**Appendix II**

Questionnaire on the Implementation of the Principles

and Guidelines for the Elimination of Discrimination

against Persons Affected by Leprosy and their Family Members

Introduction

The purpose of this questionnaire is to collect information from States 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 what are the major obstacles to implementation.

The questionnaire was elaborated by the International Working Group on Leprosy and Human Rights (IWG). In developing this questionnaire, particular attention was paid to the areas that require early stage implementation as articulated in the Principles and Guidelines. The questionnaire includes (i) basic epidemiological and clinical management status of leprosy, (ii) healthcare (Guideline 11), (iii) abolishment of discriminatory laws (Guideline 1.1.(a)), (iv) establishment of a national committee (Guideline 14.1), (v) awareness-raising, translation and dissemination of the Principles and Guidelines (Guideline 13), (vi) the Government reporting to the UN human rights treaty bodies and Universal Periodic Review under the Human Rights Council (Guideline 14.2), and (vii) adoption of a National Plan of Action.

Member States of the United Nations are kindly requested to submit responses to the questionnaire set out below. When answering the questionnaire, States are invited to reflect on both challenges and achievements. Additional relevant information is welcome. If the information requested in the questionnaire relates to the States’ report to the UN human rights treaty bodies, reference to the specific reports or documents may be provided.

1. **General**

**Q1.** Please give data on the following (please disaggregate by gender and age if possible):

1. number of annual new cases of leprosy detected during the year 201X
2. number of those who have successfully completed medical treatment for leprosy during the past XX years
3. number of persons who exited treatment against medical advice
4. number of sanatoriums, leprosy colonies and related residential sites that exist in your country
5. **Participation in decision-making**

**Q2.** 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?

1. **Legislation**

**Q3.** What action has your Government taken to modify, repeal or abolish discriminatory laws, regulations or practices in order to eliminate discrimination, including terminating forced segregation? (Please attach a copy of the related documents.)

1. **Incidents of discrimination**

**Q4.** Please cite identified cases of discrimination, disaggregated by its different forms if possible, including *de facto* discrimination, in your country towards persons affected by leprosy and their family members?

1. **Healthcare programmes**

**Q5.** Please describe any early-detection programmes that ensure prompt treatment of leprosy in your country.

**Q6.** Please designate whether free care is provided for persons diagnosed with leprosy for

( ) psychological or social work counseling

( ) reaction treatment

( ) wounds care

( ) reconstructive surgery

( ) prosthesis provisions

( ) others (specify)

**Q7.** Has your Government taken action, or does it plan to take action, to disseminate a “know your rights” brochure to all persons affected by leprosy and their family members? If yes, please attach a copy of the brochure.

**Q8.**

* 1. Do healthcare staff travel to remote areas in order to provide services to persons affected by leprosy? If so, is financial support given to them to travel to such places?
  2. Is a travel allowance available to persons affected by leprosy who have to travel for treatment?

**Q9.** Does your Government have a national healthcare plan concerning leprosy? If not, please explain what measures are in place to develop such a plan.

1. **Political participation**

**Q10.** Do persons affected by leprosy and their family members enjoy the following rights fully and equally as others concerning (Please check those that are applicable.):

( ) citizenship

( ) obtaining identity documents

( ) right to vote

( ) right to stand for elections

( ) right to serve the public in any capacity

( ) participation in the decision-making process related to their rights

( ) others (specify):

1. **Living in the community and housing**

**Q11.** Is freedom to choose where to live ensured for persons affected by leprosy and their family members?

**Q12.** If they so wish, is governmental support to reunite with their families given to those who were forcibly isolated by State policies by reason of leprosy?

1. **Standard of living**

**Q13.** In your country, is the right to an adequate standard of living recognized and promoted without discrimination for those affected by leprosy and their family members living in poverty?

**Q14.** What actions has your Government taken to ensure the standard of living of those affected by leprosy and their family members? (Please check those that are applicable and provide details.)

( ) collaborative programmes that involve the Government, civil society and private institutions to raise funds and develop programmes to improve the standard of living

( ) provision of education to children affected by leprosy or children of persons affected by leprosy

( ) access to vocational training programmes

( ) government grants-in-aid for persons affected by leprosy or organizations run by them

( ) access to micro-credit

( ) Government pension (specify amount, subject, means (e.g. lump sum)

( ) financial assistance for housing and healthcare

( ) other measures

1. **Other economic, social and cultural rights**

**Q15.** Do persons affected by leprosy and their family members enjoy equal rights as others with regard to (Please check those that are applicable and provide details.):

( ) work

( ) education

( ) establishing a family

( ) access to public places, including hotels, restaurants, and buses, trains and other forms of public transport

( ) access to cultural and recreational facilities

( ) access to places of worship

( ) others

1. **Women, children, the elderly and other vulnerable groups**

**Q16.** What action has been taken to promote and protect the human rights of (a) women, (b) children, (c) the elderly and (d) members of other vulnerable groups who have or have had leprosy, as well as their family members? (Please provide details.)

1. **Awareness-raising and training**

**Q17.** Has the Government adopted any of the following to promote awareness-raising of the issue of discrimination against persons affected by leprosy and their family members? (Please check those that are applicable and provide details.):

( ) policies for awareness-raising

( ) national action plan for awareness-raising

**Q18.** Which of the following measures have you taken to raise awareness about leprosy? (Please check those that are applicable and provide details.):

( ) inclusion of information in elementary and secondary education

( ) inclusion of information in higher education institutions including medical schools and nursing schools

( ) training of teachers (pre-service and in-service)

( ) training of health workers and medical personnel

( ) training of other public officials (Please specify.)

( ) development of trainer’s training programmes

( ) development of teaching materials

( ) dissemination of handouts, leaflets to the general public

( ) organizing seminars and training

( ) organizing national or local campaigns

( ) provision of information to community and religious leaders

( ) inviting the media to portray persons affected by leprosy and their family members with dignified images and terminology

( ) taking of measures such as holding exhibitions to recognize the skills, merits and abilities of persons affected by leprosy and their contribution to society

( ) encouraging creative persons, including artists, poets, musicians and writers, particularly those who have personally faced the challenges of leprosy, to make a contribution to awareness-raising through their specific talents

( ) supporting grassroots efforts to raise awareness

( ) campaigning on national and/or World Leprosy Day

( ) making use of oral history programs, museums, monuments and publications

( ) others

1. **Discriminatory language**

**Q19.** Please describe what actions the Government has taken with regard to discriminatory, labeling and offensive language, including:

(a) effective measures to remove discriminatory and offensive terminology such as the term “leper”, or equivalent terms, from all forms of expression including social media

(b) establishing a protocol to correct misconceptions about leprosy

1. **Translation and dissemination**

**Q20.** Has the Government translated the Principles and Guidelines into national and local languages? Has the Government also taken appropriate measures, using various resources such as technical devices, so that all people in your country would be able to understand, including those who are visually impaired, hearing impaired or illiterate?

If yes, please attach a copy or copies of such translation(s).

1. **Report(s) to the Human Rights Council, treaty bodies**

**Q21.** Has the Government included information on the current situation and measures you have taken concerning the implementation of the rights of persons affected by leprosy and their family members in (Please check those that are applicable.):

( ) national report to the Human Rights Council under the Universal Periodic Review (UPR)

( ) national reports to the UN human rights treaty bodies such as the UN Convention on the Rights of Person with Disabilities (please specify the treaty body/bodies) applicable)

( ) report under the World Programme for Human Rights Education

( ) others (Please specify.)

1. **Adoption of a national plan of action and establishment of a national committee**

**Q22.** Have you drafted and or adopted a national plan of action to implement the Principles and Guidelines? If yes, please attach a copy.

**Q23.** Have you established a national committee? If yes, please give concrete information about the committee, including its mandate, size, and members.

**Q24.** Do you require technical assistance for the implementation of the Principles and Guidelines? If so, have you sought assistance of: (Please check those that are applicable.)

( ) Office of the UN High Commissioner for Human Rights

( ) expert groups within or outside your country

( ) WHO

( ) UNDP

( ) others (Please specify.)