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*International Bioethics
Committee (IBC)*

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Preliminary Proposals for the Implementation of the International Declaration on Human Genetic Data

Article 25 of the International Declaration on Human Genetic Data states that “the International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IGBC) shall contribute to the implementation of this Declaration and the implementation of the principles set out therein”.

33 C/Resolution 23 “Implementation of the International Declaration on Human Genetic Data”, adopted by the General Conference of UNESCO at its 32nd session in October 2003, invites the Director-General “to take the necessary steps to enable UNESCO’s International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IGBC) to contribute appropriately to the implementation of the Declaration and dissemination of the principles set forth therein”.

An initial exchange of views between members of IBC was therefore held during a reserved session at the Eleventh Session of IBC (Paris, 23-24 August 2004). This document, which is not to be considered as definite, reflects the discussions held on this occasion and will constitute the basis for further reflection, enrichment and development.

Implementation of the International Declaration on Human Genetic Data

Introduction

The International Declaration on Human Genetic Data, adopted by the General Conference of UNESCO in 2003, sets forth the principles which must underlie the collection, processing, use and storage of human genetic data.

The Declaration recommends that States should take these principles into consideration in formulating their legislation and policies and in setting their measures for the collection, processing, use and storage of human genetic data.

Because of the significant acceleration in deriving human genetic data as a result of the continued scientific advances in genetics and biology, it is imperatively urgent that the Declaration be implemented.

The following are proposals for the implementation of the International Declaration on Human Genetic Data presented in tabular form under four headings, namely, “What to do?”, “How to do it?”, “By whom?” will the guidelines be implemented?” and “For whom?” are the guidelines intended?”.

These proposals are basically related to “key implementation articles” in the Declaration, namely, Article 24 (Education, Training and Dissemination), Article 11 (Genetic Counselling), Articles 6(b), 18, 19, 23(b) (International Cooperation) and Article 25 (Follow up).

N°	What to do?	How?	By Whom?	For Whom?
1.	Education concerning ethics and human rights issues associated with the collection, processing, use and storage of human genetic data	<p>1.1 Introduction of bioethics education material at secondary level</p> <p>1.2 Through e-learning, introduction of a course on bioethics education with special emphasis on genetic data</p> <p>1.3 Production of audiovisual material for the support of educational material on bioethics</p>	<ul style="list-style-type: none"> ➤ States (Relevant Ministries - Education, Health, Justice, etc.) ➤ Local Authorities ➤ UNESCO ➤ Competent intergovernmental and non-governmental organizations ➤ Distance Higher Education Institutions ➤ (Public and Private) Research Institutions ➤ States (Relevant Ministries in collaboration with national bioethics committees or similar bodies) ➤ UNESCO ➤ Competent intergovernmental and non-governmental organizations 	<ul style="list-style-type: none"> ▪ <i>Students and parents</i> ▪ <i>Patients and families</i> ▪ <i>Ethics committees and similar bodies</i> ▪ <i>NGO's concerned in bioethics</i> ▪ <i>General public</i>
2.	Training on the ethical aspects of the collection, processing, use and storage of human genetic data at appropriate levels	<p>2.1 Preparation and implementation of training programmes for teachers at both secondary and university levels</p> <p>2.2 Preparation and implementation of training programmes for relevant actors involved in the collection, processing, use and storage of human genetic data</p>	<ul style="list-style-type: none"> ➤ States (Relevant Ministries) ➤ (Public and private) Universities ➤ UNESCO ➤ Competent intergovernmental and non-governmental organizations ➤ States (Relevant Ministries) ➤ National Bioethics Committees ➤ Professional scientific and medical societies ➤ Local, regional and federal authorities ➤ UNESCO ➤ Competent intergovernmental and non-governmental organizations 	<ul style="list-style-type: none"> ▪ <i>Teachers at both secondary and university levels</i> ▪ <i>Public and private decision-makers</i> ▪ <i>Lawmakers</i> ▪ <i>Staff of relevant Ministries concerned with bioethics</i> ▪ <i>Administrative and clerical staff of forensic divisions.</i> ▪ <i>Relevant staff of Insurance Companies</i> ▪ <i>Staff of employment agencies (public and private)</i>

N°	What to do?	How?	By Whom?	For Whom?
3.	Dissemination of information on ethical aspects of the collection, processing, use and storage of human genetic data	<p>3.1 Publication of brochures disseminating the Declaration and / or highlighting the principles set forth in the Declaration</p> <p>3.2 Organization of awareness-raising programmes especially in developing countries</p> <p>3.3 Organization of lectures, seminars, panel discussions at international, regional and national levels</p> <p>3.4 Drafting of the simplest and most explicit commentary on key articles in each section of the Declaration</p> <p>3.5 Translation of the Declaration into a large number of languages</p>	<ul style="list-style-type: none"> ➤ UNESCO ➤ National Commissions for UNESCO (in collaboration with National Bioethics Committees) ➤ UNESCO ➤ National Commissions for UNESCO ➤ National Bioethics Committees ➤ Competent non-governmental organizations ➤ Media (Press, Radio, TV) ➤ UNESCO ➤ National Commissions for UNESCO ➤ National Bioethics Committees ➤ Relevant professional societies ➤ Competent non-governmental organizations (anti-discrimination organizations) ➤ UNESCO ➤ UNESCO ➤ National Commissions for UNESCO 	<ul style="list-style-type: none"> ▪ <i>General public with special emphasis on relevant practitioners in: Medicine, Research, Law, Insurance, Employment</i>
4.	Counselling concerning ethics and human rights issues associated with the collection, processing, use and storage of human genetic data	<p>4.1 Provision of proper professional genetic counselling on the significance and ethical implications of the collection, processing, use and storage of human genetic data</p> <p>4.2 Provision of genetic counselling for families or groups who may be affected by genetic testing of one of their members</p>	<ul style="list-style-type: none"> ➤ States (Relevant Ministries) ➤ Competent non-governmental organizations (i.e. concerned in defending patients' rights) ➤ Medical and scientific professionals ➤ Professionals (nurses, etc.) trained in genetic counselling or genetic analysis ➤ Specialized institutions 	<ul style="list-style-type: none"> ▪ <i>Patients</i> ▪ <i>Families</i> ▪ <i>Vulnerable groups</i>

N°	What to do?	How?	By Whom?	For Whom?
5.	International cooperation in the area of human genetic data	<p>5.1 Bilateral and multilateral agreements among States for benefit sharing and the international dissemination of scientific knowledge concerning human genetic data and human proteomic data, particularly between industrialized and developing countries</p> <p>5.2 Bilateral and multilateral agreements among relevant research institutions to foster the sharing of scientific knowledge resulting from human genetic data, including publication, in due course, of the results of their research</p> <p>5.3 Organization of international or regional workshops aimed at providing a standard framework of legislation and regulations for the collection, processing, use and storage of human genetic data</p>	<ul style="list-style-type: none"> ➤ States ➤ UNESCO ➤ Competent intergovernmental and non-governmental organizations ➤ (Public and private) research institutions ➤ UNESCO ➤ National Commissions for UNESCO 	<ul style="list-style-type: none"> ▪ <i>Scientists</i> ▪ <i>Researchers</i> ▪ <i>Professional in health services</i> ▪ <i>Students</i> ▪ <i>Patients</i>
6.	Follow-up of the Declaration	<p>6.1 Monitoring and evaluation of implementation on the commitment of States to provide periodic reports</p> <p>6.2 Quantitative and / or qualitative assessment of the impact of the Declaration in the areas of :</p> <ul style="list-style-type: none"> • Public debate • Public awareness • Professional Guidelines • National legislation <p>6.3 Formulation of opinions or proposals to further the effectiveness of the Declaration, addressed to General Conference</p>	<ul style="list-style-type: none"> ➤ States ➤ National Commissions for UNESCO ➤ UNESCO (IBC, IGBC) ➤ UNESCO (IBC, IGBC) ➤ National Commissions for UNESCO ➤ UNESCO (IBC, IGBC) ➤ National Commissions for UNESCO 	<ul style="list-style-type: none"> ▪ <i>International Community</i>