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PROMOTION AND PROTECTION OF HUMAN RIGHTS

Human rights and bioethics

Report of the Secretary-General

Summary

At its fifty-ninth session, the Commission on Human Rights, in resolution 2003/69, invited the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the Office of the High Commissioner for Human Rights and the other United Nations bodies and specialized agencies concerned to report to the Secretary-General on the activities conducted in their respective areas to ensure that the principles set forth in the Universal Declaration on the Human Genome and Human Rights are taken into account. The Commission also invited Governments that had not yet done so to consider establishing independent, multidisciplinary and pluralist committees of ethics to assess the ethical, social and human questions raised by the biomedical research undergone by human beings and, in particular, research relating to the human genome and its applications. The Commission invited Governments to inform the Secretary-General of the establishment of any such bodies, with a view to promoting exchanges of experience between such institutions.

The Commission requested again that the Sub-Commission on the Promotion and Protection of Human Rights consider what contribution it could make to the reflections of the International Bioethics Committee on the follow-up to the Universal Declaration on the Human Genome and Human Rights. The Sub-Commission had appointed Ms. Iulia-Antoanella Motoc as Special Rapporteur to undertake a study on human rights and the human genome, based on her working paper (E/CN.4/Sub.2/2003/36) which was submitted to the Sub-Commission at its fifty-fifth session in August 2003. In 2004, the Sub-Commission, in decision 2004/112, requested the Special Rapporteur to submit to it an interim report at its fifty-seventh session and a final report to its fifty-eighth session.

The present report contains summaries of substantive information provided pursuant to resolution 2003/69 by the Governments of Azerbaijan, Croatia, Cuba, Cyprus, Germany, Greece, Lithuania, Mauritius, the Philippines, Qatar and the United States of America, as well as information on the activities of human rights bodies and the Office of the High Commissioner for Human Rights.

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Introduction

1. At its fifty-ninth session, the Commission on Human Rights, in its resolution 2003/69, took note of the report of the Secretary-General on human rights and bioethics (E/CN.4/2003/98 and Add.1) and invited the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), the Office of the High Commissioner for Human Rights (OHCHR) and the other United Nations bodies and specialized agencies concerned to report to the Secretary-General on the activities conducted in their respective areas to ensure that the principles set forth in the Universal Declaration on the Human Genome and Human Rights are taken into account.
2. In the same resolution, the Commission invited Governments that had not yet done so to consider establishing independent, multidisciplinary and pluralist committees of ethics to assess, notably in conjunction with the International Bioethics Committee of UNESCO, the ethical, social and human questions raised by the biomedical research undergone by human beings and, in particular, research relating to the human genome and its applications. The Commission also invited them to inform the Secretary-General of the establishment of any such bodies, with a view to promoting exchanges of experience between such institutions.
3. The Commission requested the Secretary-General to submit a report based on these contributions for consideration by the Commission at its sixty-first session. The present report is submitted to the Commission in accordance with the requests contained in resolution 2003/69.
4. By note verbale dated 28 July 2003, Member States were invited to report to the Secretary-General on activities conducted with regard to Commission resolution 2003/69. By communications dated 6 October 2004, the Secretary-General reminded Member States and the relevant United Nations bodies and specialized agencies to submit their contributions pursuant to that resolution to OHCHR by 1 November 2004.
5. By 29 November 2004, replies had been received from the Governments of Azerbaijan, Croatia, Cuba, Cyprus, Germany, Greece, Lithuania, Mauritius, the Philippines, Qatar and the United States of America. Information was also compiled on the activities of human rights bodies and OHCHR.

I. REPLIES FROM GOVERNMENTS

A. Azerbaijan

[29 October 2004]

[Original: Russian]

1. The Government of Azerbaijan reported that the Azerbaijan National Committee on Bioethics and Ethics of Science and Technology was established on 24 March 1999 by the Azerbaijan National Academy of Sciences with the support of the National Commission for UNESCO. The National Committee is a non-governmental research centre and operates with the status of a social non-governmental and non-administrative organization. The National Committee, together with the commissions attached to scientific and educational centres, performs educative and advisory functions. More specifically, it contributes to the resolution of ethical issues in the region, conducts studies addressing ethical issues within various fields of science, works to improve the content and methods of ethics education in the country, and, where necessary, provides assistance to the Republic's legislative bodies. Members of the National Committee and its commissions also communicate directly with the administration of any institutions which are alleged to have breached ethical standards.

2. The Government reported that the first Republic Conference of the National Committee was held in Baku on 28 and 29 June 2002. The topic of the conference was "Bioethics and ethics of scientific knowledge and technology". Members of the Committee have also participated in international and regional forums, including meetings of the UNESCO Intergovernmental Bioethics Committee and the International Bioethics Committee, and they took part in the International Conference on Bioethics in Central and Eastern Europe, which was held on 11 and 12 November 2002 in Vilnius.

B. Croatia

[28 October 2003]

[Original: English]

1. The Government of Croatia reported that in April 2001 it adopted a decision to set up a National Bioethics Committee for Medicine, with the aim of monitoring legal and ethical questions within the framework of the development and application of medical science; to make recommendations, offer opinions and draft reports regarding these questions; and to initiate new legislation and revise existing laws. The Committee, composed of 20 independent experts from the natural and social sciences, works within the Ministry of Health and holds six meetings a year. It is mandated to report to the Croatian Parliament once a year.

2. The Government also reported that the Croatian Parliament, in July 2003, ratified the European Convention on Human Rights and Biomedicine, as well as the Additional Protocol on the Prohibition of Cloning Human Beings and the Additional Protocol on Transplantation of Organs and Tissues of Human Origin.

C. Cuba

[27 October 2004]

[Original: Spanish]

1. The Government of Cuba emphasized that it attaches great importance to the efforts which have been undertaken within the framework of the United Nations system to promote a life sciences ethic, and in particular with the aim of the effective realization of the right of all individuals and peoples without distinction of any kind to access to the benefits of scientific and technological progress. The Government noted that it has on several occasions been a co-sponsor of the draft resolution of the Commission entitled "Human rights and bioethics".
2. The Government affirmed its belief that the realization of everyone's right to enjoy the benefits of scientific progress and its applications is a first priority under existing international human rights instruments. It drew attention to what it sees as the overprotection of intellectual property rights and the corresponding detrimental effect on access to the benefits of scientific progress for hundreds of millions of people with scarce economic resources, particularly in developing countries, and condemns corporations challenging before the courts efforts to improve access to such benefits. It condemns the blockade imposed by the Government of the United States of America which denies Cubans' access to major scientific developments, including health products. The Government of Cuba reported that new blockade measures approved 6 May 2004 by the Government of the United States of America increase, inter alia, restrictions on the granting of licences for educational travel and academic exchanges between Cuban and American citizens and institutions.
3. Bioethics committees have been set in Cuban scientific and health institutions, and the Government reported that staff in these sectors adhere to a strict code of ethics which reflects not only relevant resolutions of the United Nations General Assembly, WHO and UNESCO, but also the belief upheld by Cuba's national hero, José Martí, that "Homeland is humanity". The Government further noted that internationalist solidarity has inspired the work of health and other professionals who have provided their services abroad.
4. Acknowledging that scientific and technical progress opens up immense prospects for the improvement of human health, the Government also expressed concern about the potential for dual uses of science and the corresponding threat of terror based on military threats. The Government reported that it will promote and join in any possible international effort for ensuring cooperation in the peaceful use of science.
5. The Government recognizes the importance of the adoption of a legally binding and universal instrument that would contribute to averting the potential risks of cloning for purposes of reproduction, and it advocates the international community taking advantage of the broad consensus that exists with regard to the need to proscribe that practice, which it views as contrary to human dignity. It considers that cloning for therapeutic purposes could contribute to the enhancement of the quality of human life and health. Rather than a prohibition, cloning must be regulated so that research in this field in no case leads to the use of embryos for the creation of new human beings.

D. Cyprus

[1 November 2004]

[Original: English]

1. The Government of Cyprus reported that a multidisciplinary committee was established under the Bioethics Law of 2001 (Establishment and Operation of a National Bioethics Committee, L. 150(I)/2001). The Cyprus National Bioethics Committee (CNBC) is an independent body, not subject to the administrative control of any ministry, independent officer, department or service, and has jurisdiction and authority assigned to it through legislation. It is composed of 13 members, including the President. The members of the Committee are appointed by the Council of Ministers and are selected from a list of reputable and prestigious personalities. CNBC has the power and the competency to establish Research Ethics Committees (RECs) for the ethical review of biomedical research protocols on human beings (scientific and medical research) as well as RECs for the review of clinical trials on medicinal products.

E. Germany

[18 November 2004]

[Original: English]

1. The Government of Germany indicated that, as encouraged by the resolution “Human rights and bioethics”, it has established the National Ethics Council. It was inaugurated on 8 June 2001, providing an independent, multidisciplinary and pluralist national forum for dialogue on ethical issues. It is intended to be the central organ for interdisciplinary discourse between natural sciences, medicine, theology and philosophy, on the one hand, and social and legal sciences on the other.

2. The National Ethics Council currently has 25 members who represent the scientific, medical, theological, philosophical, social, legal, ecological and economic communities. It holds monthly meetings in Berlin. The Council is independent and is bound solely by the function laid down in the decree that established it. It determines its own work programme and procedures. It publishes opinions, recommendations and reports on a variety of topics. The members of the Council place particular importance on work with the public. The Council works together with other bodies concerned with ethics in Germany, and with comparable institutions of other States and of international organizations.

F. Greece

[5 November 2004]

[Original: English]

1. The Government of Greece reported that the National Bioethics Committee published recommendations on the collection and use of genetic data on 16 September 2002. The text underlines the importance of obtaining the free consent of the person concerned when using or processing his or her genetic data. Noting Economic and Social Council resolution 2001/39 on

genetic privacy and non-discrimination, more specifically its paragraph 3, the Government stated that the Committee has deemed the prevention of genetic discrimination a particularly important area of work, especially in the employment context. The Government indicated that the National Bioethics Committee's recommendations have recognized the need for specific legislation in this area.

2. The Government drew attention to paragraph 4 of the Council resolution which encourages the development and implementation of standards providing greater protection with regard to the collection, storage, disclosure and use of genetic information taken from genetic tests that might lead to discrimination or invasion of privacy. It was reported that the Committee sees a need for special legislation addressing "biobanks" which store personal and genetic information.

G. Lithuania

[17 November 2004]

[Original: English]

1. The Government of Lithuania reported that the Lithuanian Bioethics Committee (LBEC) was established at the end of 1995 as the body responsible for dealing with bioethics issues and facilitating the development of bioethics policy in the country. The Committee consists of 17 members, half representing the field of biomedicine and the rest from non-medical areas including law, ethics, philosophy, psychology and theology. The major area of the Committee's activity is the protection of patients' rights in the fields of biomedical research as well as the coordination of the ethical review of biomedical research protocols in Lithuania. As a consulting body, LBEC takes part in the development of health-care legislation where ethical issues are present. It also plays an important role in informing and educating the biomedical community and the general public about moral dilemmas arising in the context of new developments in modern biomedicine.

2. The Government reported that the Law on Ethics of Biomedical Research was adopted by Parliament in 2000 and came into force on 1 January 2001. The Law regulates the activities of the Lithuanian Bioethics Committee, regional biomedical research ethics committees, and also provides guidance on the application of principles protecting the rights and dignity of research subjects. The Government also reported that the Kaunas regional biomedical research ethics committee was established in 2002.

3. In 2002, Lithuania ratified the European Convention on Human Rights and Biomedicine, as well as its Additional Protocol on the Prohibition of Cloning Human Beings.

H. Mauritius

[16 November 2004]

[Original: English]

1. The Government of Mauritius reported that the Ministry of Health and Quality of Life has set up an Ethics Committee to assess the ethical, social and human questions raised by biomedical research involving human subjects. The Committee is directed to operate in

accordance with existing international guidance on bioethics so that it may provide adequate safeguards and protect the rights and welfare of individuals and vulnerable groups involved in biomedical research.

2. The Mauritius Research Council (MRC), established in 1992 to promote and coordinate the Government's investment in research, has also produced ethics guidelines for research involving human subjects. In March 2004, MRC organized a workshop to consider various ethical and regulatory issues related to research, focusing on areas relevant to Mauritius; provide an overview of existing guidelines; discuss recent changes to ethical guidelines and the associated implications; and consider possible measures to further implement these changes in Mauritius. At the time of writing, MRC was preparing a report which would address the role of various stakeholders engaged in research.

I. Philippines

[29 October 2004]

[Original: English]

1. The Government of the Philippines indicated that the National Ethics Committee (NEC) of the Philippine Council for Health Research and Development, Department of Science and Technology (DOST), concurs with resolution 2003/69, especially with regard to provisions addressing the importance of respect for human rights and the dignity of persons; the safeguarding of the human genome; the necessity of obtaining informed consent from individuals and tribes or communities before participation in medical or scientific experimentation; the need to protect privacy and ensure the confidentiality of genetic data; and the return of the benefits of research to participating individuals or communities.

2. The Government reported that a resolution on human genome research and human rights was prepared by the Scientific Core Group on Human Genome Research, led by the National Academy of Science and Technology (NAST), which is part of DOST. The resolution was further refined through a wide-ranging consultative process involving the scientific community, educators, legislators, representatives of religious groups and civil society. The resolution calls on the Government to develop, promote and support research on the human genome, taking into account the position of the Constitution of the Philippines on equal protection of the mother and the unborn from the moment of conception. The resolution was ratified by NAST in its annual general meeting on 10 July 2003, and endorsed by the National Research Council of the Philippines and the Philippine Council for Health Research and Development.

J. Qatar

[25 November 2004]

[Original: English]

1. The Government of Qatar reported that a committee in charge of ethics in medicine is presently operative in the country.

K. United States of America

[1 November 2004]
[Original: English]

1. The Government of the United States of America reported that the President's Council on Bioethics was established in 2001 to address the ethical and public policy questions arising from any advances in biomedical science and biotechnology. To date, the Council has issued several reports, dealing with matters such as human cloning, enhancement (including the uses of techniques and practices involving genetic screening, selection, and modification), stem cell research, and reproductive biotechnologies (including reproductive genetic biotechnologies). The President's Council on Bioethics has worked directly with the International Bioethics Committee of UNESCO, providing an overview of the Council's work in April 2004 and providing comments relating to the proposed Declaration on Universal Norms on Bioethics. The President's Council on Bioethics and its staff have also worked directly with bioethics committees of other States, as well as with the many independent, professional ethics committees within the United States.

II. INFORMATION ON THE ACTIVITIES OF HUMAN RIGHTS BODIES AND THE OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS

1. In resolution 2003/69, the Commission requested the Sub-Commission on the Promotion and Protection of Human Rights to consider what contribution it could make to the reflections of the International Bioethics Committee on the follow-up to the Universal Declaration on the Human Genome and Human Rights and to report on this matter to the Commission.

2. In its decision 2004/120, the Commission on Human Rights, taking note of Sub-Commission resolution 2003/4, approved the decision of the Sub-Commission to appoint Ms. Iulia-Antoanella Motoc as Special Rapporteur to undertake a study on human rights and the human genome, based on her working paper which was submitted to the Sub-Commission in August 2003 (E/CN.4/Sub.2/2003/36). The working paper set out to address some of the potential conflicts between health law, intellectual propriety and human rights regimes from a human rights perspective, taking into account four issues: the human genome - common heritage of mankind; human genetic manipulation and human rights; discrimination; and intellectual property and genetics. The Special Rapporteur was requested to submit her preliminary report to the Sub-Commission at its fifty-sixth session and her final report to the Commission at its current session.

3. The Sub-Commission received the preliminary report of the Special Rapporteur (E/CN.4/Sub.2/2004/38), which set out to consider the question of genetic discrimination in greater detail, addressing a number of issues including privacy, the use of genetic information in the context of employment and determinations of insurability, as well as special considerations related to vulnerable groups. In decision 2004/112, the Sub-Commission requested the Special Rapporteur to submit an interim report to the fifty-seventh session, and a final report to the fifty-eighth session.

4. In the course of preparing her interim report to the Sub-Commission, the Special Rapporteur has undertaken consultations with a range of relevant experts in the subject from United Nations specialized agencies and representatives of Governments responsible for bioethics and human rights. At the direction of the Sub-Commission and the Commission, this work has been carried out with the support of OHCHR and has included a mission to Paris where the Special Rapporteur consulted in November 2004 with representatives of UNESCO and interested Governments.

5. OHCHR contributed to the activities of the Inter-Agency Committee on Bioethics (IACB). The first meeting of IACB took place in March 2003 at UNESCO headquarters. OHCHR indicated at the meeting that its work on bioethics would be guided by the recommendations of the Expert Consultation on Human Rights and Biotechnology which met in January 2002 (see E/CN.4/2003/98, annex). Priority issues for OHCHR include: discrimination based on genetic characteristics (including consideration of possible new forms of discrimination which may arise from advances in genetic sciences); impact of biotech developments on gender and sex; benefit sharing and patenting of the human genome; and reproductive human cloning.

6. The second meeting of the IACB was hosted by WHO in November 2003 and focused on identifying areas for future collaboration amongst agencies. OHCHR reported on its areas of activity that could be of particular relevance to the Committee, including work carried out by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. On the issue of benefit sharing, OHCHR noted that the Special Rapporteur has addressed the relationship between international trade agreements and the right to health. In July 2003 he visited the World Trade Organization to discuss issues such as the impact of trade-related intellectual property rights on the enjoyment of the right to health (see E/CN.4/2004/49/Add.1). Similarly, the work of the Committee on Economic, Social and Cultural Rights (CESCR), will have a bearing on issues such as benefit sharing. Article 15 of the Covenant recognizes the right of everyone to enjoy the benefits of scientific progress and to benefit from the protection of the moral and material interests resulting from any scientific production for which he or she is the author. CESCR has provided guidance on the human rights principles that should be taken into account in the interpretation and implementation of intellectual property rights - including those that apply in the area of biotechnology - and will continue to work in this area. At its thirty-third session, CESCR began discussion on a draft general comment on article 15, and this discussion will continue at its thirty-fourth session in April 2005.

7. OHCHR also participated in the fourth meeting of IACB, hosted by UNESCO on 10 December 2004. Much of the meeting was devoted to the review of a draft declaration on bioethics and included an opportunity to work with the Drafting Group of the International Bioethics Committee. Comments made during the meeting indicated the need for a closer link in the draft declaration to human rights as entitlements of individuals.

III. CONCLUSIONS AND RECOMMENDATIONS

The Commission may wish to endorse Sub-Commission decision 2004/112 and request the Special Rapporteur to submit her final report to the Commission at its sixty-third session.
