

SECOND INTERNATIONAL SUMMIT OF NATIONAL BIOETHICS

ADVISORY COMMISSIONS

TOKYO, JAPAN 3 NOVEMBER 1998

THE UNIVERSAL DECLARATION ON THE HUMAN GENOME -

*A VITAL UNESCO INITIATIVE**

The Hon Justice Michael Kirby AC CMG

* The paper "Bioethics and Human Rights: The Role of UNESCO" sets out the contribution of UNESCO (Division of the Ethics of Science and Technology) to the Summit. The within Paper represents an additional, personal reflection of the author based upon his experience as a member of the UNESCO International Bioethics Committee.

SECOND INTERNATIONAL SUMMIT OF NATIONAL BIOETHICS

ADVISORY COMMISSIONS

TOKYO, JAPAN 3 NOVEMBER 1998

THE UNIVERSAL DECLARATION ON THE HUMAN GENOME -

A VITAL UNESCO INITIATIVE

The Hon Justice Michael Kirby AC CMG*

THE FIFTIETH ANNIVERSARY

This meeting convenes on the eve of the fiftieth anniversary of the adoption, by the General Assembly of the United Nations, of the *Universal Declaration of Human Rights*¹. That *Declaration* has been described as the catalogue of fundamental rights "for six billion

* Justice of the High Court of Australia. Member of the International Bioethics Committee of UNESCO. Formerly Special Representative of the Secretary-General for Human Rights in Cambodia, member of the WHO Global Commission on AIDS and President of the International Commission of Jurists.

¹ A Cassese, *Human Rights in a Changing World* (London, 1990); M Lippman, "Human Rights Revisited: The Protection of Human Rights under the *International Covenant on Civil and Political Rights*" (1980) 10 *California Western International Law Journal* 450.

persons"². Its influence has been enormous. Recent writings have demonstrated, contrary to uninformed suggestions, that in the preparation of the *Universal Declaration*, many delegates from developing countries in what we now call the Third World, reflecting the variety of human religious and ethical experience, played a vital part in framing its terms³. A moment's reflection on the tremendous growth of the global movement for the protection of fundamental human rights and freedoms, will teach the abiding influence of that *Universal Declaration*. By seizing a critical moment in human history, by articulating deep-felt and universal principles and by effective follow-up in promoting and building national, regional and international institutions to convert its noble language into practical effect, the United Nations played a vital role of leadership, example and inspiration. At a time of uncertainty and cynicism, we do well to remember that initiative.

Elucidation of the content of human rights is a never-ending journey. Each new generation discovers from its own experiences new meanings to the principles already stated and new problems

² S P Marks, "From the 'Single Confused Page' to the Decalogue for Six Billion Persons': The Roots of the *Universal Declaration of Human Rights*" in the Present Resolution (1998) 20 *Human Rights Quarterly* 459.

³ B Ramcharan, "The Universality of Human Rights" (1994) 53 *ICJ The Review* at 105.

requiring the adoption of new principles. Within the United Nations, UNESCO⁴ continues to play a vital function in this regard.

Some of the most profound challenges to human rights arise from science and technology only recently developed, or still unknown, in 1948 when the *Universal Declaration of Human Rights* was adopted. Science and technology, as well as bringing enormous benefits to humanity, present significant puzzles and challenges to humanity which engage UNESCO's vigilant attention. I suppose that the greatest technological developments of the past fifty years include those in the areas of nuclear fission, informatics and human biology and genetics. UNESCO is not only concerned with the scientific, social, educational and cultural implications of such developments. In accordance with its mission, it is deeply involved in the elucidation of the ethics of such endeavours.

In 1998, the Director-General of UNESCO (Professor Federico Mayor) set up the World Commission on the Ethics of Scientific Knowledge and Technology⁵. But before this, in 1993, the

⁴ United Nations Educational, Scientific and Cultural Organisation. UNESCO has published many accessible documents on genomic ethical issues. See eg UNESCO *Courier*, "Progress, risk and responsibility" (May 1998 issue).

⁵ Established by UNESCO 29C/Resolution 13. See announcement UNESCO DG/note/98/20/rev (3 April 1998).

International Bioethics Committee (IBC) of UNESCO was created with a mission that includes the drawing up of normative instruments bearing on the protection of human rights with regard to issues raised by genetics and biology. The IBC has so far held four sessions. A fifth session is scheduled to take place in the Hague, the Netherlands, from 2-4 December 1998.

The deliberations of the IBC have not been confined to issues concerning human rights and the human genome. Thus, at its fourth session, the members of the IBC explored several topics, including ethics in food and plant biotechnology, the protection of human rights in the context of experimental treatment of human beings and the special issues presented to bioethics by concerns particular to women⁶. However, the IBC has given much of its attention since its establishment to the human rights implications of the discovery, mapping and development of the human genome. Under the inaugural presidency of Madame Noelle Lenoir (a member of the Constitutional Council of France) and well-served by its secretariat headed by Mr Georges Kutukdjian, IBC drew up a draft *Universal Declaration on the Human Genome and Human Rights*. This draft instrument was considered and adopted with certain modifications by a committee of governmental experts convened by UNESCO in

⁶ International Bioethics Committee of UNESCO, *Proceedings of the Fourth Session* (October 1996) Vol II (UNESCO, Paris).

July 1997. The recommendations were conveyed to the General Conference of UNESCO⁷ in November 1997.

On 11 November, the General Conference unanimously and by acclamation adopted this second *Universal Declaration*, together with a resolution for its implementation⁸. I have come to this meeting in Tokyo, by the decision of the Director-General of UNESCO, because of the high importance which he and UNESCO attach to your work and because of the hope which UNESCO expresses that the new *Universal Declaration* will be useful to your deliberations in this area vital for the future of human rights.

Faced by scientific developments of such complexity and importance as that presented by the Human Genome Project (with all of its diversity and many ramifications) it would be easy to despair and to allow the chariot of unbridled science to take humanity where it will. But, neither in the field of nuclear fission nor informatics nor human biology and genetics, is that a path which humanity can contemplate. Complex and difficult although the tasks are, it is essential that human beings remain in charge of the ethical concerns and play a part in charting the rules by which science and

⁷ 29th Session, Paris, 1997.

⁸ 29C/Resolution 17.

technology go forward. By taking its initiative, and propounding its new *Universal Declaration*, UNESCO seeks to provide assistance, to offer a framework within which national regimes can be developed, to emphasise the essential unity of the interest of our species in this topic and to avoid the development of sharply inconsistent regimes and approaches or, worse still, abandonment of the topic altogether as too difficult or impossible to bring under a human ethical discipline.

UNESCO's aim in offering the *Universal Declaration on Human Rights and the Human Genome* is nothing if not bold. Yet if one is contemplating the new challenges to human rights in the coming generation, there can be none which are more important and more urgent than those which relate to human biology and genetics. For these will define who are the "humans" of the coming millennium to whom human rights belong.

THE CORE IDEA: HUMAN DIGNITY

It is not possible in the allocated time for me to detail the many provisions of UNESCO's *Universal Declaration*. I will annex a copy of the new *Universal Declaration* to my printed paper.

- The first part of the *Universal Declaration* propounds the core values of dignity and diversity in the human species - ideas which run through the entire text. The starting point is that "everyone has a right to respect for their dignity and for their

rights regardless of their genetic characteristics⁹. No one is to be reduced merely to their genetic characteristics¹⁰. Mutations in the genome are natural¹¹. In its natural state, the genome is not to give rise to financial gains¹².

- The second part of the *Universal Declaration* specifies a number of rights of the individual. These include the rule that research, treatment or diagnosis affecting an individual's genome shall be taken only after assessment of risks and benefits¹³ and with the prior free and informed consent of persons concerned¹⁴. This includes the right of each individual to decide whether or not to be informed of genetic outcomes¹⁵. There is a general prohibition on discrimination based on genetic characteristics¹⁶. Any limitations on the principles of consent and confidentiality are strictly confined¹⁷.

⁹ Art 2(a).

¹⁰ Art 2(b).

¹¹ Art 3.

¹² Art 4.

¹³ Art 5(a).

¹⁴ Art 5(b).

¹⁵ Art 5(c).

¹⁶ Art 6.

¹⁷ Art 9.

- The third section lays down rules governing research on the human genome. No research or its applications may prevail over respect for human rights, fundamental freedoms and human dignity¹⁸. The benefits of advances should be made available to all¹⁹. Practises which are contrary to human dignity "shall as reproductive cloning of human beings, shall not be permitted"²⁰. It is to be noted that this last prohibition, which has engaged the specific attention of the UNESCO Director-General²¹ is addressed to the "deliberate reproduction of an identical human being" and is not necessarily addressed, as such, to more basic experiments with cloned material²².

¹⁸ Art 10.

¹⁹ Art 12.

²⁰ Art 11.

²¹ See F Mayor, Presentation by the Director-General of UNESCO, Human Cloning (June 1998) (UNESCO).

²² For a recent discussion which concludes with categorical opposition to cloning of human beings see the Report of the Union for Europe Group of the Members of the European Parliament, *Report on Cloning*, 1998. A slightly differing view is expressed by Professor M Revel, member of the IBC, in *The Scientist*, Vol 12, No 2 (January 19, 1998) at 1: "An Outright, Upfront Condemnation of Cloning Research is Premature".

- The fourth part of the *Universal Declaration* lays down conditions for the exercise of scientific activity. It imposes on States obligations to foster freedom of research but also to consider ethical, legal, social and economic implications of such research²³. I am sure that you will support that provision of the *Universal Declaration* which provides that States should recognise the value of promoting the establishment of independent, multi-disciplinary and pluralistic ethics committees to assess the ethical, legal and social issues raised by research on the human genome and its application²⁴.

- The fifth section of the Declaration, also addressed to States and to the international community, contains provisions for upholding human solidarity in this matter of universal concern to our species and international cooperation to ensure, amongst other things, that developing countries benefit from, and are not merely the object of, the research²⁵.

²³ Art 14.

²⁴ Art 16.

²⁵ Art 19.

- The final parts of the *Universal Declaration* concern the promotion of the principles contained within it²⁶ and the machinery for implementation and follow-up²⁷.

One of the obvious practical problems, presented by such a bold *Declaration* concerned how the IBC should work in the future - reflecting, independently, the important ethical judgments which have to be made but responding to these problems in ways that will be useful to member States of the United Nations, with all of their diversities and differences.

Satisfactory mechanisms for consultation, which respect the ethical integrity and independence of the IBC and its members and the legitimate interests of member States making up the United Nations and its agencies, have been worked out²⁸. The newly appointed IBC which will convene in December comprises 36 members, acting in their personal capacities, with experience in the life sciences, human and social sciences, law, human rights, philosophy, education and communication. The constitution of the IBC draws upon the different cultural and religious traditions of our

²⁶ Arts 20 and 21.

²⁷ Arts 22-25.

²⁸ The IBC's statute was adopted at the 154th session of the Executive Board of UNESCO. See 154EX/Decision 8.4.

planet. I have the honour to serve on the IBC. In fact, I provide a bridge to the Ethics Committee of the Human Genome Organisation, which is chaired by Professor Bartha Knoppers (Canada). It is my experience that each of these bodies works with integrity and independence but with their members' feet planted firmly on the ground. And with a suitable sense of awe at the enormous challenges which are presented by the dynamic forces of science and technology. And also a sense of urgency to address the current ethical issues, with an understanding of the best scientific knowledge which alone can form the valid foundation of accurate ethical assessments.

We cannot afford the luxury of hand-wringing any more than we can sensibly retreat to the negativism of the Luddites. Overwhelmingly, genomic research will be for the benefit of humanity. It behoves us all, in international bodies such as the IBC, and in national commissions such as are gathered here, to respond to the challenges efficiently, knowledgably, thoughtfully and in language which ordinary people and their elected leaders, not just scientists, understand and act upon.

A CALL TO ACTION

One of the distinguished members of the IBC, Judge Mohammed Bedjaoui, recently the President of the International Court of Justice, whilst acknowledging that the role assumed by

UNESCO, its IBC and the new *Universal Declaration* involves "by no means an easy task"²⁹ asserts, rightly in my view that:

"A legal framework for potential new practices or those already engaged in which concern the human body is absolutely essential in that it protects man in his freedom and dignity ... '[H]uman dignity' ... is an expression which seems simple: one immediately apprehends its prospective import, if not its exact meaning. But paradoxically, it is also an expression full of fragility, for in the name of the same argument of 'human dignity' some refute the legitimacy of euthanasia, whilst others claim it as the ultimate right of those who wish to 'die in dignity'³⁰!

UNESCO's *Universal Declaration* accepts the difficulties of language, concepts and applications. But it at least provides a framework for national and international follow-up. It identifies the key basal rights of the individual which need to be defended. It specifies a criterion by which (at least at this stage of our knowledge) some activities should be forbidden and others promoted and encouraged. It gives expression to some fundamental rules for humanity in an area that touches closely the human future. It gives guidance to national bioethics committees and it encourages them to

²⁹ M Bedjaoui in *Proceedings of the Third Session of the International Bioethics Committee of UNESCO* (September 1995) Vol I at 144. See also D Beyleveld and R Brownsword, "Human Dignity, Human Rights, and Human Genetics" (1998) 61 *Modern Law Review* 661. Volume 61 No 5 of the *Modern Law Review* is a special issue dealing with "Human Genetics and the Law: Regulating a Revolution".

³⁰ M Bedjaoui, *ibid.*

take action, finding basic unity around a few common themes. The machinery of implementation and the detailed national expression of laws and practices will vary greatly from one country to another. But at least a framework to ensure consistent and compatible national initiatives has been afforded. It is to commend your attention to the new *Universal Declaration* that I have been asked by the Director-General to come to this meeting.

Fifty years ago, no one was sure where the *Universal Declaration of Human Rights* would lead to. The challenges to, and divisions of, humanity were enormous. Who would have thought then that the mighty network of national and international human rights rules and institutions would be established, in such a relatively short time, gathering around those principles to which the *Universal Declaration of Human Rights* gave such eloquent expression? Now there is a second *Universal Declaration*. It is before the international community. Its subject matter is of great importance. It deserves your attention. I hope that it will have your support.