Macintyre, K; Bakker, MI; Bergson, S; Bhavaraju, R; Bond, V; Chikovore, J; Colvin, C; Craig, GM; Cremers, AL; Daftary, A; +17 more... Engel, N; France, NF; Jaramillo, E; Kimerling, M; Kipp, A; Krishnaratne, S; Mergenthaler, C; Ngicho, M; Redwood, L; Rood, EJJ; Sommerland, N; Stangl, A; van Rie, A; van Brakel, W; Wouters, E; Zwerling, A; Mitchell, EMH; (2017) Defining the research agenda to measure and reduce tuberculosis stigmas. The international journal of tuberculosis and lung disease, 21 (11). pp. 87-96. ISSN 1027-3719 DOI: https://doi.org/10.5588/ijtld.17.0151

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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 pro-
grammes, 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 dis-
cussed 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 reduceTB 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.1 ‘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.2 The Global Fund has declared TB stigma
to be among the most commonly identified barriers to
fighting the epidemic,3 and United Nations agencies
have called for an end to discrimination in health

care.1

Many experts believe that it will be difficult to find
the estimated 4 million missing TB cases without
addressing TB stigma.1,4 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,
the capacity to measure and evaluate the success of these interventions needs to be fostered.5–8

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.10–13 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.5,14–19 TB stigma can also be present at the level of societal discourse where cultural and social determinants may be more or less important.14,20 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,20,21 which are produced in different ways.9

‘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.22,23 ‘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.24 ‘Enacted stigma’ refers to behaviours, including micro-aggression, 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
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, in-depth 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’. 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.’

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. Some argue that TB stigma is hard to distinguish from xenophobia, elitism and racism. Other researchers suggest it is so bound up with HIV stigma that trying to tease them apart may be a fool’s errand.

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). 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. In the case of MDR-TB, there may be treatment-adherence 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. 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.

**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).

We recognise that TB stigma interacts on complex levels with psychological, social and political factors. The impact of stigma is therefore not unidirectional and not always negative. For example, stigma can make some patients more adherent and some less adherent. Furthermore, stigma’s consequences may vary for different groups, individuals, and settings.

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

<table>
<thead>
<tr>
<th></th>
<th>Anticipated stigma</th>
<th>Courtesy stigma</th>
<th>Internalised/ self-stigma</th>
<th>Enacted or experienced stigma (discrimination)</th>
<th>Structural stigma (policies, laws, architecture, human rights)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General public</td>
<td>25–27</td>
<td>13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subgroups at higher</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>risk of TB patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care workers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Policy makers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TB—tuberculosis; STP—STOP TB Partnership.
approaches 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).

Table 2 What are the main drivers and facilitators of TB stigma(s)?

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

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

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.
Although normative influences upon stigma have been mapped in broad strokes,\textsuperscript{16,17,19,45} multi-country studies are few.\textsuperscript{12,13,32,74} 

\textbf{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.\textsuperscript{11} 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.\textsuperscript{59} 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,\textsuperscript{74} 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.\textsuperscript{75} Publishing negative findings is as crucial as documenting success.\textsuperscript{4,11} Whether or not effective interventions will perform equally well across settings is a research question that must be answered empirically.

\begin{table}
\centering
\caption{How consequential are TB stigmas? Where are TB stigma(s) impacts felt?}
\begin{tabular}{|l|c|c|c|}
\hline
\textbf{No} & \textbf{Research questions/research topics} & \textbf{Foundational studies references} & \textbf{Level of measurement/population} & \textbf{Study designs and methodology} \\
\hline
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 Social network studies \\
8 & Does stigma contribute to the erosion of social capital and social networks (social impacts)? & 70 & Health system, community leaders, key spokespeople & \\
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 \\
\hline
\end{tabular}
\end{table}

\textsuperscript{TB} = tuberculosis; \textsuperscript{HCW} = health care worker; \textsuperscript{CHW} = community health worker; \textsuperscript{PTLFU} = pre-treatment loss to follow-up.
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.

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

<table>
<thead>
<tr>
<th>Table 4</th>
<th>What is the global footprint of TB stigma(s)? What explains this variation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Research questions/research topics</td>
</tr>
<tr>
<td></td>
<td>Foundational studies references</td>
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<tr>
<td></td>
<td>Level of measurement/population</td>
</tr>
<tr>
<td></td>
<td>Study designs and methodology</td>
</tr>
<tr>
<td>11</td>
<td>How do we optimise existing TB stigma scales so that they can be used cross-culturally?</td>
</tr>
<tr>
<td>12</td>
<td>How do we leverage existing survey data?</td>
</tr>
<tr>
<td>13</td>
<td>How do we measure levels of TB stigmas in key population groups?</td>
</tr>
<tr>
<td>14</td>
<td>Is it possible to develop valid ‘mini scales’ and ‘rapid assessments’ that capture TB stigma?</td>
</tr>
<tr>
<td>15</td>
<td>What explains the variation in stigmas across and within countries? Are there protective factors in some settings?</td>
</tr>
</tbody>
</table>

TB = tuberculosis; PLHIV = people living with human immunodeficiency virus.
Table 5 What can be done to reduce TB stigma? (i.e., which interventions work?)

<table>
<thead>
<tr>
<th>No</th>
<th>Research questions/research topics</th>
<th>Foundational studies references</th>
<th>Level of measurement/population</th>
<th>Study designs and methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>Does increasing specific kinds of knowledge reduce TB stigma? What is protective?</td>
<td>13,76</td>
<td>Patient-level</td>
<td>Pragmatic trials, RCT, stepped wedge designs</td>
</tr>
<tr>
<td>17</td>
<td>Which legal and policy reforms reduce TB stigma?</td>
<td>77</td>
<td>Household-level</td>
<td>Repeat legal environment assessment Trend analyses</td>
</tr>
<tr>
<td>18</td>
<td>Which educational interventions reduce TB stigma?</td>
<td>32,68</td>
<td>Structural/Health System Medical ethics education/ interpersonal skills/stigma awareness training</td>
<td>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</td>
</tr>
<tr>
<td>19</td>
<td>Which types of individual-level psychosocial, nutritional, economic supports foster resilience to TB stigma?</td>
<td>11,36,31,78</td>
<td>Pragmatic trials</td>
<td>Assess the role of peer or health worker support</td>
</tr>
<tr>
<td>20</td>
<td>How can infection control and contact tracing behaviours be modified to reduce stigma?</td>
<td>79</td>
<td>Household-level</td>
<td>Pragmatic trials, RCT, stepped wedge designs</td>
</tr>
<tr>
<td>21</td>
<td>How effective are shifts in language and rhetoric to reduce stigma?</td>
<td>80–85</td>
<td>Patient-level</td>
<td>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</td>
</tr>
<tr>
<td>22</td>
<td>What interventions are effective with those who stigmatise?</td>
<td>32,76,83</td>
<td>Patient-level</td>
<td>Pragmatic trials, RCT, stepped wedge designs</td>
</tr>
<tr>
<td>23</td>
<td>How effective are interventions adapted from other stigma arenas (e.g., mental health, leprosy, HIV)?</td>
<td>24,77,80,86–88</td>
<td>Patient-level</td>
<td>Pragmatic trials, RCT, stepped wedge designs</td>
</tr>
<tr>
<td>24</td>
<td>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?</td>
<td>89,90</td>
<td>Patient-level</td>
<td>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</td>
</tr>
<tr>
<td>25</td>
<td>How well do effective stigma reduction interventions translate to other settings?</td>
<td>12,91,92</td>
<td>Case control</td>
<td>Multi-site studies</td>
</tr>
<tr>
<td>26</td>
<td>Are some people more resilient to stigma? How can allies be cultivated to combat discrimination?</td>
<td>37,59</td>
<td>Patient-level</td>
<td>RCT Pragmatic trials</td>
</tr>
<tr>
<td>27</td>
<td>Which interventions are effective against intersectional stigmas?</td>
<td>32</td>
<td>Facility-level</td>
<td>Pragmatic trials, Nested studies in evaluations of non-stigma interventions</td>
</tr>
</tbody>
</table>

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.
Acknowledgements

We are indebted to the anonymous reviewers for constructive comments.

The Global Health Bureau, Office of Health, Infectious Disease and Nutrition (HIDN), US Agency for International Development (USAID, Washington DC, USA), financially supports this study through Challenge TB under the terms of Agreement No. AID-OAA-A-14-00029. The authors’ views expressed in this publication do not necessarily reflect the views of the USAID or US Government.

Conflicts of interest: none declared.

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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 limitée par le besoin d’outils 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.

Dada la gran influencia que ejercen los estigmas relacionados con la tuberculosis (TB) en la detección y 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 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.