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

**Questionnaire for the**

**WORLD HEALTH ORGANIZATION**

**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 drafting group elaborated the hereunder questionnaire in order to collect information from relevant special procedures, treaty bodies and international 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?

**Yes. The principles and guidelines were received from WHO HQ. The resolution and the principles and guidelines for elimination of discrimination against persons affected by leprosy and their family members were discussed in leprosy programme managers meeting.**

**2**. Please provide available data on the following (disaggregated by gender and age if possible:

* **Registered prevalence of leprosy by region by WHO region at the end of 2014. There was no data available from EURO region**

|  |  |  |
| --- | --- | --- |
| **WHO Region** | **Cases registered** | |
| **Number** | **Rate per 10,000** |
| **African** | **19,968** | **0.26** |
| **Americas** | **29,967** | **0.33** |
| **Eastern Mediterranean** | **2,212** | **0.04** |
| **South-East Asia** | **119,478** | **0.63** |
| **Western Pacific** | **3,929** | **0.02** |
| **Total** | **175,554** | **0.31** |

* Number of new annual cases detected globally during the past five years by WHO region;

**Number of new cases detected by WHO region for the past five years is presented below. There was no data available from EURO region.**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **WHO Region** | **Number of new cases detected** | | | | |
| **2010** | **2011** | **2012** | **2013** | **2014** |
| **African** | **25 345** | **20 213** | **20 599** | **20 911** | **18 597** |
| **Americas** | **37 740** | **36 832** | **36 178** | **33 084** | **33 789** |
| **Eastern Mediterranean** | **4 080** | **4 357** | **4 235** | **1 680** | **2 342** |
| **South-East Asia** | **156 254** | **160 132** | **166 445** | **155 385** | **154 834** |
| **Western Pacific** | **5 055** | **5 092** | **5 400** | **4 596** | **4 337** |
| **Total** | **228 474** | **226 626** | **232 857** | **215 656** | **213 899** |

* Number of those who have successfully completed medical treatment for leprosy during the past five years (by region/country);

**72 out of 121 countries reported treatment completion rates** of both multi-bacillary (MB) and pauci-bacillary (PB) types of leprosy. The treatment completion rates were in the range of 45% to 100% in both types of leprosy.

* Number of persons who exited treatment against medical advice.

This data was not reported by Member States

**3**. Do you give attention to those affected by leprosy in times of crisis and disaster? If yes, please include in your response examples of attention you give to those that became disabled as a result of leprosy.

**South Sudan:** Rapid assessment was carried out employing a consultant to know the status of leprosy services status and define a plan for establishing diagnosis and treatment services in the special circumstanced experienced by the people of South Sudan.

**Nepal:**

Leprosy programme was supported in case validations and tracing of registered cases was carried out in several districts highly affected by the April Earth Quake.

Four projects were supported by WHO Global leprosy programme to enhance access to clinical diagnosis and treatment of persons affected by leprosy in **Haiti, South Sudan, The Philippines and Somalia**

**A separate funding line** for supporting leprosy services under special situations and extra-ordinary circumstances is made available for enhancing access to leprosy diagnosis and multidrug therapy (MDT).

**4.** Are leprosy services integrated into existing general health services in leprosy endemic countries? If not, what are the main challenges?

Leprosy services as reported by Member States are integrated into general health services in most of the countries. In some countries, leprosy services are provided jointly with Tuberculosis control or Neglected tropical diseases.

The main challenges reported are:

Sustaining expertise on leprosy among health staff in an integrated health setting

Retaining focus on leprosy control with competing health priorities in general health services

Funds for specialised services in management of conditions caused by leprosy

Discrimination against persons affected by leprosy in health care settings

**5.** How do you assess the level of access to information, diagnosis and free access to treatment with MDT of leprosy affected persons in leprosy endemic countries?

MDT is available at all health facilities treating leprosy

Information campaigns are regularly carried out in all endemic countries to enhance awareness and to promote self-reporting on occurrence of a skin lesion.

**6.** What aspects of discrimination against leprosy affected persons and their family members have been addressed within your specific mandates?

**Inclusion of persons affected by leprosy** WHO promoted inclusion of persons affected by leprosy in leprosy services. WHO brought out “guidelines for strengthening participation of persons affected by leprosy in leprosy services” in 2010.

The guidelines were promoted in all national programme managers meeting. Representatives of persons affected by leprosy were engaged in discussions on planning of national programmes, Technical advisory group meetings and WHO Expert committee meetings to define policies and guidelines on elimination of leprosy by WHO.

**7.** Have these issues been brought to the attention of the United Nations Human Rights Council in any of your reports? Please provide details of these, if any, including reference to such documents.

WHO GLP presentation on ‘current status on elimination of leprosy in the world’ on 18 June 2015 in ‘Symposium on leprosy and Human Rights.

WHO participated in meetings and symposium conducted but United Nations Human rights council to present leprosy situation and WHO policies and guidelines in management of leprosy and to seek advice on global leprosy strategy in promoting inclusion of persons affected by leprosy in leprosy services.

**8.** Is there any inter-agency mechanism to deal with issues of discrimination against leprosy affected persons and their family members?

**9.** What, in your view, are the main gaps or obstacles towards ensuring the elimination of discrimination against leprosy affected persons and their family members at both national and international levels?

Stereotypes prevailing in the community

Low awareness in the community about leprosy as a treatable disease

Grade 2 disabilities in at least 6% of new cases

Discriminatory laws influencing quality of life affecting mobility, marriage and employment opportunities are still active in many countries

**10.** Are there best practices that you can share with us of actions taken by Member States towards eliminating discrimination against persons affected by leprosy and their family members?

Information on good practices is randomly available and most of the reports are anecdotal. Systematic data collection in these areas will help dissemination of good practices for information and possible adoption.

**11.** What appropriate mechanism(s) would you suggest to be put in place to ensure the effective implementation of the Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members at the national level and within the human rights machinery at the international level?

Elimination of discrimination against persons affected by leprosy needs to be disseminated among all stakeholders both Government organisations and non-state actors for improving awareness and gradually implementation.   
  
Global leprosy strategy 2016-2020 endorsed by national governments and partner organisations contains a strategic pillar that calls for promotion of inclusion and stoping discrimination.

**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**](mailto: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)