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

**Questionnaire for**

 **NON-GOVERNMENTAL ORGANIZATIONS**

**Response by:**

**THE LEPROSY MISSION ENGLAND & WALES**

**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?

The Leprosy Mission England and Wales was aware of the P&Gs throughout the process of development through to the passing of the UN resolution through the ILEP network. Its representatives attended the consultations in Geneva providing input into the wording of the final document.

1. 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?

As far as I am aware the UK Government has done nothing to make citizens aware of the Principles & Guidelines, apart from a brief reference to the Principles and Guidelines in the revised UK Health Protection Agency Memorandum on Leprosy aimed at the medical profession (https://www.gov.uk/government/publications/leprosy-memorandum-2012).

**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.

An early day motion (2369) was raise in Parliament in November 2011 (<http://www.parliament.uk/edm/2010-12/2369>) calling upon the UK government to take action against leprosy related discrimination. However there was no direct action as a result. As stated above, after lobbying from The Leprosy Mission, the Health Protection Agency then updated its Memorandum on Leprosy to include reference to the Principles and Guidelines stating that the Leprosy Panel supports its aims. However, as far as we are aware the UK Government has done nothing in terms of policies, action plans or other measure to promote awareness-raising of the issues of discrimination against persons affected by leprosy. Although there are only about a dozen new cases in the UK each year, those The Leprosy Mission England and Wales have spoken to have mentioned that they were concerned about telling people about their condition for fear of discrimination.

**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?

Following lobbying by The Leprosy Mission England and Wales the Home Office changed immigration guidelines so that leprosy is now no longer listed as a reason for denial of entry to the UK. As far as we are aware there is no other discriminatory laws, policies or practices in the UK and people affected by leprosy and their family members have freedom to choose where to live.

**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.

Leper is the original terminology and is associated with disgust, outcast, horror, social unacceptability, revulsion. The Leprosy Mission England & Wales has been lobbying for a change in this terminology, raising awareness through its Don’t Call me a Leper Campaign (<http://www.leprosymission.org.uk/take-action/dont-call-me-a-leper.aspx>) It has also requested that the BBC not use this terminology. This received a positive response. Changes were made in response to this request but the term it is still frequently used by the UK media.

**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?

The Leprosy Mission believes, as a matter of principle, that people affected by leprosy should be involved in decision-making processes about matters that affect them. For this reason The Leprosy Mission has been active in supporting development of leprosy-affected people’s organisations in various countries; in the formation of self-help groups who are involved in local-level advocacy; and in the development of these self-help groups into larger federations or cooperatives that can be a clear voice for people affected by leprosy. We also seek to involve people affected by leprosy in the project ‘cycle’ within projects that we are planning to implement.

During our advocacy with the UK government on the development of the Memorandum on Leprosy we ensured that people affected by leprosy were involved in the stakeholder meeting to give input into the content of the Memorandum on Leprosy.

**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?

As far as we are aware people affected by leprosy in the UK enjoy equal rights in these areas.

**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?

As far as we are aware people affected by leprosy in the UK enjoy equal rights in these areas. There are no legal barriers, but there is often a perception by people affected by leprosy that they may not be welcomed.

**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.

As far as I am aware there has been no specific action taken by the UK Government.

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

No action. However there is a need for action to be taken on this in the UK and for the media to be advised by the Government that the term ‘leper’ is offensive and should not be used in the media; neither should it be used by public officials.

**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.

Not as far as we are aware.

**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?

None as far as we are aware, as little action has been taken.

**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?

Requirement for all governments to produce a national plan of action, in consultation with people affected by leprosy, and forward it to the UN Human Rights Commission and to report on progress against it annually to a national commission (which includes people affected by leprosy and those who represent them) and the UN Human Rights Commission.

**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?

Change of the immigration guidelines removing leprosy as immediate grounds for denial of visa.

**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.

No formal cases of discrimination – but articles such as this <http://www.thesun.co.uk/sol/homepage/woman/health/health/6362518/Brits-fight-against-leprosy.html> highlight the stigma in society that prevents people from being open about their condition.

**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 December 2015** to:

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

or

Secretariat of the Human Rights Council Advisory Committee

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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)