

**CITIZENS RIGHTS AND NEW TECHNOLOGIES:
A EUROPEAN CHALLENGE**

**Report of the European Group on Ethics in Science and New Technologies
on the Charter on Fundamental Rights related to technological innovation
as requested by President Prodi on February 3, 2000**

Brussels, May 23, 2000

EGE web site : [http:// europa.eu.int/comm/secretariat_general/sgc/ethics/en/index.htm](http://europa.eu.int/comm/secretariat_general/sgc/ethics/en/index.htm)

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PART I:
WHY A GREATER EMPHASIS ON ETHICS IS SO ESSENTIAL TO EUROPE?

Contemporary European civilisation is at the same time based on science, technology and multiculturalism. This multiculturalism, however, is moderated by the Graeco-Latin and Judeo-Christian traditions. These are the historical sources of European values, modern science and technology, and the roots of human rights, which ordains the respect of all individuals, including those of a non-European cultural background. Pluralism, tolerance, and open dialogue about cultural and moral differences constitute therefore a distinctive sign of the European idea. Its implementation requires discussion among all parties in a civil society as a primary source of legitimisation of the rules, to be followed by all.

European diversity is a wealth. European acculturation must include enlightening all citizens about multiculturalism, i.e. how vital it is to inculcate a culture that fosters the importance of many cultures getting along well together.

European education must also stress the importance of inculcating the culture of science and technology. Only then can citizens adopt an informed and balanced attitude towards advances in science and technology. Such an attitude is opposite to technophile or technophobe blindness. Science and technology must increase - and not decrease - freedom and choice for everyone.

This increase in freedom and choice not only involves new discoveries and future inventions, but also safeguards the wealth inherited from the past. Science and technology must be at the service of safeguarding human heritage. Insofar as science and technology replace nature and tradition whilst maintaining the idea of democracy and humanity, the legitimacy of this substitution depends on the capacity of this civilisation to show more active generosity than nature and tradition show.

This means that science and technology should strive to alleviate the suffering, inequality, injustice, and discrimination that tradition and nature have brought out. Moreover, science and technology should not introduce new suffering, inequality, injustice, servitude, constraints or discrimination. In this respect science, technology and multiculturalism face many challenges in the field of biotechnology and ICT. These challenges require not only recognition and the promotion of individual autonomy, but also vigilance with regard to social solidarity between all the individuals. This is to say that supporting individual rights does not mean the setting up of an egoistic society. A market economy in Europe must therefore not exclude a safety net, that is protection for all based on strong collective values.

PART II:
THE GROUP'S APPROACH OF THE RELATIONSHIP
BETWEEN CITIZENS RIGHTS AND NEW TECHNOLOGIES.

A. Background Sources.

In suggesting provisions establishing the rights of the citizen or of the person when faced with science and new technologies, the Group did not refer only to its own opinions, but also to a variety of international instruments. The first is the European Convention on Human Rights as far as it is part of the body of Community law, reflected in particular by the case law of the Court of Justice in Luxembourg. However the Group has also drawn on other international instruments - binding or declaratory - and on European law concerning its areas of competence covering information technologies and life sciences.

These instruments include for example:

International legal instruments	European legal instruments
<u>biomedicine and genetics:</u>	
- UN Universal Declaration on the Human Genome and Human Rights (1998)	- the Directive on the protection of biotechnological inventions (1998), which excludes the patenting of inventions which should be contrary to public order or morality
- Council of Europe Convention on Human Rights and Biomedicine (1997)	- the Directive on in-vitro diagnostic medical devices (1998) which refers to the protection of the integrity of human persons
<u>information technologies:</u>	
- Council of Europe Convention on Data Protection (1981).	- the Directive on the data protection (1995), which refers to the principle of respect for privacy

The Opinions of the Group are the following:

EGE opinions
N°1.- Use of Performance-Enhancers in Agriculture and Fisheries (12/03/93);
N°2.- Products derived from Human Blood or Human Plasma (12/03/93);
N°3.- Legal Protection of Biotechnological Inventions (30/09/93)
N°4.- Gene Therapy (13/12/94)
N°5.- Labelling of Food derived from Modern Biotechnology (05/05/95)
N°6.- Prenatal Diagnosis (20/02/96)
N°7.- Genetic Modifications of Animals (21/05/96)
N°8.- Patenting of Inventions involving elements of Human Origin (25/09/96)
N°9.- Cloning Techniques (28/05/97)
N° 10 - The 5 th Research Framework Programme (11/12/99)
N° 11 - Human Tissue Banks (21/07/98)
N° 12 - Human Embryo research (23/11/98)
N° 13 - Healthcare and information Society (30/07/99)
N° 14 - Doping in Sport (11/11/99)

Furthermore, the Group refers also to the opinions and reports published by the national ethics committees in the Member States or other relevant national bodies. The work carried out by these committees on a wide range of issues constitutes a useful source of inspiration for deliberations on ethics, and contributes to define ethical norms to be taken into account in national regulations or national policies. The Group urges the European Commission to make this information widely available and usable.

B. Basic ethical principles emerging from EGE Opinions

In its advisory task, the Group has identified ethical issues arising from the use of new technologies, both biotechnology and information and communication technology (ICT). It has done so with a view to helping European decision-makers both on legal and policy matters.

The Group considers the following starting points, which reflect Europe's social dimension:

1. - the Charter should highlight the two basic ideas, which are hallmarks of European society: dignity and freedom.
2. - the Charter cannot but refer explicitly to those technologies that deeply affect people's lives. In particular, ICT is increasingly pervasive, transforming people's lifestyles, identities, and choices on many levels, and contributes to changing education, health, social services, culture, etc.
3. - the Charter must not be confined, as the European Convention on Human Rights is, to stressing individual rights, rather it should include social rights according to the fundamental European value of solidarity.
4. - it is no longer enough to simply state "vertical" rights intended to protect citizens in their relations with public authorities. Therefore the Group also proposes listing "horizontal" rights to protect people's rights in their everyday life, vis-à-vis public and private bodies.

In its proposals, the Group expresses key ideas regarding the different areas in question:

Molecular genetics and biotechnology

Here the Group wishes to emphasise three particularly serious types of risk:

- "merchandising" the human body, its components and products;
- new forms of discrimination stemming from the knowledge of the genetic characteristics of humans;
- the instrumentalisation of the human beings through genetic manipulation of human beings, which the Group has deemed ethically unacceptable but which could become a reality at a time when human power over life is increasing considerably.

Information and communication technologies

These technologies are increasingly ubiquitous, permeating individual and social activities as well as objects of everyday use, influencing many aspects of daily life and work. Given the many opportunities these technologies offer, including the combination of genetic and ICT (eg. biobanks), it is vital to watch over their problematic aspects and in particular:

- to improve the protection of privacy (data protection), respecting people's right to maintain boundaries, but also to preserve privacy, autonomy, confidentiality, and solitude;
- to arm individuals against the introduction of systems likely to reduce their freedom and autonomy (video surveillance, behaviour control, and personal profiling based on Internet transactions) or likely to increase people's dependency on selection and decision mechanisms which are not transparent or understandable.

The ethics of responsibility

The Group wants to emphasise the major importance of the ethics of responsibility, which is a corollary of the risks linked to science and new technologies. Technoscience makes us more powerful but at the same time more vulnerable. This is shown by the damage recently caused in the course of new experimentation such as gene therapy or by the disastrous consequences of viruses on the web. Modern technology demands more accountability and even liability. It requires affirming for instance:

- the consumer's right to food safety, a principle which is considered by the Group as "an ethical imperative" (see the Opinion concerning "the labelling of foods derived from modern biotechnology"- 5/5/1995).
- the individual's right to information security, in the same way deemed "an ethical imperative to ensure the respect for human rights and freedoms of the individual, in particular the confidentiality of data..."(see the Opinion about "ethical issues of healthcare in the information society" 30/7/99).

Thus in the Group's view the precautionary principle commonly related to environmental law is applicable to all kind of fields, especially new technologies. It entails the moral duty of risk assessment pertaining to research and new technologies as well as the individual's right to fair reparation in case of damage. If not mentioned specifically in the Charter itself, such an approach with all its legal consequences must still be kept in mind. It is the expression of prudence as a genuine ethical virtue.

C. Towards a Charter with binding legal effect

The Group declared it was in favour of a Charter with binding legal effect. If not included in the Treaty itself, the Charter could at least be annexed to the Treaty in a declaration having the same binding legal effect. It is timely to assert legally the fundamental rights which underpin European identity. It is essential to launch a strong political message regarding the founding values of the European construction towards European citizens particularly in the context of enlargement. Furthermore, the use of new technologies, which are not confined to national borders, should be framed by binding rules based on clear common ethical values.

For the rest, the Group has bowed to the constraints of a Charter that is intended to be a permanent reference instrument. The group has limited itself to short, operational provisions. Two additional factors encouraged the Group in this approach. First, the rapidly progressing nature of the life sciences and information technology make it impossible to lay down very detailed provisions which fairly soon could become obsolete; second, the Group took account of the need to preserve the multicultural nature of European society which precludes issuing strict prohibitions.

<p style="text-align: center;">PART III: SPECIFIC PROPOSALS AND COMMENTS</p>
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The Group has considered the Draft Charter (CHARTE 4149/00 CONVENT 13), examined the articles relevant within its mandate, and proposes the following alternatives and comments.

Article 1

Draft Charter: "*Dignity of the human person*"

The dignity of the human person shall be respected and protected in all circumstances.

EGE proposal: "Dignity and freedom of the human person"

Everyone's dignity and freedom must be respected.

Comments:

The respect of the dignity of the human person is at the root of the ethics of science and new technologies as well as of human rights. It is clear that by asserting "the inherently equal dignity of all members of the human family", the Preamble to the Universal Declaration of Human Rights is aimed at prohibiting all acts which do not conform to the ideas of humanity. Dignity, although a strong juridical and ethical concept in Europe, is a delicate idea when transposed into legal language. Indeed it states that humans have inalienable value, neither specifying who the person or the human being is, nor what the actions and situations which affect this intangible value are. "Any human being is all humanity". Jean-Paul Sartre summarised the scope of the principle of dignity, which is different from all other principles of law and rights.

Other rights and liberties are “neither general nor absolute”, as is commonly stated by European Constitutional Courts.

The right to dignity, on the other hand, is impossible to restrict in any way for the reasons above mentioned. There is nevertheless a philosophical debate about the real meaning of such a principle.

- According to some people, all rights and freedoms stem from dignity, as an inherent value of the human person. Thus ideally there should be no conflict between dignity and freedom.

- But it cannot be denied that there are conflicts between this idea in the current debate. The bioethical discussion in particular illustrates this kind of conflict in a wide range of issues such as abortion and euthanasia.

The Group believes that clearly associating the ideas of dignity and freedom is the best way to ensure that the principle of dignity does not lead to an authoritarian society. In associating dignity and freedom, the Group underlines the necessity to debate what appears contrary to dignity according to society and to the person concerned.

This does not mean of course that the Group does not recognise the unique value of dignity as a principle of law. The Group referred many times to it in its diverse opinions. (see its Opinion on the Fifth Research Program (11/12/97) which states that the dignity of the human being has to be respected by researchers; see also its Opinion on healthcare information (30/7/99) which notes that amongst the ethical principles involved “human dignity serves as a basis for requirement of privacy, confidentiality and medical secrecy”; and its Opinion on doping in sport (11/11/99) which suggests that doping can be contrary to the dignity of the athlete).

The balanced approach of the Group associating dignity and freedom in the same article of the Charter is thus aimed at supporting a European society open to the debate.

Article 2

Draft Charter: “Right to life”

1. Everyone has the right to life.

2. No one shall be condemned to execution.

Comments:

The Group fully agrees with this belief already mentioned in Article 2 of the ECHR.

Nevertheless, it has some remarks to make on its use in the context of bioethics.

1. The principle of the right to life is not used in international texts on bioethics such as the Council of Europe’s Convention on Human Rights and Biomedicine and the UN Declaration on the Human Genome and Human Rights. This is not by chance. It is because the recognition of the right to life in the context of bioethics raises a number of delicate questions, for instance “to whom does this right apply?” “is this right applicable to the unborn child, as seems to be the case under article 40 of the Irish Constitution?” Is this right likely to be imposed by law if the person concerned is willing to shorten his/her life for personal reasons? These questions directly refer to the difficult issues of the status of the embryo and of euthanasia.

2. As stipulated in the Group’s Opinion on human embryo research (23/11/98), “The respect for different philosophical, moral or legal approaches and for diverse national cultures is essential to the building of Europe”. In this same Opinion, the Group avoided to use the expression “the right to life” which appeared as rather ambiguous. That is why the opinion in question refers to “the respect for human life, from the embryonic stage”.

3. It should thus be pointed out that in establishing the right to life, in general, without associating it more explicitly with the prohibition of death penalty (that is to say in the same paragraph of the article concerned), the risk is that the Charter could lead to jurisprudence which might be the basis of European harmonisation on these controversial issues, which may be undesirable at the present time.

Article 3

Draft Charter: “Right to the respect of integrity”

1. *Everyone has the right to the respect of his physical and mental integrity.*
2. *In the fields of medicine and biology, the following principles in particular must be respected:*
 - *prohibition of eugenic practices*
 - *respect of the informed consent of the patient*
 - *prohibiting the making of the human body and its products a source of financial gain*
 - *prohibition of the cloning of human beings*

EGE proposal: “Right to the respect of integrity”

- 3.2 (a) - **respect of the informed consent of the person.**

Comments:

Unlike the right to life, the principle of informed consent does not raise specific difficulties in the context of bioethics. On the contrary, this principle is at the very origin of modern biomedical ethics. It was introduced in law firstly to condemn the horrific experiments carried out during the last world war on human guinea pigs. It has been since reaffirmed in a number of later international forums, such as the World Medical Association (which published in 1964 the well-known Declaration of Helsinki). It is noticeable that the only provision, which deals with bioethics in the UN Covenant on Civil and Political Rights of December 16, 1966 (article 7) states that “ no one shall be subjected without his/her free consent to medical or scientific experimentation”.

That means that before consent is sought, information must be given specifying the alternatives, risks, and benefits for those involved in a way they understand. When such information has been given, free and informed consent must be obtained. Depending on the nature of the intervention (or research), different consent procedures may be used. When the persons informed have reduced autonomy, special rules apply. Indeed vulnerable persons deserve special consideration and protection by the law.

Several Opinions of the Group refer to the principle of informed consent in very diverse circumstances. For instance, in its Opinion on prenatal diagnosis (2/2/96), the Group states that “tests should be done only at the request of the woman or couple after they have been fully informed, namely by genetic counselling”. The Opinion on patents (25/9/96) stresses the fact that “the ethical principle of informed and free consent of the person from whom retrievals [of cells as sources of DNA] are performed, must be respected. This principle includes making the information about this person complete and specific, in particular the potential patent application on the invention, which could be made from the use of this element...”.

In the same way, the Opinion on human tissue banking (21/7/98) states that “in order to be informed, the donor’s consent must have been given on the basis of information provided in as clear and precise lay terms as possible by the doctor supervising the procurement”.

- The Group suggests using “person” instead of “patient”. Indeed there is an increasing number of persons who are not ill and who participate in scientific experimentation, for example healthy volunteers taking part in clinical trials.
- The Group recalls that consent is not sufficient, as other rights also have to be considered. For instance, the right to respect privacy and confidentiality, and to fair access to healthcare. These specific rights are guaranteed in the European Convention on Human Rights and Biomedicine as in the UN Declaration on the Human Genome and Human Rights.

3.2(b) - the individual's body and its parts cannot be traded.

Comments:

Financial gain from the use of the human body and its products is one of the most delicate questions in bioethics. The prohibition against financial gain from the human body and its products is now mentioned in the two main international instruments on bioethics:

- article 21 of the European Convention on Biomedicine and Human Rights states that "the human body and its parts shall not, as such, give rise to financial gain";
- article 4 of the UN Declaration on the Human Genome and Human Rights provides that " the human genome in its natural state shall not give rise to financial gain".

Nevertheless these provisions do not clarify the questions raised by the widespread industrial use of human body products to make pharmaceuticals or genetic tests kits.

- Does it preclude patenting human genes? Certainly not, at least according to the recent Parliament and Council Directive 98/44 on the legal Protection of Biotechnology inventions. This directive states that "an element isolated from the human body or otherwise produced by means of a technical process, including the sequence or partial sequence of a gene, may constitute a patentable invention, even if the structure of that element is identical to that of a natural element"(article 6.2.).
- Does it refer to the traditional distinction between patentable invention and simple discovery that are not patentable? Perhaps. In so doing it is in conformity with the Opinion of the Group on the ethical aspects of patenting inventions involving elements of human origin (25/9/96), which states that " this distinction...involves, in the field of biotechnology, a particular dimension. Which means that " the simple knowledge of the complete or partial structure of a gene cannot be patented". But it is doubtful that the provision in question will only be interpreted as referring to the distinction between invention and discovery which in the field of life sciences is by the way more and more flawed.

- Does it mean that the Charter reaffirms the principle of non-commercialisation of the human body? In its Opinion on products derived from human blood and human plasma (12/3/93), the Group strongly approved this principle in asserting that “ the human body in general and the human blood in particular are not marketable”. In its Opinion on human tissue banks (21/7/98), the Group noted that “all Member States of the European Union adhere to the principle that donations of human tissues must be free, following the example of blood, and this rules out any payment to the donor”. But in the same Opinion, the Group stresses the fact that “ the issue of the commercialisation of human tissues” especially those “ which have been processed and prepared for therapeutic purposes” is “ controversial”. One must be aware that, although rooted in European cultural traditions, this principle is already under challenge in USA. In the US an increasing number of patients whose cells provided genes that have been patented are asking for financial rewards. But no Court agreements have to the knowledge of the Group yet appeared.

In expressing these remarks, the Group especially wants to underline that the subject is very complex. Moreover the Group considers that the draft Charter’s wording on the prohibition of making financial gain from human body is much too vague. It is not only ambiguous with regard to patent law but it could also be interpreted as involving activities like professional sport.

Therefore the Group proposes a provision more specifically emphasising the protection of individuals from organ or tissue trafficking which would affect their dignity and rights. This prohibition of trade does not preclude the patenting of inventions derived from human elements nor the compensation for tissue bank services as far as long as legal conditions and strict limits for this in international conventions, or national laws if any, are satisfied.

3.2(c) Any discrimination based on ..., genetic characteristics, health conditions..., shall be prohibited.

Comments:

Referring to the Article 19 “Non-discrimination” of the Draft Charter (CHARTRE 4137/00 CONVENT 8) the Group proposes to add the two following items: “genetic characteristics” and “health conditions”.

Although the principle of non-discrimination is already established in the Treaty itself, the Group still considers it essential to refer explicitly to it in the Charter again to reinforce the prohibition against discrimination. Non-discrimination also includes non-stigmatisation. Discrimination does not mean selection or distinction as such, but unfair discrimination unduly depriving anybody from their rights. Article 6 of the UN Declaration on the human genome and human rights states that “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”. This article must be reaffirmed at the EU level.

The social dimension of Europe implies taking into account new forms of discrimination due to genetic testing and screening. Genetic tests to discover predisposition or pre-symptomatic diseases may be useful in promoting health measures. On the other hand, such tests might be tempting for employers or insurance companies who wish to exclude individuals at risk of developing a disease. Such tests are becoming available on the European market. For instance a test which can detect a woman’s predisposition to a certain type of hereditary breast cancer is now being imported from the US. Many other genetic tests will be available soon perhaps even through the internet. It would be remiss if the Charter did not deal with this topical issue.

That is why the Group proposes supplementing the article in the draft Charter on discrimination by adding discrimination based on genetic characteristics or health conditions. The prohibition to discriminate on the basis of health and disability is now found in legislation from several European countries.

The Group is presently studying the issue of the use of genetic testing in the workplace. Its Opinion is to be published in November 2000.

**3.2(d) (Option 1) Human reproductive cloning is prohibited
(Option 2) No mention of cloning.**

Comments:

The Group is divided on the question of cloning. In its Opinion on cloning techniques (28/5/97), the Group firmly condemned reproductive cloning, that is “cloning aimed at the birth of identical individuals”. Distinguishing reproductive and non reproductive cloning (related for instance to human cells research), the Group stated that although “ many motives have been proposed” to justify human reproductive cloning, “considerations of instrumentalization and eugenics render any such acts ethically unacceptable...”. The Group recommended “ to clearly express condemnation of human reproductive cloning in the relevant texts and regulations...” . Consequently the Decision adopting the Fifth Framework Research Programme (1998-2002) excludes funding of research aimed at reproductive cloning.

The Group has not substantially changed its Opinion, although however, some members believe that it is not appropriate to forbid cloning in the Charter itself, and one member is opposed to use of the term “reproductive cloning”, preferring a prohibition against “cloning of human beings”. Those who consider inappropriate to mention cloning in the Charter argue that:

- Other practices such as the creation of chimeras or hybrids are not mentioned although they would also violate human dignity. Not mentioning them would in turn result in reproductive cloning of individuals being considered more acceptable.

- To mention a specific technique in a rapidly moving field also risks making the provision in question obsolete. One must note for instance that national legislation which prohibits specific techniques - such as the Human Fertilisation and Embryology Act, 1990, in the UK - has been in his respect overshadowed by

scientific progress. For instance, article 3 (d) of this Act states that it is not authorised to “replace a nucleus of a cell of an embryo with a nucleus taken from a cell of any person, embryo or subsequent development of an embryo”. But yet today there are similar techniques for the replacement of a nucleus that are thus not mentioned in this legislation. Similarly the Spanish law on artificial reproduction of 1988 forbids oocyte freezing. Recent developments show that this technique may be viable and safe. Thus the Spanish National Commission on Artificial Reproduction has asked for the change of the law. These examples show why it seems wise to certain members of the Group not to mention any technique, cloning or others.

- The reference to cloning is a condemnation of a certain use for technique rather than the affirmation of the principles, which lead to this condemnation. Yet, most people would consider that dignity of the human person implicitly excludes cloning of individuals.

- Furthermore, the philosophical and scientific debate on cloning is still open and it should be stressed that prohibition of a specific technique may prevent important discussions about human genetics.

All the members of the Group agree that the dignity of the person born by cloning, would not be in question, but they consider that the act of producing such a human being might be contrary to dignity. They also agree that the debate must continue, and that informing the public about applications of genetic techniques to human beings, and the strong ethical concerns which are raised must continue as well.

Specific additional article

EGE proposal: “Prohibition of eugenics”

Eugenic practices aimed at organising the selection and the instrumentalisation of persons are prohibited.

Comments:

As said before, the Group has referred to eugenics in its Opinion on cloning techniques (28/5/97). However, it admits that eugenics has a wide and controversial meaning, which has changed across the ages. From its origin in nineteenth century the term “eugenics” was intertwined with human genetics. The original idea was that society must foster the breeding of those who possessed favourable traits and to discourage the breeding of those who did not. At the time this seemed only common sense to many scientists and politicians in Europe. But after World War II and the fall of the Third Reich, eugenics as an acceptable social theory, appeared to be dead.

One must acknowledge that now the eugenics question is today being raised again. The Group roundly condemns in particular the following eugenic practices:

- Practices which involve for instance forced sterilisation, forced pregnancies or abortions, ethnically enforced marriages, etc, all acts which are expressly regarded as international crimes by the Statute signed in Rome on July, 18, 2000 to create the permanent International Criminal Court.
- Eugenics, as the Group said about reproductive cloning, may also involve genetic manipulations on human beings such as the modification of the germ line in view of enhancement, without any therapeutic aim.

Eugenics differs from other individual practices carried out to avoid the birth of a disabled child (preimplantation or prenatal diagnosis on severe and incurable diseases for instance). But would the possibility of being able to choose the sex of the future child be condemned as eugenics? The question is at present controversial even if many national legislation excludes such practices.

Considering the difficulty in defining eugenics, some members consider inappropriate to have it in a fundamental text such as the Charter, which deals with basic principles.

Nevertheless the majority of the Group believes that the Charter would be missing the point if it did not refer to one of the main challenges of human genetics. The Group only proposes more precise wording, which is inspired by the French law on bioethics of 1994.

Article 15

Draft Charter: "*Freedom of expression*"

1. Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers.

2. Art, science and research shall be free of constraint.

EGE proposal:

15.1 : to be added at the end : “as well as freedom to participate in public life.”

15.2 : to be deleted: “ of constraint.”

Comments:

About the right to participate

The Group agrees fully with the provision related to freedom of expression. Indeed in the context of the information society, everyone understands this freedom not only as a right to information but also as a right to participate. Given the far-reaching implications of new technologies, people must be given a more active role in the shaping of these technologies. Procedures have to be developed to encourage and enable participation, such as ‘consensus conferences’, which help citizens understand technological choices and to voice their interests, or ‘participatory systems design’ which gives them the chance to intervene in the development of a system or application

of direct relevance to their work or personal life. Furthermore, people must be provided with guidance on the ethical and practical implications of new technologies, and the limitations and the appropriateness of their use. The Group strongly stressed this idea of participation, which would be a landmark in European democracy, namely in its Opinion on healthcare information (30/7/99). This Opinion states that “the right to participate in the medical decision-making process is a key part of the notion of the citizen as a stakeholder”. Which means that “the citizen must not only have access to his/her electronic health record”, but that “procedures (e.g. consensus conferences...) have to be developed to encourage and support the participation of citizens’ collectives and users in the design of systems”. In this context, the Group calls attention on the notion of ‘electronic democracy’. This does not mean only to facilitate voting but also to foster public participation.

The additional phrase proposed by the Group refers to certain provisions of national Constitutions such as for example the Finnish Constitution (article 13) and the Portuguese Constitution (article 48.1).

About freedom of research

Scientific and artistic creativity have often been regarded as an expression of the human spirit. For instance, in the German Constitution of 1949 it is provided that “art and science, research and teaching shall be free”. Article 12 of the UN Declaration on the human genome and human rights proclaims in the same way that “freedom of research, which is necessary for the progress of knowledge, is part of freedom of thought”.

Nevertheless freedom of research is no more absolute than any other liberty. In the field of life sciences in particular, which involves the respect for human life and human dignity, researchers have to follow rigorous ethical principles. This balanced approach is reflected in many Opinions of the Group. For instance, the Opinion of the Group on "the Fifth Framework Research Programme" (11/12/97) calls for reconciling “the freedom to carry out research activities with the imperatives linked to the protection of the fundamental rights of European citizens...”. In the same way, the Opinion on embryo research (23/11/98) deems “that it is crucial to recall that the

progress in knowledge of life sciences, which in itself has an ethical value, cannot, in any case, prevail over fundamental human rights and the respect which is due to all the members of the human family”.

The question of setting limits to research, balancing respect of dignity with the duty to carry out research for improving knowledge, contributing to man’s understanding of the world and life, alleviating suffering and bettering the quality of life, is certainly a delicate one. But it has to be faced and it is the role of ethics to help in so doing.

In insisting on the importance of the freedom of research, the Group wishes:

- not only to point out the necessity for all the powers that be – economic, social, political – to respect the moral and intellectual independence of researchers;
- but also to encourage European authorities as well as Member States of the EU to take positive measures in support of the free pursuit of research, especially fundamental research which is not immediately financially profitable. The idea is that to foster the intellectual and material conditions favourable to the free conduct of research is a key element of democracy.

15.3 Each individual has the right to benefit from sciences and technology.

Comments:

This article refers to the principle of justice, which implies fair access of all individuals to the benefits of scientific advances. This presupposes assessment and evaluation of such scientific progress. It has also to do with the principle of equal access to health, a principle put forward in several Opinions of the Group. For instance, in its Opinion on gene therapy (13/12/94) the Group stressed that “appropriate measures should be taken to assure equal access to gene therapy in the European Union” insofar as it is safe. To assert the right to benefit from science and new technologies is also a way to shed light on the importance of scientific and technological knowledge which must be part of the basic education of every European citizen.

Such a provision is not new. It is included in the UN Covenant on Economic, Social and Cultural Rights (December 1966) and in the UN Declaration on the Human Genome and Human Rights. Even if this provision does not allow claiming subjective rights before a court, it is important that the Charter gives a positive stand on technological developments, which are crucial to the welfare of European citizens.

Article 16

Draft Charter: “*Right to education*”

- 1. No person shall be denied the right to education, including in particular the right to receive free compulsory education.***
- 2. The founding of educational establishments shall be free of constraint.***
- 3. The right of parents to have their children educated and taught in accordance with their religious and philosophical convictions shall be guaranteed.***

EGE proposal:

16.1 to be added at the end: “which shall facilitate mutual understanding between cultures”.

Comments:

Cultural pluralism is a valuable characteristic of European society. The Group believes it important that a strong support is given to education at all levels to help the citizens from different cultures and traditions to live, communicate, and work together. Education has a fundamental role in promoting the active participation of all individuals and at all ages in awareness-raising and decision-making, thus allowing equity and social cohesion to develop. The implementation requires new working methods and modes of action, which recognise the rights, and civic responsibilities of citizenship.

This implies not only promoting knowledge of different cultures but also developing mutual understanding, which is the prerequisite for respect and tolerance.

The proposal of the Group is thus here to insist on the respect of pluralism, which the Group has mentioned, for example, in its Opinion on embryo research (23/11/98). It should be noted that many national Constitutional courts as well as the European Courts recognise pluralism as an essential condition of democracy.

The Group considered also the article 15 on data protection of the working document CHARTE 4137/00 CONVENT 8.

Article 15

Draft Charter: "*Data Protection*"

Every natural person shall have a right to protection for his personal data.

EGE proposal:

15.1. Everyone has the right to protection for their personal data.

15.2. In the field of data protection, the following principles in particular must be respected:

- respect for confidentiality of personal individual data;**
- right to determine which of one's own data are processed, by whom and for what purposes;**
- right to have access to one's own data and to correct or delete them.**

Comments:

Europe has become an information society like all developed regions of the world. Faxes, computers, the internet, mobile phones ...are common tools for everybody: public institutions, private companies, individuals. Technology has given rise to the so-called 'new economy'.

The considerable amount of personal data, which are collected, stored and spread all over the world is even more of a reason now than before to rethink the respect for privacy. Indeed through Internet, our lives are more and more in the open. That is why respect for privacy in this new context must not only reside in the respect for confidentiality. It must also involve the right to refuse to give access to one's own data or the right to refuse the collection of these data. In this sense, data protection underlines the necessity to recognise the citizen as a stakeholder. As it is said for example in the Opinion on healthcare information (30/7/99), information and communication technologies must offer to the individual the chance to enhance their choices and self-determination. The provisions above proposed by the Group are inspired by the idea of self-determination used for the first time by the German Constitutional Court in a judgement made in 1983.

Along these lines, these provisions refer to three fundamental principles:

- the principle of confidentiality reflecting the idea that personal data are part of the identity of the individual;
- the principle of autonomy linked to the principle of consent;
- the right to information which must be an 'active' right in the context of data protection. It includes the right to know what categories of information are available and the right to decide whether or not to be provided with this information.

15.3. No person shall be subject to surveillance technologies, which aim at or result in the violation of their rights or liberties.

Comments:

The Charter must take into account recent technological developments such as video surveillance in public, be it for co-ordinating traffic, for 'profiling' people's habits, or for identifying potential suspects, which may raise concerns related to the violation of rights or liberties of citizens.

The provision suggested by the Group does not define an individual right but much more a principle to be respected in a democratic society. Nevertheless it may be invoked before a court and thus reinforces individual rights.

CONCLUSION

The EGE's approach to the ethics of science and new technologies is meant to be positive with regard to scientific and technical progress, in the sense that this progress is meant to stimulate personal development without damaging social solidarity. Thus it also follows the spirit of the primary sense of the word 'bioethics' as defined in 1970 "to ensure that the biomedical and biotechnological sciences serve human development, taking into account the complexity of the international society and of nature, as well as their interactions".

The Group believes that scientific progress and technological development should match the needs and aspirations of citizens in a way, which is respectful of EU values involving a new concept of citizenship.

Citizenship traditionally has been based on political rights in public life, namely the right to vote, and to be elected. The new idea of European citizenship has a much broader sense, as it now includes not a more direct and active participation of the citizens into debate and public life.

Apart from participation, there is another prerequisite for ensuring effective protection of citizens' rights in the context of new technologies: that is education. The Group strongly insists on the eminent role of European authorities in promoting structures for education not only in direction of the youngest generations as future citizens, but to every body throughout lifetime. Indeed citizens need to be informed and enlightened to participate fully in democracy. Information society gives entirely new possibilities to underline the social dimension of the European citizens' fundamental rights by enabling everyone to be constantly informed and thus to contribute actively to the solidarity and community spirit without which the building of Europe would be meaningless. Technical possibilities to foster participation and education must be used to promote an interactive society and a society where mutual understanding between the different national cultures and traditions is ensured.

In view of the enlargement of the European Union to countries with different civil and legal traditions, it is all the more crucial to deal with the increasing multiculturalism in a way, which strengthens cohesion among all EU states.

We must construct a Europe where everyone plays a part, where everyone is a stakeholder, and no one is excluded.

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Summary of the European Group on Ethics proposals concerning the draft Charter on Fundamental Rights

(working document CHARTE 4149/00 CONVENT 13)

Article 1 Draft Charter: *"Dignity of the human person"*

The dignity of the human person shall be respected and protected in all circumstances.

EGE proposal: "Dignity and freedom of the human person"

Everyone's dignity and freedom must be respected.

Article 3 Draft Charter: *"Right to the respect of integrity"*

1. Everyone has the right to the respect of his physical and mental integrity.

2. In the fields of medicine and biology, the following principles in particular must be respected:

- prohibition of eugenic practices*
- respect of the informed consent of the patient*
- prohibiting the making of the human body and its products a source of financial gain*
- prohibition of the cloning of human beings*

EGE proposal:

3.2 (a) - respect of the informed consent of the person.

3.2 (b) - the individual's body and its parts cannot be traded.

3.2 (c) Any discrimination based on ..., genetic characteristics, health conditions..., shall be prohibited.

3.2(d)(Option 1) Human reproductive cloning is prohibited

(Option 2) No mention of cloning.

Specific additional article

EGE proposal: “Prohibition of eugenics”

Eugenic practices aimed at organising the selection and the instrumentalisation of persons are prohibited.

Article 15 Draft Charter: *“Freedom of expression”*

1. Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers.

2. Art, science and research shall be free of constraint.

EGE proposal:

15.1: to be added at the end: “as well as freedom to participate in public life.”

15.2: to be deleted: “ of constraint.”

15.3 Each individual has the right to benefit from sciences and technology.

Article 16 Draft Charter: *“Right to education”*

1. No person shall be denied the right to education, including in particular the right to receive free compulsory education.

2. The founding of educational establishments shall be free of constraint.

3. The right of parents to have their children educated and taught in accordance with their religious and philosophical convictions shall be guaranteed.

EGE proposal:

16.1 to be added at the end: “which shall facilitate mutual understanding between cultures”.

(working document CHARTE 4137/00 CONVENT 8)

Article 15 Draft Charter: "*Data Protection*"

Every natural person shall have a right to protection for his personal data.

EGE proposal:

15.1 Everyone has the right to protection for their personal data.

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