



Division of the Ethics of Science and Technology
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EVALUATION OF THE UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS

Questionnaire

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 by 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, privacy and intellectual property issues. The information gathered from this questionnaire will help guide UNESCO as it addresses these challenges.

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

PREFACE INFORMATION

Name:

Position:

Affiliations in the field of bioethics:

Mailing address:

Tel:

Fax:

E-mail:

I. INITIATIVES YOU HAVE TAKEN RELATING TO THE *UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS*

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

Media ___ Another person/institution ___ Conference ___ Other ___

2. What efforts have you taken, personally or as part of an organization or association, to disseminate and promote the principles of the *Universal Declaration on the Human Genome and Human Rights*?

3. What course curriculum or research programmes are you aware of in your country that address the impact or implications of the *Universal Declaration on the Human Genome and Human Rights*?

4. In your knowledge, what national recommendations have been made or are intended to be made in your country concerning the *Universal Declaration on the Human Genome and Human Rights*?

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5. What parts of your activities or research programmes, if any, address the question of the disclosure of genetic information to third parties, in particular whenever children are concerned?

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6. In the event that you have been involved in activities that address issues outlined in the *Universal Declaration on the Human Genome and Human Rights*, with what governmental departments or committees have you communicated?
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7. If you are involved in activities pertaining to bioethics, how have you involved stakeholders in your work?

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8. What future plans do you have concerning the implementation of the *Universal Declaration on the Human Genome and Human Rights*?

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9. Have you produced any publications related to the *Universal Declaration on the Human Genome and Human Rights* ? If yes, please list them.

Books:

Title:
Publisher:
Date:
ISBN #:

Title:
Publisher:
Date:
ISBN #:

Reports, Proceedings, etc.:

Title:
Publisher:
Date:

Title:
Publisher:
Date:

Articles:

Title:
Date:
Periodical:

Title:
Date:
Periodical:

10. What conferences, meetings, etc., if any, have you attended pertaining to the *Universal Declaration on the Human Genome and Human Rights*?

11. What other recent events, if any, have you organized pertaining to the *Universal Declaration on the Human Genome and Human Rights*?

II. SUGGESTIONS FOR UNESCO

12. Have you attended any International Bioethics Committee (IBC) or Intergovernmental Bioethics Committee (IGBC) meetings?

Yes ___ No ___

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

Yes ___ No ___

b. What comments do you have about the meetings?

Please send your responses as soon as possible:

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