



Two quotes from TB patients (Kazakhstan) from TB Photovoices: "When I was in the hospital, I was not allowed to go out. But I ripped up the fence to be free" (left).
"When I was treated for TB, all roads were closed. It was forbidden to go out." (right).

TB STIGMA

Stigma and discrimination are recognized as some of the most commonly identified barriers to fight the TB epidemic.¹ Reducing TB stigma is therefore essential because it hinders care seeking, contact tracing, outbreak investigations, treatment initiation, adherence and quality of care. Moreover it degrades social capital; it deprives people with TB of their rights and the respect of others.² Ultimately

it can also contribute to catastrophic costs when people with TB are pushed out of their homes, communities and jobs – losing their security, support system and means of income. Stigma not only harms patients, but also erodes health care workers' commitment to high quality care. An effective approach must therefore protect everyone's rights as a cornerstone of patient-centered care.

KNCV's philosophy and tools

KNCV's philosophy on reducing TB stigma is to build empathy and mutual respect among communities, health care workers and TB patients. It aims to reduce the tendency to label, blame, shame and control by strengthening the awareness of our own judgements. To do so, KNCV has developed several innovative tools to understand, measure, assess and effectively address TB Stigma at its root.



1. TB STIGMA MEASUREMENT GUIDANCE:

An overview of best practices, covering the full scope of established methodologies. The guidance can be used for a whole range of stigma measurements: from baseline assessments to end line evaluations.



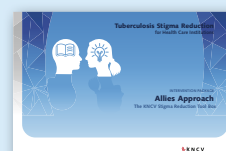
2. TB PHOTOVOICES:

Empowers people, affected by TB, HIV or both diseases to express and communicate their experiences. It re-builds their self-esteem through group coaching and teaching them how to use photodocumentary to express their emotions and feelings. The final product - a series of images and quotes - can be used to sensitize key audiences such as decision makers, civil society and health staff as well as for peer support to other TB patients in their physical and spiritual healing process.



3. FROM THE INSIDE OUT:

Dealing with TB-related self-stigma and shame; " is designed to help individuals identify, understand, and address self-stigma and anticipated stigma. We provide a framework and tools to address and reduce self-stigma in people with tuberculosis (TB).



4. THE ALLIES APPROACH:

Tuberculosis stigma reduction for health care institutions: a health care facilities toolbox, which focuses on stigma at the emotional, cognitive, and practical levels. This approach addresses self-stigma in health care workers, stigmatizing behavior of health care workers and the stigma facilitating policy in facilities. The Allies Approach fosters a dynamic mutually-supportive alliance between patients and care providers.

1: World Health Organization, Ethics guidance for the implementation of the End TB Strategy. 2017, Geneva: WHO.

2: Jaramillo, E., S. Sahu, and C. Van Weezenbeek, Ending TB-related stigma and discrimination. Int J Tuberc Lung Dis, 2017. 21(11): p. 2-3.

Monitoring and Evaluation

The three TB stigma intervention toolkits are underpinned and supported by tailored Monitoring and Evaluation frameworks and tools to facilitate assessment and responsive adaptation of interventions:



TB Photovoices

- Baseline & follow up survey using validated self-stigma and empowerment scales.
- Feedback on process (Participants and facilitators).
- Exit interviews with viewers of exhibitions
- Follow up discussions with participants 3-4 months after intervention.



From the Inside Out

- Baseline and follow up survey using validated self-stigma and self-compassion scales
- Feasibility assessment of interventions package
- Quantitative data collection to understand patient experience



The Allies Approach – TB stigma reduction for health care institutions

- Baseline and follow up survey on knowledge, behavior and attitudes, with validates self-compassion and self-stigma scales
- Assessment of facility policies, infrastructure and organizational norms and culture
- Feasibility assessment of intervention package
- Qualitative data collection to understand participant experience

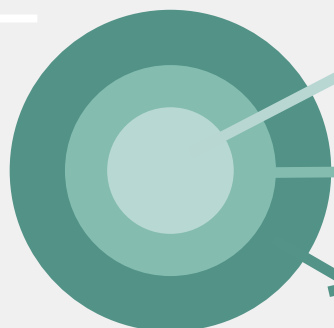
Stigma - spaces and scope of intervention and corresponding tools

Measurement:

TB Stigma
measurement
Guidance¹



Stigma
Assessment
Toolkit³



Person: PhotoVoices¹
From the Inside Out^{1,2}
We are the Change²

Facilities: The Allies Approach¹

Community: Understanding and challenging
TB stigma - Toolkit for action⁴

¹KNCV Tuberculosis Foundation, ²KNCV Tuberculosis Foundation and Work for Change, ³Stop TB Partnership, ⁴ZAMBART Project and International HIV/AIDS Alliance



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KNCV Tuberculosis Foundation is the world's leading TB expert agency. Established in 1903, KNCV delivers evidence for policy and technical assistance for impact in TB care and prevention worldwide.