



Division of the Ethics of Science and Technology  
Social and Human Sciences Sector  
1 rue Miollis, 75732 Paris Cedex 15, France  
Tel. : +33(0)1 45 68 39 39/49 29  
Fax : +33(0)1 45 68 55 15  
E-mail: [a.smeltzer@unesco.org](mailto:a.smeltzer@unesco.org) / [l.treguer@unesco.org](mailto:l.treguer@unesco.org)

## EVALUATION OF THE UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS

Questionnaire addressed to  
NATIONAL COMMITTEES, INSTITUTIONS and FACULTIES

### INTRODUCTION

In line with its Constitution, UNESCO has long been setting standards in its fields of competence, with the particular aim of maintaining, increasing and diffusing knowledge with regard to human rights and fundamental freedoms.

On 11 November 1997, at its 29th session, UNESCO's General Conference adopted the *Universal Declaration on the Human Genome and Human Rights*, which remains the only instrument of universal scope in the field of bioethics. The Guidelines for its implementation, endorsed by the General Conference in 1999 (30 C/Res. 23), provide for an evaluation of both the results obtained through the Guidelines and of the impact of the Declaration worldwide. Five years after the adoption of the Declaration, this evaluation is one of UNESCO's priority tasks for the current biennium.

The evaluation will be examined at a joint session of the International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IGBC) in 2003 and, together with all relevant recommendations, will be presented by the Director-General to the Organization's governing bodies.

We face many challenges in the search for an equilibrium between bioethics, trade, freedom of research, the exchange of information and privacy and intellectual property issues. The information gathered from this questionnaires will help guide UNESCO as it addresses these challenges.

In this context we ask you to assist us by completing this questionnaire and distributing it to other relevant organizations and individuals. We would be grateful if the form could be completed as clearly as possible and returned as soon as possible.

Ref.: SHS/EST/02/335

**PREFACE INFORMATION**

Official title:

Acronym:

Title in English:

Title in French:

Principal Contact:

Mailing Address:

Tel:

Fax:

E-mail:

Internet address (URL):

**I. INITIATIVES TAKEN BY YOUR INSTITUTION RELATING TO THE *UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS***

1. How did your institution become aware of the *Universal Declaration on the Human Genome and Human Rights*?

Media \_\_\_ Another person/institution \_\_\_ Conference \_\_\_ Other \_\_\_

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2. What efforts has your institution taken to implement the *Universal Declaration on the Human Genome and Human Rights*?
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3. What research programmes have been implemented based upon the provisions of the *Universal Declaration on the Human Genome and Human Rights*?
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4. Do national committee programme activities, course curriculum or research programmes exist that address the impact or implications of the *Universal Declaration on the Human Genome and Human Rights*? If so, what areas or specific articles of the Declaration are covered?
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5. In particular, do parts of your institution activity, course curriculum or research programmes address the question of the disclosure of genetic information to third parties, in particular whenever children are concerned?

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6. What national recommendations are you aware of that have been or are planned to be made concerning the *Universal Declaration on the Human Genome and Human Rights*?

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7. What governmental departments or committees have you communicated with to address issues outlined in the *Universal Declaration on the Human Genome and Human Rights*?

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8. How have you involved stakeholders in your activities in the field of bioethics?

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9. What future plans does your institution have concerning the implementation of the *Universal Declaration on the Human Genome and Human Rights*?

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10. Publications produced by your institution related to the *Universal Declaration on the Human Genome and Human Rights*:

Books:

Title:  
Publisher:  
Date:  
ISBN #:

Title:  
Publisher:  
Date:  
ISBN #:

Reports, Proceedings, etc.:

Title:  
Publisher:  
Date:

Title:  
 Publisher:  
 Date:

Periodicals:

Title:  
 Frequency:  
 Date:

Title:  
 Frequency:  
 Date:

11. Conferences, meetings, etc. organized at the initiative of your institution pertaining to the *Universal Declaration on the Human Genome and Human Rights*:

12. Other recent events undertaken by your institution pertaining to the *Universal Declaration on the Human Genome and Human Rights*:

**II. SUGGESTIONS FOR UNESCO**

13. Have you or a representative of your institution attended any International Bioethics Committee (IBC) or Intergovernmental Bioethics Committee (IGBC) meetings?

Yes \_\_\_ No \_\_\_

a. If yes, were the topics studied relevant to you and your institution?

Yes \_\_\_ No \_\_\_

b. What comments do you have about the meetings?

14. In order for UNESCO to disseminate this questionnaire as widely as possible, please attach a list including the names and addresses of individuals, committees or institutions conducting activities pertaining to the concepts and principles contained in the Declaration.

**Please send your responses as soon as possible to:**

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