---|
| 225. Date that the PWTB first sought medical attention for symptoms? 09/09/99 if unknown | [__][__]/[__][__]/[__][__] |
| 226. How many visits to the formal health care system were made before TB was diagnosed? 99=don't know | [__][__] |
| 227. Why was the TB investigation initiated? (choose 1) 1=PWTB sought care for TB symptoms 4=Active case-finding/screening 2=Routine screening of an HIV+ client 5=Other (specify): …………………………. 3=Referral from other health facility          99=don't know | [__][__] |
| Physical exam findings          1=yes, 0=no, 99=don't know | [__][__] |
| Chest X-ray          1=yes, 0=no, 99=don't know | [__][__] |
| Sputum sample(s)          1=yes, 0=no, 99=don't know | [__][__] |
| Needle aspirate          1=yes, 0=no, 99=don't know | [__][__] |
| Urine LAM          1=yes, 0=no, 99=don't know | [__][__] |
| Other (specify, below)          1=yes, 0=no, 99=don't know | [__][__] |

| | |
|---|---|
| Specify _____ | |
| _____ | |
| _____ | |
| 228. Was TB diagnosis confirmed mycobacteriologically? | [__][__] |
| 229. If yes, how was TB diagnosis confirmed? (tick all that apply) | [__][__] |
| a. Confirmed by smear microscopy     1=yes, 0=no, 99=don't know<br>b. Confirmed by liquid or solid culture     1=yes, 0=no, 99=don't know<br>c. Confirmed by GeneXpert/Rif     1=yes, 0=no, 99=don't know<br>d. Confirmed by urine LAM     1=yes, 0=no, 99=don't know | [__][__] |
| 230. Date that the TB diagnosis was made? 09/09/99 if unknown     [__][__]/[__][__]/[__][__] | |
| 231. Type of TB?<br>    1=PTB S+, 2=PTB S-,3=EPTB 99=unknown | [__][__] |
| 232. New or retreatment case?<br>    1=new, 2=relapse, 3 failure, 4= return after default, 5=other,<br>    99=unknown | [__][__] |
| 233. Date when the PWTB was notified of his/her TB diagnosis?<br>    (07/07/77 if not notified, 09/09/99 if unknown) | [__][__]/[__][__]/[__][__] |
| 234. Date when TB treatment started? | [__][__]/[__][__]/[__][__] |
| 235. If TB treatment was never started, what was the main reason?<br>    1=Drug stock out, 2=TX Consultations needed, 3=PWTB refusal,<br>    4=Early death, 5= Contraindication, 6=Not authorized to dispense<br>    TBTX, 7=Waiting list for TB TX, 8=Other | [__][__] |
| 236. What were the other reasons? (if any) | [__][__] |
| 237. If TB treatment started more than 48hrs after TB diagnosis, what<br>    was the main reason?<br>    1=Drug stock out, 2=TX Consultations needed, 3=PWTB refusal,<br>    4=Early death, 5= Other | [__][__] |
| 238. What were the other reasons? (if any) | [__][__] |
| 239. Did the PWTB have drug-resistant TB?<br>    1=yes, 0=no, 99=unknown | [__][__] |
| 240. Which TB Treatment regimen was the PWTB following?<br>    1= Cat I, 2=Cat II, 3 =Other, 99=Unknown, 77=NoTX | [__][__] |
| 241. Were sputum samples taken and examined at the appropriate<br>    times? (i.e., at two months and five months)<br>    1=yes, both times 0=no, 3= once only, 77=not applicable | [__][__] |
| 242. Was the PWTB started on retreatment regimen if the five months<br>    sputum was positive?<br>    1=yes, 0=no, 77=not applicable 99=don't know | [__][__] |

| | |
|---|---|
| 243. How was TB treatment adherence?<br>1=Fully adherent (more than 90% of doses taken)<br>2=Between 70%-90% of doses taken<br>3=Less than 70% of doses taken<br>77=not applicable, treatment had just begun<br>99=unknown | [__][__] |
| 244. What other PWTB factors (if any) impacted quality of TB care?<br>1=Language barriers, 2= Staff shortage,3= Collaboration challenges,<br>4=Lack of family/supporters, 5=Other, 77=Not applicable, 99=Unknown | [__][__] |

## HIV DIAGNOSIS AND MANAGEMENT

| | |
|---|---|
| 245. Under what circumstances was the HIV test conducted?<br>1=PICT of TB PWTB, 2=VCT, 3=Part of clinical work-up, 99=Unknown,<br>5=PWTB already known to be HIV+ | [__] [__] |
| Date that a blood sample(s) was taken for HIV test | [__][__]/[__][__]/[__][__] |
| 246. What was the HIV test result?<br>1=HIV positive, 2=HIV negative, 3=In determinant, 88=Not tested,<br>99=Missing result | [__] [__] |
| 247. Date that the HIV diagnosis was made? 09/09/99 if unknown | [__][__]/[__][__]/[__][__] |
| 248. Date of HIV post-test counseling (09/09/99 if unknown) | [__][__]/[__][__]/[__][__] |
| 249. Was anti-retroviral therapy (ART) started in hospital or was the<br>　　PWTB on ART when diagnosed with TB?<br>1=yes, 0=no (skip to #), 3=already on ART, 99=unknown | |
| 250. Date when ART was started?<br>07/07/77= HIV NEG<br>08/08/88=not tested<br>09/09/99= unknown | [__][__]/[__][__]/[__][__] |
| 251. If ART was not started, what was the main reason?<br>1=Drug stock out, 2=TX Consultations needed, 3=PWTB refusal,<br>4=Early death, 5= Contraindication, 6=Not authorized to dispense ART,<br>7=Waiting list, 8=Other | [__] [__] |
| 252. Other reasons for no ART provision to HIV+ TB PWTBs | |
| 253. How consistently was ART taken?<br>1=Fully adherent (at least 90% of doses taken)<br>2=Between 70%-90% of doses taken<br>3=Less than 70% of doses taken<br>77=No ARTs started, 99=Unknown | [__] [__] |
| 254. Was Cotrimoxazole (CPT) started?<br>1=yes, 0=no, 77=not applicable: HIV NEG,<br>88=not tested, 99=missing | [__] [__] |
| 255. When was Cotrimoxazole started? | [__][__]/[__][__]/[__][__] |

| | |
|---|---|
| 256. If Cotrimoxazole was not started, what was the main reason? 1=Drug stockout, 2=TX Consultations needed, 3=PWTB refusal, 4=Early death, 5= contraindication, 6=not authorized to dispense ART, 7=waiting list, 8=other | [__] [__] |
| 257. Result and date of latest CD4 count before discharge/death? 999=if unknown (09/09/99 if unknown) [__][__] [__] [__][__]/[__][__]/[__][__] | |
| 258. Was HIV diagnosed before TB? | [__] [__] |
| 259. If yes, was client prescribed Isoniazid preventive therapy (IPT)? | [__] [__] |
| 260. If no, why not? | |
| 261. What other factors influenced HIV care? | |

## CLINICAL CARE IN HOSPITAL

| | |
|---|---|
| 262. Date of admission to hospital? (09/09/99 if unknown) | [__][__]/[__][__]/[__][__] |
| 263. Was PWTB weighed upon admission? 1=yes, 0=no,99=unknown | [__] [__] |
| 264. What was PWTB's body weight at admission | [__] [__] |
| 265. CD4 count at admission (9999=if unknown | [__] [__] [__] [__] |
| Indicate the total number of times the following tests were performed between admission and discharge/transfer/death? | |
| 266. Body weight measured | [__] [__] |
| 267. Respirations measured | [__] [__] |
| 268. Pulse measured | [__] [__] |
| 269. Blood pressure taken | [__] [__] |
| 270. Temperature measured | [__] [__] |
| 271. Chest sounds measured | [__] [__] |
| 272. Hemoglobin/Anemia measured | [__] [__] |
| 273. Other diagnostic blood tests | [__] [__] |
| 274. Liver function tests | [__] [__] |
| 275. Urine Tests | [__] [__] |
| 276. Chest X-ray performed | [__][__] |
| 277. How long was the largest time span between clinical assessments by a clinician? In hours | [__][__] [__] |
| 278. Were signs of worsening condition noted? (tick yes if respiration rate>30/min, pulse>120/min, or temperature >39ºC, or other unstable vital) 1=yes, 0=no, 99=unknown | [__][__] |
| 279. Were actions taken to address the worsening condition? 1=yes, 0=no, 99=unknown | [__][__] |
| Which actions were taken? 280. 281. 282. 283. | |

| | |
|---|---|
| 284. How much time elapsed between worsening was noted and when action was taken? (in hours) | [__][__] |
| 285. Were treatment complications identified?<br>1=yes, 0=no, 99=unknown | [__][__] |
| 286. What treatment complications were found (if any)? (77=none)<br>1=yes, 0=no, 99=unknown | [__][__] |
| 287. In addition to TB, did the PWTB suffer from any other comorbidities?<br>1=yes, 0=no, 99=unknown | [__][__] |
| 288. Did PWTB receive other treatment/support beyond TB treatment?<br>1=yes, 0=no, 99=unknown | [__][__] |
| a. IV fluids<br>1=yes, 0=no, 99=unknown | [__][__] |
| b. Corticosteroids<br>1=yes, 0=no, 99=unknown | [__][__] |
| c. Diuretics<br>1=yes, 0=no, 99=unknown | [__][__] |
| d. Bronchodilatators<br>1=yes, 0=no, 99=unknown | [__][__] |
| e. Supplementary food<br>1=yes, 0=no, 99=unknown | [__][__] |
| f. Other (describe:)<br>1=yes, 0=no, 99=unknown | [__][__] |
| 289. How long was the largest time span between clinical assessments by a clinician? (In hours) | [__][__] [__] |
| 290. Were there delays in provision of medication due to stock outs? | [__][__] |
| 291. If yes, which ones? | [__][__] |
| 292. What was the length of time between when blood was drawn and when test results were acted upon? (in hours)<br>(99=unknown, 77=not applicable if no tests or TX) | [__][__] [__] |
| 293. Was there a need for PWTB financial contributions to cover the costs of tests and/or treatments?<br>1=yes, tests only, 2= treatment only, 3= tests and treatment, 0=no, 99=unknown, 77=not applicable | [__][__] |
| 294. Did PWTB's financial constraints contribute to delay in timely testing and/or treatment?<br>1=yes, 0=no, 99=unknown, 77=not applicable | [__][__] |
| 295. Was the PWTB discharged from the hospital?<br>1=yes, 0=no | [__] |
| 296. Date of hospital discharge | [__][__]/ [__][__]/[__][__] |

| 297. What was the main reason for discharge? | [__] |
|---|---|
| 1=To receive palliative care | |
| 2=Request of PWTB or relatives | |
| 3=Condition allowed ambulatory treatment | |
| 4=Transfer to another facility | |
| 5= Other (specify) | |
| 298. What was PWTB's weight at discharge? (in Kg) | [__][__] |
| 299. Where was the PWTB transferred? | |
| 300. Why was the PWTB transferred? | |

## MORTALITY

| 301. Did the PWTB die? | [__] |
|---|---|
| 1=yes, 0=no | |
| 302. If yes, when did the PWTB die? | [__][__]/[__][__]/[__][__] |
| 303. If no, date of treatment outcome | [__][__]/[__][__]/[__][__] |
| 304. Where did the PWTB die? | [__] |
| 1=At home, 2=In this hospital, 3=In hospice, 4=Other health facility | |
| 5=Other (specify) | |
| 305. What was the direct cause of death? | |
| 306. What is the source of information on cause of PWTB's death | [__][__] |
| 1=Necropsy, 2=Verbal autopsy, 3=Clinical data, 99=Unknown, | |
| 77=Not applicable | |
| 307. What was the underlying cause of death? | [__][__] |
| 1=TB, 2=Other opportunistic infection of HIV, 3=Other, | |
| 99=Unknown, 77=Not applicable | |
| 308. On what basis was this determined? | |
| 309. What were the contributing causes of death? | |

310. Additional details that may be pertinent for performance improvement: _____

_____

_____

_____

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# Chapter 16

# Stigma Scale Validation and Reporting of Stigma Measurement

*Ellen Mitchell, Julia van den Land, and Jens Levy*

## Abstract

Scale validation is an important and often overlooked aspect of stigma measurement.  Failure to use valid stigma scales undermines efforts to measure and evaluate interventions to reduce stigma. This chapter breaks down stigma scale validation procedures into sequential steps. Psychometric testing can be daunting because the concepts are abstract, there is a lot of poorly defined jargon, and the mathematics are sophisticated. This chapter demystifies scale development. Short, valid stigma instruments can be built following the steps outlined in this chapter.

## Objectives

1. To explain how to develop and test stigma scales.
2. To empower researchers to validate existing scales in new settings.
3. To guide measurement reporting.

## Target Audience

This chapter is for people who need to pilot existing scales or develop their own stigma scales. The chapter is pitched to social scientists and epidemiologists, and assumes mastery of the material in the introductory chapters.

# Introduction

There are many valid TB stigma scales available. However, a lack of validated tools for each type of TB stigma means that new scales occasionally must be developed, or an existing scale shortened. If you must validate a scale, commit to the whole process.[1] The validation of a new tool is a formal psychometric technical process.

Validation of a tool cannot be accomplished via a meeting of diverse stakeholders, a set of small pilots, or qualitative interviews in different settings. Scale development should be undertaken in partnership with researchers with quantitative psychology, sociology, and epidemiology backgrounds.

It is challenging to measure stigma in a scale, so there must be a balance between capturing nuances and creating a usable tool. Follow the formative research steps in Chapters 1, 2, and 3 to identify domains and drivers before attempting to develop items for a scale.

Trying a broad range of items in the pilot phase helps trim the scale. Crafting an instrument that is as short as possible while reliable and valid is the major challenge of any scale development exercise.[2]

Stigma is a latent construct, meaning it cannot be measured directly, like empowerment, social deprivation, vulnerability, or intelligence. While we can't see latent constructs, we can measure their manifestations. For example, people who stigmatize have tendency to exclude, avoid, blame, label and stereotype people with TB.

**A quality scale has eight features:**

1. Content validity.
2. Internal consistency.
3. Criterion validity.
4. Construct validity.
5. Reproducibility (Agreement, reliability.)
6. Responsiveness.
7. No floor and ceiling effects.
8. Easy to interpret.

# Steps in Scale Development and Validation

1. **Phase 1: Survey Development** to ensure content is valid (see chapters 1, 2, and 3.)
2. **Phase 2: Pilot** to assess construct validity. This is an initial pilot of the survey to assess the psychometric characteristics of a draft scale; and its interpretation by end-users through cognitive interviews.
3. **Phase 3: Validation** to characterize the underlying structure (domains) of the scale, and to assess the comparative performance against other scales and related constructs.
4. **Phase 4: Revision**. This is the removal (trimming) of scale items that do not perform well to get the minimum number of scale items that to capture the domains of stigma.

## Phase 1: Survey Development

### Selecting types and domains

This is a formative phase, using qualitative methods (in-depth interviews) to identify the main dimensions or domains of stigma to be measured and the mechanisms (drivers) by which it functions. This is covered in detail in Chapter 3.
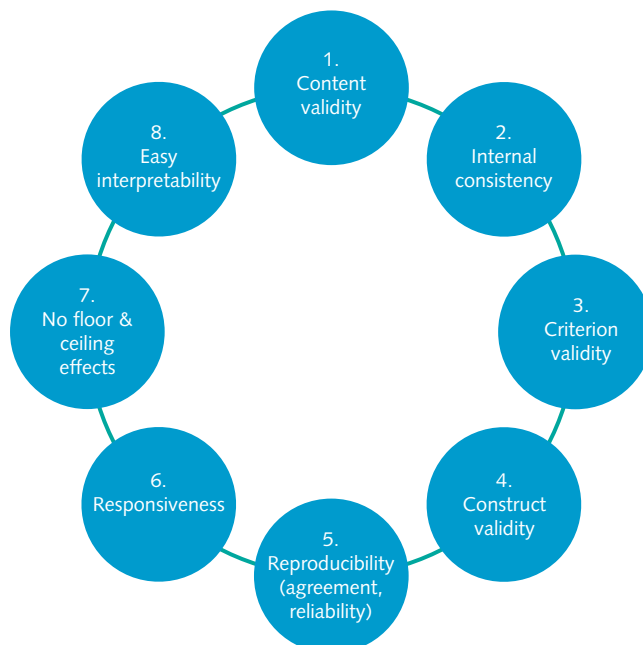
### Developing items for a scale

Items should be relatively brief and the language simple and familiar to the target participants.[3] Avoid double-negatives (e.g., *"I am not concerned when my MDR-TB patient does not wear a mask"* and double-barreled items which may measure two different constructs (e.g., *"My TB-colleagues are dedicated and hardworking"*) these create confusion.[3] A clear item would be *"I am concerned when my newly diagnosed MDR-TB patient does not wear a mask."*

Develop positive and negative items to overcome acquiescence responses (e.g., when respondents read only the first items and infer the direction of the rest.) Wording of survey items is particularly important because lack of attention can undermine the utility and validity of the TB scale.

When you are developing a scale to pilot, you must test an instrument that is longer than what you want to end up with. Experts generate at least five draft items per stigma domain to pilot, so that one or two items can be trimmed during validation.[4]

To properly validate your stigma scale, you will need to evaluate its performance in eight aspects. Then will it be a trustworthy reflection of stigma.

**Figure 1. Eight aspects of stigma scale performance evaluation**

In the following sections we define each term of the eight aspects of stigma scale performance, provide practical methods for ensuring it's fulfilment, and discuss methods to test if your scale has the desired features. First, we will introduce some of the statistical methods that are commonly used to evaluate several of these features of scale development.

## Analytic methods for survey development

Factor analysis is a statistical method of characterizing the variability of correlated factors to identify a set of items that belong to underlying unobserved constructs (domains). The goal of factor analysis is to reorganize the data and reduce the number of items so that your scale captures the maximum amount of information from the piloted items.

The statistical approaches to be performed on your pilot data set will depend on how your items were chosen. The statistical aspect of scale validation can be confusing because the same statistical method, confirmatory factor analysis (CFA), can be used for different validation tasks.

It is beyond the scope of this chapter to teach this process in a step-by-step manner. A statistician with clinimetric or psychometric skills should be involved in scale validation. We present an overview of what assessments should be made and why, and provide links to key educational resources for further elaboration.

A particularly useful statistic that is applied to measure internal consistency is Cronbach's alpha ($\alpha$) reliability coefficient. This is the proportion of the total variance of a scale score that is attributable to the underlying shared variation that reflects domains.

This source of variation is distinct from random errors associated with the individual variables of the scale, which are uncorrelated among the different elements. The value of $\alpha$ can fall between 0 and 1, which corresponds to absolutely no commonality (complete independence) between the variables in the scale and perfect commonality, reflecting a redundancy among the variables in the scale.

Factor analysis is therefore a valuable statistical tool for scale development to characterize latent constructs, such as stigma.

## Exploratory Factor Analysis

There are different kinds of factor analysis as it relates to scale development. Exploratory factor analysis (EFA) is factor analysis employed specifically to identify the underlying relationships between measured variables when a researcher has no pre-conceived hypothesis about these relationships.

This analysis is useful when the underlying construct of the domains is not already well characterized. In EFA, this methodology determines the number of factors (if any) there are among a set of variables. Exploratory factor analysis is therefore a data reduction methodology which notably overlaps with principle component analysis (PCA).

EFA involves taking a set of items and constructing a correlation matrix (for variables that are not on the same scale like sex and Likert scale) or a variance-covariance matrix (for items with the same scale, e.g., a Likert scale between 0 and 7). Operating under the assumption that there are as many factors or domains as there are items, a series of linear combinations of all of the items is generated to define each factor. The statistical software starts with selecting the factor that explains the largest amount of variance in the sample, and assigns a weight to it.

Subsequent factors or domains are successively evaluated and weighted to express the largest amount of variance in the sample uncorrelated with previous factor(s). In other words, each successive factor evaluated is uncorrelated with and explaining less variance than previous factors. Each factor captures a certain amount of the overall variance, and the factors or domains are ranked in order of the amount of variation they explain.
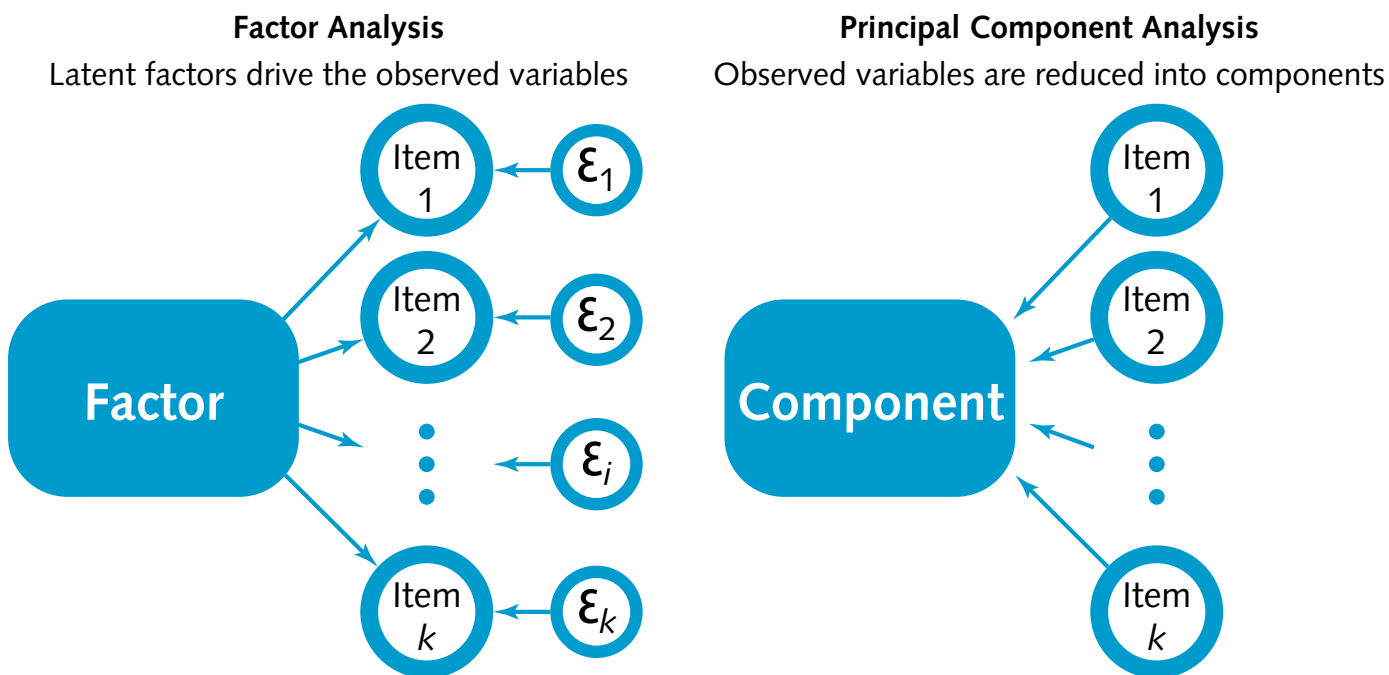
How much variance the factor explains is measured by the eigenvalue. If a factorial structure exists in the data, most of the variance is explained on the basis of the first factors or domains. Thus, any factor with an eigenvalue of more than 1 explains more variance than a single observed variable. A factor with an eigenvalue of 2.3 would explain as much variance as 2.3 items.

## Principle Component Analysis vs. Exploratory Factor Analysis

Exploratory factor analysis and principle component analysis are similar. Both methods find the components (factors or domains) that are a linear combination of the original items that summarize the data based on the trade-off between simplicity (i.e., we want as few factors or domains as possible) and completeness (we want to explain the variation in the data as efficiently as possible).

PCA tries to account for all the variance of all of the items, that is, PCA utilizes all of the variance associated with the elements with as few mutually independent underlying factors or domains as possible. Factor analysis, on the other hand, seeks to explain the independent underlying factors or domains with only as much variance that is shared among items, discarding the remaining as error. Factor analysis aims to reduce the scale to only the factors that relate to the latent variable that we are interested in (i.e., stigma).
.

## Figure 2. Visualizing the differences between factor analyses

**Factor Analysis**
Latent factors drive the observed variables

**Principal Component Analysis**
Observed variables are reduced into components



## Confirmatory Factor Analysis

Another kind of factor analysis relevant to scale development is confirmatory factor analysis (CFA). This is a multivariate statistical methodology to verify that a relationship exists between observed items and their underlying latent constructs. The primary statistical tool used to perform CFA is structural equation modelling (SEM). CFA is a special case of SEM in which domains are modeled as covariances/correlations rather than as structural relationships (i.e., regressions). In other words, factors or domains are not assumed to directly cause one another. In comparison, other SEM methodologies specify that particular factors or domains are causal in nature.

In contrast to EFA, CFA assumes you have a prior understanding of the number of factors or domains and what items will feed into each factor. This knowledge may come from published findings of earlier factor analyses that have been validated. Some of the most common uses of CFA include scale validation, construct validation, and evaluating measurement invariance. This is a necessary tool for measuring stigma.

Using existing theories or empirical research, specify an underlying 'model' that represents the relationship between your scale items and the underlying domains that you seek to measure. Using CFA, you will test whether the data fit your hypothesized domain structure or model. (See Figure 7 for an example of an underlying domain structure of a scale.)

A scree plot can help you determine how many domains you have in your scale.
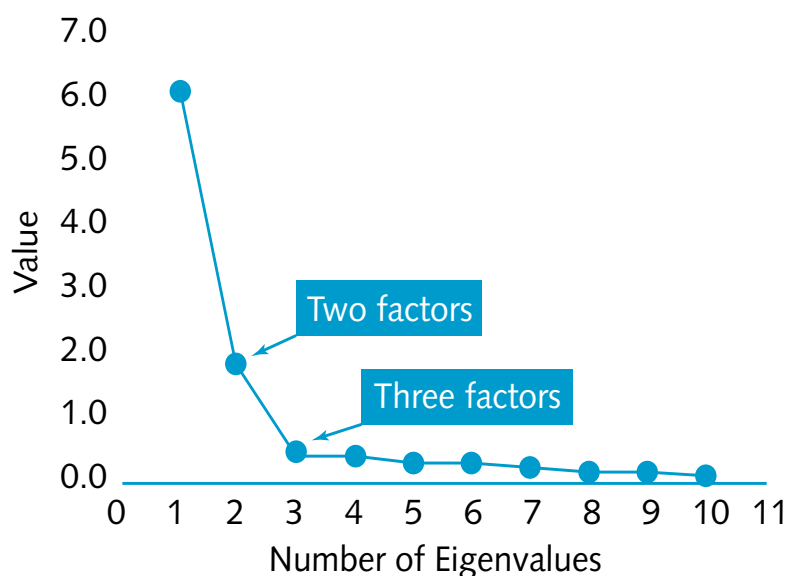
**Figure 3. A Scree plot of eigenvalues**



# 1. Ensuring and Assessing the Content Validity of your Scale

Content validity is the evaluation of whether a measure fully represents the construct, that is, whether it measures what you want it to measure.

Items in TB stigma measures should be understood by and be relevant for as many respondents as possible. The percentage of 'missing values' and respondents that use the categories 'don't know' should be as low as possible. If questions are fully understood, it is acceptable to have less than 20% missing values and/or less than 20% of the respondents answer 'do not know.'

The content validity of a scale can only be ensured if the scale items are derived from the formative findings of ethnographic, qualitative work (see Chapters 3 and17) Social validity can only be ensured via an inclusive process and early, meaningful engagement of the target populations (Chapter 1)

People affected by TB have a key role to play in the development of items and tools. They can help make sure that the tool has content and social validity (i.e., is linked to the reality of their experiences).[5–7] The social validity of a TB stigma tool depends on the technical contributions of people who know what TB stigma feels like.[8]

Content validity is assessed via cognitive interviews.

## Cognitive Interviews

During the pilot, the trained research team should recruit, consent, and conduct the survey with cognitive interviews in national and/or local languages.

Cognitive interviews use a combination of both the think-aloud and verbal probing techniques to better understand how respondents interpreted the survey items.[9] Cognitive interview sessions may be audio-taped so discourse can be analyzed and revisited by multiple investigators.

The purposes of cognitive interviews are to:

- Assess the understandability of the individual questions to a broad range of interviewees – including variation in gender, work cadres, and seniority.
- Assess the interpretations of the questions by the interviewees, including the direction of the underlying facet or construct being measured.  In other words, do the questions really measure what we think they are measuring?
- Identify questions that are too vague or ambiguous as to cause analytic and interpretive challenges later.
- Assess the feasibility of obtaining valid data through the chosen methodology (e.g., administration, directed observation, or interviews) among the target population.

The cognitive interview guide will contain probes that try to confirm if the items tap into the desired stigma domains and if they are understood. The interviewer tries to mentally recreate the environmental and personal context to reveal the cognitive process of responding to the items.[9]

Ask respondents:

- How did you decide to answer (a) question 17? Please walk me through the mental steps you took to get to your answer?
- What do you think they are really asking in question 4?
- What did you think of when you saw the word 'excluded'? Can you give an example of excluding someone?

After each cognitive interview, detailed notes should be generated on any problems. Based on these results and pilot survey responses, the research team will reformulate survey items that are confusing.

## 2. Ensuring and Assessing Internal Consistency of Your Scale

Internal consistency reliability concerns how individual items relate to each-other. Here is an example of a DR-TB stigma scale with three subscales or three domains: fear, disgust and blame.

**Figure 4. The Underlying structure of a TB stigma instrument**
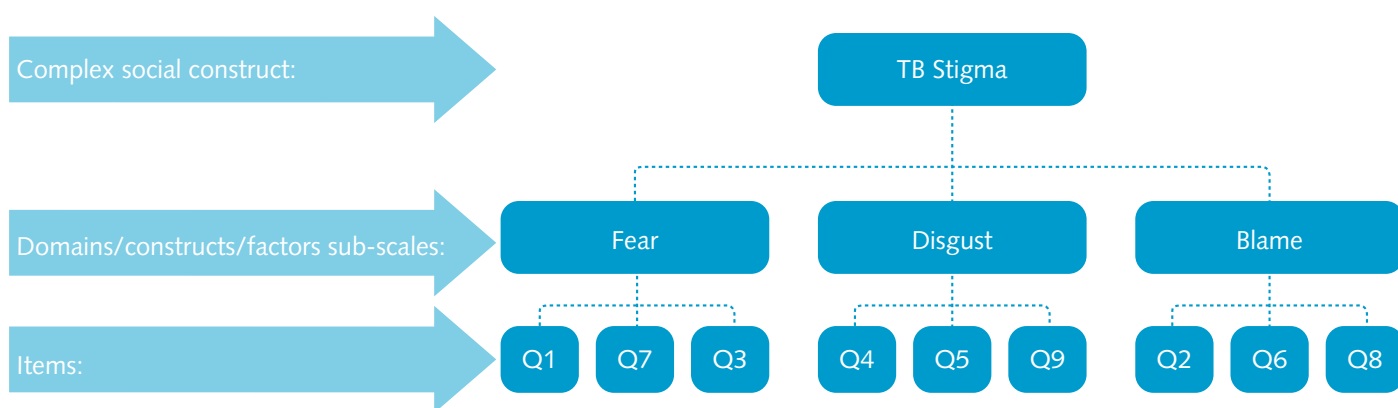


The principle statistic to evaluate the internal consistency of a scale is the Cronbach alpha ($\alpha$) reliability coefficient. The statistic varies between 0 and 1 and describes the interrelatedness of items within a test. In other words, it reflects how well items collectively capture the same singular construct. If the Cronbach's $\alpha$ increases when an item is dropped from the scale, it implies that the specific item is probably not a good fit for the scale of TB stigma. The Cronbach's $\alpha$ should be calculated for the whole scale and each sub-scale.

A scale with a Cronbach's $\alpha$ of >0.70 is considered minimally consistent, and it therefor has acceptable reliability of the scale and can be used for further analysis.[10] Values between 0.70 and 0.80 are moderate-to-good, and above 0.80 good-to-very good. Conventional wisdom is that the minimum acceptable value is 0.70. However, $\alpha$ tends to increase with more items added to the scale, so brief scales with Cronbach's $\alpha$ slightly lower than 0.70 may also be valid. The acceptable cut-off for Cronbach's $\alpha$ is a function of how complex the construct is. Some types of TB stigma are complex constructs, and therefore a $\alpha$ of slightly below 0.70 is not categorically disqualifying.

While a scale's Cronbach's $\alpha$ coefficients may be improved by excluding one or two items, retain topics that a TB-affected population rate as 'important' or even 'actionable' *even if psychometrically they don't enhance the scale*. The item reduction process should balance content and construct reliability.

## 3. Ensuring and Assessing Criterion Validity (e.g., Congruence with a Gold Standard)

If a new stigma scale is valid, it should give similar results to well-established stigma measures. It is important to assess the congruence of a new scale with validated stigma scales (where they exist).[8] For example, if you were developing a new scale to assess MDR-TB stigma among health care workers, you might consider including the Wouters TB stigma scale for HCW[11,12] for comparison during the pilot.

Criterion validity is the correlation of the stigma score results with the results of a reference standard (or other representation of the construct) when both are applied to the same sample. The correlation with the gold standard should be at least 0.70 to conclude that the new tool has criterion validity.[8]

**Figure 5. Criterion validity is the comparison of a new tool with an established one**
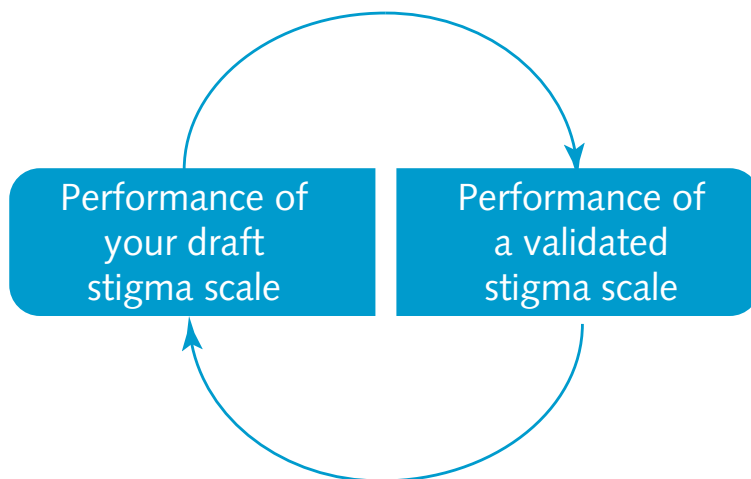


## 4. Ensuring and Assessing Construct Validity

Construct validity refers to the theoretical relationship between the behavior of the scale and the underlying construct (stigma). In other words, it aims to capture the extent to which a set of items aligns with other relevant conditions that you believe are linked to stigma. These are consequences of stigma, such as depression, negative coping, self-efficacy, etc.

Measurement of the external construct validity examines the relationship between the different subscales and relevant correlates. For example, one can assess whether a respondent's internal stigmatizing attitudes are negatively correlated with respondent's mental health.

A good stigma scale should relate to patient-relevant outcomes. Measure conditions or constructs that you expect to co-vary with stigma.[8] These might include health-related quality of life, burn out, depression, and negative coping behaviors.[13,14] Self-efficacy, social support, and self-esteem are constructs expected to be inversely correlated with TB stigma, so it is strategic to include some validated scales that measure these constructs and to verify the relationship between them.[13,14]

If you want to develop a new scale to measure stigma in TB patients, assess construct validity by comparing your results with scales that measure constructs that you think are affected by stigma, such as:

1. The Ryff Scales of Psychological Well-Being[15, 16]
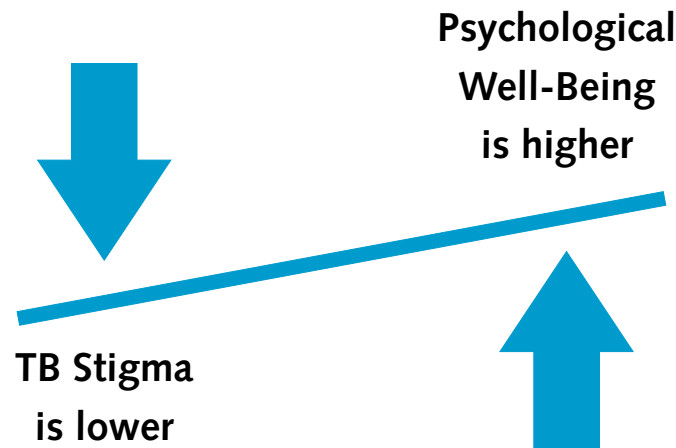2. Mason TB Treatment Efficacy Scale[17]

When creating the item pool, it is handy to group domains (also called sub-scales) together to ensure a sufficient minimum number of items in each domain.
However, when the scale is eventually finalized, the items should be re-ordered so domains are not clustered.

Researchers building a scale to measure the stigma felt by health care workers usually test the construct validity of their new scale by correlating scores with the Maslach burnout inventory (MBI) scale (described in Chapter 8). Feeling discredited for treating patients with TB can covary with burnout.[18] Terwee et al. state that construct validity has been established if at least 75% of the hypothesized relationships are borne out.[8]

Construct validity can be assessed two ways. Factor analysis can identify sets of items that are related and therefore likely to measure the same construct while excluding items that may be unrelated. Conduct principal component analysis or exploratory factory analysis to determine if your items form one single scale or if there are sub-scales (constructs, domains, or factors.) **If you choose your items from existing validated measures or based on pre-specified domains, then use confirmatory factor analysis (CFA)**.

First, assess the internal construct validity for each scale. This ensures that those items that do not successfully load above > 0.40 onto the respective theoretical stigma domain, or those that are not measuring the same construct, will be removed from the scale. After deleting items that do not sufficiently load onto a certain factor, the scale should display a good fit onto the factor and an increased internal reliability.

Any particular item in a scale may contribute to more than one underlying factor (i.e., stigma domain or component). That is, the variable *loads onto more than one factor*.

For example, agreement with "TB patients make me uncomfortable" could load on a sub-scale of items about the *fear* domain and a sub-scale of items about *disgust* domain. An item that does not clearly sit in a single domain is not a good one for your stigma scale.
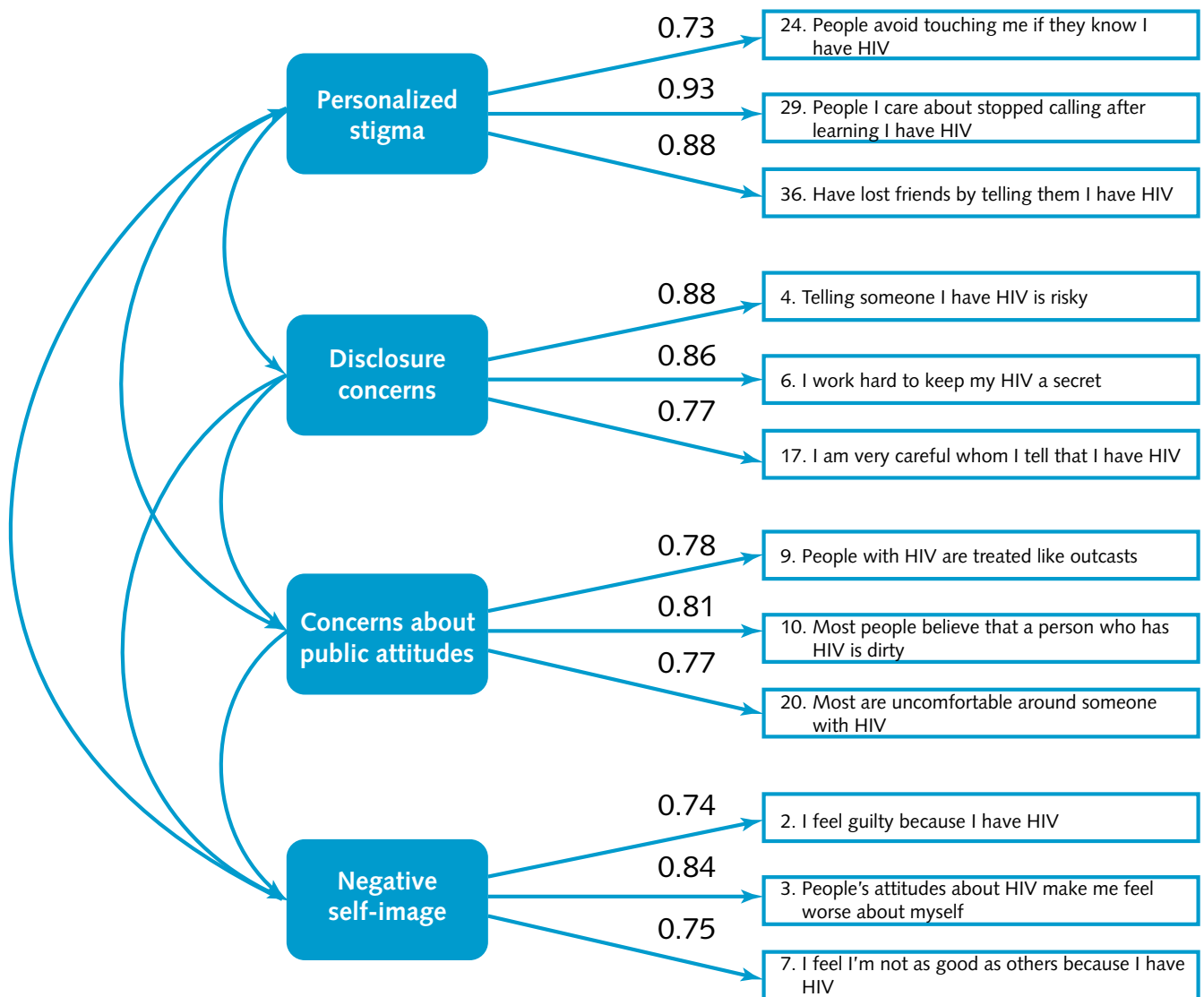
To properly identify specific factors or domains (e.g., blame or shame), it is sometimes necessary to employ techniques called factor rotation (either orthogonal or oblique rotation.) It is beyond the scope of this guidance to teach these skills, which often require a sophisticated grasp of statistical methods.

After item reduction, social scientists believe there should always be a minimum of three items per domain in the trimmed final stigma scale. Otherwise, the scale will be "over identified" when you perform a factor analysis.[4] A model is considered *identifiable* if it is theoretically possible to learn the true relationships among the model's underlying constructs after obtaining an infinite number of observations from it.

Models that are "identified" are those where the items can cluster in a single perfect fit. Those that are 'over identified' have multiple equally "right"

answers (i.e., the survey items can be sub-divided into different domains with equal statistical soundness). When there is more than one right answer, it can be hard to explain the relationships between two constructs (e.g., "TB stigma" and "treatment adherence").

# Phase 2 - Piloting a draft instrument

A rigorous pilot of the draft scale assesses the performance of individual items as well as the psychometric properties of the sub-scales.8 A pilot phase should involve both quantitative and qualitative methods. The wording and structure of the survey instrument must reflect the terms and framings used by respondents to describe their experiences and behaviors.[20]

Below is an example of the structure of a stigma survey instrument that KNCV built to measure DR-TB Stigma among DR-TB patients. It captured five different types of stigma. Under each type of stigma, there were several domains, each of which was measured via several items distributed throughout the instrument.

**Figure 8. Five DR-TB stigma scales with different domains per type and number of items (questions) per domain**
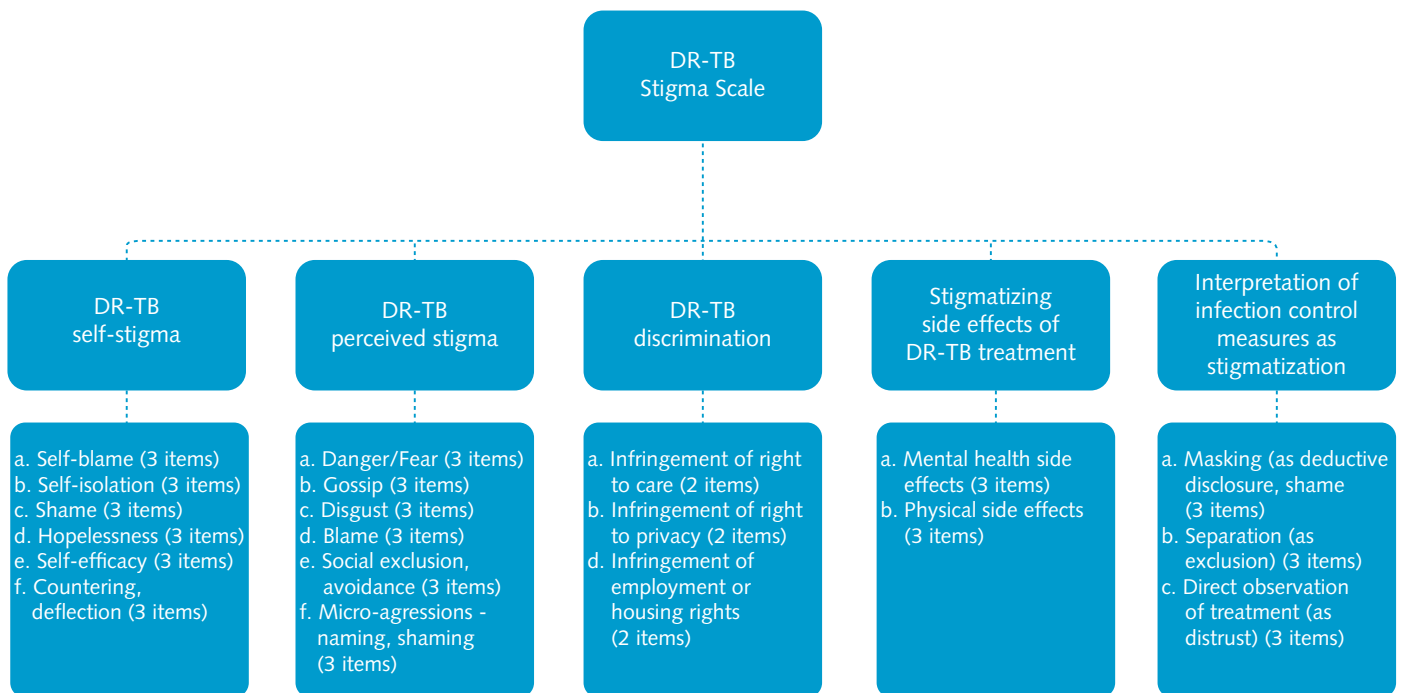


# 5.    Reproducibility (Agreement, Reliability)

Reproducibility can be broken down into two types: agreement and reliability. Reproducibility ensures that when a scale is used twice, for example, in pre/ post evaluation, any difference reflects real changes and not measurement noise. Sometimes this is referred to as 'test retest validity" or "longitudinal validity".

The reproducibility of the tool should be measured by surveying a sub-sample twice. One or two weeks is sufficient time gap to measure inter-individual reliability.[8] A sub-sample of 50 people is considered sufficient for a test-re-test reliability assessment.[8] Bland and Altman recommend that one report it as the mean difference in score of repeated measures ± 1.96 x standard deviation of the difference.[8]

Reliability is most often measured using the interclass correlation (ICC) for agreement. Employ a weighted Cohen's kappa for ordinal measures, and avoid statistics that do not account for systematic differences (e.g., Pearson's correlation coefficient.)[8]

## 6.    Responsiveness

Responsiveness is the ability of a scale to measure relevant changes over time. A good stigma scale should be sufficiently nuanced to measure reductions or increases in stigma that are the result of exposures. This is especially important when a scale is developed as part of a baseline in advance of a stigma reduction intervention. If your goal is evaluation of a stigma reduction intervention, we recommend gearing the items in any stigma scale toward inclusion of stigma domains that are susceptible to intervention. It makes little sense to measure TB stigma domains in great detail if they are immutable or beyond your locus of control.

The responsiveness of the scale is the tools' capacity to detect shifts that have occurred as a result of exposure to the intervention. An ROC (receiver operator curve) is often used to measure responsiveness compared to a gold standard and an adequate agreement is an AUC (area under the curve) of 0.70.[8] If the pilot of the tool shows low responsiveness, then you may consider adding additional response categories to tease out more distinction.

## Response categories

Another issue is the optimal number of response categories for an item. The most commonly used response formats are five- or seven point Likert scales (Table 1.) Hinkin (1995) concluded that five to seven response categories are adequate for most items.[21] Respondents tend to prefer seven categories.[22] The more categories you provide, the greater your ability to capture subtle shifts, which is crucial if your scale will be used as part of a baseline prior to a stigma reduction intervention. Ensuring enough categories increases the power of the scale to detect small improvements and helps prevent floor and ceiling effects.

| Please indicate the extent of your agreement or disagreement with the following statements: | How often…? | How true is…? |
|---|---|---|
| Strongly disagree | Never | Completely false |
| Disagree | Rarely | False |
| Somewhat disagree | Occasionally | Somewhat false |
| Neutral | Sometimes | Neutral |
| Somewhat agree | Usually | Somewhat true |
| Agree | Frequently | True |
| Strongly agree | All the time | Completely true |

Visual analog scales (VAS), numeric rating scales, and verbal rating scales (VRS) of different lengths are all possible response types which may work for lower literacy populations. A thermometer is a commonly used visual analog scale for measuring attitudes.

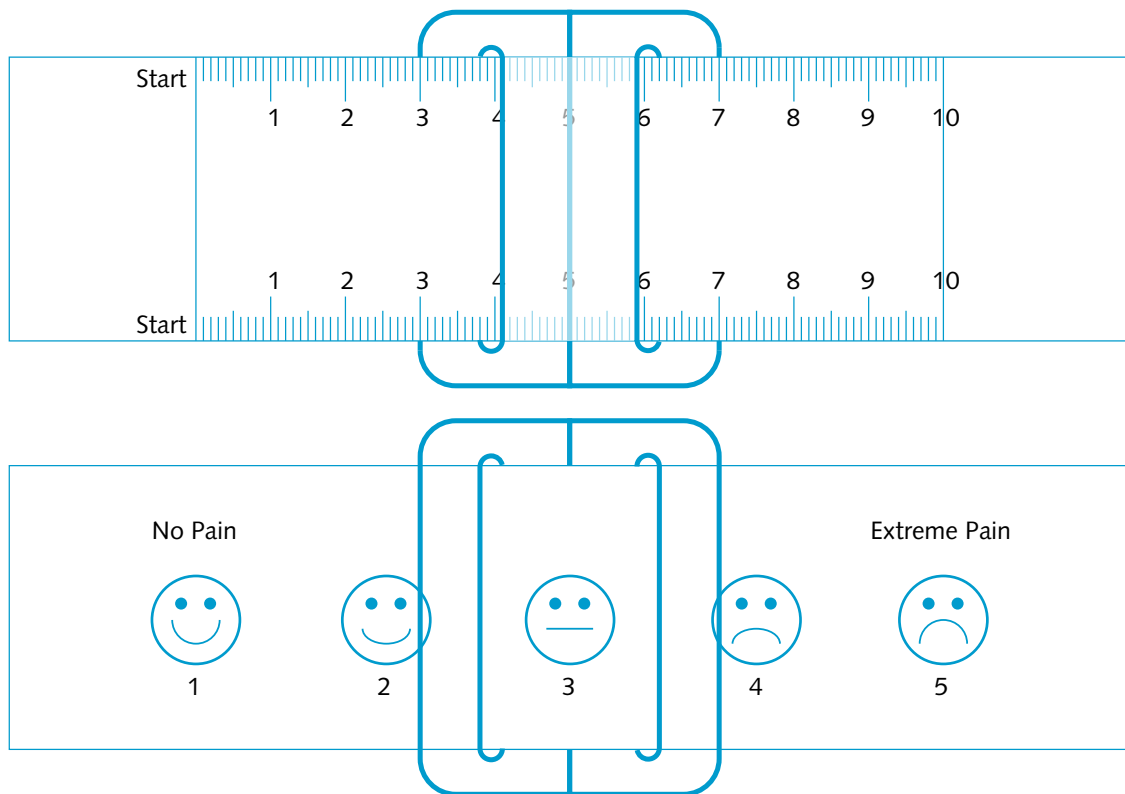## Figure 9. Example of visual analog scale



## Figure 10. Example of visual analog face scale to measure feelings or agreement



Faces are also a commonly used visual for depicting the range and intensity of feelings.

# 7.   Floor and Ceiling effects

To assess the floor or ceiling effects (aka skewness) of the responses to your scale you should chart and report the distribution of scores. We would like to see fewer than 15% of responses in the highest or lowest category.[8] If you have more than 15% of responses in the extremes of the scale, it suggests that the scale does not measure the full range of the concept well enough.

When four-point Likert scales are used, there is a possibility that 90% or more of the respondents are only using one category. So if an item tends to always evoke one of the most extreme values (1 or 5 on a 5-point scale), one could consider removing this item from the tool, since there is no room for variance.

# 8.   Interpretability ("So what?")

A good stigma scale should have scores that predict outcomes of interest. With a new scale, you should aim to provide end-users with information on how to understand the results. Describe the mean score and standard deviations for subpopulations, including gender, age, and other sociodemographic groups if you expect the score may vary by these characteristics. If you can discern the minimally important difference (MID) in the scores that are linked to people's relevant outcomes, describe them. Often in a new scale, it is not yet clear how improvements in the stigma score are linked to improvements in people's lives.

If major problems with the instrument are discovered during the pilot phase (2), the tool should be substantially revised and the pilot repeated.

## Sample Size of the Pilot

There is no scientific rule for calculating the sample size of the pilot, but include a minimum of five to ten respondents per item being piloted, with a minimum sample of 100. In the hypothetical case of the 20-item stigma scale, the number of respondents in the pilot would be between 100 and 200. Enough tools should be tested until at least 30 respondents report some stigmatizing attitudes or behaviors. The more respondents in the pilot the better.

## Sampling Strategy

As the goal of the pilot is to identify problems, rather than making estimations or causal statements, do not randomly draw a sample. It is better to aim for diversity and ensure the sample includes those with lower than average literacy and numeracy, as well as those for whom respondent burden (e.g., time of administration) is a barrier to participation (i.e., health care providers.)

A purposive sample is useful for the qualitative component of the pilot. At least one quarter should be respondents who may experience self- administration challenges (e.g., those with low literacy levels, elites, elderly, etc.)

## Survey Interviewers

Experienced interviewers are preferred over medically qualified staff, as the latter may be too intimidating or directive in their mode of questioning. Moreover, families may be reluctant to be candid about items related to discrimination or non-compliance in the presence of senior medical staff. It is vital to ensure that those collecting data cannot be drawn into possibly controversial discussions, which may result in bias and conflict of interest. Other factors influencing the interviewers include mobility, acceptability, and availability.

## Interviewer Training

PATH has developed two curricula that can be adapted and used for training survey staff. The first builds skills in assuring privacy and confidentiality for providers. It was intended for reproductive health care providers, but the main principles are applicable to interviewing on any sensitive topic, including stigma. Please see:
*Ensuring Privacy and Confidentiality in Reproductive Health Services: A Training Module and Guide. For Service Providers*
http://www.path.org/publications/files/RH_ensuring_privacy.pdf

The second curriculum is aimed at improving health workers' TB communication and counseling skills, and some of the exercises can be used to strengthen data collector's non-verbal communication skills. See:
*Interpersonal Communication and Counseling for Clients on Tuberculosis and HIV and AIDS. PATH, 2009:*
http://www.path.org/publications/detail.php?i=1770

Details of your formative work, your item and scale development, item generation and reduction, and the engagement of end-users in the pilot process should be fully described in your scale validation report.

## Conclusion

While it is not generally necessary to develop a new stigma scale, it is always necessary to pilot one. In this chapter we have defined the procedures for developing and validating a TB stigma scale. We have specified the correct statistical approaches and provided practical examples. The steps in this chapter will help researchers avoid common pitfalls in stigma measurement.

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# Chapter 17

# Analyzing Qualitative Data

*Amrita Daftary, and Gill Craig*

## Abstract

There are many approaches to qualitative research, which, although systematic, requires flexibility and an iterative approach to developing codes and themes derived from participants' own words. Many researchers draw on concepts developed in grounded theory to analyze their data, but grounded theory may not be practical in non-academic settings. We offer an alternative that is increasingly used in policy contexts. The framework approach involves the in-depth analysis of a subset of interviews to develop a coding framework which can later be applied to all transcripts. This also allows for a teamwork approach to analysis once the framework has been agreed upon, tried, and tested. Although software packages are available to help researchers store and manage their data, licenses are expensive and it can be time-consuming to learn. The framework was initially developed as a means to analyze data without software. In this chapter, we also discuss a variety of approaches to evaluating the quality of qualitative research, which includes, but is not limited to, critical appraisal tools. Transparency and accountability in reporting of the qualitative research processes are crucial, including the perspective of researchers and their role and investments in the research.

## Objectives

1. To explain how to conduct qualitative data analysis
2. To reinforce techniques for enhancing the quality of qualitative research

## Target Audience

This chapter is for everyone engaged in the qualitative exploration of stigma who wishes to strengthen the rigor and depth of the analysis.

# Introduction

There are many approaches to analyzing qualitative data and most begin with the reading of the transcripts of participants to understand their views in their own words. Ways in which people talk about illness, for example, can reveal a lot about the meanings they attach to their experiences. We briefly discuss some approaches to qualitative data analysis and thereafter focus on the Framework method as a feasible and useful way to identify and examine the drivers and dimensions of TB stigma. We conclude with strategies to enhance the quality of qualitative data interpretations. These strategies should be adopted and integrated into the research process from the study outset, and not simply during analysis and write-up.

# Analyzing qualitative data

Many researchers borrow from principles developed in grounded theory during their analysis, which encourages researchers to identify concepts and themes directly from participants' words and/or field observations.[38] Under pure grounded theory, any preconceived ideas about stigma drawn from the literature and presumptions about TB stigma are bracketed to allow for theory development (understandings of stigma drivers and dimensions) to emanate strictly from the data.

**The qualitative analyst must use reflexive practice to 'read between the lines' and move from realist interpretations to in-depth critical interpretations**

Grounded theory researchers accomplish this through a process of theoretical sampling (collecting data which helps to build a theory and prove or disprove it, as described in Chapter 3), and constant comparative analysis (drawing comparisons across and between different portions of the data, to identify underlying patterns or themes that may be refined and contextualized through subsequent readings of the data, discussed later in this chapter).[48,62] Grounded theory, however, can be difficult to practice in TB stigma studies, as this research will likely be informed by earlier understandings of stigma from the outset. Grounded theory can also be time-consuming because successive cycles of data collection and analysis might trigger the need for additional data and new interviews to build the theory. In many settings, this form of iterative data collection and analysis is not feasible.

Qualitative researchers may also draw on social theories around stigma from the literature to guide and refine their analysis. For researchers who have the interest and resources to adopt this in-depth critical approach, we recommend using the references in Chapter 3 to guide analytic interpretations.

Given the resource intensiveness of these traditional approaches to qualitative data analysis, we recommend another approach that borrows on the basic principles of grounded theory which may be helpful to field researchers.

# Framework method of analysis

The Framework method of analysis is one approach to data management that is becoming increasingly popular in social policy research.[63-65] Unlike other approaches, it does not have a philosophical underpinning or theoretical approach. It is flexible and allows for teams to work collaboratively on qualitative data interpretation. The stages are as follows:[64]

**Transcription:** Audio-recordings or observations are transcribed and, if applicable, translated. Transcripts have wide margins to allow for line numbering and labeling themes. The goal is to capture the content of the interview or focus group, including attention to emotional outbursts or conversational tone, but with less attention to details such as pauses or overlapping speech. The researcher should allocate adequate time for transcription and, if needed, translation.

**Familiarization:** The researcher becomes familiar with the data through successive readings of the transcripts, especially if the researcher was not directly involved with data collection.

**Coding:** The data gets sorted by breaking it down into smaller segments that can be paraphrased or labeled with a code. This is done by identifying the meaning of and asking questions about the data. Codes may reflect comments, keywords, ideas or concepts, incidents, or events. Once a code has been identified, it can be labeled with a meaningful name. The code may be open (based solely on ideas emerging from the data) or closed (based on ideas developed within literature reviews). Open coding is encouraged during initial stages to ensure interpretations more closely reflect the participants' voice.[66] The researcher will then look for more instances of this code across different interview transcripts using a process of comparative analysis.

**Developing themes:** Codes that describe similar concepts or ideas can then be grouped together to form categories or themes. Categories are groups of codes that reflect similar events, ideas, or comments and help to describe the phenomenon under investigation. The researcher may refine or change the codes with repeated readings of the transcripts and through comparing the "fit" of the code in relation to other instances. An "other" code within each category can allow researchers to retain codes that do not fit with the emerging analytic framework.

**Developing a thematic framework:** A thematic framework is developed through indexing emerging themes or categories identified from a subsample of transcripts. Depending on the number of interviews or focus groups, the researcher will select a smaller number on which to base their thematic framework. The idea is not to select the first few interviews, but to choose a

broad range of interviews to ensure that the framework is based on rich data and reflects a wide range of experiences. If this is being done as a team, then the researchers should meet to compare and refine their codes.

Below is an excerpt from a codebook that was developed for analyzing stigma domains.

**Table 1. Stigma Domains Codebook**

| Code (Domains) | Definition | Example | Notes on Application |
|---|---|---|---|
| Fear of transmission | Worries about becoming infected, precautions taken, beliefs about infectiousness. | "We could have all gotten it from her." | Do not apply to general fears (use peril code instead). |
| Peril/dangerousness | Statements, ideas, notions about risks posed by PWTB, including dangers posed by unpredictability and irrationality. | "..They become crazy on those medicines…" | Do not apply to transmission fears (use fear of transmission code). |
| Positive stereotypes | Any positive traits ascribed to PWTB. | "He could barely walk and he still came." | |
| Negative stereotype | Any negative traits or assumptions about motives, behavior, feelings, intent, terms, connotations, or labels for PWTB. | "With proper DOT and guidance, they can get through the treatment, but unsupervised they will struggle." | Do not apply to co-morbidities. |
| Rhetorical link made to stigmatized co-morbidity | References to PWTB having diabetes, HIV, alcohol dependency, drug dependency, hepatitis, nicotine dependence, etc. | "..They become crazy on those medicines…" | |
| Blame/responsibility | References to 'fault' or fault finding, guilt, or attribution. | "I should have kept on with the pills, but it was too much for me." | |

**Applying the thematic framework:** Once the framework has been developed, it is then applied to all the transcripts. Several iterations of this framework may be developed and 'tested' on the data.

**Charting:** The data is charted into a framework matrix or spreadsheet, which briefly summarizes or paraphrases the main analytical categories and connects these categories to excerpts or quotes from the interviews or focus groups (see Table 2). Line numbers can provide a quick cross-reference back to the original

data. Charting can be done using a spreadsheet in MS Word® or Excel® or for larger datasets.

## The use of Computer Assisted Qualitative Data Analysis Software

Framework was developed as a 'low tech' approach to analyzing data, which did not require software. However, more recently software packages have become available which deal specifically with Framework (e.g., QSR NVivo). The license for such software packages can be expensive, and becoming proficient in the use of these packages requires training. The software only helps to store and manage the data, however. It does not perform qualitative analysis. The researcher must interpret the data while practicing reflexivity.

## Table 2. Example of charting using a framework approach

| Experience of Stigma | 1.1 Reaction of Others | 1.2 Perceived Impact on Employment | 1.3 Perceived Impact on Relationships |
|---|---|---|---|
| Participant 1 | Worried what people would think (lines 23-30). | Fear I would lose my job because I'm a healthcare worker (lines #). | Could not tell fiancée, assumption of bad blood (lines #). |
| Participant 2 | Shocked because they thought only people who use drugs got TB (lines 45-48). | Fear I wouldn't be allowed into people's homes (lines #). | Did tell husband but not children, fear of gossip (lines #). |
| Participant 3 | Associations with HIV (lines 49-59). | Fear I wouldn't get a job in the future (lines #). | Lonely, not able to tell anyone initially but then told friend (lines #). |

**Mapping and interpretation:** At this stage, the analyst is trying to move beyond description to analysis and interpretation. Table 3 illustrates how an analysis moves from first order coding with the use of labels (thin description), into second-order analysis (categories), and finally into third order analytical categories (thick description). In this example, this highlights the social context of adherence and is a particular example of stigma and its intersection with gender and vulnerability. This process should be tested across different interviews to tease out further examples of adherence and stigma, gender (including men), and vulnerability.

## Table 3. Illustrative Example of Coding Qualitative Data (Craig et al., 2015.)[67]

| 1st order Coding: Labels | 2nd order Coding: Categories | Line | Participant 1 Area 1 Clinic 1<br>Excerpt from an Interview with Immigrant TB Patients | Notes on Process of Analysis | 3rd Order Analytical Categories |
|---|---|---|---|---|---|
| *Store and take medicines in secret* | <u>Medicine management: secrecy</u><br><br><u>Acceptable illnesses</u> | 1<br><br>2<br><br><br>3 | I keep medication in a secret place and take medication at a secret time. The other illness (diabetes) they (relatives) know about it and | Difficulties taking medication as a guest in a relative's house sleeping on a mattress on the floor. No privacy. Nowhere to store or take medicines. | *Medication management governed by place x space x time, this challenges behavioral approaches to adherence.* |
| *Acceptance of long term condition by relatives (diabetes)* | <u>Anticipated stigma: material impact homelessness</u> | 4<br><br>5 | accept it. The first thing I will lose [if diagnosis becomes common knowledge] is my | Diabetes has traditionally been seen as stigmatizing, but this is accepted. Why is this? Look for other examples of illness that is accepted. | *Examples of anticipated/felt stigma, which will have material effects. Here, anticipated stigma intersects with gender and serves to potentially isolate through the loss of access to network and social capital. Stigma will render the women homeless and vulnerable, as they will be older, refugee woman.* |
| *Loss of housing and relationship* | <u>Anticipated stigma: exposure</u><br><br><u>Anticipated stigma: loss of access to social network (+material support)</u> | 6<br><br>7<br><br>8<br><br><br>9 | accommodation and the relationship. My situation could then be communicated to other [people from my country] who I rely on for help and support. | Note impact of stigma has material effects in terms of the threat of homelessness. | |
| *Disclosure to wider community* | | | | | |

## Evaluating qualitative research

There are many approaches to evaluating and enhancing the merit of a qualitative study. For example, Lincoln & Guba (1985)[33] discuss quality in terms of reliability and validity, which they define specifically in relation to qualitative research (see Table 4, noting that concepts used in conventional inquiry are not exactly reflective of concepts applied in qualitative inquiry). Drawing on these principles, we recommend qualitative researchers embarking on TB stigma research consider the following strategies to enhance their work, from study conceptualization and data collection through analysis and write-up.

**Table 4. Approaches to evaluating qualitative research (Adapted from Lincoln & Guba, 1985)**

| Conventional Inquiry | Qualitative (Naturalistic) Inquiry | Methods to Ensure Quality |
|---|---|---|
| Internal validity | Credibility – how true or trustworthy are the findings? | Prolonged engagement in the field; data triangulation. |
| External validity | Transferability – how applicable are the findings to other contexts? | Thick description of setting and/or participants. |
| Reliability | Dependability – are the findings consistent or can they be repeated? | Audit – researcher's documentation of data, methods and decisions; researcher triangulation. |
| Objectivity | Confirmability – are the findings reflective of (grounded in) the data? | Audit and reflexivity. |

**Reflexivity:** This is the ability of researchers to recognize their own values and influence (e.g., their own social and cultural contexts, positions in society, assumptions, experiences) on their research, as these might influence their choice of research topic, the questions they ask and the way in which they ask them, and how they observe, analyze, interpret, and represent the data.[1,32,33] Being reflexive is not a passive task, where researchers simply surmise their values and assumptions, but rather an active task whereby researchers continuously check their assumptions. For example, they may consider alternative interpretations of the data, look for narratives that would challenge an identified trend, and be transparent about their research decisions, including sampling strategy, line of questioning, coding framework, and focus on specific themes.

A common way to begin reflexive practice is for researchers to record their assumptions and investments in the research in a diary, and to use this data to further inform the context of their research. Such an approach recognizes that knowledge is co-constructed between researchers and participants (a notion that was introduced in Chapter 3), and lends itself to reflecting on issues of power within research relationships and issues of difference between researchers and participants. For example, in enquiring about TB stigma, researchers should be cautious about misclassifying narratives as representative of stigma when these narratives may be more telling of related yet distinct social constructs, such as racism or sexism.

**Prolonged field engagement:** Deep knowledge about the sociocultural norms and practices that prevail in a study setting is vital to enhance the credibility of qualitative findings.[33,34] Researchers embarking on qualitative research into TB stigma should situate themselves in the field setting to familiarize themselves with local norms and practices, to ensure that their data interpretations are adequately informed by the context in which they were collected. In the absence of opportunities to directly immerse themselves in the field for a long period of time prior to data collection, researchers can consult with stakeholders and gatekeepers in the community (e.g., clinic managers, champion patients, and community leaders) to gain familiarity with the setting. They may also recruit local field staff to assist with data collection to ensure that social realities of the study setting guide interviews, questions, and recruitment strategies are acceptable, and study findings are not misinterpreted.

**Thick descriptions:** Thick description[35] refers to the depth of analysis that goes beyond superficial descriptions of events or individual behaviors (thin) to include an analysis of the context that shapes and informs those events and behaviors (thick). The collection of rich, illustrative, personal stories that are meaningful to participants and exemplify their experiences with TB and stigma can allow readers to situate those narratives or observations to the cultural, geographic, and medical context. Thick descriptions allow for qualitative analyses to be transferred to similar, other contexts.[33,36] When conducting interviews, focus groups, or observations, researchers should ask questions and record notes to produce a rich account of participants' experiences, perspectives, and/or the social environment in which those experiences happen (e.g., in the case of observations).

**Triangulation:** Triangulation is the process of using multiple methods, data sources, analysts, or theoretical frameworks to arrive at a rich, robust, and comprehensive understanding of the research problem. Triangulation can validate findings, but is more useful to the qualitative paradigm. Triangulation helps researchers check and contextualize consistencies and differences in narratives and identify nuances.[32,37]

For example, if interviews with patients and providers elicited similar understandings around trust, these data can support emerging ideas about patient-provider relationships and interaction quality. If providers, however, shared perspectives that contrasted those shared by patients, the researcher is pushed to question why these differences in perspective exist, and if they indicate the interview dynamic or level of rapport/trust established during data collection with diverse groups of participants, or if this difference reflects a challenge encountered primarily by patients but not considered as relevant by health providers. Both situations can lend themselves to important analytic insights. Triangulation can also inform subsequent data collection (e.g., clinic observations may be probed in interviews with healthcare workers), as introduced in Chapter 3.

**Negative case analysis:** This is one of the most important practices in qualitative analysis, whereby inconsistencies in the data or unique cases that defy an emerging pattern are actively investigated.[32] Inconsistencies can strengthen emerging theories, as they push qualitative researchers to identify when, how, and why the negative case (e.g., TB patients who perceive no stigma in a setting where stigma is commonplace) has deviated from the 'norm' (e.g., patients who encounter the typical expected experience with TB stigma).

**Constant comparison:** The method of constant comparison is borrowed from grounded theory.[38] It involves researchers checking for patterns within and across all interviews, developing categories, and identifying exceptions which refute those categories. Researchers may practice constant comparison by repeatedly reading and reviewing their data transcripts and field notes, and returning to the code-book, maps, and/or charts to alter codes, categories, and definitions. This allows categories to be refined and ensures that findings are not based on unique experiences, although these should also be reported.

**Audit trail:** An audit trail entails documenting a clear process of analysis to enhance the confirmability of qualitative interpretations.[34,36] This includes documenting research decisions as well as implementation and analysis hurdles. For example, document how and when participants were recruited or observations were conducted, refusals or difficulties, how data were transcribed and/or translated, how codes were developed (who was involved and how were points of discordance between coders resolved, how themes were identified, contextualized, and refined, how negative cases were analyzed, how thematic saturation was assessed) and other research-related decisions and strategies. A like-minded researcher should be able to follow the documented steps and come up with a similar decision or interpretation.

**Qualitative appraisal tools:** Other approaches that aim to ensure rigor in qualitative research have different merits and disadvantages. Barbour (2001) talks about the danger of checklists replacing researcher judgment about the merits of particular approaches.[39] The CASP approach to qualitative research appraisal is a common tool for appraising rigor. It involves asking ten questions (http://www.casp-uk.net/casp-tools-checklists). COREQ is a similar but lengthier 32-item checklist (https://academic.oup.com/intqhc/article-lookup/doi/10.1093/intqhc/mzm042). Journal editors have also produced a variety of other checklists. The British Medical Journal (http://www.bmj.com/about-bmj/resources-authors/article-types/research/editors-checklists) and The International Journal of Tuberculosis and Lung Disease (http://www.theunion.org/what-we-do/journals/ijtld/body/IJTLD_Guidelines_for_Qualitative_Research.pdf) have checklists.

## Conclusion

There are different approaches to analyzing qualitative data and evaluating the merits of qualitative research. In this chapter, we have provided an overview of one analytical approach adapted from the framework method, and offered strategies for field researchers qualitatively studying TB stigma to assess and enhance the quality of their work.

## Acknowledgements

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# Glossary

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| Anticipated Stigma | The fear of disparagement (fear of enacted stigma) even in the absence of having the mark (stigma). |
| Biogenic Explanations | To situate the origin or cause of something in a biological or genetic frame, or to define a phenomenon as organic. This is often a strategy to deflect blame with stigmatized conditions. |
| Blame | A common rhetorical framing and a domain of stigma. This is when responsibility for a health condition is attributed to a particular person, or when a causal attribution is constructed, whether or not it is plausible or evidence based. |
| Case Mix Adjuster | A variable used to adjust for differences in respondents or facilities, so that meaningful comparison can be made. |
| Change Agent | Any person within an institution that has enough social capital, respect, and leadership to catalyze new behaviors among the staff, through example, mentoring, advocacy or other means. |
| Change Process | An effective change process is a recipe for selecting, adapting, implementing, and scaling up effective practices to achieve and sustain health results. |
| Cognitive interviewing | A combination of both the think-aloud and verbal probing techniques to better understand how respondents interpreted the survey items (Haeger, Lambert, Kinzie, & Gieser, 2012). |
| Commitment to Change | This is the determination to carry a process to the end. The change is complete when all program levels work together to continually produce desired results as they implement and support the changed practices. When stakeholders are committed to change, they don't give up when they encounter barriers, nor do they stop when donors turn their resources toward other needs. |
| Construct validity | This is the degree to which a scale measures what it claims, or purports, to be measuring. The internal consistency or reliability can then be measured by the Cronbach's alpha ($\alpha$) reliability coefficient (values between 0.70 and 0.80 are moderate to good, and above 0.80 good to very good.) |
| Contact-interventions | Interventions to increase knowledge and understanding of stigmatized persons through social contact. |
| Content Validity | In psychometrics, content validity (also known as logical validity) refers to the extent to which a measure represents all facets of a given construct. |

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| Continuation Phase | This phase requires a combination of two drugs to be taken for the first four months for new cases, and treatment with a combination of three drugs for re-treatment cases for five months. |
| Courtesy Stigma | This is a type of secondary stigma. It is the vicarious social taint experienced by those who interact with stigmatized people.[1] Courtesy stigma may reduce the social standing of family, friends, and caretakers. |
| Cronbach's Alpha | Measure of the consistency between questions, or the reliability of a set of items (scales) for measuring the same concept. Cronbach's alpha ($\alpha$) is a reliability coefficient, whereby values between 0.70 and 0.80 are moderate to good, and above 0.80 good to very good. |
| Deconstruct | To demystify a phenomenon by revealing its supporting structures and ideas. |
| Defaulter | A stigmatizing word used to describe a TB patient who interrupts treatment or is not compliant with treatment. No longer used. Now called a "person lost to follow up". |
| Destigmatization | The process of countering the drivers of stigma through intervention to reduce discrimination, name calling, and feelings of blame and shame. |
| Design Effect | A statistical concept that refers to the degree that a sample must be expanded to try to compensate for any variance artificially reduced by the study design. |
| Diagnostic Delay | The time interval between first TB diagnostic test and the patient receiving the TB diagnosis, if it exceeds two days. |
| Dimension | A group of conceptually similar items. See also domain. |
| Dirty work | Employment that others regards as degrading or demeaning.[2,3] Professionals who serve the health or social needs of stigmatized persons may be vicariously tainted, and their roles are discredited in the professional hierarchy. A type of loss of prestige experienced by certain types of healthcare workers (e.g., addiction counselors, mental health professionals, and abortion providers). |
| Disclosure carryover | When people are afraid of the reactions they would get if they were known to have TB in the past or present. |
| Discrimination | A statistical concept unrelated to discrimination which refers to the scale's ability to distinguish stigma from non-stigma. |
| Domain | The sub-component or dimension of a complex social phenomenon. For stigmas, domains may refer to rhetorical framings, including labeling, stereotyping, cognitive separating (i.e., us versus them), emotional reactions (e.g., fear, shame, disgust), interpersonal discrimination (i.e., expected, believed, or experienced), and structural discrimination.[4] |

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| Enacted Stigma | Behaviors designed to discredit or diminish. A synonym of discrimination. |
| Exit Interviews | Interview conducted as a client is leaving a health service encounter to determine the quality of care before recall bias sets in. |
| Exclusionary sentiments | The desires to exclude PWTB from full community participation, or deny them their rights. |
| Factor Analysis | Detection of any hidden hypothetical variables, either for explorative reasons or for reduction of a large number of variables into a limited number of dimensions. This occurs by identifying 'unreliable' items, with little in common with other items, and 'invalid' items that do not discriminate between factors. |
| Focus Group Discussion | A group discussion guided by a facilitator, during which group members discuss a certain topic. A focus group discussion is a qualitative method to obtain in-depth information on the concepts, perceptions, and ideas of a group. |
| Hawthorne Effect | See reactivity (observer effect) |
| Health Seeking Delay | A long time interval between initial symptoms and arrival at the first health care provider (more than 30 days.) |
| In-depth Interview | An open-ended, discovery-oriented method that elucidates the mechanism, processes, and consequences of stigma. The goal is to deeply explore the respondent's perspectives and to uncover unconscious associations. |
| Intensive Phase | This phase of TB treatment consists of a combination of four drugs for the first eight weeks for new cases, and a combination of five drugs for the first eight weeks followed by four drugs for the next four weeks for re-treatment cases. |
| Item | A question in a scale or survey instrument. |
| Label Avoidance | Avoiding overt self-identification with a stigmatized group. |
| Likert Scale | The most widely used scale in survey research, which is often used in questionnaires. When responding to a Likert questionnaire item, respondents specify their level of agreement to a statement. |
| Microaggressions | Subtle forms of interpersonal stigmatization or slights and denigration. |
| Negative affect | Refers to emotional reactions toward PWTB (e.g., fear, shame, disgust, pity, hatred), |
| Normalization | To create conditions where behaviors and attitudes appear normative. |
| Over identified model | A problem caused by a scale having too few items to represent a domain (e.g. social exclusion). An over-identified matrix reduces the ability of statisticians to assess the correlation or covariance among the sub-scales (domains) in a scale. |
| Perceptions of dangerousness | The idea that PWTB somehow represent a risk to society. |
| Physical Clue | A marker behavior that may be used as an indicator for a particular behavior that is not observed directly. |

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| Probability-based sampling | Any sampling method that uses simple random sampling, systematic random sampling, stratified random sampling, and cluster or area random sampling. |
| Protest | A formal objection to negative representations of people with TB. |
| Psychometric Testing | Testing the reliability and the validity of a questionnaire |
| Public Stigma | Describes negative attitudes, beliefs, and behaviors held by the general public. |
| Reactivity | ( Hawthorne effect, observer effect) The tendency of people who are observed to change their behavior as a consequence of being observed. |
| Referral Delay | An excessive time interval between arrival at first point of care and first TB diagnostic test ( over one day.) |
| Reflexive Practice | A way of conducting research that is self-critical. It queries the inherent biases of the researcher and how these may influence the study results. |
| Reliability | Extent to which a result of a measurement corresponds with reality. |
| Scalability | The extent to which a group of variables together form a reliable entity, so that they score consistently on a (Likert) scale. |
| Self-stigma | Refers to the internalization of public stigma by a person (Corrigan et al., 2014). This internalization can lead to denial of symptoms and rejection of treatment, and may contribute to isolation from valuable social support.[5] |
| Semantic Differential | is a rating scale in which users must choose between two opposites (e.g. TB patients are a) responsible or b) irresponsible). |
| Shame | The degree to which the dispersion of data departs from a normal |
| Skewness | distribution. |
| Social distancing | When someone tries to avoid a PWTB. |
| Social Validity | The degree to which an intervention or approach to a problem takes into consideration the wants, needs, and norms of the community in which it is implemented. |
| Stereotype | The relationship between an attribute and a stereotype that |
| Stigma | assigns undesirable labels, qualities, and behaviors to a person. Labeled individuals are devalued socially, leading to inequality and discrimination.[6] For example, a TB patients is always assumed to be infectious, and therefore is labeled as dangerous, which justifies behaviors and policies that create social distance (e.g., triage, separation). |
| Stigmatization | The social process by which a condition affects the lives of all those who are impacted by it. |
| Structural Stigma | Societal-level conditions, cultural norms, and institutional practices that constrain the opportunities, resources, and wellbeing of stigmatized populations. Hatzenbuehler and Link (2014). |
| Taxonomy | Structure of a questionnaire of dimensions and items. |

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| The Stigma Complex | The interrelated, heterogeneous system structures, from the individual to the society, and processes, from the molecular to the geographic and historical, that construct, label, and translate difference into marks.[7] |
| Topics Guide | A check list with the main topics for focus group discussions or interviews. This keeps track of the research objectives while giving flexibility insight. |
| Treatment Carryover | When people afraid of people knowing they were treated for TB in the past. This is the perceived need for secrecy that may linger after a person recovers. |
| Treatment Delay | A long time interval between the date of a TB diagnosis and when TB medicine was dispensed to the patient, in excess of one day. |
| Triangulate | A process of contrasting diverse sources of information and different data to identify divergent perspectives, validate key information, and explore disparities to yield a rich analysis of a situation. |
| Triangulation | A process used to validate the data obtained in a study, usually involving alternative data sources or collection processes. |
| Validation | Process of qualitative and quantitative testing of a set of items in a measurement tool to determine whether they collectively measure a complex social construct or not. |
| Value Claims | Assertions designed to prove that some idea, action, or condition is good or bad, right or wrong, worthwhile or worthless, or appropriate or inappropriate according to certain preferences. |
| Varimax Rotation | Rotation of the axes of factors to maximize the variance (variability) of the new variable (factor), while minimizing the variance around the new variable. |
| Voyeurism | A unique form of verbal stigma in which acquaintances visit a person with TB, but not out of concern for the person or a desire to keep them company. Rather, visitors aim to observe how the person is faring to be able to report to others and generate gossip. |

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