



**ERASE STIGMA - ERASE THE SHAME**

# STIGMA TOOLBOX AND MEASUREMENT GUIDE

**KNCV Tuberculosis Foundation is moving to tackle the stigma attached to tuberculosis (TB) and discrimination against TB patients.**

The stigma around TB creates a major challenge to individuals affected by TB, and to global elimination of the disease. The effect of stigma's 'mark of disgrace' is present in the shadows of society and significantly increases the suffering of patients, their families and the general community. The fear of TB stigma may prevent a person seeking diagnosis and care, harming that individual and enabling the spread of TB within the community. Stigma can also undermine anxious health care workers concerned about contracting TB themselves or harbouring negative views of TB patients.

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*Illness is nothing to be ashamed of, but stigma and bias shame us all. – Bill Clinton –*  
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## Back on the global agenda

Stigma is back on the global agenda. In June 2017, The United Nations agencies issued a joint statement calling for an end to discrimination in healthcare facilities. It was a call to action that the focus should not be limited to eliminating TB, but also to eradicate the effects of stigmatizing, which often go hand-in-hand with the disease.

## Core to our mandate

Addressing stigma is core to KNCV's mandate. This goes back to the very roots of our association, which originated from community organizations in 1903, and it has been part of our approach ever since. Because as long as stigma prevents people from seeking help, we will never reach our ultimate goal: a TB free world.

## Rooting out stigma: the KNCV stigma toolbox and measurement guide

Together with a large group of stakeholders and the financial help of our USAID partner, KNCV has developed a TB stigma measurement guide. It determines the level of stigma among for example patient groups or health care workers, and then presents a means to monitor trends that can help capture the outcomes of TB stigma reduction efforts. KNCV's TB stigma reduction toolbox is designed for community-based organizations and national TB program staff who seek to foster dignity and mutual respect in health care settings and communities. The TB Stigma Measurement Guide and TB Stigma Reduction Tool Box will be presented in December of 2017.



## “I’m not guilty for having TB”

Meet Paulina, a 25 year old artist from Russia. In May 2015 she was rushed to the hospital and diagnosed with TB. “I never thought it would happen to me. They told me to pray but then I couldn’t expect I would spend the next six months in a place hardly anyone knows exists. It’s hard to accept the reality when it turns out that you are a ‘defective’ person.” Discussing her disease was hard. “People are afraid to talk about this openly. Even a doctor told me to not tell anybody, or I would be branded for life. A feeling of justice and of protest made me change my mind. I didn’t think I was guilty for being ill and I didn’t want to hide my disease from anybody. There were lots of emotions. After three months of treatment I pulled myself together. I realized I didn’t just want to talk about it, I wanted to scream about it so the whole world would know. TB is a dangerous infectious disease which is still widely spread. If we’ll keep silent about it, the problem will never be solved. Imagine a person who has TB but doesn’t know about it. He might spread the disease for a long time before being properly diagnosed and cured. But he still never tells this to anybody, simply because he feels ashamed. How many more people will walk around with the disease without knowing?” So instead of being silent Paulina wants her story to be heard. She communicates through her art, painting portraits of people with TB, showing their faces to inspire others who are afraid to tell. “Most people are not just scared to speak out – they are afraid to remember the time when they were ill, because it’s their nightmare. But I don’t want to forget. This time gave me a lot. And I think mostly because of the painting. It was good art-therapy.”



## Fighting stigma, local context

To combat TB stigma, we need to understand the underlying drivers and domains, the consequences, the burdens and promote the available interventions. The methods and indicators used include a mix of established best practices and experimental approaches. We focus on common methods that may be applied across most settings such as in-depth interviews and focus groups discussions.

## From the top down

From these insights, we will be able to build a locally relevant, solid evidence base around existing and new tools and interventions. These will assist national programs and community groups to assess the complex set of issues and effects of stigmatization, and start to reverse or disrupt its processes and effects. Stigma reduction should have an impact on multiple levels. From reducing societal TB stigma that influences healthcare seeking behaviour to reducing individual and institutional stigma levels using evidence-based approaches.

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

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+31 70 416 72 22 | [info@kncvtbc.org](mailto:info@kncvtbc.org)  
IBAN: NL37INGB0000000130