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PROMOTION AND PROTECTION OF HUMAN RIGHTS

Human rights and bioethics

Report of the Secretary-General, submitted pursuant to Commission resolution 2001/71*

* This report is submitted late so as to include the most recent information.

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Executive summary

The Commission on Human Rights in its resolution 2001/71 invited the Secretary-General to submit a report to the General Assembly at its fifty-sixth session on human rights and bioethics. In his report (A/56/643) the Secretary-General recommended that responsibility for further action be allocated to the bodies or agencies that have already developed programmes of activities in this field. Therefore, he recommended that the United Nations Educational, Scientific and Cultural Organization and the World Health Organization, in cooperation with the Office of the High Commissioner for Human Rights (OHCHR), carry out further consultations with other United Nations bodies and specialized agencies on the best way to ensure effective cooperation and coordination of activities. Such consultations should consider, inter alia, the inter-agency committee proposed by UNESCO, the working group of independent experts, as suggested by the Commission on Human Rights, as well as the mandate of such bodies. The outcome of the consultations should be included in a report to the General Assembly at its fifty-seventh session.

In January 2002, the High Commissioner for Human Rights organized a consultation of high-level experts on human rights and bioethics to consider possible issues on which OHCHR might provide follow-up to the UNESCO Universal Declaration on the Human Genome and Human Rights, and to consider priorities in the work of OHCHR in the area of human rights and the human genomics aspect of biotechnology. The report of the Expert Consultation is annexed to the present report.

The report contains summaries of substantive information provided pursuant to resolution 2001/71 by Costa Rica, Cuba, Mexico, Poland and Venezuela.

With a view to submitting the most up-to-date information available, the secretariat has requested the relevant United Nations bodies and specialized agencies to submit any additional information they may wish to be made available to the Commission on Human Rights at its fifty-ninth session. The information received will be circulated as an addendum to this report.

Introduction

1. The Commission on Human Rights in its resolution 2001/71 invited the Secretary-General to submit a report on the basis of the contributions received from the relevant bodies to the General Assembly at its fifty-sixth session concerning the coordination of activities and thinking on bioethics throughout the United Nations system. In his report (A/56/643) the Secretary-General addressed the issue of coordination of activities on bioethics and the possibility of establishing a working group of independent experts from, among others, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization and the World Intellectual Property Organization (WIPO), which would reflect, in particular, on the possible follow-up to the Universal Declaration on the Human Genome and Human Rights (hereafter "the Declaration").

2. The Secretary-General recommended that responsibility for further action be allocated to the bodies or agencies that have already developed programmes of activities in this field. Therefore, he recommended that UNESCO and WHO, in cooperation with the Office of the High Commissioner (OHCHR), be requested to carry out further consultations with other United Nations bodies and the specialized agencies on the best way to ensure effective cooperation and coordination of activities and further reflection and follow-up on the implementation of the Declaration. Such consultations should consider, inter alia, the inter-agency committee proposed by UNESCO, the working group of independent experts, as suggested by the Commission on Human Rights, as well as the mandate of such bodies, and the outcome of the consultations should be included in a report to the General Assembly at its fifty-seventh session.

3. On 24 and 25 January 2002, the High Commissioner for Human Rights organized a consultation of high-level experts on human rights and bioethics to consider possible issues on which OHCHR might provide follow-up to the Declaration and to consider priorities in the work of the Office in the area of human rights and the human genomics aspect of biotechnology. In view of the importance of this consultation, the report of the Expert Consultation is annexed to the present report.

4. OHCHR has received responses to the request for information made by the Commission in resolution 2001/71 from the Governments of Costa Rica, Cuba, Mexico, Nicaragua, Poland and the United States of America. These are also reflected in the report. With a view to submitting the most up-to-date information available, the secretariat has requested the relevant agencies to submit by 28 February 2003 information they may wish to be made available to the Commission on Human Rights at its fifty-ninth session. The information received will be circulated as an addendum to this report.

I. SUMMARY OF INFORMATION RECEIVED FROM GOVERNMENTS

Costa Rica

5. The Government of Costa Rica submitted a very comprehensive report with information, inter alia, on historical developments in the field of bioethics, definitional issues related to bioethics and Costa Rican legislation on bioethics. The Government also reported on

developments at the regional level, notably the establishment of the Pan-American Institute of Bioethics in 1994. The Institute is based in Santiago. The work of the Institute has achieved significant results in the Latin American region as well as internationally.

6. Scientific research and experiments on human beings are regulated by Executive Decree No. 5463-SPBS, of 5 December 1975. It stipulates that any type of research which would create a risk or danger for human beings may only take place with explicit consent from the people involved. Article 6 of the Decree provides the details for obtaining the required consent. It also established scientific committees in charge of ethical control and supervision of scientific research projects.

7. Genetic manipulation and research on the genetic codes of foetuses are prohibited. This is clearly stated in Executive Decree No. 24029 of 3 February 1995 which regulates assisted reproductive techniques.

Cuba

8. The Government of Cuba referred to the importance of efforts made within the United Nations system to promote ethics in the life sciences and, in particular, the aim of the genuine realization of the right of all individuals and peoples, without discrimination of any kind, to enjoy the benefits of scientific and technological progress.

9. The Government highlighted the fact that Cuba was a sponsor of General Assembly resolution 53/152 which endorsed the Universal Declaration on the Human Genome and Human Rights, and expressed its support for any effort made towards the peaceful use of science and the international cooperation needed to guarantee it. Stating that the human genome is part of the common heritage of mankind, the Government also expressed support for open access for both the general public and specialist personnel in every country to knowledge relating to the human genome, and opposed any form of discrimination on the basis of knowledge relating to an individual's genetic code.

10. The Government of Cuba furthermore submitted that under the international human rights instruments in force, one of the main priorities is the realization of the right of everyone to enjoy the benefits of scientific progress and its application. On that basis, the Government regrets what it considers the adverse impact that the current international intellectual property system has on access to the benefits of scientific progress by hundreds of millions of persons, chiefly from developing countries. The Government of Cuba also condemns the actions of transnational corporations that have launched legal challenges against the efforts of certain developing countries to make the benefits of scientific-technical progress around the world accessible to their citizens, notably in the cases of access to medicines required by persons living with HIV/AIDS. Furthermore, the Government condemns the embargo policy imposed by the Government of the United States on Cuba, which the Government alleges deprives Cubans of access to scientific advances.

11. Cuban health personnel and scientific researchers follow a code of ethics based on values recognized by the relevant international organizations, but also based on the belief, upheld by Cuba's national hero, Jose Martí, that "Mankind is our country".

Mexico

12. The Government of Mexico explained that the right to the protection of health was incorporated into the Mexican Constitution in 1983. Since that time, various institutions have involved themselves in developing the subject.

13. Courses in bioethics and in bioethics and human rights are taught at a number of educational institutions at the tertiary level.

14. A National Bioethics Commission was established in Mexico in 1992 as an autonomous federal body of the Ministry of Health with the aim of studying and researching all aspects of the subject. The Commission makes recommendations on standards of ethical behaviour for professionals in medicine, the health services, and social and private bodies dealing with problems and dilemmas involving the health and dignity of individuals. Although its recommendations or resolutions are not binding, its technical value and scientific and moral weight give it great impact. Institutional Bioethics Committees have furthermore been set up to encourage adherence to the ethical and professional obligations of respect for life and human rights. The Commission functions on the basis of the Universal Declaration of Human Rights, the International Covenants on Human Rights and the Convention on the Rights of the Child. It is guided by:

(a) The need to promote biomedical progress for the most needy;

(b) The need to object to and oppose all discriminatory practices; and

(c) The importance of reinforcing the human right to health.

15. Mexico is a member of the International Bioethics Committee.

Poland

16. The Polish Constitution prohibits scientific experiments on humans, including medical experiments, without freely expressed consent. The Constitution also stipulates the right to privacy and the principle of confidentiality of data concerning the human person, with the exception of instances provided by law.

17. The Act concerning the profession of physician of 5 December 1996, is the primary regulation related to medical ethics in connection with progress in biology, medicine and biotechnology. The key provision of this act in relation to the Declaration is article 29, which stipulates that a medical experiment can only be conducted following approval of the project by an independent bioethics commission.

18. Polish law does not contain any specific regulations regarding experiments on the human genome, besides the general provision on conducting medical experiments. The act on genetically modified organisms of June 2001 does not refer to genetic modifications of the human genome.

19. A system of bioethics commissions has been established. Their clearance is required in order to conduct any biomedical/experimental research. The Minister of Health has established a Bioethical Appeals Commission, which considers appeals from the decisions of local bioethics commissions.

20. In April 2001, the Polish Senate submitted to the Sejm (the lower house of parliament) a draft act on the establishment of the National Bioethics Council. The Council is to be attached to the Office of the Prime Minister as a central advisory body on ethical, legal and social problems emerging in connection with progress in the biological and medical sciences.

Venezuela

21. According to the Government of Venezuela, the ideas expressed in resolution 2001/71 are compatible with the relevant provisions of the Venezuelan Constitution of 1999.

22. Although no national bioethics commission has been established in Venezuela, several national institutions have established bioethics commissions. Some of these commissions have started to develop studies on the issue of bioethics and human rights.

23. The National Council of Scientific and Technological Research established in 1999 a code on bioethics and biosafety which serves as a framework for all work taking place in Venezuela regarding bioethics.

24. In 2001, the Ministry of the Environment and Renewable Environmental Resources was contemplating the introduction of a by-law to the law on biodiversity regarding registration, control and monitoring of products containing and/or derived from genetically modified organisms. The by-law would also address the issue of the establishment of a national commission on biosafety.

Annex

REPORT OF THE EXPERT CONSULTATION ON HUMAN RIGHTS AND BIOTECHNOLOGY (Geneva, 24-25 January 2002)

Introduction

1. At the request of the High Commissioner for Human Rights, a group of experts on human rights and biotechnology met in Geneva on 24 and 25 January 2002. The terms of reference for the meeting were:

(a) In accordance with Commission resolution 2001/71, to consider possible issues on which the High Commissioner and the Office (OHCHR), might provide follow-up to the Universal Declaration on the Human Genome and Human Rights ("the Declaration") of the United Nations Educational, Scientific and Cultural Organization; and

(b) To consider more generally the issues and areas for action deserving priority in the work of the High Commissioner and OHCHR in the area of human rights and biotechnology (being limited to the issues relating to human genomics).

2. During the meeting the experts identified the following three broad areas in which issues of priority in respect of human rights and biotechnology arose:

Benefit-sharing and patenting of genetic material;

Discrimination;

Gender and sex.

A fourth issue, reproductive human cloning, was identified as a current priority in view of the decision of the General Assembly in resolution 56/93 of 12 December 2001 to establish an ad hoc committee "for the purpose of considering the elaboration of an international convention against the reproductive cloning of human beings" (para. 1).

I. SOME GENERAL POINTS ON THE DECLARATION, BIOTECHNOLOGY, HUMAN RIGHTS AND ETHICS

3. The Declaration is the principal text of the United Nations system in the area of human biotechnology and human rights. Together with the Guidelines for its implementation adopted in 1999, the Declaration sets out a framework for dealing with new human rights issues posed by advances in technology relating to the human genome. In doing so, it complements the ethical approach which has in the past been applied to medical and biotechnological dilemmas.

4. The experts discussed the complex relationship between ethical and human rights approaches, which share common foundations in respect for human dignity and belief in the inherent autonomy of the individual and in the integrity of each human being. While often

complementary, the norms created by ethics are not necessarily the same as human rights norms. Moreover, the application of ethical norms and of human rights to a given situation can produce very different results. Recognition and appreciation of these similarities and of differences between the two approaches are of great importance as nowhere more than in the field of biotechnology were the two approaches commonly applied simultaneously.

5. The concept of a human rights-based approach to issues of biotechnology studied by the experts underpins much of the present report. Such an approach involves (as its name suggests) the viewing of a particular issue from the perspective of the rights and obligations imposed by international human rights norms. A human rights-based approach is being applied to an increasing number of fields of endeavour as the full extent of human rights obligations is becoming clear (a good example is the emergence of a right-based approach to development programming). In casting relations between actors in terms of rights and obligations, a human rights-based approach:

(a) Places emphasis on *participation* of individuals in decision-making;

(b) Introduces *accountability* for actions and decisions, which can allow individuals to complain about decisions affecting them adversely;

(c) Seeks *non-discrimination* among individuals through the equal enjoyment of rights and obligations by all individuals;

(d) *Empowers* individuals by allowing them to use rights as leverage for action and legitimizing their "voice" in decision-making; and

(e) Links decision-making at every level to the *agreed human rights norms* at the international level as set out in the various human rights covenants and treaties.

A human rights-based approach to biotechnology thus looks at all the relevant human rights of all actors involved and, in the case of conflict, would seek to balance the various rights in order to maximize respect for all rights and right-holders.

6. The prominence of both ethical and human rights approaches to biotechnology is largely related to its subject matter, which is often the very basic components of human life. On such issues there are a number of competing views which are community-, religion- or culture-specific. On some matters, resolution of divergences or agreement amongst the competing views may well be impossible. In this regard, the experts noted the central role played by consensus-building before taking normative action. A balance must thus be struck between responding to the increasing pressures to act normatively in this area (particularly in response to market-driven pressures to exploit biotechnological techniques commercially) and the need to reach a consensus before so acting.

7. Human rights thus have a highly nuanced role to play in the area of biotechnology. A human rights approach will not provide all the solutions to the complex dilemmas now before the international community. It is, however, a crucial component in dealing with these dilemmas, and needs to be recognized as such. The experts considered that a large amount of work still

needed to be done in analysing advances in biotechnology from a human rights perspective. OHCHR was uniquely placed in terms of its mandate and expertise either to undertake or to coordinate this analysis. In doing so it should work in close collaboration with other selected specialized agencies of the United Nations.

8. The fast-moving nature of biotechnological developments has implications for both ethical and human rights approaches. This means that any formal steps taken to regulate the technology must be very carefully considered. Such regulation should avoid being technology specific, as far as possible, if it is to avoid being made redundant by new technological "breakthroughs". Conversely, and as far as is possible, efforts should not be wasted in regulating a technique which may eventually prove to be impossible or unfeasible in practice.

9. The increasing commercial, legal and social importance of biotechnological procedures suggests that they should be the concern of a number of international institutions. The experts, several of whom were members or past members of the International Bioethics Committee (IBC), recognize the lead role played by UNESCO in this area, particularly in relation to the scientific and ethical evaluations of developments. Similarly, the World Health Organization (WHO) plays a crucial role in translating the developments into the medical and public health fields. In addressing the priorities identified by the experts in this report, OHCHR would benefit greatly from close inter-agency cooperation with both UNESCO and WHO.

10. Biotechnology issues are moving more and more into the mandates of a number of other agencies and institutions. In particular, the experts identified the World Trade Organization (WTO), the World Intellectual Property Organization (WIPO), the United Nations Populations Fund (UNFPA), the Food and Agriculture Organization of the United Nations (FAO), and the United Nations Conference on Trade and Development (UNCTAD) as actors with which OHCHR should cooperate and seek new initiatives in the area of biotechnology.

II. REPRODUCTIVE HUMAN CLONING

11. Human cloning - for reproductive purposes in particular - is perhaps the area of biotechnology with the highest potential for controversy at the moment, as evidenced by the high level of attention in the media and of policy-making at the international and national levels. Recent developments in technology suggest that the reproductive cloning techniques, used somewhat successfully in relation to animals, might soon be applied to human beings. Were they to be successfully applied, a clone-child could be produced which would have a genetic make-up identical (or virtually identical) to that of another individual or embryo. The concerns these possible developments raise for the general public are understandable. Were individuals to be given a real power to create genetic copies of themselves or of others, fundamental issues concerning human dignity and identity would arise.

12. The experts agreed that a core concern in this area was that of *determinism*. While individuals have always employed a variety of techniques in an attempt to ensure certain qualities in their offspring, the current challenge for the international community is to decide how far individuals should be allowed to use biotechnology to determine traits of their children,

for example to secure resistance to certain diseases or the presence of certain physical features. Without adopting a deterministic point of view, the experts saw a need for actors, including the High Commissioner, to make a clear case for the benefits of diversity in humankind. This will be discussed further in relation to discrimination in section E below

13. As noted above, a human rights approach cannot by itself provide the answers to all of these questions. It can, however, ensure that the voices and interests of each interested actor are built into the debate and taken into account. This is particularly relevant in relation to women, children, and all those seeking to realize their right to health. Moreover, a rights-based approach protects the legitimate interests of those seeking to benefit from technological advancements. This has been widely recognized (for example, article 12 of the Declaration and article 15 of the International Covenant on Economic, Social and Cultural Rights (ICESCR)).

14. The birth of a cloned human being has not yet been achieved. The possible consequences of such a procedure are not entirely clear. There is, in the view of the experts, a general need for caution in considering a legal response. Premature attempts at prohibition and comprehensive regulation would have disadvantages that would be difficult to correct once an international convention was adopted. However, in the context of the United Nations, a momentum appears to have formed concerning the need for an international legal instrument dealing with reproductive human cloning. The General Assembly has decided to establish an ad hoc committee to "consider the elaboration of an international convention against the reproductive cloning of human beings" (resolution 56/93 of 12 December 2001). The experts noted with satisfaction that OHCHR participated as an observer in the meetings of this committee, and encouraged continued participation in the working group of the Sixth Committee which will carry on the work of the ad hoc committee.[a]

15. As a result of this development, the issue of reproductive human cloning should be accorded priority in the work of OHCHR. In doing so, the fundamental goal should be to ensure that the human rights aspects of the issue are identified and effectively introduced into the debate of the ad hoc committee and into the wider international and public debate. In particular:

(a) There is a need for a serious and detailed human rights analysis of the issues involved in reproductive human cloning to be undertaken;

(b) If a treaty ban is negotiated, extreme care should be taken in drafting the definition of the proscribed activity. The prime concerns in this respect are:

(i) That too broad a definition will result in the proscription of therapeutic techniques that appear to be essentially beneficial to humankind and are supportive of an individual's rights to health and life; and

(ii) That a definition which is in some way linked to current scientific techniques risks being unable to be applied to future, as yet unknown, techniques;

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[a] This report does not take into account substantive developments in the ad hoc committee since the meeting of the group of experts.

(c) If a treaty ban is negotiated, attention must also be focused on implementation and monitoring of the obligations parties assume under the treaty, so that no more is prohibited than can be effectively implemented. In this regard, the danger of driving the proscribed activity into unregulated environments must be addressed.

16. The experts considered that an effective way of overcoming many of the problems and shortcomings of a legal ban on cloning techniques identified above would be to focus the ban on an individual's *intention* to copy genetically another human being rather than on the technique itself. Action taken to clone an embryo with the intention of creating a copy of another person would thus be the focus of the ban.

III. BENEFIT-SHARING AND THE PATENTABILITY OF GENETIC MATERIAL

17. The experts considered the linked issues of the ability to patent genetic material and the sharing of benefits deriving from commercial exploitation of that material to be the most important issues in the area of human rights and biotechnology at this time.

18. The urgency and importance of these issues are related to the growing commercial exploitation of genetic techniques and the increasing commodification of genetic material. In broad terms, six developments have led the experts to this situation:

(a) First, the "discovery" of the large commercial value of genetic techniques and material and the intense pressure to exploit this value;

(b) Second, this has been accompanied by a similar realization that while much of the richest genetic diversity exists in developing countries, genetic research in endogamous communities would provide clues about a population's genetic predisposition/resistance to certain diseases;

(c) Third, and regardless of this rich genetic diversity, the costs associated with harvesting or surveying genetic material in developing countries are far less than in developed countries. This is particularly relevant in respect of genotyped clinical trials (pharmacogenomics) involving the study of behaviour responses and sensitivity to drugs;

(d) The fourth development is the contemporaneous global and regional liberalization of trade in goods and services, which facilitates the international trade in genetic materials and in services for clinical trials;

(e) The last is the use of patents and other instruments to claim intellectual property in respect of human genetic and genomic material, and the global standardization of intellectual property protection regimes in the form of the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS), negotiated in the context of WTO.

19. These broad developments have fostered market and regulatory systems which allow:

(a) Genetic material to be removed from individuals, particularly in developing countries, and exported for commercial exploitation with little or no immediate benefit to the individual or society;

(b) Little or no immediate benefit to those who participate in surveys of genetic characteristics in order to develop genetic products;

(c) Benefits from commercial exploitation of an individual's genetic and genomic material to accrue solely to a patent-holder; and

(d) A concentration of biotechnological knowledge in developed countries and a focus of research on the medical concerns of developed countries.

20. These developments have raised the broad question of how the common genetic heritage of humanity should be used, and for whose benefit. In human rights terms, a number of specific and serious issues arise, including:

(a) The right to privacy, in particular:

(i) The question of prior informed consent to scientific experiments, surveys and the removal of genetic material; and

(ii) The use of an individual's genetic information;

(b) The right to health, including States' obligations to:

(i) Recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (ICESCR, art. 12);

(ii) Respect and promote the practice of solidarity towards individuals, families and population groups who are particularly vulnerable to or affected by disease or disability of a genetic character (Declaration, art. 17); and

(iii) Ensure that the applications of research, including applications in biology, genetics and medicine concerning the human genome, seek to offer relief from suffering and improve the health of individuals and humankind as a whole (Declaration art. 1 (b));

(c) Respect for the rights of indigenous peoples, particularly relating to the human body and use of resources;

(d) The rights of individuals to benefit from scientific progress and its applications (ICESCR, art. 15);

(e) Rights to property, including intellectual property; and

(f) The obligations of States to share scientific knowledge (ICESCR, art. 15, Declaration, arts. 12 (a), 18 and 19).

21. While noting the importance of intellectual property rights in today's society, the experts noted the serious concerns raised regarding the appropriateness of applying patent laws to genetic material and the human genome, particularly in terms of the requirements of novelty and inventiveness. In this respect, the experts noted the recent Draft Report on the Follow-up of the International Symposium on "Ethics, Intellectual Property and Genomics" published by the IBC in August 2001 (SHS-501/01/CIB-8/2) and the recommendations made therein relating to the patentability of genetic material. As part of the follow-up to the Declaration, the experts suggested that the High Commissioner might consider convening a meeting of experts from the various relevant agencies to consider the relationship between human rights and the developing international law of patents.

22. The experts noted that, from a human rights perspective, the enormous benefits promised by biotechnology must not be restricted to one group or society. The sharing of these benefits involves not only compensation for the contribution of genetic materials, but also the facilitation of technology transfers between developed and developing countries (Declaration, art. 19). The growing trend of biotechnological research being largely restricted to developed countries risks the development of a "genetic divide" between these societies. A priority for the work of the High Commissioner should be a study of the various options to facilitate benefit-sharing in this area, both in terms of compensation and in terms of technology transfer. In regard to the former, the examples from a number of developed countries of National Genetic Reserves could be studied as possible models for preserving the genetic assets of developing countries.

IV. DISCRIMINATION

23. *Relevance of the genome to discrimination.* The recent advances in genetic and genomic science (particularly the mapping of the human genome) have allowed a new appreciation of the fundamental similarities and limited differences between individuals and between peoples. These developments may impact on the principle of non-discrimination in both positive and negative ways. The experts considered the area of discrimination and biotechnology to be of priority for the work of the High Commissioner and OHCHR.

24. In terms of positive developments, the current mapping of common variations in human DNA called single nucleotide polymorphisms (SNP maps) reveals a 99.9 per cent genetic similarity between all human beings. As such, it provides a powerful symbolic tool in the fight against many forms of discrimination. However, in many instances (notably relating to race, sex and other immutable characteristics of human beings), discriminatory behaviour often exhibits a social pathology based more on perceptions than on measurable differences between individuals. There is a clear danger then that the scientific "proof" of a shared genetic makeup could be used to downplay the extent of real discrimination in our societies and thereby to undermine efforts to

combat it. Already some actors have used the results of the mapping of the genome to deny the continued relevance of the concept of race in the struggle against discrimination. By ignoring the essentially prejudicial nature of discrimination, this approach threatens the significant advances in fighting discrimination made to date.

25. The same scientific advances raise a multitude of new bases for illegitimate discrimination between individuals. The experts expressed a specific concern in two respects:

(a) The real possibility that an individual's existing genetic characteristics can be used as a basis for discrimination. This is of particular concern in relation to discrimination in employment and discrimination in the provision of insurance. An example would be the discovery by an employer that an employee has a genetic disposition to a certain disease which might be relevant to the employee's capacity to carry out his or her duties. Were the employer to terminate the employment based on this information, a clear question of discrimination would arise; and

(b) The possibilities of genetic manipulation might eventually allow allegedly "undesirable" genetic traits to be progressively eliminated. This gives rise to concern about which genetic traits are so "undesirable" that their elimination should be encouraged or allowed. Additionally, the likely high cost of these procedures suggests that, initially at least, only those with sufficient resources may benefit from these procedures.

26. Discrimination based on genetic characteristics is expressly prohibited by article 6 of the Declaration. The experts noted that a number of States have legislated or are in the process of legislating against forms of genetic discrimination.

27. *Discrimination in employment and insurance.* The experts noted the central role of both employment and insurance to the individual's ability to function as a citizen in modern society. These roles have been recognized in human rights terms (ICESCR, arts. 6 and 9). Genetic information will become increasingly important in the assessment of both suitability for employment and risk for insurance coverage. While the exercise of an individual's right to health should in no way be limited by her or his genetic characteristics, in the sphere of employment and general insurance (including life assurance), genetic characteristics may sometimes be legitimately used to discriminate between individuals in relation to the availability and, if available, the costs of insurance. In this case, a human rights approach demands that the employer must demonstrate a legitimate occupational requirement and the insurer a clear increase in probability and risk of a claim justifying a refusal to insure or a higher premium. Regulation in this area is thus desirable for at least three reasons:

(a) To prevent the application of genetic screening by State or non-State actors for illegitimate reasons or without the prior informed consent and pre-/post-test counselling of the person concerned;

(b) To avoid discrimination based on perceptions rather than empirical data and rigorous risk assessment; and

(c) To avoid a situation in which individuals desist from submitting to genetic testing for fear that adverse results will be placed on their medical records and used as a basis of discriminating against them in the future, or that results might be misconstrued and used as a basis for discrimination. The experts noted that the experience with HIV/AIDS was instructive in this regard.

28. The experts agreed that in following up the Declaration, the High Commissioner should accord priority to:

(a) A study of the new forms of discrimination that may arise from advances in genetic science; and

(b) Raising, together with the Secretary-General, the issue of genetic discrimination in employment and insurance coverage in the context of the Secretary-General's Global Compact initiative.

29. A key aspect of genetic discrimination in employment and insurance is the storage and protection of genetic data, in particular the gradual accumulation of information on an individual's medical record which could in the future be used in a discriminatory way at present unforeseen. This situation is exacerbated by the significant advances in information technology which have occurred over the same period as those in biotechnology. In this regard the experts noted the proposal of the Director-General of UNESCO that an international instrument be drafted setting out principles under which genetic data should be handled. In particular, they noted the Draft Report on Collection, Treatment, Storage and Use of Genetic Data (September 2001) of the Working Group on Genetic Data of the IBC which identified 19 guidelines for the application of human rights norms in this area (SHS-503/1/CIB-8/3, paras. 29-46), including: the acceptability of the purpose for which genetic data are collected; transparency of the purpose; limitation of use; informed consent; confidentiality/anonymity; sharing of information; and use of historical or archived collections.

30. The experts felt that priority should be placed on promoting increased security of genetic data in order (a) to limit the risks of illegitimate discrimination; and (b) to encourage individuals to undergo genetic tests without fear that the information might be used to discriminate against them. The High Commissioner is uniquely placed to make suggestions for improving security of genetic data from a rights-based perspective. To this end, the experts identified involvement in the proposed UNESCO text on genetic data as a priority in the work of the High Commissioner.

31. *Genetic manipulation and discrimination.* The issue of genetic manipulation is a very broad area presenting many human rights issues. The focus of the experts' discussion was the discrimination aspects of the procedure. As the scientific procedures are not yet established, the experts suggested that the High Commissioner should closely follow developments from a human rights perspective. Priority should be accorded to activities promoting the values of difference and diversity in humankind, as recognized in the Declaration, especially articles 1 and 2.

V. GENDER AND SEX

32. Many if not most of the biotechnological techniques discussed by the experts touch on the process of human reproduction. The ability to reproduce is fundamentally important to most women and men in most societies. The possibilities and challenges which biotechnology pose in the area of reproduction are addressed to women and men. While males may be subjected to discrimination on the basis of such dominant sex-associated genetic traits as those defining haemophilia, the experts agreed that the position of women deserves special attention. Three areas of priority were identified in this respect:

(a) *Discrimination.* Women are more likely to suffer discrimination, be it linked to their reproductive role and social attitudes that sometimes unjustifiably accompany it, or in pursuing their reproductive rights. The experts considered it crucial to distinguish between issues relating to gender (a social construction) and those relating to sex (biological differences). While gender is more operative in some issues (such as, for example, participation), the scientific basis of biotechnological developments equally raises the issue of sex. While it should be stressed that discrimination based on genetic characteristics linked to an individual's sex can equally affect men and women, much of the discrimination against women in the area of biotechnology is related to their biological difference from men. In particular, concerns have been raised regarding the use of genetic testing to avoid the birth of female babies;

(b) *Benefiting from technology*. The increasing number of choices relating to reproduction and the health of a future child are not matched by the support necessary to enable women to take advantage of many of the new options, whether for financial or other reasons. Biotechnological advances have increased (and promise to continue increasing) the options available to women and men to reproduce and to produce healthy children. These options are particularly important to women who have no opportunity to reproduce sexually or those with certain genetic traits that they desire to avoid passing on to their offspring. The rights of these women to equitable access to science and to reproduce must be highlighted in the debates on new techniques by reference to all relevant human rights norms;

(c) *Participation.* While both women and men have an equal interest in the future use of technologies linked to reproduction, the reality of women's participation in decision-making and debates on these issues often demonstrates an inequality. The experts underlined the crucial role of equal participation in decision-making, from the design of a clinical trial of new biotechnological techniques to the broader level of debate on the significance of biotechnological developments such as is occurring today in the United Nations and elsewhere. A priority for the High Commissioner's work should be to consider the extent to which women participate in these debates and decisions, and the means for ensuring their effective participation.
