**ELIMINATION OF DISCRIMINATION AGAINST LEPROSY AFFECTED PERSONS AND THEIR FAMILY MEMBERS**

**Questionnaire for**

**NON-GOVERNMENTAL ORGANIZATIONS**

**Persatuan Mandiri Kusta (PerMaTa)**

***Independent PALs Association – South Sulawesi, Indonesia***

**BACKGROUND**

In its resolution A/HRC/29/5, the Human Rights Council requested the Advisory Committee to undertake a study which reviews the implementation of the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members, together with the obstacles thereto, and to submit a report containing practical suggestions for their wider dissemination and more effective implementation and to submit a report at its thirty-fifth session.

The resolution also requests the Advisory Committee, in its elaboration of the report, to take into account the views of Member States and as appropriate relevant international organizations, including the World Health Organization, the Office of the United Nations High Commissioner for Human Rights and relevant special procedures, national human rights institutions, and non-governmental organizations, as well as the work done on the issue by relevant United Nations bodies, specialized agencies, funds and programmes within their respective mandates.

In this context, the Advisory Committee decided, at its fifteenth session held in August 2015, to establish a drafting group in charge of the preparation of this study.[[1]](#footnote-1) The purpose of this questionnaire is to collect information from non-governmental organizations in order to identify the current state of implementation of the Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members (the Principles and Guidelines); how the Principles and Guidelines apply to different situations in different countries, especially the good practices that may be shared; and the major obstacles to implementation, including views on how best to further strengthen the implementation of the Principles and Guidelines.

**1.** Are you aware of the Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members adopted by the United Nations General Assembly in December 2010 (resolution 65/215)? If yes, how did it come to your attention?

**We are not yet aware or become aware of guidelines and principles for the elimination diskriminsi against people affected by leprosy and their families**

**2.** What mechanism has the Government (Federal or State level) put in place to disseminate the Principles and Guidelines to its citizens? e.g. translation into national and local languages; media; or any other mechanism?

**Mechanisms that have been made by the government until now we just do not know it**

**3.** Have any policies, action plans or any other measures been taken at the national level to promote awareness-raising of the issue of discrimination against leprosy affected persons and their family members? Please provide details on measures taken.

**We do not know there is a policy, action plans or measures taken at national level**

**4.** What measures have been taken (Federal or State level) to modify, repeal or abolish discriminatory laws, policies or practices, including terminating forced segregation, in order to eliminate discrimination against persons affected by leprosy and their family members? Is freedom to choose where to live ensured for persons affected by leprosy and their family members?

**Do not know, or maybe no action**

**5.** Which is the terminology originally used in your native language in respect of persons affected by leprosy? Please also provide, aside from the specific terminology in your native language, a translation of it in English. Are there any popular myths associated with persons affected by leprosy? Please provide a short description.

**Leprosy is still considered a hereditary disease, the disease of curse, illness due to witchcraft. In addition, the disability caused by leprosy was considered that leprosy can not be cured. People who have had leprosy still avoided by many people, including some health workers because they are afraid of contracting.**

**6.** Are those affected by leprosy and their family members being consulted with and/or actively participating in the decision-making processes that deal with matters related to them?

**They have not been actively involved**

**7**. What measures have been taken at the national level to ensure persons affected by leprosy enjoy fully and equally rights with others regarding the rights of citizenship; obtaining identity documents; the right to vote; the right to stand for elections; the right to serve the public in any capacity or other civil and political rights?

**We do not know**

**8.** What measures have been taken to ensure persons affected by leprosy enjoy equal rights with others with regard to the rights to work and education; establishing a family; access to public places, including hotels, restaurants; and buses, taxis, trains and other forms of public transport; access to cultural and recreational facilities; access to places of worship or any other economic, social and cultural rights?

**The government just form a group of self-care, then there is no effort from the government to ensure that people affected by leprosy have a equal rights.**

**This time we tried to join the movement of persons with disabilities in general, because they are quite good and organized. but the results can not we get yet (a special issue of leprosy)**

**9**. What actions have been taken to promote and protect the human rights of (a) women; (b) children; (c) the elderly; (d) members of other vulnerable groups who have or have had leprosy, as well as their family members? Please provide details.

**The Human Rights protection in Indonesia (at this moment) is only aimed at women and children, the Government has issued several laws. But for cases of leprosy has been no action taken by the government.**

**10**. What actions have been taken at the national level with regard to discriminatory, labelling and offensive languages directed at leprosy affected persons?

**We do not know**

**11**. Have Governments drafted and/or adopted a national action plan to implement the Principles and Guidelines? Please attach a copy. Has a national committee been established? Please provide some details as to its mandate, size and composition of members.

**We do not know**

**12.** What major obstacles, if any, have Governments faced in implementing the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members?

**We do not know**

**13.**  In your view, what follow-up mechanisms should be put in place at the national and international levels to effectively implement the Principles and Guidelines?

**In our opinion, the mechanism that is essential at both national and international is to socialize about the guidelines and principles of elimination of discrimination against persons affected by leprosy, so that all people aware of the guidelines and principles.**

**14**. Are there any concrete measures taken by Governments at different levels that you can share with us regarding actions taken to eliminate discrimination against leprosy affected persons and their family members in your country?

**We do not know**

**15**. Please provide identified cases of discrimination experienced by leprosy affected persons and their family members in your country, disaggregated by its different forms, including de facto discrimination.

**In our region (South Sulawesi) are still a lot of discrimination, one of which adalag my neighbors divorced by her partner being caught leprosy, people who are affected by leprosy difficulty marketing of products (especially food), shunned by society, and dismissed from work, and others.**

**Deadline for submission of responses:**

All parties are encouraged to submit their responses via email or fax as soon as possible but no later than **30 October 2015** to:

[**hrcadvisorycommittee@ohchr.org**](mailto:hrcadvisorycommittee@ohchr.org)[Subject: HRCAC Elimination of discrimination against persons affected by leprosy]

or

Secretariat of the Human Rights Council Advisory Committee

Attn. Ms. Dina Rossbacher

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Thank you in advance for your contribution.

For more information about the Advisory Committee, please visit <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/HRCACIndex.aspx>

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1. A/HRC/AC/15/L.3 [↑](#footnote-ref-1)