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(1992)

**“Scientists’ responsibilities
in acquiring knowledge and developing
intervention technologies
with regard to the human genome.”**

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The *Human Genome Mapping and Sequencing Project* is an outstanding example of the moral and social responsibilities faced by scientists. Acquiring knowledge of the human genome, as well as developing intervention techniques to be used in the genome, are not morally or socially neutral, since they involve human subjects, societies and the human species itself. This acquisition and this development must be guided by basic ethical principles based on respect for human dignity and human fights.

The first part of my presentation will be an overview of four areas of responsibility arising from the Human Genome Research Project. Although these areas interact, they can be separated for the needs of this presentation. In the second part, shorter, I will present the Universal Movement for Scientific Responsibility (MURS).

Four areas of responsibility for scientists

1. The first area of responsibility for scientists is related to the acquisition of scientific knowledge.

Until recently, a distinction was made between the acquisition of knowledge ("Science for Science") and the application of knowledge in technologies ("Science for Technology"). While this distinction is still theoretically valuable, one must recognize that, in practice, the frontier between them is becoming increasingly blurred, because within modern societies, such domains as politics, economics, technology and science are more and more interrelated and interdependent. Consequently, one cannot make a radical separation between pure science (which is not subject to any ethical norm), and applied sciences (which must be governed by ethical rules).

With this in mind, and as a general principle, any knowledge concerning the human genome or any potential technique of intervention in the human genome are ethical and therefore would be welcomed, provided that they respect human dignity and human rights. On the other hand, science and technology which are potentially detrimental to individuals, as well as to populations, must be totally [199] rejected, even if they greatly benefit science itself. This limitation is set more to guide than to stop research.

Basic values and fundamental principles of a society are usually expressed in the national guidelines of research and experimentation involving human subjects. In this regard, it is fortunate that more and more associations of researchers and scientific bodies have adopted deontological codes of research. Scientific journals also ensure that the results of research they publish are in accordance with these codes. It is evident, then, that the first ethical evaluation of research occurs among peers, since scientists are at the forefront of scientific and technological development. They are the first to be able to analyze the positive or negative consequences of their findings.

Where major innovative projects are concerned, however, such as the human genome project, involving present and future generations, the circle of peers must be extended. Preserving and promoting both multi-disciplinarity and interdisciplinarity thus become an imperative. When scientists analyse a problem in collaboration with experts from human sciences (ethics, law, theology, sociology, and so forth), using a common language of communication, they have a wider analysis spectrum than that of a single discipline. The contribution of ethics, law and theology in the defining Of fundamental values and principles is paramount. Multi-disciplinary bioethics committees are among the best possible safety mechanisms for researchers and society, considering the exponential growth of research in human genetics today.

Scientific journals, such as *Human Gene Therapy*, welcome public debates and accept articles by experts in human sciences ; conferences such as this 2nd International Bioethics Seminar in Fukui are open to multidisciplinary and interdisciplinarity for assessing research on the human genome. All this openness to dialogue and discussion is an example of another safety mechanism for avoiding potential abuse.

2. The second area of responsibility for scientists concerns awareness of the potential for misapplication of their findings.

In science, as well as in ethics, an awareness of the elements involved in a problem is the first step towards its solution. It is also the first step towards wisdom - and humanity stands in great need of this wisdom when using science and technology which involve the human genome .

It must be recognized that scientists, throughout history, have played, and will continue to play a vital social role in improving the general well-being of individuals and populations, even if some of their discoveries proved to be detrimental, as in the case of nuclear physics used for military purposes. Because of their expert knowledge, scientists are called upon to alleviate suffering and to improve the welfare of society in general. Science and technology, therefore, are needed to meet these challenges.

Scientists involved in genome mapping and sequencing must recognize that they occupy a pivotal position, thus far unknown in the history of science : their field of research is not only *around* or *outside* the human being, but rather *inside* the very blueprint of the human being, that is to say, decoding genetic information.

As soon as research findings and techniques involve present and future generations, they are no longer morally neutral, and ethical concern must go hand [200] in hand with the task of the scientist. As the saying goes, "No science without conscience".

It must first be acknowledged that the genome project is likely to have great humanitarian repercussions, especially where preventive, predictive or remedial medicine is concerned. Gene therapy, in particular, raises high hopes for the treatment of genetic diseases affecting families and populations which are at risk. Scientific literature, the media, and notably this Seminar have identified and assessed many of the potential risks. The following is a partial list of some examples :

- the advent of a new form of eugenics
- the negative psychological impact of predictive medicine
- possible discrimination in regard to insurance and employment
- discrimination against "bad-gene" carriers
- threat to the privacy and confidentiality of genetic data
- the potential use of human genes for commercial purposes
- the reprogramming of the human genetic code for non-therapeutic purposes
- the rise of reductionist thinking.

All such risks must be considered very seriously by all concerned in science and human sciences.

3. The third area of responsibility for scientists is to make society a partner in the management of knowledge orientation and biotechnology applications, bearing in mind the interests of present and future generations.

Four different ways of making this partnership effective will be considered here.

The first step in involving society is to inform it and to keep it informed. In view of their particular expertise, scientists are in a distinctive position to perceive side effects or potential dangers of research earlier and better than others. As a result, they will be enabled to inform or even to provide timely warning to the public when necessary. Informing the public is the first moral and social responsibility of a scientist. Two major qualities are involved in informing the public. The first one is to be objective, without sidestepping issues or exaggerating the likely benefits of research. The second one is to inform fully and completely, without minimizing or ignoring possible dangers.

The second step in involving society is to consent and to contribute to public debates. This is the best way of guaranteeing that new orientations conform to the basic values of society. Debates should be planned before launching projects which have a major impact on society and its future. Otherwise society would be obliged to deal with the consequences of decisions made by exclusive scientific circles. Although a public debate can be long and tiresome, it is better to let the public express their fears. Patience is required in order to keep in step with society, thus making sure they are not misdirected. -When scientists agree to open themselves up to public criticism, they are proving their sincerity as researchers.

The third step in involving society is that scientists should participate in the political decision-making process, either as individuals or through their scientific association.

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Scientists' contribution to social politics is important and must be endowed with the same qualities as their participation in social decisions.

Although it would be unfair to hold scientists responsible for the outcome of their research, they are still accountable for the unwise applications of such research by politicians. Their duty is to intervene in cases of the abuse of scientific findings. Should they abstain, it might be interpreted as an evasion of responsibility.

The fourth step in involving society is to participate in international reflection and discussion, and to contribute to the elaboration of international guidelines which are to be laid down for research.

Over the past few years we have observed that barriers between countries are ceasing to exist. This is leading to the emergence of societies which are decreasingly isolated ideologically, politically and economically. The same process is taking place on the scientific level where genetic research has acquired an international dimension, as in the case of tile analysis of the human genome.

In order to avoid unsound or premature practices in research and its applications, scientists must contribute to an international consensus for respecting ethical research norms. This is particularly important in situations where various countries may not be in agreement over what is acceptable or not.

4. The fourth and last area of responsibility for scientists is to preserve and promote a holistic view of the human being, so as to avoid "genetic reductionism".

In order to deal successfully with the risks and benefits of the Human Genome Project, it is necessary to perceive human beings in all their complexity and uniqueness.

A holistic approach Supports the view that personal and social human behavior is the result of a complex phenomenon in which genes play an important part without, however, ruling the whole. With this in mind, it is evident that, while an individual is a "gene vector", he is not exclusively a "gene stock". This means that, although the individual has a "genecity", he is also a "personality" resulting from the interaction between genes and environment. In contrast to this, genetic

reductionism is an ideology which reduces the human being's bio-psycho-social complexity solely to the laws of genetics.

The detrimental consequences of such reductionism might include the following :

- genetic determinism,
- social discrimination between "good gene" and "bad gene" carriers,
- the lessening in tolerance of imperfections and handicaps,
- a quest for "genius genes",
- fetal diagnosis and screening for convenience only,
- objectivization of the human being by means of genome manipulation, all of which would tend to lay the foundations for eugenics.

To conclude the first part of this presentation, the responsibility of all scientists and humanists is to be evermore vigilant as time passes.

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Universal Movement for Scientific Responsibility (MURS)

Now, I would like to introduce the Universal Movement for Scientific Responsibility (MURS). This second, shorter part of my presentation, springs naturally from the first. The Movement began in France in 1974. At present, Professor Dr Jean Dausset, Nobel Prize winner for medicine, is the President. The Movement spread to Canada (Quebec) last year. At least two other countries, namely Belgium and Spain, are also about to join, and MURS hopes that other countries will do the same.

The Movement's general principle is as follows,

The acquisition of knowledge should not be hindered. This knowledge should be used only for the benefit of human dignity, integrity and destiny.

The Movement has high hopes that this principle will soon be officially recorded in the Universal Declaration of Human Rights.

The next two principles concern human genetics more directly.

Due to present limitations of our knowledge, the human genetic blueprint should not be modified in such a way that the modifications are passed on through heredity.

This implies that while somatic gene therapy is acceptable germ line therapy is not for the moment.

The human body with all its elements : cells, tissues, organs and genetic material, is of inestimable value and therefore should not be used as a source of profit.

This implies that human genes must never be open to patenting.

The Movement's objectives are as follows,

To set up a permanent forum by means of which experts (in science and human sciences), as well as persons interested in the subject, will discuss such problems concerning humanity as are generated by the development of science and technology.

To awaken social consciousness regarding the preceding problems by weighing benefits and risks.

To serve as a platform to inform the public of the results of debates and to set out alternatives for decision-makers.

To stimulate reflection upon the future of humankind and the planet and upon the measures which should be taken from now on in order to guarantee the well-being of generations to come.

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Conclusion

The Human Genome Mapping and Sequencing Project is an outstanding example of the moral and social responsibilities faced by scientists. Four areas of responsibility arising from this Project were overviewed in this presentation. These areas of responsibility must be shared nationally and internationally by scientists and humanists.

MURS is gathering momentum as an international movement. National branches are juridically and Culturally autonomous, yet they share the same philosophy, the spirit of which is as follows :

Scientific knowledge and its technological applications must be used only with respect for human dignity, human integrity, and the general well-being of present and future generations.

In this spirit, collaboration between various national branches of MURS could lead to an international network of reflection, discussion and action regarding the responsible management of scientific findings and their applications.

To conclude this presentation, I Would like to express my profound gratitude to Professor Dausset and the organizers of this International Bioethics Seminar for the privilege of being here today.

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