

## **Global Partnership for Zero Leprosy**

### **Research Agenda Working Group**

#### **Subgroup on [Stigma](#)**

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## **Introduction**

Compared with other leprosy-associated issues, the topic of stigma and discrimination has received little attention from the International Federation of Anti-Leprosy Associations (ILEP) members, the World Health Organization (WHO), and national programs. Yet, it is consistently the number one issue and challenge described by persons affected by leprosy in most areas of the world. Discrimination and attitudinal biases are often mentioned as the primary barrier to inclusion for persons with other disabilities and are a key topic in the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD). Stigma is often the factor that turns an impairment into a disability and causes social exclusion. The mental health consequences of living with disabilities and the associated stigma and discrimination are increasingly an area of interest in the neglected tropical disease (NTD) field.

Stigma is highly relevant in the context of the Global Partnership for Zero Leprosy (GPZL), as zero discrimination is a declared goal. Moreover, stigma is a barrier to zero leprosy due to its effect on leprosy prevention, treatment, case management, and prevention of disabilities.

To achieve zero leprosy and to have a meaningful impact on stigma and discrimination, future research should address major challenges at the national and international levels. The priorities for this research should fit with or optimally integrate with those of the [ILEP's Triple Zero Campaign](#), [the WHO Global Leprosy Strategy 2016-2020](#), and the aspirations of the GPZL and the Neglected Tropical Disease NGO Network (NNN). The GPZL Research Agenda Working Group's Subgroup on Stigma examined these reports to make an inventory of needs related to leprosy stigma and discrimination. The Subgroup also drew on the report of a global research priority review conducted by the Leprosy Research Initiative (LRI) in 2018 and considered the work of the various task groups of the NNN's [Disease Management, Disability and Inclusion \(DMDI\) Working Group](#), which has a Task Group on Mental Wellbeing and Stigma that works on related issues.

Based on this review, the following were identified as important needs and challenges to be addressed in the leprosy field related to stigma:

- Documenting (and mapping) the level of stigma in communities and health services
- Addressing community stigma as a barrier to zero transmission, e.g., as a barrier to
  - Treatment seeking, early diagnosis, and disclosure
  - Treatment adherence
  - Prevention of disabilities
- Addressing negative attitudes and behaviors against persons affected by leprosy as barriers to inclusion in the community, with special reference to women and girls, and in access to health services
- Documenting the impact of stigma and discrimination on the mental health of persons affected by leprosy (and other NTDs) and identifying and evaluating ways to prevent and mitigate this impact
- Mitigating the effects of stigma and discrimination among persons affected by leprosy (especially internalized stigma) and among their family members
- Validating stigma and mental health assessment tools from the [NTD Disability and Morbidity Toolkit](#) in more leprosy-endemic countries
- Applying the health-related stigma concept (1): pioneering joint stigma reduction interventions for persons with NTDs and/or disability groups

## Goals of the Research Prioritized by the Stigma Subgroup

The goals of the research recommended by the Stigma Subgroup are to

- Reduce stigma as a barrier to treatment seeking, case detection, diagnosis, treatment adherence, self-care, and rehabilitation
- Mitigate the impact of stigma and discrimination on mental wellbeing and all aspects of social participation among persons affected by leprosy
- Increase active participation of persons affected by leprosy in leprosy services
- Improve social inclusion of all persons affected by leprosy through disability-inclusive development

## Research Priorities, Current knowledge, and Key Questions

In 2018 the Leprosy Research Initiative (LRI), a combined venture of several ILEP partners and other NGOs supporting work in the field of leprosy, conducted an extensive review of leprosy research

priorities that had been defined in 2013. Their efforts involved an inquiry panel, focus group discussions, a global e-survey, and a Delphi panel. The purpose was to draft an updated set of research priorities aligned with the current developments and challenges in the field of leprosy. The effort involved a wide range of stakeholders, including persons affected by leprosy, representatives from organizations working in the field of leprosy, medical staff, policy makers, and researchers. The main questions identified were 1) which leprosy-related research topics are considered to be the most important and 2) how are they ranked according to priority by the stakeholders?

The LRI results were grouped according to the three zeros in the ILEP Strategy: Zero Transmission, Zero Disability, and Zero Discrimination. The Stigma Subgroup reviewed these results and did not identify any major missing topics. The Subgroup then took the top eight research priorities for Zero Discrimination from the LRI study and grouped them into four major priority themes that could be studied together in large, coordinated multi-country projects. Changes were made to the wording and emphasis of several of the topics. The four priority themes are listed below, together with key research questions for each.

### *1. Interventions to Reduce Stigma as a Barrier to Zero Leprosy*

Several stigma interventions such as contact intervention, peer counseling, and socioeconomic development have been tested (2,3). Also, the effectiveness of using “champions” and involving persons affected by leprosy in stigma reduction have been demonstrated (4,5). The positive effects of a sustained social marketing campaign in Sri Lanka have been shown, but results in terms of stigma reduction were never measured (6,7). The effects of a multi-media modified leprosy elimination campaign in India were measured but never published in a peer-reviewed journal.<sup>1</sup> The interventions described in these studies should be tested in additional settings and cultures, and ways to scale up such interventions should be investigated through operational research. A few surveys have been done in recent years to document the types, prevalence, and severity of stigma in leprosy-endemic countries (2,8–13). However, such studies are needed in all leprosy-endemic countries and in countries and areas where leprosy-related stigma is known to be a problem. Baseline data are needed for monitoring the effect of interventions. It is important that such baseline and stigma monitoring studies use standard tools. The Participation Scale (14) and the 5-Question Stigma Indicators are recommended in the [Monitoring and Evaluation Guide](#) that accompanies the WHO Global Leprosy Strategy 2016-2020. These and a number of stigma-assessment tools have been validated cross culturally (15–22), but additional validation studies are needed—especially validation of the short 5-Question Stigma Indicators in the Monitoring and Evaluation Guide and the SARI Stigma Scale (20). Stigma levels are known to vary significantly, even at local levels, which has direct repercussions for targeting interventions (23). Stigma baseline studies should also address health services-related stigma, which is still a common, but rarely studied phenomenon in many leprosy-endemic countries. An instrument for this purpose was recently developed and validated to assess attitudes of health care providers towards persons affected by leprosy in southern India (24).

Guidelines for participation in research studies have been formally adopted by WHO (25), but the implementation often has been rudimentary. It is essential for research projects to include persons affected by leprosy among the investigators, where possible, and on steering committees. Similarly, these persons should be involved in decisions that may impact them and in the implementation of

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<sup>1</sup> <http://www.cominit.com/bbcmmediaaction/content/impact-data-bbc-world-service-trust-leprosy-project>

leprosy services. Studies examining how this can best be done in various situations and the effects of this involvement are urgently needed.

Research into the effectiveness of stigma reduction interventions should include feasibility, acceptability, and the impact of community involvement, skills building, and empowerment and participation of persons affected by leprosy. Such studies should also include cultural validation of tools to determine the level and type of stigma in communities and health services and among persons affected by leprosy and to monitor and evaluate the effect of the interventions.

➤ *Key questions*

- What is the effectiveness of various stigma-reduction interventions in different settings, and which interventions can be used on a large scale?
- What is the prevalence of different types of stigma and their geographic distribution in leprosy-endemic areas?
- How often and in what ways do stigma and discrimination against persons affected by leprosy occur in the health services? How do stigma experiences develop over time?
- What are the effects of the participation of persons affected by leprosy in research and health services? What are best practice models to implement this?

## *2. Understanding Perceptions of Leprosy and the Reasons Behind Them*

Patient and community knowledge, beliefs, fears, and practices play major roles in the perception of leprosy (15,26,27), in the perceived need for early diagnosis and treatment, and in the prevention and management of disabilities (28–33). These factors need to be well understood so that interventions targeted to specific beliefs and attitudes can be used instead of generic messages.

Research is needed on the perceptions of the disease and explanatory models (personal conceptualization of the cause, course, and consequences of leprosy). Research into experiences with the disease and its consequences is also needed as a basis for developing optimal communication and behavior change approaches. A standard toolkit using mixed methods should be cross-validated and adopted for studying the perceptions and explanatory models regarding leprosy.

➤ *Key question*

- What do patients and community members know, believe, fear, and do concerning leprosy that would be relevant for developing tools for health education and behavior change regarding stigma, disclosure, treatment seeking, treatment adherence, and prevention of disabilities?

## *3. Mental Wellbeing of Persons Affected by Leprosy*

The negative impact of having leprosy and leprosy-related visible and other disabilities and especially of experiencing stigma and discrimination on the mental wellbeing of persons affected by leprosy has long been recognized (34-38). However, population-based studies of mental distress, anxiety, and depression among this population and their family members are scarce. There is evidence that various forms of counseling can help greatly to mitigate the mental health impact of leprosy (39-41). Studies are needed to examine the association between mental distress, anxiety, and depression and various health and programmatic outcomes, such as case detection, treatment adherence, self-care, and rehabilitation.

Studies are also needed on mental wellbeing of persons affected by leprosy and on the associations between mental health, health care-seeking behavior, and accessibility of services (e.g., diagnostic or treatment delay, treatment compliance, participation in self-care groups). Such studies should be part of or directly linked to intervention studies to prevent a negative impact on and/or to improve mental wellbeing among those suffering from anxiety, depression, or other mental health conditions.

➤ *Key questions*

- What is the prevalence of mental distress, anxiety, and depression among persons affected by leprosy and their family members?
- What is the impact of mental distress, anxiety, and depression on health care and programmatic outcomes, such as case detection, treatment adherence, self-care and rehabilitation?
- How can a negative impact on mental wellbeing be mitigated once it has occurred?

#### 4. *UN Principles and Guidelines for the Elimination of Discrimination*

The UN Human Rights Council adopted [\*Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members\*](#) in 2010. However, very few studies have addressed the implementation of this important document. Studies are needed to assess the (local) implementation and impact of these principles and guidelines, and interventions should be developed to improve this practice.

➤ *Key questions*

- What is the status of the implementation of the UN *Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and Their Family Members*?
- What is the impact of these principles and guidelines?

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