## **SUPPLEMENT: TB STIGMA**

# Defining the research agenda to measure and reduce tuberculosis stigmas

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SUMMARY

Crucial to finding and treating the 4 million tuberculosis (TB) patients currently missed by national TB programmes, TB stigma is receiving well-deserved and long-delayed attention at the global level. However, the ability to measure and evaluate the success of TB stigma-reduction efforts is limited by the need for additional tools. At a 2016 TB stigma-measurement meeting held in The Hague, The Netherlands, stigma experts discussed and proposed a research agenda around four themes: 1) drivers: what are the main drivers and domains of TB stigma(s)?; 2) consequences: how consequential are TB stigmas and how are negative impacts most felt?; 3) burden: what is the global prevalence and distribution of TB stigma(s) and what

explains any variation? 4): intervention: what can be done to reduce the extent and impact of TB stigma(s)? Each theme was further subdivided into research topics to be addressed to move the agenda forward. These include greater clarity on what causes TB stigmas to emerge and thrive, the difficulty of measuring the complexity of stigma, and the improbability of a universal stigma 'cure'. Nevertheless, these challenges should not hinder investments in the measurement and reduction of TB stigma. We believe it is time to focus on how, and not whether, the global community should measure and reduce TB stigma.

**KEY WORDS**: discrimination; human rights; social justice; respect; equity

TUBERCULOSIS (TB) STIGMA is beginning to receive some well-deserved attention at the global level. 'Zero suffering' is one of the three goals of the World Health Organization's End TB Strategy, and reference to stigma is common in key implementation documents. The Global Fund has declared TB stigma to be among the most commonly identified barriers to fighting the epidemic, and United Nations agencies have called for an end to discrimination in health care.

Many experts believe that it will be difficult to find the estimated 4 million missing TB cases without addressing TB stigma.<sup>1,4</sup> Experts also believe that the full potential of new drugs and regimens for multidrug-resistant TB (MDR-TB), paediatric TB and latent tuberculous infection (LTBI) cannot be realised without addressing TB stigma. Increasingly, countries using Global Fund support are attempting to reduce TB stigma and discrimination across and within elements of their TB programmes. However,

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the capacity to measure and evaluate the success of these interventions needs to be fostered.<sup>5–8</sup>

To begin to address this gap, an expert meeting took place in May 2016 to discuss the measurement issues surrounding TB stigma. This article outlines a research agenda for improving the measurement of and action on TB stigma, and is a product of that meeting. The ultimate aim of this research agenda is catalytic. We want researchers, TB activists, and programme managers to measure TB stigma appropriately and enable them to design, implement and evaluate interventions to reduce the impact TB stigma has on patients, families, health workers, communities and the epidemic itself. While there are many ways to define stigma, we draw on Weiss et al.'s definition: 'a social process, experienced or anticipated, characterised by exclusion, rejection, blame or devaluation, that results from experience, perception, or reasonable anticipation of an adverse social judgment about a person or group'.9

### **METHOD**

Expert meeting

At a 3-day TB stigma measurement meeting hosted by the KNCV Tuberculosis Foundation in The Hague, The Netherlands, in 2016, stigma experts gathered to discuss the status of TB stigma measurement science and define which steps might be taken to improve tracking of TB stigma dynamics. Using free mapping, small group discussions and plenary debate, the group distilled the priorities and the proposed study designs or methodologies for the main research priorities summarised under four themes: Theme 1 (drivers): what are the main drivers and domains of TB stigma(s)? Theme 2 (consequences): how consequential are TB stigmas and how are TB stigma(s) impacts felt? Theme 3 (burden): what is the global prevalence and distribution of TB stigma(s) and what explains any variation? Theme 4 (intervention): what can be done to reduce the extent and impact of TB stigma(s)?

## General principles

In advance of the meeting, we leveraged information from studies already conducted on TB stigma, and commissioned four new studies, including two systematic reviews of published stigma scales and interventions. <sup>10–13</sup> Link et al., Weiss et al., Pescosolido et al. and others have described the extent of how TB stigma can be observed, felt and resisted at different levels of society. <sup>9,14–19</sup> TB stigma can also be present at the level of societal discourse where cultural and social determinants may be more or less important. <sup>14,20</sup> We also learned from research on stigmas other than for TB, with the caveat that not everything will translate readily. Finally, we built on

the work that has outlined the typologies of stigma, <sup>20,21</sup> which are produced in different ways. <sup>9</sup>

'Anticipated stigma' (perceived stigma) is the worry that one will be devalued or tainted if one is found to have a TB diagnosis. While these fears may not actually materialise, anticipated stigma may interfere with care seeking and treatment adherence. 'Secondary stigma' refers to the taint that care givers, friends, family members, health workers or those in TB-associated industries (e.g., miners), may experience because of their link to TB or TB patients.<sup>22,23</sup> 'Internalised stigma' or 'self-stigma' captures the idea that individuals may come to endorse negative attitudes about themselves, and therefore behave or think according to these negative messages.<sup>24</sup> 'Enacted stigma' refers to behaviours, including microaggression, discrimination, rejection, isolation and denial of rights. It is useful to distinguish between enacted stigma and experienced stigma as two sides of the same coin, seen from the perspective of either the stigmatiser (enacted) or the stigmatised (experienced). Finally, 'structural stigma' describes laws, policies and institutional architecture that may be prejudicial or denigrating.

#### **RESULTS**

We developed a matrix of types of stigma and the populations that may produce them or be affected by stigma. We separated types of stigma (anticipated, courtesy, internalised/self, enacted or experienced and structural) from the drivers and consequences of stigma. The drivers of stigma(s) are factors that facilitate the stigmatisation process (e.g., infectiousness of TB, power differentials, ignorance, discriminatory laws). The consequences of stigma (e.g., non-disclosure, poor adherence, depression, stress, poor health-seeking behaviour, self-isolation, reduced quality of life, social distancing, forced isolation) must also be captured and measured, and need to be separated from the drivers or causes of stigma.

Based on this approach, we considered a matrix of types of TB stigma and the populations that may produce them or be affected by stigma. Table 1 links the different forms of stigma and the specific groups (dyads) involved in producing them. A more complete picture would be three-dimensional, including the social and political spaces in which TB stigma(s) are enacted (Table 1).

Research agenda for the measurement of TB stigma For each of the four key research thematic areas, we defined the main research questions, foundation studies, levels or subpopulations and study designs or methodologies most fitting to address these questions. One conclusion reached was that much of the existing TB stigma research has focused on TB patients (individuals who made it into a health

Table 1 Matrix of illustrative scales used in referenced studies, by type of TB stigma and affected population

	Anticipated stigma	Courtesy stigma	Internalised/ self-stigma	Enacted or experienced stigma (discrimination)	Structural stigma (policies, laws, architecture, human rights)
General public Subgroups at higher risk of TB TB patients Health care workers Policy makers	25–27 28	13	15,29–31 33	32 33	STP legal environment assessment

TB = tuberculosis; STP = STOP TB Partnership.

system). There may thus be much we still do not know about the prevalence, degree and impact of TB stigma among missing cases: those who fail to make it into the facilities. We therefore propose that future work should cast a wider net to include a broader set of actors, including the general public, community leaders, media, policy makers, health care workers and community health workers (HCWs/CHWs), and explore protective as well as risk factors.

Theme I: What are the main drivers and domains of TB stigma(s)?

To address this theme, one must articulate the complex constructs underlying stigma. So far, indepth qualitative work around why and how stigma emerges and which facilitators sustain it remains scarce. As one reviewer notes, 'most authors on TB stigma seem to point to the fundamental cause of the stigma being the perceived contagiousness of TB'. 34,35 In contrast, in their study of TB stigma in five health systems in Nicaragua, Macq et al. found that the 'determinants of stigma ... were the content and channels of information, and issues of domination and power.' 36

A persistent quandary around disentangling TB stigma from other stigmatised identities hinders study of the drivers of TB stigma. In other words, it remains unclear how and when the roots of TB stigma differ from other stigmatised identities such as having human immunodeficiency virus (HIV) infection, being poor, homeless, an immigrant, or being dependent on drugs or alcohol.<sup>37,38</sup> Some argue that TB stigma is hard to distinguish from xenophobia, elitism and racism.<sup>9,39</sup> Other researchers suggest it is so bound up with HIV stigma that trying to tease them apart may be a fool's errand.<sup>13,40–42</sup>

Specific drivers may depend on the type of stigma, setting, population and type of TB. Structural stigmas can be driven by power differentials, whereas anticipated stigma thrives on misinformation. Drivers may also differ by epidemic characteristics (low- or high-burden settings) or by the populations impacted (age, sex and class). 9,14,43,44 Stigma toward people with MDR-TB and extensively drug-resistant TB (XDR-TB) and those with LTBI is likely fostered and sustained by distinct sets of underlying factors. The drivers of MDR-TB stigma may be weighted distinct-

ly from drug-susceptible TB stigma in three ways. First, one of the classical facets of any stigma construct is the social designation of 'dangerousness'. If a person has MDR- or XDR-TB, doubts about curability may fuel the social construction of MDR-TB patients as embodying a mortal risk to others. The second classical facet of stigma is the conscious attachment of blame for one's mark or condition. 19,45 In the case of MDR-TB, there may be treatmentadherence behaviours that may at times contribute to the development of drug resistance, creating rhetorical opportunities to blame individuals for their disease. Third, MDR-TB patients are more likely to experience perception-altering side effects as a consequence of their treatment and catastrophic costs due to the length of their treatment, both of which can heighten their vulnerability to stigma.<sup>46</sup> Hearing loss, psychological side effects and impoverishment can reinforce the social construction of MDR-TB patients as 'deviant', 'unpredictable' and 'other'. Given the complexity of TB stigma, we believe that qualitative research before, during or after quantitative research is essential to ensure that the nuance and meanings are not lost in the numbers (Table 2).

Theme II: How consequential are TB stigmas? How are TB stigma(s) impacts felt?

Understanding when and how TB stigma is problematic is vital. Figure 1 illustrates the potential impacts of stigma along a person's trajectory of TB infection, disease and recovery. Assessing stigma at the individual behavioural level is crucial to determine how TB stigma hampers case finding and recovery from TB or MDR-TB. A recent systematic review of TB scales concluded that researchers should optimise existing TB stigma scales and develop new ones to better capture specific micro-, meso- and macro-level constructs (Figure 1).<sup>53</sup>

We recognise that TB stigma interacts on complex levels with psychological, social and political factors. 41,43,54 The impact of stigma is therefore not unidirectional and not always negative. For example, stigma can make some patients more adherent 29,55 and some less adherent. Furthermore, stigma's consequences may vary for different groups, individuals, and settings. 15,42,44,57,58 Intersectional ap-

<b>Table 2</b> What are the main drivers and facilitators of TB stigmate
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No	Research questions/ research topics	Foundational studies references	Level of measurement	Study designs and methodology
1	How do the drivers of TB stigma vary across contexts and among types of stigma?	9,39,47	Individual: patients Health system: HCWs/health managers/CHWs Community: leaders, key spokespersons Structural: policy-level triggers or drivers	Qualitative research: ethnography content review
2	What are the structural drivers of TB stigmas?	39,48	Societal systems and structures: laws, policies, institutions, rhetorics, architectures	Qualitative research: ethnography, policy mapping
3	What are the drivers and facilitators of compound stigmas in key populations?	24,37,38,49–51	Individual: patients Health system: HCWs/health managers/CHWs Community: leaders, key spokespersons TB-affected populations who are also marginalised for other reasons	Ethnography, oral history, in- depth interviews
4	How are the drivers of MDR-TB stigma and LTBI stigma different from those of drug- susceptible TB?	52	Individual: patients Health system: HCWs/health managers/CHWs Community: leaders, key spokespersons Key TB affected populations	Qualitative research: ethnography

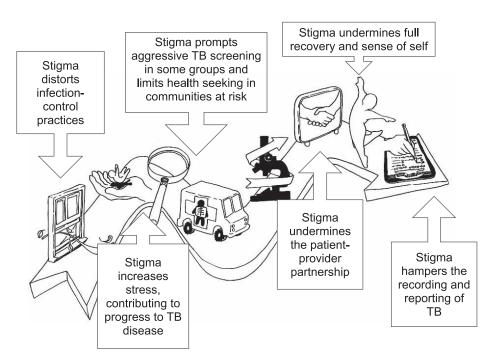
TB = tuberculosis; HCW = health care worker; CHW = community health worker; MDR-TB = multidrug-resistant TB; LTBI = latent tuberculous infection.

proaches that address multiple forms of exclusion are essential.  $^{13}$ 

Different types of stigma (anticipated/felt, courtesy, internalised/self and enacted) impact at distinct levels (individual, family, community). Building on existing work, we identified the main research questions and gaps in our understanding of the impact of TB stigma(s) (see Table 3).

Theme III: What is the global prevalence and distribution of TB stigma(s)? What explains any variation?

Policy makers, civil society, research organisations, donors and activists are keen to know where TB stigma is most problematic so that they can channel scarce resources. This theme focuses attention on the macro level: how prevalent is TB stigma across the globe, and how can valid global comparisons be made? (Table 4).



**Figure 1** Potential impacts of stigma along a person's TB care itinerary or trajectory (artist: R Takahashi). TB = tuberculosis.

Table 3 How consequential are TB stigmas? Where are TB stigma(s) impacts felt?

No	Research questions/research topics	Foundational studies references	Level of measurement/population	Study designs and methodology
1	Does TB stigma contribute to poor care seeking or delay in diagnosis?	59,49,60–64	Symptomatic persons with undiagnosed TB	Interviews, life histories
2	Does stigma hamper quality and completeness of contact and outbreak investigations? Does stigma reduce willingness to disclose TB disease to contacts?	60,63–65	HCWs, persons with TB	Record review, key informant interviews (patients and HCWs)
3	Does stigma hamper TB screening/diagnosis? Do health workers hesitate to ask TB patients about other stigmatised identities, diseases or behaviours?	59,33,66,67	Individual: patients Health system: HCWs/health managers/CHWs Community: leaders, key spokespersons	
4	How do health workers experience TB stigmas when they provide TB services, does it impact care?	59,33,68	HCWs	Interviews, surveys, focus groups
5	Does TB stigma hamper treatment initiation?	54,69	PTLFU	PTLFU surveys
6	Does TB stigma(s) worsen TB outcomes via poor adherence or loss to follow-up, death?	25,56	TB patients who drop out of anti-tuberculosis treatment Relatives of those who have died of suspected TB	Cohort studies, mortality studies, verbal autopsy studies
7	Does stigma contribute to catastrophic costs?	28	Affected households	Macro- and micro-economic analysis
8	Does stigma contribute to the erosion of social capital and social networks (social impacts)?	70	Health system, community leaders, key spokespeople	Social network studies
9	Does stigma hamper full recovery and long-term self- worth (mental health and quality of life)?	24	Current and former TB patients	Cohort study; medical record review; surveys (patient, care giver, family)
10	How consequential are stigmas for public and individual health and human rights?	13,59	Health system; legal and ethics framework	Tracking systemic discrimination, harassment, isolation or breaking confidentiality

 $TB = tuberculosis; \ HCW = health\ care\ worker; \ CHW = community\ health\ worker; \ PTLFU = pre-treatment\ loss\ to\ follow-up. The pre-treatment by the$ 

Although normative influences upon stigma have been mapped in broad strokes, <sup>16,17,19,45</sup> multi-country studies are few. <sup>12,13,32,74</sup>

Theme IV: What can be done to reduce the extent and impact of TB stigma(s)?

Sommerland et al. report that the strength of the evidence for interventions to reduce TB stigma is limited.<sup>11</sup> Well-designed trials to assess the effect of changing societal, community, and individual attitudes and behaviours to reduce stigma(s), as well as interventions maximising resistance, resilience, and strengthening or multiplying allies, are needed.<sup>59</sup> Adapting effective interventions designed to address other stigmas, such as leprosy, HIV or mental health, may be an effective way forward.

We proposed to build on the stigma-reduction framework of Heijnders and Van der Meij,<sup>74</sup> and chose the 'onion' as a familiar frame. As TB stigma may operate at all levels from the individual to the community, to health system level and to the wider societal or structural levels (where policies operate),

our responses must also target particular social spaces (Figure 2).

We recommend that all implementation science specify which drivers, protective factors, actions or behaviours are being targeted and which behavioural, psychological or social theories underpin the intervention. One way of gaining clarity is to insist on determining if an intervention addresses the drivers of TB stigma (fundamental intervention) or if it aims to mitigate its consequences (symptomatic intervention). While both types of interventions may be needed, transparency on where in this chain of 'driver-to-consequence' the intervention takes place could help us understand which interventions are working, and why.

Practitioners should partner with researchers to evaluate the media materials, curricula and counselling guides that are in use.<sup>75</sup> Publishing negative findings is as crucial as documenting success.<sup>4,11</sup> Whether or not effective interventions will perform equally well across settings is a research question that must be answered empirically. Rood et al. and

No	Research questions/research topics	Foundational studies references	Level of measurement/population	Study designs and methodology
11	How do we optimise existing TB stigma scales so that they can be used cross-culturally?	10,15,29,25–28,33,36,71	Individual: patients Community Institutions Laws and policies	Cross-sectional, comparative or longitudinal surveys; prospective observational cohorts; case studies and indepth interviews
12	How do we leverage existing survey data?	1,12	Household surveys	Secondary analysis of TB non- disclosure for hypothesis generation
13	How do we measure levels of TB stigmas in key population groups?	41–43,47	Individual: patients Health workers Community: leaders Key populations: men, miners, PLHIV, prisoners, migrants	Based on qualitative work from thematic area 1.2, conduct surveys
14	Is it possible to develop valid 'mini scales' and 'rapid assessments' that capture TB stigma?	55,72	Structural: policy use at national and global level for monitoring and comparing over time	Embed in existing and continuing surveys, e.g., prevalence surveys; catastrophic cost surveys
15	What explains the variation in stigmas across and within	4,13–15	Structural: legal frameworks	Ecological analyses Mapping of legal frameworks

**Table 4** What is the global foot print of TB stigma(s)? What explains this variation?

TB = tuberculosis; PLHIV = people living with human immunodeficiency virus.

stigmas across and within countries? Are there

protective factors in some

settings?

Sommerland et al. argue that as TB stigma is often compounded with other forms of discrimination, combined stigma-reduction efforts are likely to be synergistic (Table 5). 11,13

Several behavioural-change theories could be used to inform the design of stigma-reduction efforts in public health. It remains true that some domains of stigma (e.g., reified beliefs, attitudes and behaviours) may be difficult to change, being sustained by powerful interests, habit, culture, history and social determinants.

## **CONCLUSION**

Given the goal to eliminate suffering in people with TB, and the urgent need to find and treat the 4 million missing patients and strengthen the fight against MDR-TB, there is an increasing mandate for valid methods to estimate the burden of TB stigma(s).

One of the main outcomes of the above-mentioned expert meeting in May 2016 was that, while the world wants simple tools and checklists, complex dilemmas remain to be resolved, including clarity on what causes TB stigmas to emerge and thrive in different contexts and populations. The challenge of unpacking and measuring the intersectional aspects of TB stigma, and the low likelihood of a 'cure' for universal stigma being found, oblige diverse and innovative approaches. While existing validated scales are useful, new TB stigma scales need to be developed and rigorously validated to fill the gaps.

Collectively, the meeting participants believed that a powerful social force such as TB stigma is amenable

to appraisal and amelioration. We hope those interested in reducing the suffering due to TB stigma will use the proposed research agenda to join efforts in achieving better measurement of TB stigma with the ultimate goal of developing clear, focused and effective interventions. People affected by TB have a key role to play in the development and implementation of interventions to ensure that science is linked to the reality of their experiences, and that proven strategies for resistance, resilience and countering are funded and fostered. While the research agenda presented will require considerable resources and planning, we are convinced that it is now time to focus on the 'how', and not the 'whether', to measure and reduce TB stigma.

using adapted legal

environment assessments

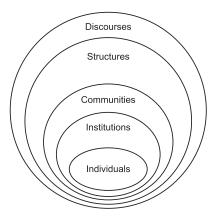


Figure 2 An onion framework: spaces for intervention to reduce stigma.50

 Table 5
 What can be done to reduce TB stigma? (i.e., which interventions work?)

No	Research questions/research topics	Foundational studies references	Level of measurement/population	Study designs and methodology
16	Does increasing specific kinds of knowledge reduce TB	13,76		Pragmatic trials, RCT, stepped wedge designs
17	stigma? What is protective? Which legal and policy reforms reduce TB stigma?	77	Structural, e.g., progressive legal interventions for non- adherence; worker privacy for DOT on the job	Repeat legal environment assessment Trend analyses
18	Which educational interventions reduce TB stigma?	32,68	Structural/Health System Medical ethics education/ interpersonal skills/stigma awareness training	Use of simulated patients with students to assess language used with communicating or providing information Assessments of teaching case presentations about people with TB —observe language used
19	Which types of individual-level psychosocial, nutritional, economic supports foster resilience to TB stigma?	11,36,31,78	Patient-level Household-level	Assess the role of peer or health worker support
20	How can infection control and contact tracing behaviours be modified to reduce stigma?	79	All levels/ultimately structural and discourse levels	Pragmatic trials, RCT, stepped wedge designs
21	How effective are shifts in language and rhetoric to reduce stigma?	80–85	Discourses, laws, media, policies, recording and reporting forms	Study using comprehensive critical analysis and discourse analysis of language used; norms present or not present Content review of print and online media to determine how TB is portrayed (e.g., epidemiology, patient names or images)
22	What interventions are effective with those who stigmatise?	32,76,83	Household/family/care givers Policy makers HCW	Pragmatic trials, RCT, stepped wedge designs
23	How effective are interventions adapted from other stigma arenas (e.g., mental health, leprosy, HIV)?	24,77,80,86–88		Pragmatic trials, RCT, stepped wedge designs
24	What interventions are effective against the consequences of stigma? Is stigma reduced by new technology such as video based-DOT/telemedicine and SMS reminders that may increase privacy and confidentiality?	89,90	Organisational/health system: HCW and managers/CHWs Individual: patient and family	Adding new questions to health facility and individual survey questions; qualitative methods looking at individual responses Matched case control study: enrol patients in the interventions not only compare adherence and health outcomes to non-intervention groups, but ask questions about extent of stigma and shame
25	How well do effective stigma reduction interventions translate to other settings?		Diverse settings	Multisite studies
26	Are some people more resilient to stigma? How can allies be cultivated to combat discrimination?	12,91,92	Patient-level	Case control Participant observation
27	Which interventions are effective against intersectional stigmas?	37,59	Patient-level	RCT Pragmatic trials
28	Does improving TB service delivery quality reduce stigma? e.g., ls stigma reduced by rapid diagnostics or shorter regimens?	32	Facility-level	Nested studies in evaluations of non-stigma interventions Pragmatic trials

TB = tuberculosis; RCT = randomised controlled trial; HCW = health care worker; HIV = human immunodeficiency virus; DOT = directly observed treatment; SMS = short message service; CHW = community health worker.

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#### \_\_ R É S U M É

La stigmatisation vis-à-vis de la tuberculose (TB) reçoit enfin, au niveau mondial, une attention bien méritée, car elle est cruciale pour identifier et traiter les 4 millions de patients atteints de tuberculose (TB) qui sont actuellement manqués par les programmes nationaux TB. La capacité à mesurer et à évaluer le succès des efforts de réduction de la stigmatisation TB est cependant par le besoin d'outils limitée supplémentaires. Lors d'une réunion de mesure de la stigmatisation TB qui a eu lieu à La Haye en 2016, les experts en stigmatisation ont discuté et proposé un programme de recherche autour de quatre thèmes : 1) Moteurs : quels sont les principaux moteurs et domaines de la stigmatisation TB ? 2) Conséquences : quelles sont les conséquences de la stigmatisation TB? Comment les impacts négatifs sont-ils surtout ressentis? 3) Fardeau : quelle est la prévalence mondiale et la distribution de la stigmatisation TB? Comment s'expliquent les variations? 4) Intervention: que peut-on faire pour réduire l'étendue et l'impact de la stigmatisation TB? Chaque thème a ensuite été subdivisé en sujets de recherche à examiner pour faire avancer les choses. Ceci inclut de clarifier les causes qui font émerger et croître la stigmatisation vis-à-vis de la TB, la difficulté à mesurer la complexité de la stigmatisation et l'absence de probabilité d'un remède universel. Néanmoins, ces défis ne devraient pas entraver les investissements dans la mesure et dans la réduction de la stigmatisation relative à la TB. Nous pensons qu'il est temps pour la communauté mondiale de se concentrer sur la manière de mesurer et de réduire la stigmatisation liée à la TB et non pas de se demander s'il faut le faire.

#### \_ R E S U M E N

Dada la gran influencia que ejercen los estigmas relacionados con la tuberculosis (TB) en la detección y el tratamiento de los 4 millones de pacientes que se pasan por alto en los programas nacionales contra la TB, se otorga hoy a la estigmatización una atención bien justificada y tardía a escala mundial. Sin embargo, la falta de instrumentos adecuados limita la capacidad de medir y evaluar la eficacia de las iniciativas tendentes a aminorar los estigmas asociados con la TB. En una reunión celebrada en el 2016 en La Haya sobre la medición de la estigmatización por TB, expertos en el tema analizaron y propusieron un programa de investigación en torno a los siguientes cuatro temas: 1) los factores determinantes: ¿Cuáles son los principales factores y las dimensiones de la estigmatización por TB?; 2) las consecuencias: ¿Qué tanta repercusión tienen los estigmas relacionados con la TB? ¿De qué manera se suelen percibir las repercusiones negativas?; 3) la carga: ¿Cuál es la prevalencia mundial de estigmatización por

tuberculosis y cómo se distribuye? ¿Cómo se explican las variaciones? 4): la intervención: ¿Qué puede hacerse a fin de disminuir la magnitud y el impacto de la estigmatización por TB? Luego, cada tema se subdividió en los aspectos de investigación que se deben abordar con el fin de avanzar en el programa. Estos aspectos incluyeron una mayor claridad sobre las causas que hacen surgir y progresar los estigmas relacionados con la TB, la dificultad de medir la complejidad de los estigmas y la improbabilidad de un 'remedio' universal a la estigmatización. Sin embargo, estas dificultades no deberían obstaculizar las inversiones encaminadas a medir los estigmas relacionados con la TB y a reducirlos. Los autores consideran que llegó el momento de centrar los esfuerzos en decidir la forma como la comunidad mundial debe medir y reducir la estigmatización por TB en lugar de deliberar sobre la pertinencia de hacerlo.