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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 report of the Director-General of the United Nations Educational, Scientific and Cultural Organization, submitted in response to Economic and Social Council decision 2010/259.

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* E/2011/100.

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

Summary

In its decisions 2008/233 and 2010/259, the Economic and Social Council decided to invite the Director-General of the United Nations Educational, Scientific and Cultural Organization (UNESCO) to consult with Member States and relevant United Nations entities, including the United Nations Inter-Agency Committee on Bioethics, on (1) the implementation of and follow-up to Economic and Social Council resolutions 2001/39 and 2004/9 on genetic privacy and non-discrimination, (2) the normative instruments adopted within the United Nations system that are relevant to this topic and (3) a possible inter-agency coordination mechanism in this field. The Director-General was requested to report on the results of these consultations to the Council at its substantive session of 2011.

In response to the Economic and Social Council resolutions, UNESCO has carried out a number of actions to assess the current situation at the national and international levels in the domain of genetic privacy and non-discrimination, and to identify the optimal mechanism for continuing international reflection in this area, based on consultations carried out with Member States, relevant United Nations agencies and other intergovernmental organizations.

Contents

I. Background

1. The Economic and Social Council considered the issue of genetic privacy and non-discrimination at its 2001, 2004, 2007 and 2008 sessions. Guided by the purposes and principles elaborated in the major international instruments in the field of human rights and bioethics, and responding to the rapid pace of scientific advancement in life and medical sciences that bear great promise for detecting, treating and preventing diseases, the Council considered the ethical and legal issues arising from the need to safeguard genetic privacy and fight discrimination based on genetic information in such fields as medicine, employment and insurance.

2. In 2001 and 2004, the Council adopted two substantive resolutions (2001/39 and 2004/9) in which it urged States to ensure that no person is subjected to discrimination based on genetic information. In these resolutions, together with a decision adopted at its 2007 session (2007/269) the Council requested the Secretary-General of the United Nations to consult Member States and relevant United Nations agencies on the implementation of the international instruments concerning this issue and to recommend the most appropriate forum for the consideration of the issue of genetic privacy and non-discrimination.

3. Based on a very low rate of response from Member States and United Nations agencies, the Council adopted decision 2008/233 of 22 July 2008, in which it decided to invite the Director-General of UNESCO:

(a) To consult with relevant United Nations entities on the implementation of and follow-up to Economic and Social Council resolutions 2001/39 and 2004/9, the Universal Declaration on the Human Genome and Human Rights, the International Declaration on Human Genetic Data, the Universal Declaration on Bioethics and Human Rights, and other norms and instruments adopted within the United Nations system that are relevant to genetic privacy and non-discrimination, as well as on a possible inter-agency coordination mechanism;

(b) To report to the Economic and Social Council on relevant developments in the field of genetic privacy and non-discrimination at its substantive session of 2010, and on a possible inter-agency coordination mechanism, in consultation with and taking into account the views of Member States.

4. Further on this issue, at its substantive session of 2010, the Council adopted decision 2010/259, by which it deferred its consideration of genetic privacy and non-discrimination until 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 United Nations Inter-Agency Committee on Bioethics and from further exchanges among United Nations agencies and other intergovernmental organizations on the issue.

II. Actions taken by UNESCO in response to the Economic and Social Council resolutions

5. As the agency designated to lead the necessary follow-up actions to the Economic and Social Council resolutions on genetic privacy and non-discrimination, and following the decision of the Director-General in this respect, UNESCO has launched two parallel consultation processes:

(a) Consultations with Member States on relevant developments in the field of genetic privacy and non-discrimination;

(b) Consultations with other United Nations agencies and international organizations/institutions engaged in this area, including the existing coordination mechanism — the Inter-Agency Committee on Bioethics.

6. The present report presents the results of these two consultations to inform further action by the Economic and Social Council in this area.

A. Consultation with Member States

7. UNESCO launched consultations with Member States through a questionnaire on existing legislative and institutional measures at the national level in the field of genetic privacy and non-discrimination. The aim of the questionnaire was to identify whether Member States have taken legislative measures to safeguard genetic information, either through specific legislation targeting this area or more general legal protection provided for other types of information that also cover genetic privacy and non-discrimination. The questionnaire also sought to identify non-legislative mechanisms that help Member States address the issue of genetic privacy and non-discrimination. Moreover, in response to the specific request contained in Economic and Social Council decision 2010/259, the questionnaire sought the views of the respondents on whether there was a need for an inter-agency coordination mechanism in this area.

8. Eighteen Member States responded to the questionnaire (4 responses from the Arab region; 6 from the Asia-Pacific region; 6 from Europe and North America; and 2 from Latin America and the Caribbean region). It is important to note that owing to the low response rate (9 per cent), the information collected from the questionnaires does not allow for a comprehensive understanding of the current situation, but can still provide valuable insights to enrich discussion through concrete examples provided by the respondents.

Existing specific and general legislation

9. The responses concerning the specific legislation in the area of genetic privacy and non-discrimination were divided into three categories — countries that have specific legislation (6), countries that do not (7) and countries that are in the process of enacting such legislation (5). The most frequently cited purpose of the existing and draft legislation is to protect individual data, to safeguard data concerning families, groups and communities, and to preclude third parties, such as employers and insurance companies, from accessing such information.

10. The majority of respondents reported having general legal provisions that cover genetic privacy and non-discrimination in the country (15 countries). Most often these provisions concern the protection of individual genetic data and limitation of access to this data by third parties, usually the employers and insurance industry. Some general legislation also protects genetic data of families, groups and communities.

11. Fourteen countries responded that there is indeed a need to develop specific legislation to address genetic privacy and non-discrimination within their borders. It was indicated that the specific legislation is needed in order to ensure privacy and

non-discrimination in the policies and practices concerning biobanking, management of electronic clinical files, forensic identification, biometrics and the sale of genetic tests over the counter.

Existing non-legislative mechanisms dealing with genetic privacy and non-discrimination

12. Apart from the laws and regulations in the area of genetic privacy and non-discrimination, there are also various institutional mechanisms that can be used to address the risks of potential misuse of genetic data for discrimination purposes. According to the responses from the Member States, the most common mechanisms are:

(a) Official appellate bodies, such as the High (Supreme) Court, the Office of the Human Rights Ombudsman, the National Commission for Human Rights;

(b) Universities, where subjects such as genetics, ethics, human rights and health law are part of medical school or law school curricula;

(c) National bioethics committees that issue opinions, recommendations and reports on issues involving genetic privacy and non-discrimination (9 countries reported having such committees, while 6 reported not having them);

(d) Medical associations that issue codes of conduct covering issues of genetic privacy and non-discrimination.

13. Some countries reported having specific non-legislative mechanisms that ensure or promote genetic privacy and non-discrimination, such as:

(a) The General Inspector of the Protection of Personal Data;

(b) Institutional review boards that review privacy issues concerning specific research projects from an ethical perspective;

(c) The Commission for Access and Use of the Human Genome of the Ministry of Health;

(d) The National Data Protection Authority.

Possible need for a coordination mechanism

14. Countries were divided in their opinion concerning the need to have a special inter-agency coordination mechanism devoted exclusively to genetic privacy and non-discrimination. Nine countries agreed with this need (2 from the Arab region; 3 from the Asia-Pacific region; 3 from Europe and North America; and 1 from Latin America and the Caribbean region), four considered it redundant and five were not in a position to answer the question. However, the analysis of the arguments provided in favour of a separate inter-agency mechanism reveals that the Member States are interested in having international initiatives in the area of genetic privacy and non-discrimination in order to strengthen their national capacities to address these issues, especially where no laws or mechanisms exist in this area. Accordingly, as clarified by some Member States, there is a need to have a coordinating mechanism with a capacity to carry out various functions, such as facilitating information exchange between the agencies concerned and fostering collaboration in designing international programmes or legislative initiatives in this area. This does not necessitate the creation of a new inter-agency coordination

mechanism per se since these functions fall squarely within the mandate of the Inter-Agency Committee on Bioethics.

B. Consultation with other United Nations agencies and international organizations and institutions

15. In parallel to the consultation process with Member States, UNESCO has launched consultations with the Inter-Agency Committee on Bioethics and with the relevant United Nations agencies and intergovernmental organizations on the issue of genetic privacy and non-discrimination. A specific questionnaire was designed to ask the members and associate members of the Committee, as well as other relevant intergovernmental organizations and institutions (see annex I) for information concerning international legal instruments or programmatic activities in the area of safeguarding genetic privacy and promoting non-discrimination on genetic bases. The questionnaire also asked if the organization had identified a need to develop specific initiatives to address genetic privacy and/or non-discrimination. Moreover, the respondents were asked whether they considered it necessary to have a separate inter-agency coordination mechanism dedicated exclusively to these issues.

16. Seven of 16 organizations consulted have responded to the enquiry. Two of the organizations responded that given the subject matter of the questionnaire, they were not in a position to make a substantive contribution. Five organizations (UNESCO, the World Health Organization (WHO), the European Commission, the Council of Europe and the Organization for Economic Cooperation and Development (OECD)) responded with substantial information concerning their engagement in the field of genetic privacy and non-discrimination.

United Nations Educational Scientific and Cultural Organization

17. Within its standard-setting action in the field of bioethics carried out by the Social and Human Sciences Sector, 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. In addition, the International Bioethics Committee of UNESCO has on several occasions focused specifically on these issues, for instance, in a report on confidentiality and genetic data (2000) and in the preliminary study on human genetic data: its collection, processing, storage and use. The Committee has also explored the issues of genetic privacy and non-discrimination in the framework of broader reflection in its reports on various principles elaborated in the standard-setting instruments, such as its report on consent.

18. Moreover, the UNESCO Natural Sciences Sector is collaborating with the Human Variome Project, a global consortium of institutions and researchers that collect, curate, organize and share human genetic variation data to encourage global collaborations and improve health services worldwide through translation of scientific research to meet societal needs.

19. UNESCO considers that inter-agency cooperation in the field of genetic privacy and non-discrimination is vital for enhanced effectiveness and efficiency,

and can take place in the framework of the existing forum provided by the Inter-Agency Committee on Bioethics.

World Health Organization

20. While WHO does not have international legal instruments covering the issues of genetic privacy and non-discrimination on genetic bases, it does have programmatic activities in the area, such as the Human Genetics Programme, and various analytical activities, as reflected by the numerous publications in this field. WHO has also identified good practices, effective guidelines and other tools used by the Member States in order to safeguard genetic privacy and promote non-discrimination.

21. WHO indicated that the Inter-Agency Committee on Bioethics could effectively carry out the coordinating functions for promoting genetic privacy and non-discrimination.

Council of Europe

22. The Council of Europe indicated a number of international instruments in the area of safeguarding genetic privacy and promoting non-discrimination on genetic bases, both existing and in progress. It has identified the need to develop an international instrument in these areas. Following the instructions of the Committee of Ministers in 1996, the Steering Committee on Bioethics drew up additional Protocols to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, concerning the problems relating to human genetics. It was decided that separate instruments were to be drafted, addressing, on the one hand, genetic testing for health purposes, and on the other hand, genetic testing for employment and insurance purposes. The first document was drafted and adopted in May 2008 as the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes. The Steering Committee on Bioethics is currently working on the elaboration of a legal instrument concerning genetic tests in the field of insurance.

23. The Council of Europe is also active in this field through cooperation activities. Concretely, to raise awareness about the principles contained in relevant legal instruments, it organized a seminar in Belgrade, on 1 and 2 July 2010, in the area of genetic privacy and non-discrimination on bioethical aspects of genetic studies in biomedicine. It has also identified the need to develop specific initiatives, such as easier access by the general public to objective information concerning genetic tests, in particular on the nature of these tests and the potential implication of their results. Access to this information is important to help protect the public against incomplete, inaccurate or, in some cases, deliberately misleading information presented by companies marketing such tests directly to consumers, in particular on the Internet.

24. Regarding the need for inter-agency coordination in this area, the Council of Europe indicated that the potential offered by the Inter-Agency Committee on Bioethics could be further developed where appropriate.

Organization for Economic Cooperation and Development

25. OECD has indicated a list of legal instruments that can be applied or are relevant to the regulation of the area of genetic privacy and non-discrimination. These include the Guidelines on the Protection of Privacy and Transborder Flows of Personal Data, the Guidelines for the Licensing of Genetic Inventions, the Guidelines for Quality Assurance in Molecular Genetic Testing and the Guidelines on Human Biobanks and Genetic Research Databases. Member countries of the organization report to the OECD Council on the dissemination and implementation of these instruments.

26. OECD did not indicate a need at present to have a special inter-agency coordination mechanism devoted exclusively to genetic privacy and non-discrimination.

European Commission

27. States members of the European Union are bound by the fundamental rights guaranteed under their national constitutions. Within the European Union, the fundamental rights to respect for private and family life as well as to the protection of personal data are laid down in articles 7 and 8 respectively of the European Union Charter of Fundamental Rights. In addition, under article 21 of that Charter, discrimination based on any ground, including "genetic features", is prohibited.

28. The European Commission has adopted a strategy to ensure that the Charter of Fundamental Rights — legally binding since the entry into force of the Treaty of Lisbon on 1 December 2009 — is effectively implemented.[1] It will verify that all European Union laws are in compliance with the Charter at each stage of the legislative process, from the early preparatory work in the Commission to the adoption of the draft laws by the European Parliament and the Council, and then in the application by the States members of the Union.

29. The main body of secondary legislation concerning the protection of personal data is contained in Directive 95/46/EC on data protection. However, genetic data is currently not mentioned explicitly as a sensitive category of data in this legal instrument. As a consequence, the Commission is considering, in the ongoing reform process of the Union's data protection legal framework, whether other categories of data should be considered as "sensitive data", in particular genetic data.[2] In that context, the Commission will pay specific attention to the resolutions, norms and instruments existing at the international level, as well as to documents and recommendations issued by the relevant expert bodies, such as the independent European Union Advisory Body on Data Protection and Privacy, and the European Group on Ethics in Science and New Technologies.

30. As to the need for a specific inter-agency coordination mechanism, the European Commission considers that it would be desirable to identify whether the existing infrastructure and experience which has been developed by the Inter-Agency Committee on Bioethics could also be used to coordinate activities regarding the issues of genetic privacy and non-discrimination on genetic bases.

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[1] See European Commission communication COM (2010) 573, entitled "Strategy for the effective implementation of the Charter of Fundamental Rights by the European Union".

[2] See European Union communication COM (2010) 609, entitled "A comprehensive approach on personal data protection in the European Union".

C. Discussion on genetic privacy and non-discrimination within the Inter-Agency Committee on Bioethics

31. The ninth meeting of the Inter-Agency Committee on Bioethics (Council of Europe, Strasbourg, France, 26 February 2010) was the first opportunity to initiate a brainstorming discussion on the follow-up to Economic and Social Council decision 2008/233 among relevant United Nations agencies and other intergovernmental organizations, and to explore possible future actions. The participants agreed to continue to reflect on that issue in the context of the Committee mandate.

32. The item on the "follow-up to Economic and Social Council decision 2010/259 on genetic privacy and non-discrimination" was included in the agenda of the tenth meeting of the Inter-Agency Committee on Bioethics (UNESCO headquarters, Paris, 4 and 5 March 2011) in order to present and discuss the responses received from the member States of UNESCO, the United Nations agencies and other intergovernmental organizations and institutions on that issue. The Committee also discussed its specific role in the area of genetic privacy and non-discrimination, as encouraged by the Economic and Social Council in its decision 2008/223.

33. The technical discussion involved experts from medical, academic and legal communities, as well as Committee members and associate members.[3] The invited experts enriched the debate by providing background information on the concepts of genetic privacy and non-discrimination on genetic bases, by highlighting the multiple dimensions of ethical issues arising from the recent scientific and technological developments in genetics, and by revealing the diversity of national and international initiatives designed to address those issues. The discussions pointed to the need to treat genetic data as a part of a larger domain of health information that should be accorded appropriate protection by legal or other means. It was noted that recent advancements in genetics and their practical applications in research and clinical settings had made it extremely difficult to guarantee full anonymity of data. That had led to a substantial change in the understanding of the concept and the practice of privacy. According to the experts, the primary focus of international and national public policy should be to avoid discrimination in all applicable social, institutional and clinical contexts by preventing the misuse of not only genetic information, but also all types of health-related information.

34. Some countries had taken steps to safeguard genetic data as a special type of information that needed stronger protection than that provided for other types of health information. That approach to genetics policy, known as genetic exceptionalism, called for special legal protections for genetic information as a result of its predictive, personal and familial nature and other unique characteristics. However, the presentations by the experts and the discussions that followed revealed that genetic data was not the only type of health information that could be used in order to discriminate against certain individuals or groups, making it desirable that all health information had equal protection under the law. Therefore, treating genetic

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[3] Professor Anne Cambon-Thomsen, Director of Research, Centre national de la recherche scientifique, Department of Epidemiology and Public Health, University of Toulouse, France; Professor Carlos María Romeo-Casabona, Inter-University Chair in Law and the Human Genome, University of Deusto and University of the Basque Country, Bilbao, Spain; Professor Aart Hendriks, Institute for Public Law, Leiden University Law School, the Netherlands.

information in the same way as other health information that had the potential of being misused to discriminate against individuals was a more favourable approach.

35. The debates highlighted informed consent as one of the key principles that related to the issue of genetic privacy. Many national genetic privacy laws restricted any or certain parties (such as insurers or employers) from carrying out a particular action without consent. Most laws made informed consent obligatory for a third party either to perform or request a genetic test or to obtain genetic information, as well as required consent for the disclosure of genetic information, in particular that which had a predictive power of any degree.

36. The discussion also served as an opportunity to consider the role of the Inter-Agency Committee on Bioethics, as encouraged by the Economic and Social Council in its decision 2008/223, in the area of genetic privacy and non-discrimination on genetic bases. The consultation carried out by UNESCO with its member States had revealed the need for more international initiatives in that area in order to strengthen national capacities to protect citizens from potential threats of misuse of genetic information and discriminatory practices. In order to respond to that need, there was a consensus among the participants at the meeting that the Committee could continue to carry out reflection on and observation of the developments in genetic sciences and their ethical implications.

37. Given the wide impact that the science and practice of genetics had in different domains covered by the members and associate members of the Inter-Agency Committee on Bioethics, the roles of each entity remained relevant in their specific fields of competence. Exchange of information and promotion of cooperation among the relevant organizations could be beneficial and the Committee could constitute a key forum to that end. Therefore, it was agreed that within the framework of its mandate, as defined in its terms of reference (in particular of providing a forum for debate and exchange of information, and promoting coordination of activities undertaken in that field by the United Nations and its specialized agencies), the Committee could continue to regularly address the issue of genetic privacy and non-discrimination, in order to identify areas where concerted or joint efforts would be beneficial and where major gaps and constraints affecting cooperation in the field could be addressed.

III. Conclusions

38. As the agency designated to lead the necessary follow-up actions to the Economic and Social Council resolutions on genetic privacy and non-discrimination, UNESCO has carried out a number of activities designed to assess the current situation regarding genetic privacy and discrimination, and to identify the optimal forum for continuing international reflection in this area. To this end, consultations were carried out targeting Member States and the relevant United Nations agencies and other intergovernmental organizations and institutions.

39. The consultations with Member States, conducted by means of a questionnaire, revealed that some countries have already put in place, or are in the process of elaborating, legislative and institutional measures to safeguard human rights from discrimination based on genetic information. Despite the low response rate, the data provided by the respondents does point to a diversity of existing legislative and institutional measures at the national level to safeguard human rights from potential

discrimination based on genetic information. The majority of countries responding to the questionnaire have also identified the need to develop specific legislation to address policies and practices concerning biobanking, management of electronic clinical files, forensic identification, biometrics and the sale of genetic tests over the counter. At the same time, countries have expressed the need to promote international initiatives in the area of genetic privacy and non-discrimination in order to strengthen national capacities to address these issues, as well as the need to coordinate international action in this area for enhanced effectiveness and efficiency.

40. The consultations with the relevant United Nations agencies and other intergovernmental entities were based on a questionnaire designed to solicit information concerning various normative and programmatic activities in this field. The collected information indicates that United Nations agencies (UNESCO and WHO), as well as other international and regional organizations and institutions (OECD, the Council of Europe and the European Union), have put in place, or are in the process of developing, a wide range of programmes and initiatives to safeguard human rights against discrimination on genetic bases.

41. Moreover, following the request of the Economic and Social Council, UNESCO invited the Inter-Agency Committee on Bioethics to enrich the discussion on the appropriate international response to the challenges arising from genetic science and its applications. To that end, genetic privacy and non-discrimination was included in the agenda of the tenth meeting of the Committee (UNESCO headquarters, 4 and 5 March 2011), which provided an opportunity to highlight the multiple dimensions of ethical issues ensuing from the recent scientific and technological developments in genetics. The discussions, involving the invited experts from medical, legal and academic fields, revealed the need to treat genetic data not as an exceptional area, but as a part of a larger domain of health information that should be accorded appropriate protection by legal or other means. Therefore, it was argued that the primary focus of international and national public policy should be to avoid discrimination in all applicable social, institutional and clinical contexts by preventing the misuse not only of genetic information, but also of all types of health-related information.

42. As the outcome of the discussion within the Inter-Agency Committee on Bioethics, the establishment of a specific mechanism dealing with genetic privacy and non-discrimination was not considered to be an optimal response to the wish of the Member States to promote international initiatives for strengthening national capacities in that area. It was a shared opinion that within the framework of its mandate, as defined in its terms of reference (in particular with regard to providing a forum for debate and exchange of information, and promoting coordination of activities undertaken in this field by the United Nations and its specialized agencies), the Committee could continue to regularly address the issue of genetic privacy and non-discrimination, in order to identify areas that called for concerted or joint efforts, as well as major gaps and constraints that needed to be addressed for enhanced cooperation in the field.

43. In light of the foregoing, the Economic and Social Council may wish to (a) recognize the diversity of existing initiatives undertaken by various organizations within and outside the United Nations system geared towards safeguarding human rights from the potential misuse of genetic information for

discriminatory purposes, (b) acknowledge the importance of promoting international cooperation for enhancing national capacities to address the ethical challenges arising from genetic science and its application, and (c) invite the Inter-Agency Committee on Bioethics to continue to regularly address the issue of genetic privacy and non-discrimination in order to identify areas calling for concerted or joint efforts, as well as major gaps and constraints that need to be addressed for enhanced cooperation in the field.

Annex I

List of entities addressed by UNESCO with the questionnaire on genetic privacy and non-discrimination

Members of the Inter-Agency Committee on Bioethics

Food and Agriculture Organization of the United Nations
International Labour Organization
United Nations High Commissioner for Human Rights
United Nations University
World Health Organization
World Intellectual Property Organization

Associate members of the Inter-Agency Committee on Bioethics

Organization of African Unity
Arab League Educational, Cultural and Scientific Organization
Council of Europe
European Commission
International Centre for Genetic Engineering and Biotechnology
Organization for Economic Cooperation and Development
World Trade Organization

Other agencies

United Nations Children Fund
United Nations Fund for Women (now UN-Women)
Joint United Nations Programme on HIV/AIDS

Annex II

List of existing standard-setting documents and publications on genetic privacy and non-discrimination on genetic bases

I. United Nations Educational, Scientific and Cultural Organization

Standard-setting instruments

Universal Declaration on Bioethics and Human Rights (2005)

Universal Declaration on the Human Genome and Human Rights (1997)

International Declaration on Human Genetic Data (2003)

Reports of the International Bioethics Committee

Report of the International Bioethics Committee on consent (2008)

Human genetic data: preliminary study by the International Bioethics Committee on its collection, processing, storage and use. Rapporteurs: Sylvia Rumball and Alexander McCall Smith (2002)

Report of the Working Group of the International Bioethics Committee on confidentiality and genetic data, report (2000)

Bioethics and human population genetics research. Chee Heng Leng, Laila El-Hamamsy, John Fleming, Norio Fujiki, Genoveva Keyeux, Bartha Maria Knoppers and Darryl Macer (1995)

Genetic counselling. Rapporteur: Michel Revel (1995)

Report on human gene therapy. Rapporteurs: Harold Edgar and Thomas Tursz (1994)

Report on genetic screening and testing. Rapporteur: David Shapiro (1994)

II. World Health Organization

WHO human genetics programme and ethical, legal and social implications report series

The ethical, legal and social implications of pharmacogenomics in developing countries. Report of an international group of experts (2007)

Medical genetic services in developing countries: the ethical, legal and social implications of genetic testing and screening (2006)

Genetics, genomics and the patenting of DNA: review of potential implications for health in developing countries (2005)

Review of ethical issues in medical genetics/Les problèmes éthiques rencontrés en génétique médicale (2003)

Report of the WHO Meeting on Collaboration in Medical Genetics (2002)

Statement of the WHO Expert Consultation on New Developments in Human Genetics (2000)

Report of the WHO Meeting on Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services (1998)

Statement of the WHO Expert Advisory Group on Ethical Issues in Medical Genetics (1998)

Articles on genetics and ethical, legal and social implications in the *Bulletin of the World Health Organization*

A collection of articles on human genetics and ethical, legal and social implications published in the last decade in the *Bulletin of the World Health Organization*, the International Journal of Public Health:

- DNA patenting: implications for public health research, vol. 84(5) 2006
- Genomics knowledge and equity: a global public goods perspective of the patent system, vol. 82(5) 2004
- Nations fail to agree on extent of human cloning ban, vol. 81(11) 2003
- Biomedicine and international human rights law: in search of a global consensus, vol. 80(12) 2002
- Our human genome — how can it serve us well? vol. 79(11) 2001
- The promise of stem cells, vol. 79(8) 2001

Other WHO publications dealing with the topic of genetic privacy and non-discrimination

- Genomics and world health: a report by the Advisory Committee on Health Research (2002)
- Report of the WHO meeting on current practices and controversies in assisted reproduction (2002)
- Ethical, legal and social issues of genetically modified disease vectors in public health (2003)
- Identifying regional priorities in the area of human genetics in the South-East Asia region (2003)
- Genetic databases: assessing the benefits and the impact on human and patient rights (2003)

III. Organization for Economic Cooperation and Development

- Guidelines for the Licensing of Genetic Inventions: www.oecd.org/sti/biotechnology/licensing
- Guidelines on Quality Assurance in Molecular Genetic Testing: www.oecd.org/sti/biotechnology/qualityassurance
- Guidelines on Human Biobanks and Genetic Research Databases: www.oecd.org/sti/biotechnology/hbgrd
- *Pharmacogenetics: Opportunities and Challenges for Health Innovation*

IV. European Commission

- Charter of Fundamental Rights of the European Union: article 8 on the fundamental right to the protection of personal data
- Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data
- Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, presentation, storage and distribution of human tissues and cells
- Directive 2002/98/EC of the European Parliament and of the Council of 27 January 2003 setting standards of quality and safety for the collection, testing, processing, storage and distribution of human blood and blood components and amending Directive 2001/83/EC
- Directive 2010/53/EU of the European Parliament and of the Council of 7 July 2010 on standards of quality and safety of human organs intended for transplantation

V. Council of Europe

- Convention on Human Rights and Biomedicine (ETS, No. 164, 1997)
- Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes (CETS, No. 203, 2008)
- Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (ETS, No. 108, 1981)
- Additional Protocol to the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data regarding supervisory authorities and transborder data flows (ETS, No. 181, 2001)
- Recommendation No. R (89) 2 on the protection of personal data used for employment purposes
- Recommendation No. R (97) 5 on the protection of medical data
- Recommendation No. R (99) 5 for the protection of privacy on the Internet
- Recommendation No. R (2002) 9 on the protection of personal data collected and processed for insurance purposes
- Recommendation Rec (2006) 4 on research on biological materials of human origin
- Recommendation CM/Rec (2010) 13 on the protection of individuals with regard to automatic processing of personal data in the context of profiling