

基因科技與人權教育：一個社會學的觀察

朱柔若

開課單位：中山大學中山學術研究所

一、課程說明

聯合國在 1997 年即通過 Universal Declaration on Human Genome and Human Rights，作為國際間規範，特別是不容許政府、教育機關和商業機構取得私人的基因資訊，作為各種歧視的依據。本課程旨在針對基因科技的進展所引發的人權議題，做番深入的探討，並整理先進國家為杜絕這種侵犯個人和家族隱私的行為，所採取的相關措施。最後討論社會學對這個主題可能採取的立場與可能有的貢獻。

二、教材與閱讀文獻

1. Ojeda, Auriana ed., 2002, Technology and Society: Opposing Viewpoints, San Diego, California: Greenhaven Press.
2. Ife, Jim, 2001, Human Rights and Social Work: Towards Rights-based Practice, Cambridge University Press.
3. Torr, James ed., 2000, Medical Ethics, San Diego, California: Greenhaven Press.
4. United Nations, 1997, Universal Declaration on Human Genome and Human Rights
5. Claude, Richard Pierre (柯勞得) 著，王淑英、蔡明殿譯，《全民人權教育》，台北：巨流。

三、根據課程大綱分大單元進行，教材閱讀、口頭報告、與課堂討論

四、課程進度：

1. 開學第一堂課時，分配修課同學閱讀的文獻與主題，排定報告日期，依序進行口頭報告。
2. 修課同學應於期中考週前向老師提出學期報告的題目，按照進度參與報告與討論，最後於學期末繳交論文。

五、學期成績：教材閱讀 30%，口頭報告 30%，期末論文 40%

六、討論議題

1. 何謂基因科技？
2. 基因科技的效益與代價
3. 基因科技普遍化所涉及的倫理與道德議題
 1. 基因資訊的所有權與使用權
 2. 基因資訊、基因歧視、與勞動人權

3. 基因治療與器官移植：資源的接近權
 4. 基因治療：嬰兒生命權 vs 生育自主權
 5. 基因複製：人格權 vs 所有權
 6. 人體研究：如何避免人體研究的濫用呢？
 7. 器官移植：出售人體器官究竟是不是合乎倫理的行為？
 8. 動物器官人體移植：可以解決器官短缺的問題嗎？
- 4.何謂社會學的觀點？
1. 社會學的三大範型如何看基因科技與與人權教育
 2. 社會學的觀點
 - 2.1 應然理想與實然狀況之間的落差：雙贏的空間在哪裡？
 - 2.2 價值的選擇、教育的洗禮、行動者的主張、以及法律的強制

UNIVERSAL DECLARATION
ON THE HUMAN GENOME AND HUMAN RIGHTS

A. Human dignity and the human genome

Article 1

The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.

Article 2

1. Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.
2. That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.

Article 3

The human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individual's natural and social environment including the individual's state of health, living conditions, nutrition and education.

Article 4

The human genome in its natural state shall not give rise to financial gains.

B. Rights of the persons concerned

Article 5

1. Research, treatment or diagnosis affecting an individual's genome shall be undertaken only after rigorous and prior assessment of the potential risks and benefits pertaining thereto and in accordance with any other requirement of national law.
2. In all cases, the prior, free and informed consent of the person concerned shall be obtained. If the latter is not in a position to consent, consent or authorization shall be obtained in the manner prescribed by law, guided by the person's best interest.
3. The right of each individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.
4. In the case of research, protocols shall, in addition, be submitted for prior review in accordance with relevant national and international research standards or guidelines.
5. If according to the law a person does not have the capacity to consent, research affecting his or her genome may only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law. Research which does not have an expected direct health benefit may only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and if the research is intended to contribute to the health benefit of other persons in the

same age category or with the same genetic condition, subject to the conditions prescribed by law, and provided such research is compatible with the protection of the individual's human rights.

Article 6

No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

Article 7

Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions foreseen set by law.

Article 8

Every individual shall have the right, according to international and national law, to just reparation for any damage sustained as a direct and determining result of an intervention affecting his or her genome.

Article 9

In order to protect human rights and fundamental freedoms, limitations to the principles of consent and confidentiality may only be prescribed by law, for compelling reasons within the bounds of public international law and the international law of human rights.

C. Research on the human genome

Article 10

No research or research its applications concerning the human genome, in particular in the fields of biology, genetics and medicine, should prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people.

Article 11

Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted. States and competent international organizations are invited to co-operate in identifying such practices and in taking, at national or international level, the measures necessary to ensure that the principles set out in this Declaration are respected.

Article 12

1. Benefits from advances in biology, genetics and medicine, concerning the human genome, shall be made available to all, with due regard to the dignity and human rights of each individual.
2. Freedom of research, which is necessary for the progress of knowledge, is part of freedom of thought. The applications of research, including applications in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole.

D. Conditions for the exercise of scientific activity

Article 13

The responsibilities inherent in the activities of researchers, including meticulousness, caution, intellectual honesty and integrity in carrying out their research as well as in the presentation and utilization of their findings, should be the subject of particular attention in the framework of research on the human genome, because of its ethical and social implications. Public and private science policy-makers also have particular responsibilities in this respect.

Article 14

States should take appropriate measures to foster the intellectual and material conditions favourable to freedom in the conduct of research on the human genome and to consider the ethical, legal, social and economic implications of such research, on the basis of the principles set out in this Declaration.

Article 15

States should take appropriate steps to provide the framework for the free exercise of research on the human genome with due regard for the principles set out in this Declaration, in order to safeguard respect for human rights, fundamental freedoms and human dignity and to protect public health. They should seek to ensure that research results are not used for non-peaceful purposes.

Article 16

States should recognize the value of promoting, at various levels as appropriate, the establishment of independent, multidisciplinary and pluralist ethics committees to assess the ethical, legal and social issues raised by research on the human genome and its applications.

E. Solidarity and international co-operation

Article 17

States should 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. They should foster, inter alia, research on the identification, prevention and treatment of genetically-based and genetically-influenced diseases, in particular rare as well as endemic diseases which affect large numbers of the world's population.

Article 18

States should make every effort, with due and appropriate regard for the principles set out in this Declaration, to continue fostering the international dissemination of scientific knowledge concerning the human genome, human diversity and genetic research and, in that regard, to foster scientific and cultural co-operation, particularly between industrialized and developing countries.

Article 19

1. In the framework of international co-operation with developing countries, States should seek to encourage measures enabling :
 1. assessment of the risks and benefits pertaining to research on the human genome to be carried out and abuse to be prevented;
 2. the capacity of developing countries to carry out research on human

biology and genetics, taking into consideration their specific problems, to be developed and strengthened;

3. developing countries to benefit from the achievements of scientific and technological research so that their use in favour of economic and social progress can be to the benefit of all;
 4. the free exchange of scientific knowledge and information in the areas of biology, genetics and medicine to be promoted.
2. Relevant international organizations should support and promote the initiatives taken by States for the above mentioned purposes.

F. Promotion of the principles set out in the declaration

Article 20

States should take appropriate measures to promote the principles set out in the Declaration, through education and relevant means, inter alia through the conduct of research and training in interdisciplinary fields and through the promotion of education in bioethics, at all levels, in particular for those responsible for science policies.

Article 21

States should take appropriate measures to encourage other forms of research, training and information dissemination conducive to raising the awareness of society and all of its members of their responsibilities regarding the fundamental issues relating to the defence of human dignity which may be raised by research in biology, in genetics and in medicine, and its applications. They should also undertake to facilitate on this subject an open international discussion, ensuring the free expression of various socio-cultural, religious and philosophical opinions.

G. Implementation of the declaration

Article 22

States should make every effort to promote the principles set out in this Declaration and should, by means of all appropriate measures, promote their implementation.

Article 23

States should take appropriate measures to promote, through education, training and information dissemination, respect for the above mentioned principles and to foster their recognition and effective application. States should also encourage exchanges and networks among independent ethics committees, as they are established, to foster full collaboration.

Article 24

The International Bioethics Committee of UNESCO should contribute to the dissemination of the principles set out in this Declaration and to the further examination of issues raised by their applications and by the evolution of the technologies in question. It should organize appropriate consultations with parties concerned, such as vulnerable groups. It should make recommendations, in accordance with UNESCO's statutory procedures, addressed to the General Conference and give advice concerning the follow-up of this Declaration, in particular regarding the identification of practices that could be contrary to human dignity, such as germ-line interventions.

Article 25

Nothing in this Declaration may be interpreted as implying for any State, group or person any claim to engage in any activity or to perform any act contrary to human rights and fundamental freedoms, including the principles set out in this Declaration.