



## Economic and Social Council

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Item 14 (i) of the provisional agenda\*

**Social and human rights questions: genetic privacy  
and non-discrimination**

### Genetic privacy and non-discrimination

#### Note by the Secretary-General

The Secretary-General transmits herewith a note by the Director-General of the United Nations Educational, Scientific and Cultural Organization,<sup>1</sup> submitted in response to Economic and Social Council decision 2008/233.

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\* E/2010/100.

<sup>1</sup> The document was submitted late by UNESCO.



## **Note by the Director-General of the United Nations Educational, Scientific and Cultural Organization on genetic privacy and non-discrimination**

### **Introduction**

1. In its decision 2008/233, the Economic and Social Council invited the Director-General of the United Nations Educational, Scientific and Cultural Organization (UNESCO) to consult with United Nations entities on the implementation of resolutions that were relevant to genetic privacy and non-discrimination and on a possible inter-agency coordination mechanism. It also invited the Director-General to report to it at its substantive session of 2010 on relevant developments in the field of genetic privacy and non-discrimination and on a possible inter-agency coordination mechanism, in consultation with and taking into account the views of Member States.

2. Within its standard-setting action in the field of bioethics, UNESCO has adopted three Declarations — the Universal Declaration on the Human Genome and Human Rights (1997), the International Declaration on Human Genetic Data (2003) and the Universal Declaration on Bioethics and Human Rights (2005) — in which the issue of non-discrimination is extensively addressed. With its long experience in the domain of bioethics and its expertise in the International Bioethics Committee and the Intergovernmental Bioethics Committee, UNESCO is well placed to pursue and further its ethical mandate in this respect.

3. However, given the fact that the science of genetics and its applications have an impact and implications in different domains, no single forum may be identified to address the issue of genetic privacy and non-discrimination. As such, the roles of each organization within and outside the United Nations system remain relevant in their specific fields of competence. Cooperation and coordination among organizations is therefore essential and the Inter-Agency Committee on Bioethics can constitute a key mechanism to this end.

### **Inter-agency coordination mechanism: the Inter-Agency Committee on Bioethics**

4. The aim of the Inter-Agency Committee on Bioethics, an ad hoc mechanism involving intergovernmental organizations within and outside the United Nations system, is to improve the coordination of activities carried out by the various organizations in the field of bioethics.

5. At the initiative of the Director-General of UNESCO, the Committee was established by all organizations participating at its first meeting, held in Paris in March 2003. The Committee brings together organizations of the United Nations system which have developed programmes in or which carry out specific activities related to bioethics, as well as other intergovernmental organizations and institutions. UNESCO serves as the permanent secretariat of the Committee.

6. The primary function of the Committee is to provide a forum for debate and exchange of information in the field of bioethics and related issues, with special attention to the human rights aspect, and to promote coordination of the activities undertaken in this field by the United Nations, its specialized agencies and other relevant

intergovernmental bodies. The Committee has held nine meetings since 2003. It continues to mobilize the participating organizations and institutions to explore crucial issues in bioethics in order to identify cases in which concerted or joint efforts would be beneficial or in which major gaps and constraints affecting cooperation need to be addressed.

7. The issue of genetic privacy and non-discrimination was included in the agenda of the ninth meeting of the Inter-Agency Committee on Bioethics, held in Strasbourg, France, on 26 February 2010, with a view to initiating a brainstorming discussion among relevant United Nations agencies and other intergovernmental organizations on the follow-up to Economic and Social Council decision 2008/233. From the exchange of information pertaining to activities undertaken by the organizations represented, it became evident that all are interested in further pursuing the subject. Some of the organizations have already produced relevant documents and/or formulated recommendations. It was decided that the item would be included in the agenda for the next meeting of the Committee, which is expected to be held at the end of 2010. It was suggested that specialists and other experts could be invited to further discuss the topic at that meeting.

## Action taken

8. To respond to Economic and Social Council decision 2008/233, UNESCO is engaged in the following two major initiatives:

(a) To carry on with its consultations with Member States on relevant developments in the field of genetic privacy and non-discrimination and on a possible inter-agency coordination mechanism. A questionnaire, ready for distribution, is aimed at identifying whether specific legislation exists in Member States designed to protect genetic privacy and non-discrimination or whether the issue is addressed within the context of legislation of broader scope. At the same time, the questionnaire seeks to identify possible other non-legislative mechanisms in place in Member States dealing with genetic privacy and non-discrimination;

(b) To continue to consult with other United Nations agencies, extended to other relevant intergovernmental organizations, on the implementation of activities relevant to genetic privacy and non-discrimination.

9. At present, the UNESCO secretariat is engaged in ascertaining the views of Member States and expects to be able to report thereon in full in 2011.

## Conclusions

10. Owing to the relatively nascent nature of discussions on the subject of genetic privacy and non-discrimination, the Economic and Social Council may wish to: (a) postpone the consideration of the item on genetic privacy and non-discrimination to its substantive session of 2011 so as to benefit from further, more substantive information collected from Member States, from the results of analysis by the Inter-Agency Committee on Bioethics and from further exchanges among United Nations agencies and other intergovernmental organizations on this issue; (b) request the Director-General of UNESCO to report thereon to the Council at its substantive session of 2011; (c) encourage the Inter-Agency Committee on Bioethics to further its work in this field.